# TABLE OF CONTENTS

**Introduction** ................................................................. V

**CHAPTER 1**

**Ethics and Neurosciences** (Mr Jean-Didier Vincent) ....................................................... 1  
*Session chaired by Mr Jean-Pierre Changeux*

**CHAPTER 2**

**Genetic Counselling** (Mr Michel Revel) ........................................................................ 9  
*Session chaired by Mr Jean Bernard*

**CHAPTER 3**

**Bioethics and Human Population Genetics Research**  
(Mrs Chee Heng Leng, Mrs Laila El-Hamamsy,  
Mr John Fleming, Mr Norio Fujiki, Mrs Genoveva Keyeux,  
Mrs Bartha Maria Knoppers and Mr Darryl Macer) .......................................................... 39  
*Session chaired by Mr Maurice Godelier*

**CHAPTER 4**

**The Teaching of Bioethics in the Americas**  
*Session chaired by Mrs Hélène Ahrweiler*

- Teaching of Bioethics in Latin America  
  (Mrs Lidia Vidal-Rioja and Rubén Lisker Y.) ................................................................. 67
- Bioethics Education in the United States: A Commercial Turn  
  (Mr Daniel Wikler) ........................................................................................................ 73
IV

CHAPTER 5
Preparation of a Universal Declaration on the Human Genome and Human Rights
Session chaired by H. Exc. Mr Héctor Gros Espiell

Fifth Meeting of the Legal Commission of the IBC
(Mrs Christine de Masson d’Autume) ................................................................. 81
Results of the Discussions on Bioethics at the Twenty-eighth Session
of the General Conference of UNESCO and Resolutions Adopted ...................... 85
Preliminary Draft of a Universal Declaration on the Human Genome
and Human Rights (6 March 1996) ................................................................. 91

CHAPTER 6
Third Session of the IBC (Mr Georges B. Kutukdjian) ........................................ 97

CHAPTER 7
Speeches at the Third Session of the IBC
I. Mrs Noëlle Lenoir, President of the IBC .......................................................... 111
II. Mr Federico Mayor, Director-General of UNESCO
(opening speech) .............................................................................................. 115
III. Mr Philippe Séguin,
President of the National Assembly of the French Republic .............................. 119
IV. Mr Xavier Emmanuelli, French State Secretary
in charge of Emergency Humanitarian Action .................................................. 125
V. Mr Federico Mayor, Director-General of UNESCO
(closing speech) ................................................................................................ 129
VI. Mr Roland Dumas,
President of the Constitutional Council of the French Republic ....................... 133
VII. Mr Mohammed Bedjaoui,
President of the International Court of Justice ............................................. 137
VIII. Mr Jacques Toubon, French Minister of Justice .......................................... 147

CHAPTER 8
List of Participants .............................................................................................. 151
Introduction

Ever since it was set up in 1993, the International Bioethics Committee of UNESCO (IBC) has contributed to the development of the bioethics movement, in particular through the extensive dissemination of reports on its meetings and the conclusions of its reflection on specific topics. The Proceedings of all its sessions are thus a major tool for the exchange of information that is at the heart of its appointed task.

At its Third Session, the IBC developed three topics: the neuroscience which raise numerous ethical questions arising out of research on the human brain and the medical practices that result from this research, genetic counseling which implies new relationships between medical personnel and patients and population genetics which may provide data useful for the history of migrations and for anthropology. Finally, in pursuing its work on education in bioethics, the IBC prepared a status report on the teaching of bioethics in the Americas.

A Round Table at this session brought together several parliamentarians and former ministers on the topic “Bioethics: what role for Parliaments?”. The prospects opened up by advances in genetics and the need for new legislation were the focal points of the debate. For, it is up to the legislators to meet the aspirations of citizens, respond to their concerns and demarcate the boundaries between the possible and the permissible while at the same time preserving freedom of research.

Mr Philippe Séguin, President of the French National Assembly, was present along with Mr Roland Dumas, President of the French Constitutional Council, Mr Jacques Toubon, French Minister of Justice, “Garde des Sceaux”, and Mr Xavier Emmanuelli, French State Secretary in charge of Emergency Humanitarian Action.

Volume I of the Proceedings includes, in addition to the speeches made at the Third Session of the IBC and the list of participants, reports on “Ethics and Neuroscience”, “Genetic Counseling”, “Population Genetics” and “The Teaching of Bioethics in the Americas”. Volume I also gives the results of the discussions of the Legal Commission of the IBC which has the task of preparing a universal declaration on the human genome and human rights.

Volume II contains all the documents provided, among others by the members of the International Bioethics Committee, on specific points of the topics referred to here above.

UNESCO

April 1996
Chapter 1

ETHICS AND NEUROSCIENCE

(Jean-Didier Vincent*)

The brain manages all the relationships between the human being and the world around him; it is the organic core of the person, the agent of his freedom but also of the individual and social constraints which restrict that freedom. It endows man with culture and language. UNESCO is therefore the international organization to which it logically belongs. Significantly enough, our millennium is ending with a “Decade of the Brain” decided by the United States of America and later by the European Union. This importance is reflected in what are known by convention as the neuroscience, a new discipline which comprises both the biology of the nervous system and the sciences of man and society, together with the “hard” sciences (mathematics, physics), ranging from the most theoretical and abstract aspects to medical, technological and industrial approaches. Indeed, there are few areas of knowledge that do not touch upon the neuroscience. Through their creative power, these sciences hold out the hope of contributing to the greater well-being of man by relieving his pain, repairing his infirmities, improving his performance, prolonging his life and retarding the process of ageing. But they also pose a formidable threat by providing means of coercion and new sources of dependence.

This presentation does not claim to set out an exhaustive examination, however superficial, of the content of the neuroscience. Starting out from a few examples, we intend rather to put some ideas forward to the International Bioethics Committee of UNESCO (IBC). However, one can hardly broach the subject of ethics without first defining what is meant by the neuroscience and without looking at the historical background of their development.

I. Definitions

The “sciences of the nervous system” - a term which must not be confused with the neuroscience - did not see the light of day until the late 19th century with the combined development of physiology, histo-anatomy and anatomical clinical science. At the technical level, especially in the field of medicine, their spin-off remained relatively limited for a long time, but their ideological impact was considerable in the Western world: the reflex theory

* Director of the Alfred-Fessard Institute.
which associates every action with a stimulus, the neuronal theory which takes the view that the nervous system consists of an articulation of discrete elements or neurones, and the theory of locations which links the mental functions and faculties with specific areas of the brain, all influenced the materialist philosophies which served as a foundation for the great political movements of our century.

Paradoxically enough, psychology which was long considered inseparable from philosophy, did not become an experimental science until it chose to ignore the brain and concentrate on behaviour regarded as a pattern of learning and the product of associations between stimuli and responses, inputs and outputs, without reference to the intermediate nerve mechanisms contained in the “black box”. Later, the growth of ethology based on rigorous observation of animal behaviour caused attention to turn once again to the nerve structures underlying stereotyped and innate forms of behaviour. A first synthesis was made in the late 1950s between experimental psychology, ethology and physiology, largely as an outcome of the development of techniques to study the brain directly by fitting intracerebral electrodes to record the electrical activity of the structures or to stimulate them. In the field of medicine, this was the era of neurosurgery and psychosurgery.

The 1960s brought a veritable revolution with the discovery of the chemical messengers used by the nerve cells to communicate between themselves and the identification of their receptors. This upsurge of pharmacology and biological chemistry led to the development of medicinal preparations which actively influenced certain forms of behaviour or mental states and were capable of sedation or of alleviating symptoms. In medicine, this period corresponded to a renewal of psychiatry which took pathogenic concepts on board and acquired a highly effective arsenal of therapeutic instruments.

Computer science provides a theoretical model for understanding the brain; the analogy with the computer serves as a frame of reference for what are known today as the cognitive sciences. We are now witnessing, firstly, the creation of intelligent machines (artificial intelligence) and, secondly, the study of the processing of information involved in the brain functions in animals and man. The techniques of cerebral imaging, made possible by computer science, permit an increasingly precise visual display of the activities of the different regions of the brain and provide an anatomical foundation for the study of complex functions which cannot be shown by formal logic and derived algorithms alone.

Genetics and molecular biology have been the fundamental advancements of the last ten years. It is generally accepted that the genetic patrimony of a human being comprises some 100,000 genes; the brain structure alone uses more than 50,000 of them. Although their functions are not always known, new genes expressed in the nervous system are constantly being discovered. We shall see later the hopes and fears that this harvest of new knowledge is creating in the area of gene therapy which was the subject of an earlier report for the IBC in 1994.

A final, and in our view essential, phase involves the study of the development of the brain during the evolutionary processes (phylogenesis) and in the individual (ontogenesis). The discovery of regulating genes, guiding and adhesion molecules, cell growth and death factors enables us, by explaining the structure of the brain, to understand how it works and opens up demiurgic prospects for its subsequent transformation.

All these disciplines, which have undergone successive phases of development, constitute the field of the neuroscience today. After a brief outline of the neuroscience, noting their successes and failures alike, we shall turn to their technical and instrumental impacts, in particular their therapeutic spin-off and increasing social impact. We shall endeavour to view all these processes from the ethical standpoint.

II. The State of the Neuroscience Today

We shall look successively at the fields in which we believe the most significant breakthroughs have been made, and those in which progress has been less spectacular, to say nothing of disappointments and failures.
II. 1 Breakthroughs

1. The techniques of cerebral imaging enable the brain to be observed at work and the level of activity of clearly defined regions to be known during the performance of various mental tasks. With three-dimensional reconstitution and rapid scanning nuclear magnetic resonance, man is now able to watch his own brain thinking.

2. At the level of the cells, we are perfectly familiar today with the nature of the nerve influx and the various electrical phenomena which confer upon the neuron its properties of excitability and its information-processing capabilities. Biophysical or “patch-clamp” methods provide direct access to the ionic channels and enable us to understand the way in which chemical messengers and their receptors act.

3. At the molecular level, in addition to identifying the structure of the channels, neurotransmitters and their receptors, the identification of an abundance of molecules which interact in cascades enables us to understand the functional and molecular substrates of fundamental phenomena such as pleasure, suffering, dependence, memory and the formation of cognitive maps in the brain. A new and promising field is that of development, with the discovery and isolation of growth factors, adhesion molecules which ensure both the genesis and cohesion of structures and, more recently, the molecules which are involved in guiding the nerve fibres whose connectivity reflects the complexity of the organization of paths and networks in the brain.

4. Genetics have been particularly fertile in the area of the neuroscience, revealing families of genes for the enzymes, receptors and linking proteins which take care of the different neuronal functions. The discovery of regulating genes, which are responsible for the development of the brain according to the plans of the species exposed to the influences of its environment, holds out considerable prospects not only for the understanding of the phylogenesis of the brain but also of the way in which it works. In the field of pathology, identification of the gene and of the nature of mutation has been possible in some monogenic pathological conditions of the nerve system, the most spectacular example being Huntington’s choreas.

II. 2 Less Successful Advances and Disappointments

In drawing up a scientific balance sheet, it is not usual practice to call attention to failures. The media take an interest in spectacular successes. They sometimes fail to report the disappointing outcome of the results announced in a blaze of publicity, preferring instead the spontaneous concert of voices which transforms research into a triumphal avenue.

II.2.1 Medicinal Preparations

Despite the considerable efforts made by institutional research and by the pharmaceutical industry, no genuinely new family of molecules has appeared in the last decade. It is true that a better understanding of the potential targets in the brain, in particular as a result of genetic identification of the receptors for neurotransmitters, has enabled the number of active molecules to be multiplied and their indications better adjusted to patients’ needs. But these sporadic discoveries cannot be compared with the revolution represented by the appearance several decades ago of the first tranquillizing and antidepressant molecules. Moreover, there is good reason to wonder whether the world-wide success of some products on the market for psychotropic substances does not reflect an effective marketing campaign rather than real therapeutic originality.

II.2.2 Computer Science

Artificial intelligence is a particularly fertile branch of computer research, notably in the area of robotics and expert machines; on the other hand, its contribution to the understanding of the cognitive functions of the brain has proved disappointing. The significant advances brought about by computer science remain confined to the technical sphere - for example, imaging or the processing of electrophysiological data.
II.2.3 Intervention in the Brain Itself

After the use of neurosurgery as a palliative measure to treat neuro-degenerative conditions of the brain such as Parkinson’s disease or serious behavioural problems, a genuinely substitutive therapy was proposed in the shape of the transplantation of embryonal nerve cells within degenerative or damaged cerebral structures. The complexity of the problems raised and the absence of any long-term follow-up suggest a need for extreme circumspection here.

II.2.4 The Genetics of Hereditary Diseases

The genetics of hereditary diseases is complicated by the rare nature of monogenetic conditions, our highly inadequate understanding of pathological mechanisms and the total lack of therapeutic solutions in the near future. The most convincing results are of a diagnostic nature and openly raise the problem of eugenics. Here again it is to be feared that the publicity given to a few spectacular results may create unfounded hopes among patients.

III. The Impact of Neuroscience

This occurs firstly at the instrumental level, which comprises medical and technical aspects, and secondly at the level of society.

III. 1 The Instrumental Impact

This touches upon the diversity of the techniques and disciplines involved in the neuroscience.

III. 1.1 New Molecules

The techniques of molecular biology and genetic engineering enable substances whose cell functions are often unknown to be obtained. We are in the presence of a Pandora’s box which, when it is opened, may well release potentially dangerous substances. Cloning of the receptor of tetrahydrocannabinol, the active principle of cannabis, was rapidly followed by the discovery of its endogenous ligand, anandamide, whose original chemical structure and mode of secretion by the nerve cells might lead on to the development of a new family of medicinal substances, the danger being that these may also extend the list of addictive substances. That is the reverse side of the coin encountered whenever psychoactive substances are launched on the market. The anxiolytics, and in particular the benzodiazepines whose receptors in the brain have now been identified, have a relaxing and anticonvulsant sedative effect. This effect is beneficial when the substances are administered for therapeutic purposes but heavy dependence also occurs; these substances can therefore be classified as drugs alongside illicit substances.

All molecules with a psychotropic action must of course undergo therapeutic testing on human subjects. These tests pose specific problems associated with the mental state of the patient. He may be in a state (agitation, violence, intolerable moral suffering, suicidal tendency) such that it would be totally incompatible with medical ethics not to prescribe a substance which has an effective action. In contrast to that basic principle of prescription, it is desirable - in order to prove that a new molecule has a specific psychotropic effect on depressed patients - to conduct tests against placebos and not, as is normally done, against a reference product. This kind of therapeutic test can be performed only on condition that the following recommendations are followed:

a) the study must on no account include adult patients who have refused or were unable to give genuinely enlightened consent or those whose condition and case history were so serious as to necessitate immediate use of a proven form of therapy;

b) patients in hospitals must be placed under close medical surveillance in specialized units which are trained in the prevention of suicidal behaviour;

c) the experimental protocol, which will be brief must provide for the possible premature discontinuation of the test and replacement of the tested treatment by a reference product;
d) a long-term evaluation of the risks incurred will relate, in particular, to the dangers of
dependence and tolerance;
e) therapeutic testing on children poses particular problems. The medical treatment
contract is based on the consent of the patient; in the case of children or adolescents, it
is vital to obtain the agreement of their parents or guardians. When children are
involved, the problem of obtaining the consent of the child himself arises when he
reaches the age at which he may be regarded as capable of understanding the principle
of the treatment and possibly of declining it. Children are thought to be consciously
capable of this decision from the age of 9 or 10 and they should therefore be given
information in a manner which accords with their level of cognitive and emotional
development. However, in psychiatry, many children may show, to varying degrees,
retarded or distorted faculties of judgement and understanding. In consequence, it is
more logical to refer to their mental age rather than to their chronological age.

The situation in regard to consent obtained from legal representatives is not
always easy. For example, there may be a disagreement between the two parents or
between the parents and the child (divorced couples, children who have been the victim
of abuse, etc.).

For the consent to have real value it must be freely given and enlightened;
compliance with those conditions by the parents is not always easy to secure.
Obtaining consent from the parents may not be sufficient in some cases to protect the
rights of their handicapped children. The mere fact of having a child with a severe
handicap may lead the parents and professional specialists to modify, albeit in a subtle
and involuntary manner, their ethical standards in relation to these children. There are
examples of research performed on mentally handicapped children with the consent of
their parents under unethical conditions. The administration of psychotropic substances
to children is extremely widespread in some countries and is sometimes based on
insufficiently verified psycho-pathological assumptions, e.g. the administration of
amphetamines to hyperkinetic children.

One last risk must, in our view, be highlighted in respect of the therapeutic indications
of new molecules, i.e. the abusive widening of the field of prescription. Some pharmaceutical
substances with a specific action on serious psychotic states may be administered to a patient
during minor mood or affectivity episodes that do not in themselves justify the use of
molecules which have secondary effects and are not without long-term risks. For example, it
may be dangerous to extend the prescription of palliative remedies that are useful in neuro-
degenerative conditions of the brain to purely preventive indications, e.g. against ageing. With
profits in mind, pharmaceutical companies and prescribing doctors may sometimes be tempted
to give in to strong social pressure.

III. 1.2 Neuro-technology

The rapid pace of development of computer science enables us to suspect the future
importance of an area of the neuroscience which has as yet hardly been explored, i.e. the
creation of chimeras no longer associating animal tissues of different origins but bringing
cerebral tissue together with what might be termed an electronic tissue. In the present state of
knowledge, we have prostheses which are capable of replacing and repairing a damaged
sensory or motor system. In future, the implantation in the brain itself of microelectronic
circuits might be envisaged to replace or supplement higher cognitive functions. The ethical
problems posed by such techniques are not so very far removed from those raised by implants
of animal tissue, e.g. foetal nerve cells or strains selected or converted with a view to the
secretion of specific chemical agents.

The field in which the use of microelectronic implants has made the most progress is
that of cochlear implants and, to a lesser degree, retinal implants. The technique of the
cochlear implant consists in introducing a number of stimulating electrodes into the cochlea;
these electrodes activate the fibres of the acoustic nerves by means of electrical pulses whose
characteristics are determined by those of the sound signals received by the subject. The ethical problems posed by the use of a prosthesis of this kind are far more complex in the case of young children suffering from severe deafness before learning to speak, i.e. “prelingual” children, than in persons who have become deaf after learning to speak. Firstly, these “postlingual severely deaf subjects” who are generally adults can themselves take the decision to have an implant. Secondly, it is possible to make a sufficiently objective assessment of the effectiveness of such a prosthesis. Overall, the results are positive. The epigenetic traces left in the central nerve structures involved in the learning and prolonged exercise of oral communication probably play a favorable role in the restoration of satisfactory oral communication.

The situation is quite different in the case of prelingual deaf children - firstly, because the decision to make the implant is taken by parents who are often disturbed by the deafness of their child and, secondly, because insufficient objective data is available to assess the effectiveness of the implants. In addition, we do not yet know how the central nerve structures which have received very little acoustic information will treat the information supplied by the prosthesis, which differs substantially from the physiological information.

In its Opinion n°44 of 1 December 1994, the National Ethical Consultative Committee for the Sciences of Life and Health of France (CCNE) expressed the view that as long as uncertainty prevailed, everything must be done to avoid jeopardizing the cognitive development of these children. It recommended the association of cochlear implants with tuition in the use of sign language whose effectiveness in this area is proven. With this sign language, children will have a mode of communication that will enable them to ensure their cognitive development and psycho-affective equilibrium. On the other hand, systematic limitation to the learning of sign language was not felt desirable by the Committee as it would deprive the children of the possibility of learning the oral language. In short, the CCNE favours bilingual education in prelingual deaf children.

At a world conference on the brain-computer interface, the German Academy for the Third Millennium proposed a charter governing neuro-technological research. On the whole, this charter suggests the same rules of caution and long-term follow-up as have been applied in the case of other manipulations of the brain.

III. 1.3 Genetic Manipulations

The discovery of the brain development genes, and the role that some highly discrete genetic modifications may have played in the cerebral development of pre-human primates, leads us to envisage frightening possibilities of interference with the development of the human brain. The absolute rules protecting the germline do, for the time being, shelter man from any such misguided, “demiurgic” temptations.

III. 1.4 Intervention to Enhance Human Performance

For the most part, these are techniques which permit intervention to influence human behaviour and the cognitive abilities of individuals and groups. The objectives are to understand the skills and performance of the human being during the different periods of his life, in both habitual and exceptional situations. These methods range from straightforward observation in the natural or standardized situation to tests of reactions under “extreme conditions”. Subjects are recruited on a voluntary basis. The sub-disciplines that have been identified are: psychology of the child and development, social psychology, cognitive psychology, psychology of work, ergonomics, psycho-linguistics, psychopathology, clinical psychology, neuropsychology, psycho-pharmacology. There are many interfaces with neighboring disciplines: anthropology, neuroscience, psychiatry, linguistics, sociology, educational sciences, artificial intelligence, etc. The main lines of the directives on research involving human beings formulated in the United States of America by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1974-1978) or in Canada by the Medical Research Council (1986) and later by the National Council on Bioethics in Human Research (NCBHR) are identical to those applicable to all research on human subjects in the biomedical and human sciences. More recently, they were embodied in the Opinion of the CCNE (n°38, October 1993) on research in the behavioral sciences.
We shall confine ourselves hereto drawing attention to a few specific aspects:

a) Under what conditions is it permissible to perform behavioral research on subjects whose ability to consent is doubtful (limited competence, dependence)? The vulnerable categories requiring special protection in behavioral research are: children, the mentally handicapped, persons who can easily be manipulated because of a specific weakness or dependence (e.g. drug addicts), captive institutionalized populations (prisoners, pupils, adolescents in supervised education, young people in homes, members of the armed forces, refugees).

b) How can the obligation to secure enlightened consent be reconciled with the methodological need (which may be encountered in some experimented protocols) of not telling the subject everything? In other words, what frontier can be drawn between deliberate deception for research purposes and manipulation of the individual?

c) Another major ethical problem is posed by the sharing, for research purposes, of medical and/or psychological information about individuals; this is currently prohibited in France by law and by the code of medical ethics. The CCNE for its part takes the view that some research of acknowledged interest may be performed in a context of shared professional secrecy. If, for the purposes of their research, psychologists need to process under their own responsibility certain medical data identified by the name of the test subjects, these psychologists would have to be given “special authorization” and the medical Practitioner must have been explicitly authorized by the persons concerned to divulge this data. The same requirement applies, by corollary, to practicing psychologists.

It would seem desirable for research protocols in the sciences of human behaviour to be presented, before the research is performed, for an opinion to committees which might be “consultative committees for the protection of individuals specializing in behavioral research”; their membership would have to guarantee a sufficiently wide representation of professional expertise.

Their purpose would, in particular, be to guarantee that the freedom and security of subjects are protected:

- by making sure that the proposed experiments do not pose a threat to the security or dignity of the participating persons;
- by assessing the procedures laid down for informing and obtaining the consent of the persons taking part in the study, especially when that information has to remain incomplete in the initial phase.

These investigations should also evaluate the psychological and behavioural therapeutic methods which are all too often left to the sole discretion of the researchers concerned.

III.2 Social Impact

1. Here we shall draw attention first of all to the delicate relationship between the neuroscience and the media or, more generally, public opinion.

2. Nowadays, the science of genetics wields considerable power over the human imagination. There is a strong temptation to associate the different forms of deviant behaviour and, more generally, all the character traits of an individual with genetic determinism. We can observe the publication and disclosure to the general public, often without the necessary precautions, of references to the gene of homosexuality, aggressiveness or even the gene of crime, etc.

3. When it comes to deviant forms of conduct, notably in sexual matters, there is a choice between preventive detention or the use of chemical substances which act directly on certain nerve centres and by doing so diminish the libido without, however, totally precluding the possibility of a repetition of the offence. Tolerance and respect for the autonomy of the individual must be weighed up against the social threats that an individual may pose.

4. Finally, the neuroscience lie at the heart of the immense problem of drug dependence which will not be dealt with in this report.
IV. Conclusion

This Report has no ambition other than to show the extensive scope of what are referred to today as the neuroscience. We must of course point out that Man, in his natural and cultural dimensions, is always present on the horizon of each of the many constituent disciplines involved. While the neuroscience do bring hope, notably in the area of mental health, they are also a particularly dangerous terrain for genetic manipulation and for the use of pharmacology and computer science for behavioral ends. As a possible instrument of encroachment on human liberty and dignity, the neuroscience may also turn out to be a poisoned chalice on which the worst forms of ideology may thrive. The purpose of this report is to examine in a clear-sighted way and without complacency, the hopes and risks involved and to issue a few warnings of an ethical nature.
Chapter 2

GENETIC COUNSELING

(Michel Revel)

This report on genetic counseling and its bioethical implications, is a natural extension of the 1994 Reports on genetic screening and testing, and on gene therapy, because it addresses the impact that these fields of science have on the individual person (born or to-be-born) and sometimes on Society.

The increasing availability of genetic tests confers to the specialty of genetic counseling a fast growing place in medical practice. Genetic counseling provides the link between genetic technologies, several of which have been acquired through the Human Genome Project, and patient care. It can be defined as a communication process which involves diagnosis, explanation and options (Section II. 1). This Report examines first the scope and practice of genetic counseling today, then bioethical issues related to scientific questions, to welfare of the persons receiving counseling (counsellees or consultands) and finally to moral issues for society at large.

I. The Scope of Genetic Counseling

The genetic tests listed in the 1994 Report of the International Bioethics Committee of UNESCO (IBC) to which several new DNA tests can be added in 1995, indicate that it is possible:

- to establish a diagnosis of hereditary or congenital diseases in affected patients, with accrued certainty and precision (e.g. mutation involved);
- to predict the probability of development of a disease in individuals or families not yet affected (e.g. late-onset and susceptibility genes, carrier state);
- to take measures to alleviate the clinical expression of such disease, to decrease the risk of its development and possibly prevent it (e.g. monitoring, early clinical diagnosis, somatic gene therapy);
to predict birth of an offspring with a genetic disease and allow decisions on the fate of the fetus (measures to take at birth, voluntary interruption of pregnancy);

• to offer means for avoiding conception or implantation of embryos with genetic diseases (e.g. pre-marital counseling, selective implantation, sterilization).

Genetic testing should as far as possible be accompanied by genetic counseling. The scope of genetic counseling is to communicate information and options of the above nature to patients, parents or family. This activity is to be considered as a medical act concerning a diseased condition for which a patient (including the mother of an unborn child) or a family seek help from a medical professional. It ought also to provide support in reaching decisions about options.

Considering that genetic testing will increase as new gene probes are added for the 3,000 known genetic diseases (may be 5% of all human genes), and that there could be a tendency for genetic screening, the extent of counseling may, however, progressively widen to:

• families with histories of diseases (e.g. cancers, miscarriages, psychiatric conditions);

• populations at risk due to reproductive age, environment (exposure to radiations or mutagens, lifestyle) or geographical considerations (areas with high prevalence of genetic disease, such as B-thalassemia in Cyprus, Sardinia, or such as Tay-Sachs disease in Jews of Eastern Europe origin);

• population at large (screening programs, “supermarket” genetic testing), with all the concern this may raise and which need to be weighed against health benefits.

While in many aspects genetic counseling is in the scope of medical professional practice (a predictive medicine), there are many issues which need to be regarded as being rather in the realm of scientific research since the knowledge about genes implicated in the etiology of human diseases, about the limits of their normal variability and polymorphism, about their interaction with environmental factors and with other genes, is still evolving. This ought to be reflected in the process of information communication which is part of genetic counseling. This process is delicate and requires sophistication in informing counsellees (Section III).

The way the practical options open to the counsellees are communicated are a most important part of genetic counseling and often touches upon moral, social or traditional preconceptions and stresses the ethical framework of counseling. It ought to convey the beneficial aspects of genetic testing to the counsellees: better assessment of genetic risk which often reassures, possibilities of being prepared or intervening, safer potential for healthy reproduction (Section IV). However, the moral questions, the socio-political concerns and pitfalls, should be constant preoccupations for genetic counselors (Section V).

II. The Practice of Genetic Counseling: A Survey

This part of the Report is based on answers to a questionnaire aimed to obtain a current view of how genetic counseling is being done in different countries. Answers to the questionnaire were provided by members of IBC and leading professionals. (United States of America: Dr A. Robinson, National Jewish Center for Immunology and Respiratory Medicine, Denver, Colorado; Prof. V.B. Penchaszadheh, Medical Genetics, Beth Israel Medical Center, New York, for the Latino-Americans example; United Kingdom: Dr D. Shapiro, Nuffield Council on Bioethics; Italy: Prof. A. Bompiani, Italian Society of Medical Bioethics, National Committee of Bioethics; Chile: Dr R. Cruz-Coke, Unit of Genetics, J.J. Aguirre Hospital, University of Chile; Mexico: Dr R. Lisker Y.; Argentina: Dr L. Vidal-Rioja, IMBICE; Japan: Dr D. Macer, Institute of Biological Sciences, University of Tsukuba; Israel: Dr R. Carmi, Genetic Service, Soroka Hospital, Ben Gurion University, Beer-Sheba; China: Dr Qiu
Renzong, Bioethics, Chinese Academy of Social Sciences, Beijing; Zaire: Rev. J.M. Mpendawatu, Vatican.) To highlight the opinions, excerpts of the answers are given while clearly the whole documents should be consulted.

II.1  Definitions of Genetic Counseling

The definitions given concur that it is a communication of information about diagnosed genetic conditions, in a way which allows to make a decision, as autonomous as possible, and safeguarding the emotional and ethical character of the person who asks for the consultation. While defined as based on a physician-patient relationship in many countries, the complexity of genetic counseling has led to a new profession of genetic counselors who are not physicians, especially in North-America.

- **United States of America:**
  A communication process which involves diagnosis, explanations and options (as in all medical consultation). In genetic counseling there is a stronger need for detail, especially in the explanations and options, for which empathetic and emotional support are an essential part. Counselors are involved in the ethics of the “people’s right to know”.

- **United Kingdom:**
  Counseling entails precision of diagnosis, the estimation of risks, and a supportive role to ensure that those who are given information are enable to benefit from it and from the interventions that are available.

- **Italy:**
  The objective, methods and indications of genetic consultation are:
  **Objective:** to provide information to patients (and/or blood relations of a patient) at risk of contracting a disease that may be hereditary on:
  - consequence of pathology in question
  - probability of contracting and transmitting it
  - possibility of keeping it in check and treating it
  **Methods:**
  - construction and analysis of pedigree
  - calculation of the risk of recurrence (Mendelian or empirical)
  - estimation of the consanguinity coefficient
  - more specific analysis
  **When is counselling indicated:**
  - known or presumed illness in patient or family
  - congenital malformation
  - mental retardation
  - consanguinity
  - recurrent miscarriage, infertility (more in Section II. 3).

- **Chile:**
  A medical process of communication between a physician and a consultant (counsellor) where scientific knowledge, data and facts are exchanged in order to provide a framework to understand the genetic problem of the patient and the family.

- **Argentina:**
  Better called “genetic advising” - a useful tool in preventive medicine.

- **Zaire:**
  Information on eventual pathology, not therapeutic but predictive.
II.2 Who does genetic counseling? Roughly how many counselors are there? What are their professional qualifications? Are they licensed or certified in some other way?

Differences are apparent between countries in which genetic counseling is done by specialized physicians, or by primary care providers with more or less certification and training in medical genetics, and countries in which there is in addition a professional body of genetic counselors who are not physicians. Psychologists and ethicists may be involved in some countries. The growing demand for genetic counselors of all types is obvious in all countries. When given, the number of counselors per million inhabitants vary: 6-4 (Israel, United States of America, Italy), 2.9 (United Kingdom), 1.1 (Chile), 0.3 (China).

- **United States of America:**

  Several groups of qualified professionals:
  - Medical geneticists: MDs, often pediatricians
  - PhDs in medical genetics
  - Counselors: MSc level
  - Some counseling by primary care physicians, such as obstetricians, some by nurses and social workers (these being not very well qualified at present).

  The majority of well-trained and qualified counselors (first three groups) work in clinics approved and certified by the American Board of Medical Genetics. Most professional counseling in the United States is performed by MSc level genetic counselors, who have had 2 years of training in medical genetics after graduating from college. The training program must be certified by the American Board of Genetic Counseling (ABGC). The program includes all aspects of medical and human genetics, and the students must be supervised by board-certified clinical geneticists. They must present records of 50 cases that they have counseled. The course work includes: clinical genetics, molecular genetics, cytogenetics, counseling techniques, psychosocial factors influencing counseling, ethics and population genetics. To be qualified, genetic counselors must pass an examination prepared by the ABGC. MSc level counselors work under the supervision of a doctoral level medical geneticist, under whose name charges are made.

  There are currently about 950 such qualified genetic counselors in the United States and 60 training programs. There is a professional organization, the National Society of Genetic Counselors (NSCG), which publishes a journal, the *Journal of Genetic Counseling*, and has an active continuing education program. The NSCG has a Code of Ethics to which all counselor are asked to adhere, which stresses confidentiality, autonomy and privacy.

  The demand for qualified genetic counselors exceeds the available supply. The demand will increase more due to the Human Genome Project and to the current stress on identifying those at risk of genetic disease.

  Due to the demand, the primary care providers will have to offer themselves commonly needed genetic services. Increasingly, several primary care physicians are sharing a qualified genetic counselor, as part of their organization. Primary care physicians, in general, have insufficient knowledge of basic human genetics and medical genetics. A small number of nurses, especially those in maternal and child health, have been certified by ABMG, and there is a Society of Nurses in Genetics.

  Suggestions for the future are:
  - teach more medical genetics in Medical Schools;
  - have more genetic counselors;
  - teach genetics in nursing schools.

  The future will require of all who do genetic counseling a much more sophisticated knowledge of molecular genetics (to be aware of the various research laboratories that specialize in tests for specific diseases), so that they can understand and relate to the counsellee what is involved and obtain their informed consent. The special needs for ethnic groups in the United States are referred to in Section 11.6.
UNITED KINGDOM:
In 1990, there were 125 medical staff in British genetic centres: 48 consultant clinical geneticists, the other junior or other medical staff. There are non-medical genetic registrars (about 40) with educational approval by the Joint Committee on Higher Medical Training, who keep contact with high risk families. There were another 80 genetic co-workers including genetic nurses. A two-week course is offered by the Institute of Child Health, followed by a 6-month project work. Training of general practitioner and nurses is promoted by the voluntary Genetic Interest Group (GIG).

Most individuals and couples known to be at high risk are counseled by specialists according to recognized ethical and professional principles. This should be extended to community-based population-screening services. In the future, medical genetics should be part of the core education curriculum of doctors and nurses; screening and counseling should start at the level of primary health care, e.g. in family planning clinics; it may be integrated into general obstetric care, with help of obstetricians who can provide proper support for prenatal counseling, every unit having at least one midwife trained in genetic counseling. Simple genetic information could be incorporated into school curriculum.

ITALY:
The genetic counsellor’s (consultant) function is classified as a health service. There are no special regulations. There may be conventions (agreements) between hospitals and universities or research centers (to perform genetic tests).

There are 54 public centers affiliated to the Italian Society of Medical Genetics (ISMG), with about 3-5 counselors by center (150-250 in total). There is an unestimated number of private centers. A center may comprise 3-5 professionals, typically:

- a medical geneticist or doctor with specialization in medical genetics;
- 1-2 biologists in cytogenetics and/or molecular biology;
- a psychologist;
- an ethicist.

There are also 1,500 free public family consulting rooms (dealing mainly with contraception) which should eventually be authorized to provide genetic consultancy service, if only in the form of guidance.

The professional qualification of counselors varies: generally there are heads of university centers or services for medical or human genetics. The vast majority would be MDs, teachers or specialists in human/medical genetics. Doctors and biologists have an initial post-graduate qualification in specialization schools in medical genetics, human genetics or cytogenetics. In order to acquire expertise in genetic counseling (consultancy), it is necessary to complete a period of training, which has not yet been made official.

CHILE:
Only physicians (medical geneticists and primary care physicians trained in medical genetics) are responsible for this specialized medical service. They have legal and ethical responsibilities.

MEXICO:
Formal genetic counseling is performed by trained physicians who number around 100. Many counselors have at least one year of previous training in Pediatrics. Most counselors take a 2-year graduate course in medical genetics, which are available in several of the larger cities in Mexico. The counselors are certified by a National Board of Medical Genetics.

Other physicians involved in management of patients with genetic diseases are obstetricians, pediatricians, surgeons; they may lack proper genetic training, but have the trust of families and answer questions which are in the area of genetic counseling. It has been difficult to regulate proper training.
ARGENTINA:

Genetic advising is ordinarily performed by physicians (MDs) with medical genetic qualification. Since teaching of this specialization in Medical Schools is rare, most present geneticists got training in North-America or Europe. Their background and expertise were then examined by a board from the Argentine Society of Genetics, which awards the title of specialists. Recently, courses and residency in medical genetics were implemented at the National Institute of Medical Genetics, including theoretical and practical aspects of counseling.

Thus, genetic counseling is included in the patient care by medical geneticists and does not require other licensing or certification than that of medical genetics.

The number of services for clinical genetics, cytogenetics and associated areas, is not large and they are concentrated in big cities. The demand in distant places exceeds the supply. Plans by the State to increase care services for medical genetics, forensic and genome diversity, as well as teaching programs in genetics, are far from being implemented.

JAPAN:

Genetic counseling is done by clinical physicians, especially obstetricians and gynecologists (OB&G), pediatricians. Of the 80 Medical Schools, only a handful have professors of genetics. There are no genetic counseling courses, but maybe in the near future.

ISRAEL:

Genetic counseling is done by both medical geneticists (MDs) and genetic counselors (MSc, a few PhDs), the latter engaged in more “routine” cytogenetic tests. Medical genetics is a subspecialty requiring board certification in pediatrics, OB&G or internal medicine plus 2-3 years of residency in genetics followed by board certification examination. Genetic counselors are not yet formally a profession but require an MSc in biology plus 2 years field experience in a recognized genetic institute before licensing by the Ministry of Health as clinical geneticists in genetic counseling. There are about 30 counselors in Israel (for 5.3 millions) about half of them MDs. About 10% maybe in private medical centers.

CHINA:

Geneticists work in general hospitals (internal medicine, OB&G, pediatrics, psychiatric departments), institutes of maternal and child care, institutes of science and technology in family planning. They have a diploma of medical school, have been trained in genetics in medical schools in China, but mainly abroad. No formal course of medical genetics even in Peking, no special licensing.

About 400 geneticists work in China (1.2 billions), a tiny number.

ZAIRE:

Absence of qualification or certification, which is urgently needed. The young generations should be sensitized through genetic education even in high-schools.

II.3 By what means do individuals or couples get access to genetic counseling? Is it government sponsored and/or undertaken by voluntary organizations? Is it associated only with research hospitals? Is reimbursement covered as part of the national medical treatment?

In most countries, access is by referral from primary care physicians. According to the general medical system of a country (state or private medicine), genetic counseling can be free, or partially reimbursed or dependent on the private health insurance of the patient. The need for making genetic counseling available to the needy (especially aliens, immigrants), or of having special programs, has been recognized by some countries. Some promote genetic screening and counseling at the national level.
• **United States of America:**
  Couples have access to genetic counseling, in general, through referral by primary care physicians or by self-referral. Several primary care physicians may share the service of a qualified genetic counselor. Some counseling is done in specialty clinics such as for neurofibromatosis, neurology, hemoglobinopathies, or for prenatal diagnosis.

• **United Kingdom:**
  Screening and repeated counseling is encouraged actively, at the level of primary health care, including at preconception, i.e. these services should become part of family planning. Educational material should be provided by a national genetic information centre. A National Confidential Inquiry into genetic disorders done on behalf of the Department of Health (as part of its clinical audit programme) encourages greater awareness and understanding of the significance of genetics in clinical practice, beyond specialized clinical genetics.

• **Italy:**
  Access usually through general practitioner or specialist (OB&G, pediatrics), but also direct access on basis of public or medical information. There are 1,500 State-supported Family Consulting Rooms, dealing with family planning (e.g. contraception), which should become officially authorized to provide genetic consultation. There are special programs at regional levels (e.g. diagnosis of β-thalassemia, in Sardinia and Latium).

  **Reimbursement.** It is possible to apply to the local health unit to cover expenses of genetic consultations, but there remains a problem with illegal immigrants who have no health coverage. Consultations can be in university/institute clinics, in public or private research centers. Consulting is often free of charges but laboratory analyses have to be paid and only in some cases there is partial reimbursement by the National Social Assistance Service. The State could intervene more effectively through the family consulting rooms which are free, and through programs in regions with prevalent genetic diseases such as β-thalassemia.

• **Chile:**
  Access through referral by physicians or self-referral. Genetic counseling is a regular medical service within hospitals and clinics where patients come to consult on their genetic problems.

• **Mexico:**
  Access is through government hospitals (not necessarily research hospitals) and private medicine. Referral to the geneticist-physician by other physicians who believe their patients need counseling.

• **Argentina:**
  Genetic advising is included in the care role of medical geneticists. There are no fees in hospital services sponsored by the government (State administrative departments or public universities). There is reimbursement for genetic and counseling expenses at semi-public and private centers, which is awarded by the health assistance system subscribed by patients.

• **Japan:**
  Access is through compulsory health insurance, and patients can go directly to public or private clinics. Access to some university hospitals is easier by referral. Prenatal diagnosis is not directly covered. Some local city or prefecture taxes, that cover maternity costs, may be used to defer costs to the clients. But this is not part of the National health insurance (childbirth is not viewed as a “disease”).

• **Israel:**
  Access is by referral from hospital pediatrics, neonatology wards, outpatient clinics as well as community “mother and child health” clinics. Many visits are by self-referral. Genetic
counseling is in all major hospitals, which are all university-affiliated, but also some private medical centers or health insurance clinics. Cost is covered by the National Medical Insurance, although reimbursement of laboratory tests varies and is a matter of discussion.

- **CHINA:**
  Only hospitals or institutes sponsored by the Ministry of Health, or bureaus for health of municipal/provincial governments, provide genetic counseling, which is free. But if the clinic is not the one, which has a contract with the working unit of the patient, payment is required. A reform of the health care program proposes that all clients pay a small part of the costs.

- **Zaire:**
  Genetic counseling is not reimbursed by social security although some tests, e.g. karyotyping, are reimbursed.

### II.4 When does genetic counseling characteristically get done? Is counseling directed to potential parents, couples, individuals? Are there limits on seeking genetic information about children at a time when no treatment is possible?

In most countries, counseling seems to be addressed to every situation when a genetic disease is diagnosed or even suspected. Most commonly, to couples who have an affected child and in the framework of prenatal testing. Pre-marital counseling, for consanguinity or for regional or ethnic reasons, is practiced. Counseling to individuals with late onset diseases may be more delicate. Some people may not want to know of the probability of an untreatable disease. However, there seems to be no limitation on seeking information about children for untreatable disease, and the importance of clarifying who is a carrier of an untreatable genetic disease, for better research on such diseases and for later reference if a treatment becomes available, is recognized. Genetic information may often help in correctly labeling a disease, for example in cases of mental retardation or neurological, psychiatric disorders, and counseling is then important. Screening of newborns for genetic disease is still ill-defined in its extent and scope.

- **United States of America:**
  Frequently, to couples with previous child having birth defect or mental retardation. Also, in cases of familial history of cancers, heart disease or psychiatric disorders. Other indications are: recurrent miscarriage, infertility, family history of genetic problems, or pregnancy over the age of 35 years. Also known, exposure to teratogenic drugs.

  Screened newborns identified as affected by a genetic disease should receive counseling by genetic counselors. This because the carrier state should be clarified (independently of treatment). This applies also to ethnic groups with an increased incidence of specific genetic diseases. Some genetic counseling is done to patients in specialty clinics (Section 11.3 above).

- **United Kingdom:**
  Genetic risks should be known and counseling given before a pregnancy occurs so that testing can be offered as a planned procedure (preconception stage, i.e. family planning). Prenatal diagnosis is the approach chosen by most informed couples at risk for severe genetic disease. Genetic counseling for prenatal diagnosis should be given as early as possible during pregnancy. It is essential for counselors to keep in touch with couples and inform them of new medical developments, so that the high-risk couples can decide to use testing (e.g. chorionic villus sampling or DNA testing) for having healthy children. Community-based mass-screening can involve every pregnant woman in screening for fetal abnormalities, and the need for counseling is already large and will increase.

  Prenatal diagnosis encourages reproducing: when test is not available, about half couples at risk counseled opt to stop reproducing. When offered prenatal diagnosis, 98% of at risk couples (e.g. thalassemia) use it to achieve a healthy family.
ITALY:
Genetic consultation targets both individuals and couples or parents. The point of departure is a precise diagnosis set out in writing by a physician or a health unit. It is of fundamental importance to ascertain the parent’s reason for requesting counseling, to ascertain their expectations which sometimes may vary between partners.

No restrictions are applied to the quest for genetic information concerning persons, mainly children, affected by incurable pathologies. With the consent of the person concerned or the person holding the necessary authority, the collection of data is essential in order to acquire greater knowledge of case surveyed and to further studies on the genetic/molecular basis of a disease. The ultimate aim is to improve therapeutic prospects.

CHILE:
Counseling to individuals, potential parents, close relatives, couples and individuals with consanguinity risks. In fact, to every person and members of their family. The most frequent indications are:
- birth defects, recurrent miscarriages, infertility;
- prenatal diagnosis, teratogenic drug exposure, paternity testing;
- mental retardation, psychiatric disorders, sexual deviations.

Newborns are screened only for phenylketonuria (PKU) and hypothyroidism in urban areas.

MEXICO:
Counseling is done mostly after the birth of a child with genetic disease or malformation. It is usually done in the outpatient clinic. Pregnant women afraid of having an affected baby, or consanguineous couples planning to marry, are counseled.

Newborn screening and parent counseling is done in a limited way, only for PKU and hypothyroidism. For diseases without treatment, most people would not want to obtain information.

ARGENTINA:
Consensus is that counseling must be provided once the illness has been diagnosed and the prognosis properly assessed, but each particular case should be considered separately. Genetic advising (of couples) may be a useful tool in preventive medicine; however, it must never overrule the parent’s decision.

Advice to adults at risk of developing a late onset disease should be given, although no rigid rules to follow in these cases. For children affected by untreatable disease or with short-lived prognosis, advice to parents should be provided, albeit each case is to be considered individually (more in Section II. 5).

JAPAN:
Genetic counseling is done only if requested, unless it is a disease in which a particular researcher is interested in.

ISRAEL:
Done throughout life: after birth of a child with genetic disorder, in potential couples or parents with suspected family history, even now in premarital or preconceptional counseling even without suspicious family history. Counseling is used by the public regardless of whether the disorder is treatable or not. It is voluntary, not directed.

CHINA:
Open to couples worrying about their baby being genetically normal, or who have prior defective child or affected relative, or have read in journals or books about inherited diseases and worry about a future or already born child. No limits even when no treatment.
II.5 What are the information ethics of genetic counselors? Do they consider themselves as providing non-directed advice - simply information (however complex the idea of supplying information without advice may be), or do they think of themselves as serving as well social interests in public health?

There is a definite ambiguity in the non-directive aspect of counseling. Even just listing all the options, will have some directive influence. While non-physician counselors or nurses will try to only explain the facts, the primary care physician counsel will most often be more directive. The ethics of counseling vary with who does the genetic counseling, but also with the nature of the case dealt with. A constant is that the welfare of the counsellee should always be above any consideration of public health and certainly of “society interest”. This is in fact anchored in the European Bioethics Convention, approved by the Assembly of the Council of Europe on 2 February 1995, which states the “recognition of the supremacy of the interest and well-being of human beings vis-à-vis the mere interest of society and science”.

* United States of America:
  Counseling by MSc-level (or Ph. D.) genetic counselors is non-directive, whereas counseling by primary care physicians (especially obstetricians) is more likely to be directive. The genetic counselors (MSc) do not try to serve social interests of public health: their main obligation is the welfare of counsellees.

  While non-directiveness is a widely accepted ethical principle, experience has taught that Latino patients, for example, sometimes view non-directiveness as “detachment” on the part of the counselor. The ethical challenge is to empower the patients to make their own decisions while at the same time to provide close emotional support.

* United Kingdom:
  Counseling aims to be non-directive, putting in perspective the options and their possible outcomes, together with the benefits and disbenefits. However, this does not mean simply telling people the facts and leaving them to make their own decisions. Counseling involves actively helping couples to reach decisions in the context of their unique medical, moral and social situation.

* Italy:
  The rule is that of non-guidance. But, if due to the counsellor’s personal convictions, it is felt necessary to take into account the social interests of public health, this is explained as part of the whole information given. Genetic counseling deals mainly with the problems of individuals (rather than society). The objective is not to provide a pre-established solution based on particular standards of individual or social well-being - but to explain every possible solution as objectively as possible, to allow a free and conscious choice. This may be hard to achieve; therefore, the psychologist in the counseling center plays a fundamental role as supervisor of the geneticist’s work, both in substance and in form.

* Chile:
  Counseling is more likely to be directive, but in complex problems counseling is non-directive (for example in prenatal testing or in paternity determination). The information ethics of genetic counseling is based on classical medical ethics. It should respect the autonomy of the counsellee.
• MEXICO:
Most genetic counselors view themselves as providing non-directive information. However, the evidence is that when faced with concrete clinical problems, their advice is indeed directive.

• ARGENTINA:
The details of counseling depends on the case: for example, Down’s syndrome for an aged mother would be “simple” counseling, Genetic testing for a child with ambiguous genitalia would be more complex: the counselor will predict the risk for future offsprings, advise on preserving hydroelectrolitic balance, recommend genetic sex determination before civil registration of the child’s gender. In prenatal counseling, advising should not overrun the parent’s decision.

Counseling with intent to prevent spreading of recessive genes in the society seems to be of low relevance, because of the high number of recessive genes, and the high mutation frequency of certain genes.

Advice to adults at risk for late-onset disease should be given although there are no rigid rules to follow. Advice to parents of children affected by untreatable diseases, or short life expectancy, should be given, albeit each case must be considered individually.

Most important, counselors must be cautious to avoid that counseling itself becomes iatrogenic, causing more harm. To protect a counsellee’s welfare, the information given may be only partial. As an example, take a couple - well over reproductive age - with a son affected by an X-linked disease and who was about to die. The son’s pedigree revealed that this was a fresh mutation, and the risk in other members of the family did not exceed the usual statistical probability. The mother was so deeply affected by the hopeless child that distressing her more seemed too cruel; therefore, she was not informed that she was herself the carrier of the X-linked disease, and information on the gamete in which the mutation had occurred was omitted.

• JAPAN:
Officially counseling is non-directive. However, given the unequal relationship of client and counselor, it may be very difficult to assume it is perfectly non-directive. For example, some doctors may recommend and other may refuse to perform abortions for Down’s syndrome.

• ISRAEL:
Basically non-directive, providing up-to-date, accurate, precise information in the most understandable fashion without any judgmental interventions or introduction of any public health or social factors. Since Israel is an ethnic mixture with many new immigrants, counselors face situations where counsellees need some guidance with regard to certain decisions that need to be made; however, it is always the interest of the counsellee and not of public health which is being served.

• CHINA:
Genetic counselors seem in between providing non-directive information and serving social interests in public health. They should not make decisions based on their own values for clients, even when clients, because of ignorance or frustration, want counselors to tell them what to do. It is a guiding role: often both sides share the same values, There is a feeling that these should not be against government policies, which include reducing quantity of population and raising its quality, meaning quality of life or prevention of seriously defective births. However, if the client insists to have this child, the counselor cannot intervene. There is no governmental directive, but many counselors do what they think is in the client’s best interest as well as social interest.

• ZAIRE:
The frame is non-directive information including means to remediate to the situation. However, one should not only hold a “pregnancy-interruptive” reasoning. The counseling by two experts has to be on the severity of the pathology, and be well separated from the eventual decision by the mother.
II.6 Do genetic counselors pay attention to the language difficulties and other, encountered in conveying information and/or advice, for instance to individuals from ethnic minorities?

Language communication is the key for insuring autonomy of the counsellee and free in his decisions. Difficulties in genetic counseling are numerous, and are often due to the difficulty to translate technical concepts, such as probability or heritability into words that can be understood in all what they encompass. This becomes increasingly true as the technical possibilities for gene diagnoses diversify rapidly.

There may be different sensibilities in ethnic groups in whom higher incidence of particular genetic diseases are noted. This incidence should be viewed as due to regional or ecological causes and not as ethno-racial traits. The language of counseling must not only convey information but harmonize with the cultural, social and religious environment. For example, support for the patient is more important in low socio-economic groups and non-directive counseling may be perceived as detachment, lack of interest on the part of the counselor. Moreover, immigrants and aliens are often poorly covered by health-care insurance programs.

- UNITED STATES OF AMERICA:

Ethnic groups with increased incidence of specific genetic diseases should receive counseling. Carrier states, if diagnosed, should be clarified.

The example of genetic counseling of Latino-Americans is developed by Penchaszadeh (3). The overall frequency of genetic disease is similar to other ethnic groups, with specific higher incidence of hemoglobinopathies and neural tube defects. But, almost 1/3 of Latinos in the United States have no form of health insurance. Preference for Spanish-speaking health providers contribute to a reduced access to health care, since there is a shortage of such professionals, especially genetic counselors. The primary ethical concern in genetic counseling of Latinos is the deficient access to genetic services. Another problem is stereotyping: counselors should be aware of the heterogeneity and beyond cultures, every patient should be addressed as an individual. Spiritual/religious beliefs must be taken into account for an ethically responsible genetic counseling. Individuals have a very personal interpretations of religious teachings, particularly for reproductive decisions, which are also influenced by economic concerns, limited family assistance and education. The ethics of non-directive counseling is challenged when, as frequently occurs among Latinos, the patient sees him/herself not as an autonomous individual but as a subordinate of the health professional. Women may be too submissive to the will of their husbands. A high number of pregnant women are young, single and burdened by socio-economic troubles that make genetic risk appear ridiculously low in comparison. Disbelief of genetic risks and test results, because of superstitions or beliefs in supernatural explanations, require exquisite sensitivity and respect by the counselors. Reliance on written educational materials require adjustments for literacy levels, cultural relevance. Tendency to rely on extended family for support and decision-making can lead to “unorthodox” counseling settings. View of non-directive counseling as “detachment” on the part of the counselor makes an ethical challenge to empower patients to make their own decisions while at the same time to provide close emotional support. Cultural values and the wider social context of immigrant experience, poverty, and fear of added burden by genetic conditions, must be taken into account to avoid two ethical perils: one of paternalism, that can lead to authoritarianism and enforced compliance with “eugenics” or “public health” imperatives; the opposite peril being to fail to provide adequate support. Culturally appropriate and accessible services, and social support for individuals facing genetic risks for a child, as well as for those born with genetic disabilities, should be advocated since they are essential to make a reality of the right to decide.

Language difficulties exist in a broader sense in the US society: the possibilities in molecular diagnoses resulting from the Human Genome Project will increasingly require better-informed and more complex counseling to deal with situations such as for examples: Huntington’s disease (variable mid-age onset but predictable outcome); Alzheimer disease
(multigene, late onset, environment role); cancer susceptibility genes (multigene, probability calculation, option of early treatment if diagnosed early through frequent monitoring, preventive measures). There is an increasing ethical concern about screening tests for a variety of cancers, which maybe premature but touch upon the ethics of the “people’s right to know”.

- **UNITED KINGDOM:**
  To meet the requirement for autonomy it is essential to communicate the diagnosis and its implications effectively. This can represent a major challenge since the language, culture and social level of those counseled cover such a wide range. A couple’s decision on whether to embark on a pregnancy at all, or proceed with prenatal diagnosis, may depend on how the information is transmitted.

- **ITALY:**
  Difficulty to translate technical terms and concepts such as probability into words that can be understood by the layman. It is necessary for the counselor to enter into the personality, culture, social and religious environment of the counselee. It is particularly difficult with immigrants (whose background culture is less familiar to the counselor).

- **CHILE:**
  Ethnic minorities have no access to genetic counseling due to the absence of counselors at the primary health care level provided by the National Health Service.

- **MEXICO:**
  Attention to language difficulties in conveying information is given not only when patients belong to ethnic minorities, but also when the socio-economic and cultural levels are low.

- **JAPAN:**
  Language difficulties in understanding doctors generally exist for all patients. Some physicians may use German or English names rather than the Japanese names to hide the nature of the disease or of a drug.

- **ISRAEL:**
  Language barrier is one of the most important concerns in genetic counseling. Genetic counselors are very aware of this and provide translation. Appropriate language and concepts have also to take into account that the society is a fusion of ethnic and cultural backgrounds.

- **CHINA:**
  Genetic knowledge is based on the language of atom and molecule, but traditional Chinese are familiar with the language of *Yin and Yang*. Education will help. There is a cultural barrier also: disbelief or reliance on good fortune.

- **ZAIRE:**
  Ambiguities in language and culture have to be realized to give information as precisely as possible. Certain physicians take too much liberty with this.

### II.7 Is there any government involvement in decisions about what is said in the context of genetic counseling?

The States do not openly control what is said or decided in genetic counseling. However, some countries (e.g. France and Germany) have passed laws, which does involve the State in decisions and options related to genetic counseling.
• United States of America, Japan, Israel:
   No government involvement in decisions about what is said in the context of genetic counseling. Nevertheless, there have been attempts (such as for matters regarding abortion) to limit what physician can say when working in government institutions (for example the “gag” rule which was in effect for a while in the United States of America) (Section IV.2).

• United Kingdom:
   No government involvement in what is being said, but the Department of Health takes interest in informing on beneficial uses of genetic testing or screening, and in keeping genetic counselors in touch with families who may need them.

• Italy:
   Government or regional health authorities will only intervene by defining the levels of general and specialist health assistance. Laws currently in force, safeguarding the health of individuals, including the unborn, must be observed in every respect. However, there are currently no legal regulations disciplining medical practice applied to assisted procreation, which would bring law into line with technical developments.

• Chile, Mexico:
   Government officials and the Ministry of Health are not involved. Genetic counseling is a private affair between persons; the State may be excluded from the process.

• Argentina:
   The State concern for genetic programs in public health care is limited, although it participates in public campaigns aimed at decreasing or preventing infectious, parasitic, nutritional or drug-abuse diseases.

• China:
   No government involvement so far. However, with the enforcement of the Law on Maternal and Child Health Care, officials maybe more involved. But as officials in Ministry of Health say “the Law is a soft law in which many items are advice suggested to citizens”.

II.8 Is information reported to public health authorities? Is information gained from one member of a couple provided to his or her spouse? Is it provided to other members of the family? Are these relationships handled by rules, by custom, or how?

Genetic information relating to patients counseled is not reported to public health authorities. There may be some interests to keep data bases on genetic diseases for research purposes, and care must be taken to respect anonymity. The problem of information leaking to insurance companies, or whether or not it is in the patient’s interest to inform his insurance company could be important to discuss during counseling.

Communicating information to the spouse is in most cases subject to consent by the patient or the person who asks consultation. For the unborn or child, this will be most often the mother, and informing the husband is not automatic. Paternity testing would be a case were confidentiality to the spouse is obvious. Problems may arise in pre-marital testing. Informing other members of the family, including those at risk of having the genetic disease or being carriers, is also usually dependent on consent. At present, these decisions seem to be discussed case by case with the counselor, who must be prepared to handle these delicate questions.
• United States of America:

Confidentiality is most important and, only on rare occasions, where other lives maybe endangered and the counsellees are being uncooperative, is confidentiality broken.

Of increasing importance is the potential impact on privacy by insurance companies. The counselors discuss this with the couples in detail, without telling them what to do, but stressing that the information is as private as they wish.

Information is not reported to public health authorities without the counsellee’s permission. Information is usually provided to the spouse only with the consent of the spouse who has been counseled. The counselor suggests that other members of the family, identified in the pedigree, be informed of their risk of genetic disease, if any, by appropriate counseling.

• United Kingdom:

The highest standard of confidentiality is preserved.

• Italy:

Professional secrecy in medical practice applies to counseling. The reply must be given to the individual who asked for consultation, and only he/she can give consent to divulge the information. The geneticist and psychologist may, in individual cases, stress why it would be advisable to inform the spouse or relatives, but the consent to do so by the person counseled is in any event required.

• Chile:

Confidentiality and privacy are by law, protected from the State and insurance companies. Genetic information is not reported to health authorities, only cases of infectious diseases. Information is provided to the spouse only with the consent of the counsellee, and anyhow restricted to the family.

• Mexico:

The information is not reported to public health authorities. Counseling is mostly done to couples, but transferred to other members of the family only with consent. There are no set rules, and every case is negotiated with the patients.

• Argentina:

Geneticists do not report to health authorities the knowledge gathered on the frequency and severity of genetic diseases affecting different populations. Nevertheless, each center records its activities in its own database. In addition, agreements towards having a National Registry of Genetic Diseases were recently signed between the Public Health Ministry and university institutes.

• Japan:

There is no central reporting or database for genetic disease. It is up to the spouse to tell the partner, unless there is a life threatening disease, in which case the spouse and family may be told before (or instead of) the patient. Whom to tell depends more on the doctor than on custom. Some information may be withheld even from the affected person, e.g. Huntington’s disease.

• Israel:

No report requested to public health authorities. Medical secrecy commits every physician and medical person. Patient consent is needed to forward any information to spouse or any family member. When appropriately identified and for reasonable purposes (e.g. prenatal counseling where there is a concern of a genetic disease in the family and the diagnosis needs to be verified), a physician can request genetic information without the consent of the patient. This is an exception with no written rules.
China:

Information obtained in genetic counseling has never been reported to public health authorities, as obligatory for communicable diseases. If the genetic disease may affect any member of the family, the member should share the information. Generally speaking, consent should be obtained, except if keeping confidentiality of the information will harm the third party. If the client insists not to disclose, and the disclosure of information will do no harm to the client, the counselors should balance the positive and negative consequences caused by disclosure (or keeping it confidential). These relationships are handled by custom as traditionally done; however, great efforts have been made to handle them by rule.

Zaire:

Secrecy rules transfer of genetic information to spouse, family, even to the patient’s physician, unless authorized by the person examined. The physician who does the genetic counseling has to bring the client to reveal himself the pathology or risk if this disclosure to others is useful. Secret can also be kept from one of the parents, except if the patient is a minor: then, his parents have a right to the truth. Confidentiality is also maintained toward health insurance and social security officials.

III. Scientific Issues in Genetic Counseling

III.1 Genetic Technologies

It is important to distinguish between “proof-tested” technologies and new or emerging technologies. This distinction applies both to the type of genetic test available to the counselor, and to the type of human sample on which the test is being done. The new technologies multiply the number of options that the counselor can point out to the counsellee, and often make these options more problematic than in the past. As a researcher stated: “(...) with genetics, the technology far precedes the response to what we are going to do with the technology”.

Types of genetic tests. Proof-tested technologies such as cytogenetics, karyotyping, enzyme tests, are being supplemented by numerous molecular gene probes. The gene probes can detect polymorphisms which have been associated with genetic diseases, and indicate who inherited such “pathologic” chromosome fragments and who has a non-pathologic DNA polymorphism. However, it becomes clear that many mutations can occur in genes related to a disease and that the significance of each such mutation may be different in terms of clinical disease. Detailed analysis by Polymerase Chain Reaction (PCR) sequencing techniques of such mutations or of other variable regions (short repeats) provide information which must be correctly interpreted for good counseling. For example, mutations in the gene for Gaucher’s disease or in the BRCA-1 gene for familial breast cancer are numerous, and before the pathological outcome of each one is determined, prediction of disease is uncertain.

Time is needed to allow these recent research results to mature into “proof-tested” medical practices. Although these technologies are of diagnostic nature, they have a profound impact on life and quality of life, and may have to be regulated like new therapeutic drug approvals.

The many possible sources of human sample tested raise new questions. Testing blood or tissue swab samples from newborns, children or adults, can be prompted by a visible disease, a family history or can be screening programs of various extents. Prenatal testing can be in utero, aided by echography and using fetal cells from amniotic fluid, fetal blood or chorionic villus sampling (CVS) which allows first trimester testing. These techniques, even amniocentesis, present some low risks for the mother and fetus, and have often to be approved by several independent physicians. The time in pregnancy when the results are obtained may be critical for eventual intervention. The new technologies of genetic testing on preimplantation 4-cell embryos, through single embryonic cell DNA testing by PCR, can be used in the context of assisted procreation (IVF). Their success has been shown in many
cases and they allow in principle selective implantation of healthy tested embryos in high-risk couples (examples based on experience in the Unites States and in Israel would be Tay-Sachs, cystic fibrosis, female sex selection in X-linked disease, Rhesus incompatibilities). Even though IVF is complex, lengthy and expensive, it expands rapidly in many countries. More recently, non-invasive tests on fetal cells circulating in the mother blood offer new possibilities to transform prenatal diagnosis into routine procedures applicable to low-risk genetic diseases for which the invasive techniques (amniocentesis, IVF) are too risky or expensive. Pre-marital genetic testing aimed at detecting gene carriers, and counseling heterozygous couples not to have offsprings together, is a form of pre-conception intervention. The advantages, accuracy and safety of each technology will have to be weighed carefully.

III.2 Gene Categories in Counseling

The public information about gene mutations related to diseases grows rapidly, mainly as a result of the Human Genome Project, but is not always presented in a way which allows to understand the meaning of the gene pathological function and even less of its normal function. The equation “gene = disease” is often perceived without qualification, so that it maybe useful to classify genes in order to qualify their relation to clinical pathologies. A proposal is made to distinguish genetic alterations in at least 5 groups, each with differing meanings for genetic counseling.

<table>
<thead>
<tr>
<th>Classification of genetic alterations relevant to counseling</th>
</tr>
</thead>
<tbody>
<tr>
<td>(with few examples)</td>
</tr>
<tr>
<td>I. Lethal in childhood or grave malformations</td>
</tr>
<tr>
<td>• Tay-Sachs (GM2 ganglioside, hexaminidase deficiency, life-span 4 years)</td>
</tr>
<tr>
<td>• Mucopolysaccharidoses (Hurler, San Filipo, death in 2nd decade)</td>
</tr>
<tr>
<td>• Gaucher Type II (betaglucosidase, lethal in childhood)</td>
</tr>
<tr>
<td>• Cystic fibrosis (respiratory disease, median life-span 25 years)</td>
</tr>
<tr>
<td>• Achoudroplasia (nanism, malformations, FGF receptor I)</td>
</tr>
<tr>
<td>• Trisomy 21 (Down’s syndrome, non-hereditary)</td>
</tr>
<tr>
<td>II. Viable-if-treated hereditary diseases</td>
</tr>
<tr>
<td>• Phenylketonuria (low phenylalanin diet)</td>
</tr>
<tr>
<td>• Galactosemia (exclusion of milk)</td>
</tr>
<tr>
<td>• Hemophilia (X-linked, Factor VIII or IX replacement)</td>
</tr>
<tr>
<td>III. Late appearing genetic diseases</td>
</tr>
<tr>
<td>• Huntington’s chores (40 years; early if CAG repeats &gt;&gt;32 in HD gene)</td>
</tr>
<tr>
<td>• Myotonic dystrophy (onset in adult life, CTG repeats in DM-1 gene)</td>
</tr>
<tr>
<td>• Familial hypercholesterolemia (onset 30-40 years, responds to treatment)</td>
</tr>
<tr>
<td>• Alzheimer disease (at least 3 genes, Presenilin I, II, APO-E)</td>
</tr>
<tr>
<td>IV. Predisposition genes</td>
</tr>
<tr>
<td>• Spondylarthritis (HLA B27 -600 higher chances)</td>
</tr>
<tr>
<td>• Cancer: melanoma, bladder (environment factors), breast (BRCA-1, -2 in familial cancer which are 5% of all breast cancers, so role in most cases uncertain)</td>
</tr>
<tr>
<td>• Schizophrenia (but in psychiatric diseases phenotype maybe malleable)</td>
</tr>
<tr>
<td>V. Multifactorial diseases and their genes</td>
</tr>
<tr>
<td>• Diabetes 5% incidence but 6 genes (e.g. MODY = glucokinase gene)</td>
</tr>
<tr>
<td>• Cardiovascular diseases 20% incidence but how many genes? (e.g. cholesterol receptors, angiotensin locus, coagulation factor V)</td>
</tr>
</tbody>
</table>
Remarks on gene classification:

The examples given could sometimes fit in more than one category. The classification does not aim at more than just stating: not all gene testing have the same meaning, and counseling should be appropriate.

In group I, the issues maybe mostly concerned with prevention. Premarital examination and counseling is practiced already for Tay-Sachs carriers in Jewish communities at risk; this could be the best approach because carriers are detected and encouraged not to marry, while preserving anonymity. Preimplantation diagnosis of Tay-Sachs is available, but it obviously entices much more ethical and legal problems. Screening for cystic fibrosis carriers becomes widespread. With certainty, the perception of whether the risk to have an affected child is too big or can be accepted will vary individually among couples and families. However, there will be little discussion that such genetic conditions are not compatible with the kind of life parents desire for their offsprings. Hence preventing birth of such children can be understood by many as a justified behavior.

Group II will hopefully grow in the coming years as more diseases become amenable to treatment. Thus, one may hope for a gene therapy for cystic fibrosis, through virus (Adeno- or others) based gene transfer to the lungs. However, some therapies may have their own problems: blood and platelet transfusions for hemophiliacs has taken a heavy levy of lives due to HIV blood contaminations, and parents who have lost a child - not to the genetic disease but to the therapy - may not want to have another diseased boy. Preimplantation sex determination may bean option in such cases.

Group III shows more difficulties in genetic counseling. Even if the genetic conditions have a high penetrance and disease is almost certain, as in Huntington’s disease (HD), life may be normal until the age of 38-40. The abnormal length of the CAG repeats in the HD protein gene (probably leading to accumulation of polyglutamine) varies, and the length can predict the age of onset of the debilitation. Does that justify prevention? Other diseases appearing late in life, and attributable to a hereditary gene condition, could be added to this group, provided the probability of disease is high. Many, like Alzheimer disease, seem to involve multiple genes.

Group IV raises in addition the distinction between genetic disease and genetic susceptibility. Counseling involves calculating probabilities of disease, probabilities which may also depend on the way of life and the environment. Inherited gene changes which increase susceptibility to certain cancers, or to certain psychiatric diseases, have come into the limelight, but counseling should take into account the many uncertainties.

An example to discuss are the growing number of cancer genes. A relative simple case are BRCA-1 and BRCA-2 dominant gene mutations which could account for 60% of familial breast cancers and 5% of all breast cancers. Even though probability is high (maybe 85% lifetime risk of breast or ovarian cancer), many questions have to be asked regarding age of disease, annual mammography from age 20, in order to avoid labeling the finding of BRCA-1 mutations as a death sentence. Preventive mastectomy seems an extreme measure.

The last group (V) are the increasing number of genes which are implicated in the diseases that are the most frequent in the human population such as cardiovascular diseases, diabetes and other nutritional conditions. These diseases are multifactorial and involve many
gene defects: six known for diabetes, probably more for heart disease. Detection of one or several defects may be valuable in family studies but do not allow yet to evaluate the increase in risk of getting the disease in unselected individuals. Moreover, here as well the lifestyle and environment play a considerable role.

IV. Ethical Issues in Genetic Counseling

II.1 Are All Options Open? Ethical Values of Counseling Options

The Code of Ethics of the NSGC (United States of America) states that counselors “strive to enable their clients to make informed independent decisions, free of coercion, by providing or illuminating the necessary facts and clarifying alternatives and anticipated consequences” (15). The alternatives or options to be explained often involve important ethical questions. Are all these options equally open to the counsellee? Are they all practically and morally justified and comparable?

Counseling for born individuals

The survey has indicated that there are no limits in obtaining genetic data in a child, or adult, even for untreatable diseases. What are the options available for counseling in such cases?

Risk evaluation is one option, that is telling a still healthy person that he/she has such and such probability of developing a disease at a given age. The psychological impact of such genetic predictive testing has been addressed recently in the context of screening for cancer genes” (14). While it could be feared that this may only raise anxiety, counseling had also beneficial effects because of a better assessment of risk. In a high-risk group with familial history of breast cancer, this United Kingdom study found that a quarter of the women were reassured because the risk calculation was lower than the one they perceived before counseling. In another quarter of women, who had underestimated their risk and learned that their risk was higher than thought, counseling did not seem to make them more anxious “suggesting that they would rather not confront the information”. Even in single gene diseases for which gene testing can predict an untreatable disease with almost certainty (e.g. children of Huntington disease patients), most persons concerned take the test and knowledge of the test results seems to alleviate anxiety.

Preventive options may include advising frequent monitoring for early diagnosis of the clinical disease. For example, frequent mammographies for breast cancer would appear a better option than preventive mastectomy. In other genetic diseases, less dramatic preventive treatments may be possible (diet, drugs, psychological help). Examples are present screening of newborns for PKU, hypothyroidism, with immediate treatment.

Gene therapy may become an option in the not distant future, but will most likely be limited to supplying the normal gene into somatic cells (bone marrow, skin, mucosa cells), for example in ADA deficiency, hemophilia or cystic fibrosis (see 1994 IBC Report on Gene Therapy).

Testing all members of the family is an important process to clarify the carrier state for the diagnosed genetic pathologic trait and the counselor will suggest to do so. Questions of breach of confidentiality may then arise (15). Counsellees have in such cases reported deterioration in the relations with relatives (who feel threatened by the information) although genetic counseling appears beneficial for the nuclear family (16). The right of a relative not to know of a genetic disease should be respected. Experience shows that too few individuals ask for the tests. There should be no coercion for family members to undergo a test or receive the results, although the beneficial aspects of genetic testing and counseling should be presented. The mutual responsibility should be stressed.
Confidentiality within the couple. Communicating genetic information to the spouse or partner should be done with consent of the counsellee as in other medical situations (Section 11.8). This may be more delicate when a woman consults during or prior to pregnancy, but the decision should be left to the mother. If relations within the couple respects the sanctity of their union, she will most likely give consent allowing prenatal counseling to be addressed to both member of the couple.

Prenatal counseling

Most subjects of reproductive age at risk of having an affected child with a severe single gene disorder surveyed in a United Kingdom (UK) study express their intention to use prenatal testing. Methods include detecting genetic defects in utero, or prevention by selective embryo implantation or by pre-marital testing (Section III. 1). When diagnosis is made in utero, the options open for counseling can include preparations for treatment at birth, if available, psychological preparation which will reduce the shock, planning ahead the future of the child, but will very often revolve around intervention to terminate pregnancy. As pointed out in the 1994 IBC Report on Genetic Screening and Testing, there are such divergences on the issue of abortion for severe genetic disorders that one can aspire only to the calm discussion of the ethical differences.

The option of pregnancy termination. Code of Ethics of the NSGC states that genetic counselors strive to "respect their client’s beliefs, cultural traditions, inclinations, circumstances and feelings." This is by no way easy to accomplish, as views on many issues varies. In particular, opinions and attitudes on abortion will vary with cultures and religions. In some, conception marks the point from which human life is holy and entitled to its complete rights (immediate animation in the Catholic Church) whereas, in others, the embryo will not be considered as full-fledged human being for different periods of times after conception (e.g. 40 days). This would be for example the position of Jewish law which also considers that if the fetus in utero endangers the mother’s life, the mother should be saved by killing the fetus. While these considerations do not allow free abortion, they can include situations where knowledge of a severe congenital or genetic defect will endanger the mother well-being enough to accede to her will of interrupting pregnancy. This goes to show that not all traditional religions will have the same views, and a fortiori the “inclinations, circumstances and feelings” can be vastly different among those who do not refer to tradition or religion.

It is important to stress that genetic testing and counseling should not be considered as increasing the number of abortions and being suspect of “anti-life” activities. In fact, a Dutch study shows that when no test for a genetic disease (e.g. Huntington disease) was available, 50% of the couples at risk did not want to have children, whereas 85% of them want to have children once genetic testing and counseling is available for thalassemia, the rate of procreation increased from 50 to 98% when a prenatal test became available according to a UK Report. The same applies to sterilization measures: women who had opted for sterilization because of a suspected carrier status for the fragile-X mental retardation, asked for reversal of sterilization following clarification of their carrier status which became possible after cloning of the gene in 1991, and many women of the different risk groups chose to have children Genetic testing and counseling tend, therefore, to increase reproduction by increasing safety and are to be seen in a “pro-life” light, which does not intend to increase the overall rate of abortions.

Selective implantation poses a new and interesting ethical issue in comparison to abortion. Is it preferable morally to select healthy freshly fertilized embryos for implantation than to abort a fetus at the month 3-4? Again the moral discussion may revolve around the definition of when full human life starts (see above), around analogies to “selections” in Nazi concentration camps, around whether a “mother” can be considered endangered by an embryo of which she is not yet pregnant. There are also many practical considerations related to the IVF procedure involved, the cost, the possibility of errors, but the method is being used and legal in several countries (Spain, Israel, United States of America). It is an option in counseling high-risk couples, but must be closely watched as it could technically make possible also germ-line gene therapy, trivial gender selection and eugenics (Section V).
Sex selection is still a valuable technology, e.g., for couples at high risk of X-linked
diseases (Duchenne muscular dystrophy, fragile X mental retardation, hemophilia) and various
methods may be employed (sperm fractionation, selective implantation, selective abortion).
The non-medical arbitrary abuse of sex-selection is not thereby to be justified.

Pre-marital counseling is practiced for carriers of genetic pathological traits, and may
be applicable in regional or ethnic groups with relatively high incidence. Tay-Sachs among
Ashkenazi Jews in Israel or in New York is an example: the method is suited for ultra-
orthodox groups in which sex is limited to married life and weddings are prearranged.
Interestingly, Rabbis are deeply involved in premarital genetic counselling7,8. However, in
some cultural environments, could love for a person not be seen as more ethically valuable than
healthy reproduction? In Cyprus, where premarital screening for thalassemia is mandatory,
98% of couples in which both are carriers still marry according to a UK Report

IV.2 Case-by-Case Individual Counseling versus Regulation, Laws

A consultant-centered ethics of genetic counseling means that it is initiated by a
potential patient and aimed at enabling him to make informed independent decisions.
Centering the ethics on the individual who consults and making it a duty to have is best welfare
in mind, when explaining all the options available, would seem to demand a case-by-case
approach rather than strictly following pre-established laws and regulations, that bind the
counselor by limiting the options available. The counsellee ought to be made aware of what is
legal and illegal in the particular country. However, since laws vary with place and time, the
counsellee should nevertheless be made aware of all possible options. For example, selective
implantation could be mentioned as a possibility, if appropriate in this case, even though it may
not be legal in the particular country while legal in a neighboring one. Selective implantation is
prohibited in France and legal in Spain.

The wisdom of having strict laws limiting the medical options, being it in genetics or in
assisted procreation, may be questioned. Medical ethics, and particular codes of ethics for
genetic counseling, may be sufficient guidelines within which there is room for case-by-case
advising respecting the spirit of the ethical codes. Problems posed by laws have been
encountered previously, as illustrated by Parker3,5: “Anyone attempting to establish a
(government) policy focused on genetic testing itself and sought to prohibit testing to
determine fetal sex should bear in mind recent experience with the so-called gag rule, which
attempted to regulate what physicians in (government) funded clinics could advise their
patients about abortion. Ultimately, this governmental regulation of the private interaction
of health care providers was thought to interfere with the privacy of physician-patient
interactions, to violate protection of freedom of speech and standards of care, and to leave
physicians open to charges of malpractice, and the gag rule was struck down. For similar
reasons, a policy prohibiting genetic testing to determine fetal sex for sex selection should
probably not be imposed by bodies outside the genetic counselling profession”. There may be
justified reasons to fear from trivial sex selection, but such regulations could hinder medical sex
selection in cases of X-linked diseases, such as the case of a couple who, having lost a
hemophilia child, cannot bear the risk of another affected boy and ask for medical assistance in
procreating a healthy girl. In a case by case approach, this assistance maybe granted as ethical
according to the circumstances.

Laws have to be just and consistent. As pointed out for the United States of
America if abortion is permitted through mid-second trimester without any statement of
reasons, a law prohibiting abortion on the basis of genetic information on the fetal sex would
be inconsistent. In Germany, there is self-regulating ethical rule not to provide information on
sex determination prior to the end of the first trimester, the period of legally not penalized
abortion. If such rules are part of codes of ethics from professional bodies, it may be
advisable to provide exceptions which can be dealt with case by case. Such decisions could be
under the supervision of inter-professional ethical committees, like Helsinki committees, that
could include lawyers, philosophers, religious and community leaders.
What is acceptable and bearable by couples and families in terms of genetic alterations, being physical or mental, can be best evaluated in case-by-case decisions. This will be a function of circumstances, beliefs, and feelings. While counsellors should be encouraged (by counselors, by Leagues for handicapped persons) to accept the maximum burden by correctly evaluating the consequences of a genetic condition, the options and possibilities offered by medical science should not be denied by laws, provided that the decision is made in the most autonomous way and with the best possible ethical counseling by physicians, geneticists, and religious or laic ethicists.

The IBC may find it difficult to reach a universal ground of legal agreement on such numerous sensitive issues which vary among cultures and nations, but may be able to stand behind an individual decision-making case-by-case process that operates in the framework of comprehensive ethical guidelines.

IV.3 The Physician-Patient Relationship and Genetic Counseling

What will a counsellor do with the genetic facts presented to him, and how will he reach a decision, is an important question about the bioethics of genetic counseling. In this respect, it appears important to conserve the character of physician-patient relationship in genetic counseling. The sophistication of the topics covered by molecular medical genetics, as well as the psychological and ethical issues, may require and justify the creation of a new medical specialty. In some countries, as the United States, a specialized paramedical profession of genetic counselors has emerged, who are not physicians. Nevertheless, all genetic counselors should be directed to adhere to the bioethics of physician-patient relationship. The participation of other professionals, such as psychologists and ethicists, should be encouraged as their directives will help to reach a decision and to cope with it, but the physician should remain the pivot of the team.

Involving primary care physicians in genetic counseling is also a way to remediate to the current insufficient number of trained personnel to meet the demands for genetic services.

Physicians have an intent to treat, while it may be argued that the function of the genetic counselors should only be to inform of the facts in a totally non-directive way. Indeed, studies have shown that the attitudes of obstetricians, clinical geneticists, and genetic nurses differ in counseling following diagnosis of fetal abnormality: up to 68% of physicians reported counseling in some directive way, versus 43% of the geneticists and 6% of the genetic nurses. However, the bioethics of doctor-patient relationship has evolved from the 70s to the 90s: it is no more a paternalistic (“priestly”) model but a “contractual model according to which, ethical authority and responsibility are shared by professional and client. (...) The relationship between professional genetic counselors and their consultants reflects this shared decision-making process, which guarantees to consultants the authority to make choices reflecting their own values” (quoted from Parker, Ref. 15). Sharing the decision, in a way which respects the patient’s autonomy but takes from him some of the burden, would appear to best insure the moral obligations to help the patient, to maintain or restore his welfare through trust and confidence, obligations which characterize the doctor-patient relationship.

The question of non-directive, objective counseling deserves further scrutiny. As seen in the survey (Section II. 5, United States of America), some persons consider non-directed counseling as detachment, lack of interest in their problem. In this respect, the following thoughts may be of value (Garver and Garver, Ref. 25, quoting from Friedman and Reichelt in the “Los Alamos Science” published by the Los Alamos Center for Human Genome Studies):

“The current standard for the [genetic counseling] profession is to present information in a non-directive, value-neutral way and in a manner that preserves client autonomy. Essentially that means that the counsellor should not project his or her values into the patient. But does this standard work in a practical sense? A patient with a high cholesterol level is not told by his doctor, ‘Your cholesterol is 350. It could kill you, so gather some information on cholesterol and make whatever decision you want’. The doctor’s advice will be much more directive: it is likely to include recommendations about treatment or lifestyle changes that
can ameliorate the illness. Those in the genetic counseling profession, however, still cling to the non-directive counsellor and autonomous patient model - this model is increasingly untenable”. Garver and Garver (25) continue: “This is an inadequate analogy, because when a physician counsels about a high cholesterol level or about a sore throat or most other medical conditions, it does not involve a very important ethical or moral decision by the patient. On the other hand, many medical genetic decisions involve serious questions about prenatal diagnosis, abortion, and sterilization, which have different moral and ethical implications to most patients. These serious moral and ethical decisions have to be made by the patient, with the assistance of the physician, clinical geneticist, or genetic counsellor and sometimes with the advice of his or her rabbi, minister or priest”.

The arguments are well presented, and stress the practical difficulties in non-directive counseling. One could add that often physicians do make important ethical decisions, with the patient’s or family consent, as in the case of grails, major surgery or terminal patient care. Why then do many feel that these situations are different from genetic counseling? This may stem from the fact that in genetic counseling there is usually no certain or immediate medical emergency involved and that, in the case of prenatal diagnosis, the relation to the unborn life is apprehended differently than the relation to an individual with a life-endangering illness. These appear to be secondary and subjective differences, which do not justify to take out genetic counseling from medical practice and to deprive the patient from the more directive support given by physicians.

Difficulties for physician in genetic counseling. Fully informing the consultant about genetic conditions may be difficult for physicians, certainly for primary care providers. The information is complex technically, and the ethical implications, the psychological impacts, may be beyond the physician’s experience. However, a fundamental bioethics principle is that of informed consent, which obligates “to disclose the information in such a manner that a reasonable layperson can understand it and to answer the specific questions which the individual client or research subject may raise” (15). There is obligation of dialogue with the patient. Physicians have to comply with these obligations, which means providing their own time and effort, for counseling as well as for treating. Physicians need often more education in genetics, and should closely cooperate with more specialized professional geneticists and ethicists so that the obligations of communication and information are fulfilled (to enable consultants to make free and informed reproductive and health-care decisions), but without losing the medical intent of helping the patient to maintain or restore his welfare.

Counseling is not a one time affair and should be repeated as needed. The right to a second medical opinion may have to be extended to the right of a second information by another competent professional. This should be granted by the treating physicians in order to respect their client’s own values, and help them reach the best possible decision about what to do. Giving moral support to these decisions is also a primary task of genetic counseling.

V. General Moral Issues Related to Genetic Counseling

The survey (Section 11.7) indicates no involvement of States or governments in genetic counseling, while stressing its essential individual-centered bioethics. However, one should ignore neither the impacts that genetic predictive diagnosis will increasingly have on society nor the reactions of society to it. It is a sane aspect of “preventive bioethics” to anticipate society problems which may be easier to prevent than to cure (15). There are practical and economic issues, but also moral and philosophical dilemmas which may be defused only through a committed educational endeavor toward the public and authorities.

V.1 Social, Economical, Political Issues

Voluntary aspects. Genetic counseling and testing should remain initiated by the individual or the person having legal responsibility (mother). There should not be systematic or compulsory programs imposed by society. Such obligatory screening programs may be prompted by genuine population health concerns (as in regions of high prevalence of a severe
hereditary disease), but could too easily extend to behavioral traits with supposed genetic basis: alcoholism, homosexuality, crime\textsuperscript{26,27}, creating serious concerns of reviving eugenics (Section V.2). Therefore, while society has a duty to make scientifically-proven gene testing available to the public, including prenatal or premarital counseling, it should never make it compulsory but only voluntary. Requirement for genetic testing in certain professions, where biochemical testing is usual (e.g. air pilots), may also be very problematic.

Confidentiality from employer. The predictive aspect of genetic diagnosis may prompt employers to dismiss still healthy employees by fear of eventual later disease. This would be unfair discrimination. On the other hand, knowing of a genetic predisposition may avoid exposure to chemicals, environment that could increase the risk of disease. An employee may sue a company for not having tested such a genetic trait. Thoughts have to be given to such complex issues.

Confidentiality from insurance companies ought to be respected and upheld by proper legislation. This in order to prevent exclusion or higher premium for carriers of genetic traits that may be considered to increase the risk of disease (e.g. cancer genes, mental diseases). Such problems exist in other medical tests (e.g. high cholesterol), and may also be questionable since views on etiology of diseases (e.g. cardiovascular) still evolve with research. With genetic diagnosis, problems are more complex since the number of genes testable is large, testing may precede any symptom of disease or even gestation. People may be penalized for their genotype in a way not necessarily related to their phenotype. The other side of the coin would be persons who have received information about a certain genetic abnormality and may try to obtain insurance protection, for themselves or their offsprings, without revealing the information, thereby taking unfair advantage from insurance companies.

Health insurance can certainly play a positive role by covering costs of genetic testing and counseling, or of early frequent monitoring of disease (e.g. frequent mammographies for BRCA-1) which would not be the case if the insurance covers only tests following a clinical symptom. The issues regarding insurance are, therefore, complex.

Confidentiality from State. There may be similar concerns regarding national health care systems as for private insurances. For cost-effectiveness, health-care rights of families who carry a gene pathology may be jeopardized, because of the costs of genetic testing or cost of hospitalization and care, or worse by encouraging them not to reproduce, if not to be sterilized\textsuperscript{25}. This amounts to double-jeopardy, penalizing those who suffer from a natural variation outside their control (somewhat alike health care discrimination for age).

Data banks on genetic diseases may have values for health-care and research, especially for position mapping and identification of new genes on the basis of family studies. Such data bases should remain as far as possible anonymous, or coded, and not made available for any State activity outside justified ethical research programs, which are peer-reviewed.

Supervision and education of genetic counselors. With the progress of the Human Genome Project, genetic counseling will very likely grow into a full medical specialization, if not a new professional area. Modern genetics should be taught and Medical Schools and in specialized courses. Advising, informing and educating the public about the meaning of genes, polymorphisms, mutations, certainties and uncertainties of genetic determination for health, behavior, performance, even intelligence, will be in great part in the hands of genetic counselors. Involuntarily or unknowingly, the counselors own values may influence their attitudes on these complex issues, some of which touch upon nature/nurture debates where both sides are partly right and which are never over\textsuperscript{26}. These challenges will require guidance and education of counselors beyond what is offered today by professional organizations and their codes of ethics. Who will provide guidance and whether inter-professional and international ethical bodies may be the answer should be discussed. Few would probably want politicians alone to make the rules, but controlling the counselors has to be considered with lucidity.
Commercialization of genetic testing and counseling. New DNA probes and PCR or other diagnostic systems are being rapidly commercialized. Specialized diagnostic companies offer gene testing on a commercial basis and market them actively. This creates much debate, in particular for the group of cancer genes whose value for the general public is quite unclear (Section III. 1). Along with testing, there is a possibility that counseling will also soon be commercialized privately. Although these are diagnostic activities, and could be assimilated to sugar, cholesterol or blood pressure testing provided nowadays as “supermarket” services, such direct marketing of genetic tests can lead to much more complex ethical problems. There are already advertisements for fetal sex determination and selection. Clearly, some thoughts about how to regulate private commercialization of genetic testing and counseling become urgent. Regulatory authorities should authorize the genetic tests as other therapeutic procedures.

Judicial responsibilities. Professional errors made by genetic counselors have already led to lawsuits in several countries. Particularly revealing of the ethical problems are “wrongful life” lawsuits by defective newborns for faulty genetic counseling. As one example an error led to exclude during pre-marital genetic counseling the risk of a woman for Hunter’s disease, and an affected son was born. The granting of personal injury damage to the son implies that the error caused hampered existence while the alternative would have been not to be born at all. While such judgments are consistent with a social justice of compensation for damage caused by malpractice, they raise ethical questions of whether there is a “right not to be born”. Conversely, persons afflicted by a genetic disease, but making the best of their handicapped lives, may thank their parents for not having gone to genetic counseling, because their alternative would have been not to exist. Such lawsuits should not be encouraged, as far as possible.

Justice, fairness and social equality principles should direct and prevail in all aspects of genetic counseling: its availability to all social, ethnic groups (enough appropriate counselors), its initiation (free), its contents (not paternalistic), its options (the same for all social groups).

V.2 Moral, Religious and Philosophical Quandaries

Genetic hygiene: a hazardous concept. Eradicating diseases is a dream of mankind. Medicine has had already some limited victories against a few viral, bacterial, parasitic, environmental diseases. Many may think that, as the Human Genome Project develops, the increasing power to detect and predict genetically transmitted diseases, will allow their eradication by some “genetic hygiene”. One should carefully distinguish between free decisions of individuals to take or not the risk of conceiving and ultimately the decision of bearing a genetically affected child, and between such actions or even recommendations on the part of society. The latter should be regarded as negative eugenics, a dangerous ideology which has not been accepted by Science. The former should be viewed as a private medical decision.

Eugenics concerns. Human applications of modern genetic technology do not have to lead inexorably to eugenic abuse. An essential distinction between genetics and eugenics is the importance ascribed to individual welfare rather than to society. Only if genetic testing and counseling is not done as a private, confidential and free medical practice, with only the participation of genetic, psychology and ethic experts, is there a danger of social eugenics. Societies do not have to impose systematic or compulsory genetic screening to create the danger of eugenics. Indirect actions, such as limiting health care or life insurance to living patients with genetic disease, to couples about to reproduce or to families who have certain pathogenic genes, would amount to discriminatory measures leading to eugenics. Providing advantage to individuals who bring a “clean genetic map” of their own genome or of their children - such as lower insurance premium, certain jobs or other social bonuses - while eroding acceptance and care of genetically disabled, could be enough to raise the spectrum of eugenics. In fact, a simplistic vulgarization of the scientific achievements of human
genetics, stressing genetic determinism or "genetic fatalism"\(^{(27)}\) and neglecting the personal power of accepting, overcoming or compensating handicaps, would seed in the public’s mind the seeds that already brought in this century eugenics and racial discriminations, under false scientific pretexts.

**Objections to eugenics: scientifically there are no good and bad genes.** Genes gencode proteins which have functions in the human body, its development and health. Genes are polymorphic, differing in some of their DNA sequence in different individuals according to heredity. There is no gene for cancer, or for muscular dystrophy or for Alzheimer disease, but some of the varied genes lose their function and cause or predispose to disease. Research has now established that these varieties of pathological genes are in fact often selected for some selective advantage due to certain life conditions or environment. Thus, in a certain region or human group, pathology-causing genes often show different types of mutations indicating that they do not result from one accident and a “founder” who would transmit it to all the affected patients. For example, in La Reunion, sufferers of limb-girdle muscular dystrophy have a number of different mutations in the same gene, indicating that there must have been some selective advantage to have these changes \(^{(31)}\). In some cases, epidemiological and biochemical studies have revealed that the mutant gene, in heterozygous state, protected against other diseases: the sickle cell anemia mutations protected from malaria, the cystic fibrosis mutations protected from cholera, may be even the Tay-Sachs mutation protected from tuberculosis. In areas and times where these other diseases are no longer lethal, the mutations appear to us as bad genes, and their good side is forgotten. If it seems logical to use genetics to prevent birth of homozygous affected by disease, it would make no sense to eliminate the bad genes altogether. We do not know what other beneficial functions such pathologic genes may have, and certainly cannot predict what would happen to mankind were they eradicated. Even in cases where the mutations appear new and unlikely to have been selected, qualifying for being a “gene that went bad”, the eventual advantage of eradicating the variant gene in heterozygotes should be weighed.

The human genetic heritage is imperfect. The frequency of carriers for pathogenic genes is high (1/20 for cystic fibrosis). With the number of genetic conditions, nobody could claim a 100% healthy genome. In the words of the Genethiq Group in Quebec \(^{(30)}\): “All human beings are carriers of abnormal, variant genes which can cause some pathology or susceptibility to diseases; nobody can be qualified as genetically sane or genetically deficient. Discrimination on the basis of genetic make-up would make everyone a target. One has to conceive the individual human being in all its complexity and originality”. These important thoughts point out well the moral attitude to fight eugenics or any attempt by society to make the individual responsible for “purifying” or correcting his genome to adhere to an illusory norm. The notion that the world and man are imperfect is also rooted in religions who care for the weak and diseased as a creature of God as opposed to “survival of the fittest”. Bringing or not bringing a severely diseased child to this world should be an individual decision and not a way to straighten nature (the Jewish mystical tradition states that God made the world imperfect).

Human diversity precludes to define a normal prototype. Respect of human individuality also makes illusive the desire for a “perfect child” with no genetic defect. Eliminating or repairing some pathogenic genes, as justified as it may seem, must not be extended beyond the individual inability to cope with a severely diseased child. Society cannot define what is normal. The word “defect” presupposes that we have a perfect prototype, negating human diversity. Society cannot chose its own prototype, otherwise it may decide that being left-handed, having a certain character or a certain color of eyes, hairs or skin, are genetic defects. Human diversity may be the secret of mankind’s success. The possibilities offered by genetic testing to detect genes predisposing to mental illnesses, even including schizophrenia \(^{(31)}\), have to be taken with great caution. Not only because of premature, erroneous or incomplete conclusions, but mainly because genetic traits do not necessarily equate to high heritability of a certain phenotype \(^{(27)}\). Using genetics to find a way to treat a phenotype is justified, eliminating a risk gene may be a useless and dangerous social exercise. “Each individual has her or his individual heritage, including some special gifts and advantages and some disadvantages and risks (...) everyone of us is handicapped and
challenged in one way or another.” (22) These mental genetic traits may insure human diversity, with its mix of artists, scientists, advocates of established order, as well as free-thinkers. Social environment and education make these genetic traits malleable, and this is certainly true for intelligence for which IQ is a poor measure (24,25). Every human being may be entirely the product of his genes and entirely the product of the environment. Absolute free will and genetic fatalism are two extreme views of human behavior, whose relative importance keep changing according to current philosophies, because both have part of the truth, but true life is a healthy balance between them, a synthesis of the two.

Scientism (not Science) can lead to genocide. If misunderstood, the much publicized achievements of the Human Genome Project and the growing recourse to genetic counseling have the inherent danger of nurturing a simplistic genetic fatalism, of the type which lead to the eugenic measures of sterilization for alcoholics and mentally deficient in several States in the United States of America and Scandinavia. Stefan Kuhl, in a recent book (34), researched the connection between these eugenics measures, which sounded based on a scientific genetic hygiene, and Hitler’s “Mein Kampf” and the subsequent Nazi program of eugenics, with sterilization and euthanasia for mentally retarded and chronic alcoholic. Another book by Lifton and Markussen shows that the scientific prestige of the Nazi doctrine was based on the concept of applied biology which regarded racial revitalization as deriving from Darwinism’s survival of the fittest (Francis Galton who invented eugenics in 1887 was Darwin’s cousin). It shows how this concept served the objectives of the Nazi doctrine for cleaning out contaminating elements - first the mentally retarded and sick, later the Jews and other “inferior races”.

With these and other recent historical precedents using pseudo-medical and psychiatric means to deny human rights, it is clear that great precaution must be taken not to make of science a scientism that ignores or overtakes the moral values of society. Preventive ethics is to foresee such possibilities of misunderstanding science. Genetic counselors, as those who inform the public of the possibilities offered by the modern human genetic discoveries, have a major responsibility in presenting them in an absolute ethical context. Negative eugenics as well as positive eugenics (trivial selection or engineering of sex, eye color, height or other enhancement genetics) are potential social calamities. Ignoring these social dangers could negate all the good which will come out of ethical medical genetic counseling for the individual.

VI. Conclusions

Genetic counseling, as practiced today, adheres to the highest standards of the bioethics doctrine, respecting individual freedom, human rights, and cultural values. It provides an invaluable medical service and will increasingly allow patients in all countries to benefit from the most important scientific advances produced by the international Human Genome Project. A “preventive ethics” approach implies to ensure that all these bioethic standards are maintained and to think ahead of the impacts of the new medical genetics on mankind. Preventive ethics implies to anticipate new ethical issues, with the aim of protecting the individual (born and to-be-born), his welfare, dignity and freedom, so that progress of scientific research does not infringe on them. Organizations, such as ELSI of the Human Genome Organization and the UNESCO IBC can play an immense role, not by imposing a universal order, but by harmonizing individual cultural values and science.

References
3. Penchaszadeh V. B., “Ethical Issues in Providing Genetic Counseling to Latin Americans in the United States of America”. In Vol. II of these Proceedings


See also: *Nature Genetics* 6, 1-12, 1994


See also: Levy-Lahad E. et al., “Candidate Gene for the Chromosome 1 Familial Alzheimer’s Disease Locus”. *Science* 269, 973-976, 1995


See also: *Am. J. Med. Genet*. 48, 137-144, 1993


22. Communicated by Prof. H.-M. Sass, Ruhr-University, Bochum, member of IBC


INTERNATIONAL BIOETHICS COMMITTEE

Working Group on Genetic Counseling

Rapporteurs:
Mr Sidney Altman (United States of America)
Mr Michel Revel (Israel)

Members:
Mr Ricardo Cruz-Coke (Chile)
Mr Ruben Lisker Y. (Mexico)
Mr Jean-Marie Mpendawatu (Zaire-Vatican)
Mr Qiu Renzong (China)
Mr Daniel Serrao (Portugal)
Mr David Shapiro (United Kingdom)
Mrs Lidia Vidal-Rioja (Argentina)
Chapter 3

BIOETHICS AND HUMAN POPULATION GENETICS RESEARCH

(Chee Heng Leng, Laila El-Hamamsy, John Fleming, Norio Fujiki, Genoveva Keyeux, Bartha Maria Knoppers and Darryl Mater)

I. Population Genetics

1. What is Population Genetics?

Population genetics is a discipline studying genetic variation in defined populations, including relevant aspects of population structure and geographic variability of DNA sequences and their frequencies. Their changes in time and space are controlled by evolutionary factors, among which population geneticists recognise as most important: mutation, natural selection (i.e. differential mortality and fertility of genetic types), drift (stochastic fluctuation tied to the demographic size of populations) and migration. Population genetics deals with the characteristics of genes within a population as opposed to the description of the genes in a particular individual. In this report we refer to human population genetics, but the term “population genetics” also applies to all other living organisms.

The biological relationships of human population groups and the theory of evolution can be studied as questions of broad interest to the understanding of human history. Population studies are not new, and in fact large surveys have been conducted all over the world in the last eighty years. Classical studies of genetic diversity have been dealing with antigen, protein and enzyme polymorphisms, for example HLA or blood groups. Modern genetic studies are based on the molecular analysis of DNA polymorphism. Classical studies look at expressed sequences, which represent less than 10% of the genome, whereas molecular genome diversity studies are mainly concentrated in parts of the genome that are often not expressed at the phenotypic level.
1.2 Main Trends in Population Genetics Research

1.2.1 Genetic Epidemiology

Isolated populations are the main source for observation of genetic forces acting in human evolution. While gene frequency across different populations varies for specific diseases, the total effect of genes on mortality appears similar. Pedigree information can be used to observe migration, to measure the mean-inbreeding coefficients, or to trace the linkage of disease. The method used to make a pedigree sheet, and the information sought, depends upon the objects of investigation, the quality and quantity of basic data, and their purposes. In some studies, additional clinical investigations on the hereditary diseases, or common diseases of polygenic inheritance, are included. These epidemiological surveys have been conducted at the ethnic, regional or translational level, according to the disease studied (e.g. Tay-Sachs disease in Ashkenazic Jews, cystic fibrosis in Europe, North America and recently other countries).

Comparative studies can be made on the differences in the mortality and fertility as well as on anthropometric data between consanguineous and non-consanguineous groups. They can be used to test genetic susceptibility using polymorphic markers in different communities, which can also examine genetic susceptibility to environmental agents. This makes possible the prevention of certain multifactorial diseases by careful avoidance of exposure to environmental agents.

Consanguinity and large family size are very interesting for population genetic studies, but studies of consanguineous marriages of families have the potential to raise numerous ethical and social issues. There are opportunities for genetic epidemiological research in countries where consanguineous marriage is a long-standing tradition. Such research projects can use data from many sources, for example, birth and death records, family register books, or anthropological or medical surveys, and socio-economic data in order to test inbreeding effects.

1.2.2 Genetic Screening

Population genetic studies are not new. What has evolved very quickly is the technology and level of analysis. The first genetic studies in populations came from surveys all over the world looking at frequencies of single gene diseases. This was followed by the laboratory analysis of blood samples for the establishment of allele frequencies of blood groups, HLA proteins and enzymes all over the world. Some of these studies were done on banked blood samples that were anonymous in character. Others were conducted, however, on sampled individuals from target populations, some large and open such as the Europeans, or small and isolated, like the Basques - linguistically, culturally, religiously or geographically isolated.

Based on these studies, mass screening programs for particular disease genes were adopted as was the case in Cyprus for thalassemia, or in many countries for phenylketonuria (PKU) in new-horns. Genetic screening and genetic testing have been discussed in another report of the International Bioethics Committee of UNESCO (IBC), and by numerous other persons and organisations over the last twenty years (recent reviews include: Chadwick et al., 1993; Murray, 1993; McCarrick, 1993; Nuffield Council on Bioethics, 1993; Nielson & Nespor, 1994). Many of the issues in current genetic screening programmes are relevant to population genetics research, but some significant issue are different, such as the notion of group consent. Moreover, while at present we are focusing on research, we should also foresee the applications and benefits flowing from the Human Genome Project that could well apply to whole populations. Therefore the ethical considerations must be carefully treated, since whole groups of asymptomatic individuals are the targets rather than single individuals who come forward themselves.

1.2.3 Spatial and Temporal Variation

More recently, molecular biology has enabled geneticists to work out the spatial and temporal variation of gene frequencies. Several projects have started independently in different countries, others, such as the Human Genome Diversity Project (HGDP), proceed as an international addition to the Human Genome Project (HGP). Some studies look at molecular
variation among populations, whereas others analyse genetic diversity in the broader cultural context. Samples could be, and frequently are, analysed from all over the world. However, for genetic studies the more isolated homogeneous human groups are thought to be the most informative. Some of these studies focus also on ancient DNA, since links between present day human groups are presumably to be confirmed through ancestors of those human groups which are alive today.

I.2.3.1 Multidisciplinary approaches. Genetic diversity is increasingly being seen in a much broader context. In some cases, local geneticists have been interested in the study of human diversity of the indigenous inhabitants of their countries, understanding from the beginning that only an interdisciplinary, holistic approach to this issue is capable of providing a reasonable view along with a re-evaluation of cultural and genetic diversity of populations. In this report the word “indigenous” is used in a broad sense to mean a person that lives in a given part of the world, but not only meaning the original inhabitants (cf UN Economic and Social Council, Commission on Human Rights, “Reports on Indigenous Peoples”). Research projects covering most disciplines, including anthropology, architecture, arts, bacteriology, dentistry, design, musicology, nursing, nutrition, philosophy, and medicine, as well as health care services, provide joint efforts to perceive all the peculiarities of isolated communities and give a much broader picture of, for example, the cultural and biological responses to environmental conditions and their understanding of health and disease, the natural laws that guide agriculture, settlement and architecture, and their cosmogonies.

This trend to involve broad multidisciplinary approaches in studies of populations, allowing for the participation of the community in the research, is exemplified by the “Expedición Humana” in Colombia, where the Human Genetics Institute from Javeriana University invited the whole University to join them. The aim of the “Expedición Humana” is to study the human diversity (cultural and biological) of a region of America which has been an important point in its populating and in its migrations from Asia to America. Teams of people from different disciplines travel to the communities. In each community that had previously been contacted and asked for consent, the investigators explain the different aspects they are interested in before once again asking for consent.

The information collected through all means (questionnaires, drawings, records, etc.) is then analysed some of which has already been published in a series of books. This information is given back to the community, in an attempt to provide useful analyses for the community itself. This approach to the study of the diversity of populations is less reductionist than just looking at their genes, and we would recommend such more humanistic ways of understanding the role of science and scientists. It creates, however, the expectation of follow up and continued intensive interest - essentially a complete medical service - which may be difficult to maintain unless special structures were created, which would be expensive. This is usually outside the power of individual researchers or research groups, and requires strong external financial interventions, most probably by governments.

I. 2.3.2 Human Genome Diversity Project. One example of population genetics research is the HGDP described by L.L. Cavalli-Sforza as “an international anthropology project that seeks to study the genetic richness of the entire human species” (Cavalli-Sforza, 1994). The name comes from a proposal in 1991 in the journal Genomics to make a systematic study of the genetic diversity of human populations. However, like the HGP, it shares a much older origin in the work of population geneticists over many decades (Mater, 1991; Cavalli-Sforza et al., 1994; Cavalli-Sforza & Cavalli-Sforza, 1995). The Human Genome Organisation (HUGO) responded to the 1991 proposal in the journal Genomics by establishing an ad hoc Committee to develop the global project. In January 1994, the Council of HUGO approved HUGO’s continuing oversight of the development of the HGDP (HGD Committee of HUGO, 1994; Kahn, 1994). The HGDP is being developed under the auspices of HUGO to promote global involvement and co-ordination.

The scientific aims of the HGDP stated in the 1994 HUGO Summary Document are:

a) “to investigate the variation occurring in the human genome by studying samples collected from populations that are representative of all of the world’s peoples,
b) “and ultimately, to create a resource for the benefit of all humanity and for the scientific community world-wide. The resource will exist as a collection of biological samples that represents the genetic variation in human populations world-wide and also as an open, long-term, genetic and statistical database on variation in the human species that will accumulate as the biological samples are studied by scientists from around the world”.

The main scientific value of the HGDP is:

a) deepening our understanding of human history and identity;

b) gaining knowledge about the environmental and genetic factors involved in predisposition and resistance to disease, so-called genetic epidemiology;

c) encourage the development of local laboratories where the collection of genetic samples will be collected and analysed.

Even though to date there have been numerous studies on the development of culture, language and population genetics (e.g. Cavalli-Sforza et al., 1988, 1992; Sokal et al., 1992; Feldman & Zhivotovsky, 1992), and some consistency between genetic, cultural and linguistic observations has been found, a survey of more populations in a more systematic way will extend what we already know and test current theories.

Linguistic differences suggest there are about 5,000 population groups in the world. In the short term, the HGDP will attempt to study about 500 of these populations. Even if some populations refuse to enter the project, there are still many other populations that could be surveyed. It is expected, then, that the project will be able to obtain samples from a large number of willing populations. If finding does not permit such wide sampling there is still scientific merit in collecting data from a smaller number of populations (e.g. Cavalli-Sforza, 1995).

The HGDP initially planned to centralise the collection of samples from isolated populations, some of which are already under investigation in population genetics research. This led to fears among some members of indigenous groups that the knowledge could be used for further ostracisation (Lock, 1994). However, the HGDP is now moving away from both the idea of central control to regional control and from the focus on indigenous populations, to include all populations.

Personal anonymity would be maintained by not having the names of individuals in the central repository, and by observance of established privacy rules.

The establishment of cell lines allows maintenance of a permanent record of the DNA of individuals of a population. At least two independent and physically separate collections in different countries should be kept, to maintain the resource. The HUGO HGDP Committee has said that access will be free, with some compensation for maintenance costs. Any data would be shared back into the main database, which would also include computer databases of genetic map and sequence data. There are also efforts to develop less expensive storage and micro-satellite marker techniques that can be used in local laboratories that have limited resources to ensure their fuller participation.

I.2.3.3 Analysis of ancient DNA. One of the recent trends in genetic studies is the analysis of ancient DNA samples, from fossils, preserved body remains, hair, or basically any body remains that contain DNA. There are scientific doubts about how much mutation occurs over the course of time the remains are kept in storage. However, these materials are providing an extra source of material for evolutionary studies. An example of the possible use of ancient DNA samples is the 7,000 year old frozen corpse found in the Austrian Alps has been used for analysis (Bahn & Everett, 1993). However, it may be impossible to find the appropriate persons to give consent. The question of consent is also related to the use of tissues from those who are recently deceased. In 1995, an urologist extracted sperm from a corpse in the New York city morgue at the request of the deceased man’s widow. The sperm is in cryopreservation awaiting the widow’s entry to a local IVF clinic (“Sperm extracted from corpse is world first”, Guardian, 21 January 1995, p. 12). Specific cultures may have very strong objections to these practices. DNA samples can be taken from the recently deceased and even sacred but archaeologically interesting sites such as tombs or battlefields. There could be no doubt that such samples would provide all sorts of interesting historical insights about the continuity of racial settlements and migration. Should however the anthropological interests outweigh the cultural and religious values about respect for the dead?
The ownership of these samples is sometimes claimed from those who believe the persons were their ancestors. In Israel there is a law requiring immediate reburial of all ancient body remains no matter which religious group they are thought to come from (Morel, 1995). In Australia there are laws to require return of tribal ancestors for tribal disposal rites. In both these cases scientists have been prevented from physical anthropology studies by such laws. This raises the question of group consent concern which will be discussed later. Peoples of most countries who have lost persons in war or disasters also call for the return of human remains. Can samples be taken?

II. Ethical Issues of Population Genetics Research

II.1 Philosophical Basis

The ethics of population genetics should be formulated with reference to the minimal agreed human values as expressed in international human rights law. These agreed human values are based upon recognition of the inherent dignity and of the equal and unalienable rights of all members of the human family. The rights of particular cultural groups to self-determination, including the safeguarding of cultural norms which are not in conflict with fundamental human rights, are then to be respected by research scientists. The Universal Declaration of Human Rights (1948) and the various treaties codifying human rights that have been developed from it are now all part of international law (Harris, 1991). Not only are all nations bound by human rights obligations in international law, so also are: international organisations, certain special entities such as the Vatican, special individuals such as diplomats, aliens, refugees, slaves, minorities, and persons, corporations and governments. Individuals are bound by the *ius gentium* in so far as human rights are at issue (Green, 1987).

Central to our human rights obligations is the promotion of “respect for, and observance of human rights and fundamental freedom for all without distinction as to race, sex, language, or religion” (Charter of the United Nations, Article 55 (c)). The Universal Declaration of Human Rights is founded upon the notion that there are universally recognised human values and that these values are inherent in the human individual. In the Preamble, the Declaration states that “the foundation of freedom, justice and peace in the world” is the “recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family” (Fleming, 1995).

The equality with which “all members of the human family” are to be treated as far as human rights are concerned precludes all attempts to exclude from moral consideration human beings deemed to be non-persons. There is no philosophical agreement in the international community as to what constitutes personhood. Accordingly, Article 6 of the Universal Declaration on Human Rights and Article 16 of the International Covenant on Civil and Political Rights (1966) require that every member of the human family be treated as a person, that “everyone has the right to recognition everywhere as a person before the law”.

Respect for these fundamental human values, expressed as human rights, is the essential requirement of a civilised society, even though there are some cultural differences in the expression of this respect. It stands against the eugenic temptation to reduce the value of a human individual to the sum total of its genes. Human individuals have an “inherent dignity”. The human rights documents do not give a reason why human beings are to be seen as having unique value. They simply bear witness to the fact that the international community agrees that each human individual is to be counted as valuable as any other human individual. Jacques Maritain (1954), for example, noted the practical convergence on fundamental values despite profound disagreement on ideology. Despite all the difficulties it is possible, “as the International Declaration of the Rights of Man published by the United Nations in 1948 showed very clearly, . . . to establish a common formulation of such practical conclusions”.

When one asks the question as to why these rights or values ought to be accepted the debate over the religious and philosophical foundations for human rights begins. There are also some political disputes over how human rights are to be interpreted within the framework of international law.
The ethical framework within which scientific research is conducted should also be in accordance with the ethical norms current in the culture where the research is being conducted, recognizing that the degree of importance accorded to communitarian values, varies between and within countries, populations and groups. This latter point has been well acknowledged by the recognition that “minimum ethical principles must be formulated, recognizing that, in the process of collecting, the human rights of people in participating populations should be respected and that these people are partners in work rather than merely subjects of it. Any particular region may have broader ethical concerns than those addressed here, which should only be considered as a minimum” (HGDP, 1994).

II. 2 Research Approach and Methodology

II.2.1 Informed Consent

The importance of obtaining consent from a study population is well recognised (even if not always practiced). Population genetics studies should be conducted by personnel with the appropriate qualifications, but only after informed consent has been given for any general medical examinations, and removal of blood samples (generally under 20ml) or other bodily samples. Such samples are taken to the home laboratory or other laboratories, and the components separated for analysis. The analysis of the samples requires specific consent that should be sought and given before samples are obtained (Baird, 1995). By the term “specific” consent we mean it could include consent for complete genetic analysis of the DNA or analysis for detailed purposes, but it should be clarified and informed.

The doctrine of informed consent is applied to both medical treatment and research. Before a person is asked to consent to any sampling or treatment they must be provided with certain information. This information includes at least the following, which must of course be presented in language the patient can understand:

a) a description of the procedure - which is generally easy, and should be risk free if accepted medical procedures are used for sampling;

b) a description of the risks and benefits of the resultant information.

It is worth noting that the need for consent to be “informed” may be objectively impossible to achieve. Even when correct information is carefully presented in culturally appropriate ways, it cannot be guaranteed that it has been understood. The ethical obligations that are achievable include accurate delivery of information together with the disclosure of relevant risks and benefits to the individuals and communities involved, in language that is accessible to the potential research subjects, and having regard to the legitimate cultural and religious needs and aspirations of particular communities, especially in the way in which consent is ultimately given. We should not speak so much, then, of “informed” consent as of an obligation or duty on the part of scientists to properly inform potential participants.

The application of the ethical principle of informed consent and respect for integrity is a more complex process at the level of populations. In order to ensure that that potential subjects understand the goals of research, the risks involved, the use to which research results could be put, and the rights of the groups and individuals under study, careful consideration is needed. The lines between genetic testing of individuals, genetic screening within one’s own population, and population genetics research of other populations and groups, are not always clear. We do not ethically require group consent for most genetic testing, though society may draw the line at the freedom of choice to use genetic probes for non-therapeutic purposes (e.g. sex selection is banned in several countries). The fact that some recent population genetic studies may involve investigation of several hundred genes between single individual representatives of different populations makes the question of group consent extremely difficult.

There are various levels at which consent may need to be obtained for studies of population groups. High level governmental approval is in many countries mandatory for studies on specific populations of persons. Such official clearances need in every instance to be complimented by consent from the individuals and the local groups/communities selected for study - whether the consent is obtained directly or through formal/informal leadership, group representatives, or trusted intermediaries.
It is important to identify the most appropriate persons with whom to communicate, the persons from whom clearance should be obtained, and the appropriate content and media of communication. Research will need to take account of the group’s social organisation, goals and aspirations, cultural values and mores, and laws (both statutory and customary). If the research methods involve the use of saliva, skin, hair, or blood samples, it is necessary to ensure that the collection of these body samples does not violate cultural norms and concepts relating to the human body and its functions.

The ways of approaching the communities must always take account of the particular social and cultural organisation and laws. Sometimes the leader or the individual chief of a family or familial group is the person who gives consent for the other members of the community to participate in the enquiries and biological sampling. These persons may be difficult to identify. Of course the most difficult group consent question is who can give group consent for the genome project itself—a question that no one has been able to answer (Mater, 1991).

Various groups of indigenous peoples have expressed their irritation with past population genetics research which they claim has been conducted without prior consultation and in a way where consent was obtained in terms inconsistent with their cultural norms. Practitioners of contemporary science do not always understand that the goals and aspirations of scientific projects may not always coincide with the goals and aspirations of particular cultures. It may not be ethically acceptable to some people to co-operate in the collection of saliva, skin, hair and blood samples, for the purpose of storage and the establishment of “transformed cell lines”, samples which would be basically identical to the individual of origin which are then made available for study to scientists around the world. Therefore many representatives of indigenous peoples have expressed strong concerns about the HGDP.

An important outcome of this concern and the HGDP may be the more active participation of some individuals of the community in the research projects, as well as in the better formulation of precise questions that researchers try to answer through their observation or laboratory work. These concerns apply to sampling within any population genetics project. In order to bridge gaps between scientific goals and aspirations on the one hand, and cultural goals and aspirations on the other, it will be necessary for scientific information to be communicated to individuals and communities in terms that can be understood by those communities, and if they exist, by individuals acceptable to, and counted as trustworthy by, those communities.

It will not only be necessary to identify the correct person or persons to give scientific information, but also to identify to whom the information should first be given, and what cultural mechanisms apply to the giving of consent. This will involve taking account of the fact that individualised notions of obtaining consent which tend to dominate in liberal Western societies cannot be applied “carte blanche” to people of other cultures. In secular liberal societies consent is seen as an “informed” expression of an individual’s self-will and autonomy. Consent is deemed to be informed if the subject is exposed to all relevant information, including risks. Other cultures of course may place greater emphasis on the advice of leaders who represent the continuity with traditional wisdom, or with the fate of family or group members. Relevant factors for moral decision-making in communitarian societies may derive from sources not as empirically accessible as medical data.

The moral and spiritual values which have profoundly shaped the cultures of different population groups may well result in deeply held convictions regarding bodily and familial integrity (Paulette, 1993). Information about genetic inheritance is loaded with emotional, historical, cultural, and religious significance, which may differ in different cultures and religions. The form in which the consent is given needs to be culturally appropriate as well. Not all communities are governed by bureaucratic paper consent forms and written signatures. The form in which consent is given will need to be discussed and agreed upon by each community.

II.2.2 Selection and Participation

The participation of the study group in various stages of research is one good way of keeping open communication and of developing trust between researchers and research subjects. Such anticipation may take various forms depending on the situation. In
international research projects, the involvement of the local scientists, if possible, and consultation with local groups, is an effective way of ensuring that communities or indigenous populations are treated with sensitivity, respect, and wisdom.

The style and norms that have governed international scientific research have changed over time. However, the values that express themselves in contemporary human rights documents are very ancient and have become the subject of international agreement in international law. Notions of informed consent are nearly fifty years old but depend in turn on those same human values, such as respect for human life, and which derive from the notion of the inherent dignity of the human person. Scientists must think and plan research projects well. Initially this can be done independently of the persons who might become involved. However, before seeking to implement those plans they need to refine their protocols where necessary to conform to established guidelines for research on human subjects. This has not always been done. It has been recently revealed that biomedical experiments were performed on more than 23,000 persons in about 1,400 different US Defence Department projects for over 30 years after the Second World War, and in which the requirements of informed consent were neither sought nor met. The selection of target populations included soldiers, prisoners, those considered to be mentally defective (both children and adults), hospital patients with terminal illnesses, and pregnant women. Despite the fact that these were all vulnerable persons whose involvement in research needed special ethical scrutiny, informed consent was generally not sought at all or not given (Estling, 1995). Scientists need to be particularly sensitive to projects involving human subject populations that have a history of facing discrimination, and need to consider not only the detailed planning of that research but also the human rights of the potential subjects, including the requirements of informed consent.

The planners of the HGDP got off to a bad start with misunderstandings and fears widely expressed among indigenous peoples. Because the HGDP was planning to collect blood samples, some groups called the HGDP the “Vampire project” (Lock, 1994), while other groups were angry because they believed that they were possible target populations even though no community representatives had been contacted about the Project. The Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous Peoples of June 1993 is a call for a halt to the HGDP until its impact has been discussed. Article 3.5 of the Declaration calls “for an immediate halt to the on-going ‘Human Genome Diver-sip Project’ (HUGO) until its moral, ethical, socio-economic, physical and political implications have been thoroughly discussed, understood and approved by indigenous peoples”. The Declaration is actually not anti-science, and includes a call for involvement in scientific research: Recommendation 2.11 “ensure current scientific environmental research is strengthened by increasing the knowledge of indigenous communities and of customary environmental knowledge”.

In fact the HGDP included all populations, not only indigenous populations. Since that time, the HGDP goals have shifted somewhat, but there has been a series of declarations directed against this project (Mead, 1995). The HUGO HGD Summary Document includes ethical guidelines which do address the question of participation, consent, and commercialisation (HGD, 1994). Nevertheless, the controversy continues. In February 1995, a forum of indigenous peoples in Asia issued a statement to the European Parliament in which they strongly opposed the HGDP and called for it to be stopped (ARCW, 1995). The Beijing Declaration of Indigenous Women formulated at the United Nations Fourth World Conference on Women (3 O August - 8 September 1995) demanded “that the Human Genetic Diversity Project be condemned and stopped” and that their “intellectual community rights” be recognised.

However, on 6 July, 1995, the Science and Technology Committee of the House of Commons (United Kingdom, 1995) gave its support for the project in these terms: “We consider that the Human Genome Diversity Project could indeed lead to greater understanding of events in human evolution. If differences between populations are not explored soon, the evidence will be lost. The Project should be pursued in its total context of diversity within as well as between populations if it is not to be misunderstood or misrepresented”. However, as the project guidelines themselves acknowledge, obtaining real informed consent from the cultural diversity of peoples who will need to participate if the Project is to be a success will be a challenge.
Therefore we would urge researchers to consider the history of the group that they plan to include in their research, taking into account matters not only of scientific interest, but also the ethical, social and ideological impact on the group, as a consequence of the research. The finding mechanism for the Human Genome Project in the European Community was delayed until a system for funding ethical, legal and social impact (ELSI) issues was established. In Canada up to 13% of the Human Genome Project has been spent on ELSI and educational issues, and in the United States of America 3-5% is allocated. We would also urge HUGO to continue its commitment to looking at these issues from an international perspective. Their ELSI Committee has met only twice: first in 1992, then in October 1995 to focus on population genetics, and plans to meet in 1996. The ELSI issues do not only relate to genome research, but to all of genetics and science.

II.3 Utilisation of Research Results

II.3.1 Confidentiality

As has already been well documented from the practice of genetic screening, the personal impact of genetic information is significant. These issues, related to individual privacy and possible abuse of genetic data by insurance companies and employers, have already been discussed in the IBC Report on Genetic Screening and Testing of 1994.

DNA collected from population groups would present analogous problems relating to the adequate protection of privacy (Annas, 1993); but the meaning of privacy could vary across cultures. Furthermore, it is important to note that in population genetics research confidentiality issues have to be considered at the community level as well as at the individual level.

One way of ensuring confidentiality for individuals would be not to collect or keep identifying information in the central repository. This would, however, limit the scope of research that could be done. Confidentiality for individuals in human population genetic research may be protected to a certain extent through coding and anonymity, with strong safeguards to protect the identifying information that is kept in the central repository. There may be cases where useful information for a person may be found, which may be released to individuals who should have been asked, when the information was collected, whether or not they want to know.

Confidentiality is more difficult to maintain at the level of communities. Although information regarding the identities of community samples may be restricted, in all probability, anyone who really wanted to identify communities may be able to do so. The difficulties involved in guaranteeing the maintenance of absolute confidentiality of communities and population groups should be discussed in the process of obtaining informed consent.

If all members of a community, or a population group, were found to have a gene that predisposes them to a common late onset disease, for example, could that information be protected? Health insurance companies could cancel or refuse health insurance to a population, in the same way that health insurance has been denied to individuals or members of a family in countries that do not prohibit genetic discrimination by law.

In several countries, these cases have led to legislation on genetic privacy. Although the principle of confidentiality is included in the “Outline of the UNESCO Declaration on the Protection of the Human Genome”, further national efforts to protect against such abuses may be required. Nevertheless, it should be noted that in the future it is possible some genetic information about a particular minority could be exploited by States for political purposes, leading to further repression or to justify continued repression.

This also raises the question of who should be in control of the genetic information that has been collected. For example, if national governments want the repository to be in their country and subject to their control, should this be allowed? Although the keeping of genetic information on Third World populations in central repositories of the west may be politically objectionable, the idea of maintaining repositories in a country under a repressive regime is certainly not preferable. One of the main issues is whether the genetic information is predictive or identifying.
II.3.2 Patents and Financial Benefits

Patenting has become an issue in population genetics primarily in relation to the patenting of products derived from the genetic material of indigenous peoples. In 1993, a patent filed by the United States government on the cell line of a 26 year old Guaymi Indian woman from Panama was opposed by the Guaymi General Congress, the World Council of Indigenous Peoples, the Rural Advancement Foundation International, and the World Council of Churches (RAFI Communique, Jan/Feb 1994). The patent claim was subsequently withdrawn, but on 14 March 1995, genetic material isolated from a man of the Hagahai people from Papua New Guinea’s remote highlands was patented in the United States of America, and the decision maintained after challenge. Other patent claims are also being opposed (Butler, 1995).

These patent applications have served to cast deep suspicion on the motivation behind human population genetics research in general. Although the primary aim of most researchers is the pursuit of knowledge, and not commercial gain, and scientists with other motives may be excluded from particular projects as the HGDP maintains, nevertheless, the possibility is that products derived from genetic material collected in population genetics research could be patented for commercial purposes. Moreover, as in the case of Moore vs Regents of the University of California (1990) (Nuffield Council on Bioethics, 1995) where the Supreme Court of California ruled that John Moore does not have property rights in the cells taken from his body, the people who take part in population genetics research may stand to gain nothing from whatever patents that are granted on products derived from their genetic material.

At present, opposition to patenting of human genetic material is being mounted on two levels. On the first level is the opposition to any patenting of “life”, which includes microbial, plant, animal and human life. The grounds for this may be religious, or cultural. Some indigenous groups have voiced their objections on this premise. Indeed, the patenting of naturally occurring life-forms is objectionable for many cultures. Since genetic material is seen as part of what constitutes life; as such, patenting transforms this material into a commodity that can be owned and traded in. There are a variety of arguments that are used to support this position, including lack of evidence that patents do stimulate invention, distinction between discovery and invention, need to allow access to the organisms, extended protection, the ideas of biotechnology were developed in the public, there is no special reason to privatise public goods, and a need for uniform utility patents (Busch, 1995).

On the second level, patenting is opposed on the grounds that people from whom genetic material is taken are not likely to receive any financial benefits from it. This opposition arises from past experience in which large corporations have collected genetic material and knowledge from the Third World and from indigenous populations, and then used these to develop and patent agricultural and pharmaceutical products without any benefits accruing to the original donors of the material or of the knowledge. When the International Board for Plant Genetic Resources was funded in the 1970s, for example, it created a public domain resource of 125,000 plant germ-plasm specimens. In fact, more than 90% of all the plant germ-plasm collected in the South in the last two decades has ended up in gene banks in Europe and North America (RAFI Communique, 1993a). This material has been the source for the development of products worth billions of dollars to farmers and agribusiness in the industrialised world as companies have subsequently obtained patents on hybrids. This is considered unjust by some Third World countries and NGOs because the generations of traditional farmers who had contributed to their identification, selection, and cultivation get neither financial benefit nor recognition. The same is true of pharmaceutical compounds; and, it is feared, may become true of human genetic material.

The Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous Peoples of June 1993 includes several recommendations to member states of the United Nations. Recommendation 2.7 states that “commercialisation of any traditional plants and medicines of Indigenous Peoples must be managed by the indigenous peoples who have inherited such knowledge”, while Recommendation 2.8 demands that “a moratorium on any further commercialisation of indigenous medicinal plants and human genetic materials must be declared until indigenous communities have developed appropriate protection
mechanisms”. The Declaration also would like the promotion of a “co-operative rather than competitive framework”, and an “increase in the involvement of indigenous communities” in “research and training as well as education”, that would make them participants in the process of development of industrial goods from human genome research, and beneficiaries of possible commercial profits rather than being simply suppliers of samples that may eventually lead to significant therapeutic discoveries. The same concerns have also been expressed in the Asian Regional Consultation Workshop on the Protection and Conservation of Indigenous Knowledge meetings in 1995 (ARCW, 1995).

Besides these two levels of opposition, there is also debate about what exactly may and may not be patented under patent laws. One of the first declarations on gene patenting is the ICSU Statement on Gene Patenting in June 1992, which states: “Information about nucleic acid sequences cannot be patented per se. Such sequences should be patentable solely within the context of their demonstrated significance and/or application and not of their potential products”. Furthermore, it was clearly explained that only inventions, whereby humans construct new elements that can be used, may be patented. Discoveries of natural laws, mechanisms, or elements are not patentable because no one has the right to monopolise a discovery. Identification of the genome and of the genes of which it is made up, and of the nucleotide sequences which describe the composition of these genes, constitute a discovery. As such, the human genome cannot be patented per se.

It is also argued that the human body (and its component parts) cannot be regarded as an asset, it cannot be marketed, and hence cannot be a source of financial gain (Pompidou, 1994). This is also discussed in the Draft European Convention of Bioethics, Article 11, which states: “The human body and its parts shall not, as such, give rise to financial gain”. However, in note 90, it is stated that this does not apply to discarded tissues, such as hair and nails, “the sale of which is not an affront to human dignity”. It is important to note because DNA can be obtained from discarded tissues. Nevertheless, we would like to point out that in some cultures, for example certain North American Indian cultures, this assumption is not true. Hair, even when cut, for example, has religious importance and is not regarded as discarded. The assumption that the sale of discarded tissues is not an affront to human dignity might not be valid for cultures other than those in Western societies.

Patenting has also been opposed on the grounds that it limits free and open scientific exchange, as well as access of researchers to genetic materials for research. Researchers require access to some major cell line collections, and one of the goals of population genetics research, such as the HGDP, is the creation of cell lines. Patents have already been granted on immortalised cell-lines and hybridomas which are useful in research or as monoclonal antibody sources for research and diagnosis. These cell lines are kept, reproduced and distributed by commercial companies, mainly the American Type Culture Collection (ATCC) in North America and the “Centre d’Etude du Polymorphisme Humain” (CEPH) in France, which charge for requested samples, as these services are expensive and laborious to maintain. In 1994, there was debate over the commercial access to DNA collected from 800 French families in the CEPH. The issue was divisive, as some funders wanted to ensure free access, while on the other hand, there were claims that exclusive commercial access would increase support (e.g. Nature 368 (1994), 175, 575). Eventually, the pressure led to the claim for exclusive commercial access being dropped.

Patents on these materials will require the payment of royalties which will in turn severely limit the access of scientists from poor countries to research carried out by scientists in the developed countries. This will exacerbate the gap that currently exists between North and South. The issue of patents is a primary concern of Third World scientists, who feel that their countries may end up being suppliers of genetic material for population genetics research, but they may end up having to pay for the products of these research outcomes.

This will be a barrier to Third World countries developing their own scientific strategies in the field of diagnosis and therapy based on publicly available gene sequences. And what if human genome patent claims are extrapolated to gene sequences of micro-organisms endemic in these countries? Would they also have to give up royalties for vaccines, designed by scientific teams from poorer countries against malaria, leishmania, chagas and other diseases, the micro-organism sequences of which are protected by an industrialised countries patent?
We note that public opinion in many parts of the world is against patenting of human DNA (Mater, 1994), although we recognise that the issue is complex and that there needs to be some protection of commercial investment in research. Most research finding is currently judged as an investment, and the trend is to become even more commercial. This trend is indeed a worrying one. By prioritizing the objective of financial benefits, scientists are led by the possibility of commercializing research results rather than what many consider to be the nobler aim, the discovery of knowledge.

Accordingly, this working group recommends that patenting should be limited to new applications and processes which may be developed in the course of human population genetics research, and that conditions should be developed to ensure free access and use by researchers everywhere. In the event of the possibility of population genetic research material giving rise to patentable products, the principles of informed consent should be observed, and a mutually agreed upon mechanism should be worked out in ensuring that potential financial benefits flow back to the donors of the original genetic material.

This should not be on the basis of the sale of blood or other bodily tissue but on the basis of their co-operation in a scientific program which may bring large financial rewards to the companies involved, or those secondary companies which utilise the results. Care should be taken to ensure who is the legitimate beneficiary of commercial benefits; that is, whether it should be the national government or some sort of trust find for the population group. Benefits returning to Third World countries for example, may not necessarily benefit the indigenous populations from whom the samples were taken. We also note that no undue compensation should be offered to ensure participation in sampling (Knoppers et al. 1995), which may be extremely difficult to control given the one-sided power relationship in the poorer areas of the world. We see the return of financial benefits in terms of communities not individuals.

II.3.3 Return of Research Results to Subjects of Research

It should be remembered that financial returns are not the only form of benefits of research results which could be returned to subjects of research. Perhaps a more important aspect is the return of information and research results to the communities from which data was collected. There are research projects, for example, which plan to write their research analyses and conclusions in popular form which are accessible to the communities so that they could be helpful to them in promoting concrete responses to particular problems.

The feedback of results to the communities concerned should also help to foster a greater sense of community identity in the face of aggressive cultural imperialism by industrial superpowers. But perhaps the most poignant problems of many populations involved in population genetics research is in the realm of public health. This, however, cannot be understood just as a diagnosis of symptoms and consequent medical treatment. In indigenous communities these problems are usually an intricate result of the breakdown of a traditional well-adapted cultural as well as biological relationship to the environment, due to economic and political pressures from the dominant society. At the individual level, the results of physical examinations and clinical diagnosis and options for treatment are sometimes communicated to each participant in the local languages through local health authorities and doctors as soon as possible. This is so as to utilise the health data collected for the improvement of community health, especially in the remote areas or areas with poor health services. The provision of health and medical care, however, should be appropriate to the cultural and social context of the community and should be sustained. In this, the principles of primary health care as contained in the Alma-Ata Declaration (WHO/UNICEF) of 1978 should seize as a good set of guidelines to follow.

At the community level, the health data could be utilised for the improvement of local community health. Thus, benefits should also flow back to the groups and communities in the form of contributing to the formulation and implementation of local and national health care policies that would enable communities to better their positions. These policies, as well as the health care services which are offered, should of course be decided upon by the communities.
Commercial benefits discussed in Section II.3.2 could be expressed in other ways. While there could also be provision for a one-time gift of cells or blood with no conditions, as is found in some tissue donation forms for blood and body tissues, can one individual sign away commercial rewards to future research knowledge for the population to which they belong? It may be technically possible to conduct population genetics research among students of an international university, with them giving their cells to science. It is a difficult ethical issue which we have not resolved, which while it has until now been ignored, we consider to be important.

II.3.4 Implications of Knowledge from Population Genetics Research

Some challenging implications may arise from the better understanding of human history that population genetics research could provide. The new knowledge from such research could be used to educate people of indigenous groups that would help protect their interests. On the other hand, new knowledge of human group evolution and the relationships of particular groups to others may challenge existing world-views. Some population groups have strong beliefs in mythologies or cosmogonies which explain group origins and identity, and the return of data that challenges the accepted beliefs could be a delicate issue.

Population genetics research may also throw new light on the questions of who were the first inhabitants of regional areas, the historical relationships of populations to current national boundaries, and who has the right of government. Governments may fear that indigenous peoples will be able to use the claims of prior settlement to push land claims. Which inhabitants of which time period would we consider to be the legally entitled owners of land that had been successively colonised? Population genetics data may confirm or reject the information obtained from archaeology or history. In the West Pacific for example, recent population genetic studies show that settlement was from the West not from the Americas (Clegg, 1994).

Some would say that population genetics will not tell us anything within a time frame that could make valid legal claims under a common or civil law approach (Greely, 1995). We could also say that we already know much of human history, and indigenous peoples’ claims to prior settlement may be ignored despite the clear knowledge that they were there. If ancient DNA samples are collected and markers used to trace the contemporary descendants, for example, this could be used to find the genetic descendants, but these may not be considered to be “legal heirs” to the land under most legal traditions. It is beyond the scope of the International Bioethics Committee to consider changing the legal system of ownership that tends to overlook European colonisation of the past few centuries, but we should note that there are recent legal rulings which support indigenous peoples’ original titles to government lands in Australia and New Zealand.

II.3.5 Other Issues Arising from the Use of Research Results

One fear that has been expressed about population genetics research is that access to and knowledge of a community’s complete genetic make-up make it theoretically possible to devise cheap and targeted biological weapons trained solely on that community (RAFI Communiqué, 1993b). Given that greater genetic diversity exists within any particular population group than among population groups, it is highly unlikely that specific genetically-based genocidal weapons could be developed for specific population groups. Unfortunately, other methods of so-called “racial cleansing” are available. In this respect, restrictions on biological warfare which already exist in international law should be further strengthened.

The issues of discrimination, eugenics, stigmatisation and other ideological uses and abuses of genetic research on populations are discussed in the following section. Eventually the genetic data could be used for genetic therapy and intervention. Many of the ethical issues are summarised in the Report of the IBC on Gene Therapy of 1994. Although it appears unlikely, it is possible that in the future a population or society could agree to the general use of a genetic vector to provide a medical benefit, such as immunity to an infectious disease, or compensation for a common genetic disease among a particular genetic population. Such an issue is related to the extent that traditional vaccination programs are compulsory or voluntary, and we note that such programs are, and should be, generally voluntary although public information campaigns may encourage participation.
III. Public Understanding

III.1 Ideologies

Public attitudes towards population genetics are often based on social ideologies, racism and eugenics, and can well lead to stigmatisation and genetic reductionism. The ideologies of racism and eugenics are human artefacts, socially and politically constructed, and may well prove impervious to scientific proofs. Indeed, such ideologies may improperly appropriate scientific findings to further advance and legitimise social and political programs. Research scientists need to be aware of their own assumptions and philosophical presuppositions as well as the assumptions and philosophical presuppositions of others, and to be prepared to work within a general framework of respect for human rights as expressed in international law. The pursuit of scientific enquiry as a means to legitimate ideologies is a temptation that should be resisted. Without paying attention to these issues, scientists themselves may sometimes find themselves unwittingly involved in unfair manipulations of their intentions or results, in the name of diverse ideologies.

Scientists themselves are not immune from the usual array of assumptions, dislikes, biases and prejudices, that beset the wider community. Unfortunately scientists have at various times in history believed themselves to be working in a value free domain, gathering the pure crystals of data and indeed trumping other human values and concerns in their pursuit of ever higher degrees of scientific knowledge. As Alasdair MacIntyre has observed (1982), it is a mistake, albeit “a pertinacious and long-lived one”, to imagine that an “observer can confront a fact face-to-face without any theoretical interpretation interposing itself”. But while philosophers of science may now be largely agreed that “this was an error”, it is still a temptation for scientists to imagine that you can stare a fact in the face and view it just as a fact.

This is not to assert that there are no such things as facts but only interpretations. It is, however, a recognition that facts are observed by persons and that the reporting of facts may be distorted because they are interpreted by a particular individual with a particular mind-set, because of the frailties and limitations of the observer, and because the observer fails to see the fact in its overall context. It is in the recognition of this problem that scientists themselves may become better at and more cautious in interpreting the data before them, and more able to appreciate different interpretations of the same scientific data.

To standardise the way in which the scientific enterprise is best put in service of humankind, it is necessary for scientists to have regard to those human values upon which human beings are agreed, and which human beings agree need to be defended for the full flourishing of the human community. These agreed values may be found in the human rights documents of the United Nations, values which are in harmony with the world’s deepest aspirations as to what it means to be human and living in solidarity with other human beings, and in harmony also with the moral insights of the religions and philosophies which have helped shaped the various human cultures. Since science itself has emerged from the traditions which favour the search for truth, for explanation of the natural world, then the scientific enterprise is at its best when it is pursued in harmony with the other values which also contribute to human flourishing.

III. 1.1 Racism

Population studies in the past have shown that most of the genetic diversity is to be found within every race or population, and if this is further confirmed to be true the topological classification of humans into different “races” is scientifically invalid. Nevertheless “racism” as an ideology and as an attitude is a human reality. Population geneticists point out that population genetics offers no scientific basis for the belief that certain races (however defined) are superior to other races. Indeed there is a greater diversity within populations than between populations. However, care needs to be taken in the way such an argument is formulated. Because of the potential for abuse of population genetics, we consider racism and eugenics as important issues of population genetics to consider, although some in the scientific community do not. Variation between individuals or groups could be (but not necessarily) associated with evaluative notions of “superiority” or “inferiority”, and thus foster racism as some have suggested genetic counseling does.
Population studies in the past have shown that most of the diversity within the genes studied is to be found in every race or population and, if this is true, then this information could be used to combat racism. Since current population studies show that the topological classification of humans into different ‘races’ is scientifically invalid, we should avoid the use of the term “race”. Population studies include linguistic and anthropological studies (Marks, 1995). Some such studies have been misused in the past, and today, and need to be treated with appropriate expertise and care by the investigators.

Historically, Third World people in general, indigenous people in particular, have been the objects of research by scientists from developed countries. The history of anthropology is based on the study of “exotic” races and anthropologists operated within the prejudices of their age. One example of this is the craniometry research that was done in the second half of the 19th century when Western scientists measured craniums and ranked races by their measurements. By their ranking, the white man is the most superior race, and the black man the most inferior, comparable to apes (Gould, 1981). We should also note that religious discrimination is often linked with ethnic discrimination.

The World Council of Indigenous Peoples was upset by the discussion that cells should be gathered from populations at risk of disappearing (Roberts, 1992; Pahr, 1994). At that time they mistakenly thought that the HGDP was aimed exclusively at sampling from endangered populations, which it should not be (Majumder, 1995). However, the HGDP does not contribute to the demise of the population groups it studies.

With the burden of this recent history, it should be no surprise that many Third World and indigenous people view Western research with suspicion. Researchers have responded to this by evolving research methods which involve their subjects in a more participatory fashion, or by developing research projects which not only aim to study, but also to share research findings, and whatever benefits which accrue from it, with their subjects.

Indigenous peoples’ organisations now question the purpose behind research that is done on indigenous population groups. In certain parts of the world, indigenous peoples are facing cultural extinction. Where there is mass logging of tropical rain forests, for example, indigenous people who live there are depleted of food and water resources, and driven from their homes. They eventually join the ranks of waged labourers in logging camps and cash crop plantations. As their social fabric breaks up, they are in danger of losing their identity and culture. The struggle to survive as a people is a pressing concern of many groups. In this context, the call for researchers to collect genetic materials from indigenous populations, before they disappear as distinctive genetic groups, may appear to some as grossly insensitive and callous. Furthermore, if such research receives finding from governments, the money and resources could be channeled from other pressing needs.

Populations have mixed in the past and mix more today, and some cultural anthropologists suggest it is difficult to define linguistic and genetic populations (Lock, 1994). In attitudes to bioethical questions we also find broad diversity across many cultures. This is seen in the International Bioethics Survey performed in 1993 in a variety of countries, where there was a similar range of diversity of ideas in numerous open response questions on issues such as images of disease, nature, life and genetic technology in each country, and the range within each country corresponded to the same range found between all (Mater, 1994). In this way we could see cultural diversity in a similar way to genetic diversity, neither supports the notion of race. It could be said that health discrimination and cultural or religious discrimination tend to spread and substitute for “race” discrimination, although they all involve the labelling of groups of persons.

It has been amply demonstrated that, while there is a wide range of diversity between human individuals, the average differences among human groups are small. Accordingly, there is no scientific basis for believing that there are races which are more “gifted” or “smarter” or “better”, and thus racism is not supported by contemporary scientific research. However, this argument needs to be carefully expressed or it may unwittingly appear to rely on the assumption that if you could in fact demonstrate that some races were more “gifted” than others, had “better” or “smarter” genes than others then those races would be superior, and the other races inferior,
All population genetics research should be carried out in a way that is sensitive to the ethical obligations found in international law. However, we should also be clear that those who seek to use the findings of population genetics to support movements and ideas which are hostile to fundamental human rights will no doubt do so. The correct response to this is not to say that the findings will prove the opposite, i.e. fight against racism, but to recognise that what science finds is what science finds, and these findings should be put in support of fundamental human rights which derive from the universal belief in the inherent dignity of the human individual. Such values cannot be “proved” by science, and neither can they be “disproved” by science. UNESCO should actively encourage greater public acceptance of variation and vulnerability, and promote the value of human diversity. While there are fundamental human values which should form the basis of all bioethical reflection we should nevertheless have regard to those other cultural values upon which all societies are not necessarily agreed, learning to respect the different ways different societies do their ethics.

III. 1.2 Eugenics

Eugenics, a word coined by Francis Galton in 1883, was defined by him to refer to the “science” of improving human stock by giving “the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable”. While Galton associated eugenics with racism, the new eugenics proposed since the Second World War is not necessarily racist but refers to the elimination of inherited genetic defects either by genetic counseling backed up by abortion and even infanticide, or the improvement of an individual’s genetic inheritance (cf. Kevles, pp. 251-268). So eugenics, and with it notions of “superiority” and “inferiority”, does not have to be applied to race.

Indeed it is a mistake to identify eugenics only with racism. Eugenics stems from habits of mind, from the desire to protect “my group”, and from a negative attitude to persons with physical or intellectual disabilities. Contemporary eugenics is generally not so much racist as it is connected with a desire to limit the number of people whose lives are held to be of such low quality that such lives, in terms of the burdens that they impose on societies as well as the affected individuals, are not worth living. It is naive to imagine that scientists as scientists cannot be racist, eugenicist, or paternalism.

The danger is that genetic findings maybe inflexibly interpreted as the only story of human, biological, and cultural evolution. In the first decades of this century, the racial hygiene movement, relying on eugenics based on a mistaken science, proposed negative attitudes to whole groups of human individuals. By the middle of this century eugenics had fallen into disrepute. But today, increasingly more strength is being given to genetic explanations of human behaviour, as can be seen in the scientific and popular press over the past decade (Nelkin & Lindee, 1995).

Eugenics can and is practised within a population precisely on the basis of “genetic reductionism”, that there are some lives which, it is popularly claimed, constitute a burden to the community, to the individual concerned, to that individual’s family, and whose quality of life is so low that these lives are not worth living. Such eugenics has nothing to do with race, but is based upon disability.

The problem is that in the way that the argument is often expressed there is an underlying assumption that genetic differences between individuals constitute a rational basis for labels of “superior” and “inferior”. The point is that eugenics is built upon an attitude that seeks its justification in science, just as racism is an attitude that may seek its justification in science. These are habits of mind and ways of thinking philosophically that are hostile to the key notion of the inherent dignity of the human individual and the inviolable and inalienable human rights that arise from the international consensus about the value of human beings. Human value does not change according to health, sex, race, theories of personhood, or any other factor.

With both eugenics and racism we are dealing with political and social constructs and not scientific categories. Eugenics may also be linked to distaste of persons with disabilities, to Nietzsche’s idea of the threat that the disabled and chronically sick pose to the healthy (Nietzsche, 1910), and to the economic burden on the community which comes from the provision of long-term care for the disabled, the elderly, and the chronically sick. It is very important to realise that scientific information, in and of itself, is never likely to significantly undermine race as a political category or eugenics as a political and social movement.
We should not have the misconception that eugenics is a thing of the past, although, in present times, eugenics may express itself in not so obvious ways. For example, there are cases where insurance companies have cancelled policies of families who include a member found to have a genetic risk factor for a disease. This has been called genetic discrimination (Billings, 1992).

It should also be noted that present day eugenics has been expressed at the level of national government policies. For example, the population policies of the Singapore Government is guided by eugenics - women who graduate from universities are encouraged to bear more children in the belief that their children have higher “intelligence”, while less-educated women are offered disincentives to have more than two children (Chee & Chan, 1984).

It may be pointed out that the inclusion of many groups of people as possible, including groups of persons at risk of eugenic discrimination or at risk of racism, could work against racism as the total human race will able represented in genetic maps and libraries, if we compare it to the situation where the human genetic map was only derived from one population. The concerns that persons who suffer from particular diseases have of discrimination increasingly voiced in relation to contemporary developments in genetics research. The Report on genetic screening and testing of the IBC discusses some of these issues.

III. 1.3 Stigmatisation

Stigmatisation may occur when population groups in which there is a high incidence of genetic disease are selected for scientific investigation thereby drawing attention to their genetic differences. Care needs to be taken that targeted groups do not become stigmatised in some way simply because they are of scientific curiosity, or because they are more frequently studied and more is known about them they seem to have a greater predisposition to disease. Such stigmatisation can lead to unjust discrimination.

It is not surprising that some people are suspicious of genetic research which appears to have selected them for scientific investigation. Understandably they can see a danger that researchers in these projects will target the most “interesting specimens”: because they are a fading population group. Nevertheless, the scientifically and ethically legitimate aspirations of population geneticists ought to be encouraged even where they are misunderstood. Where misunderstandings do occur, and they can occur on both sides, participating scientists, potential research subjects, and pressure groups need to be sufficiently open to each other to allow opportunity for those misunderstandings to be discussed and resolved.

III. 1.4 Genetic Reductionism and Holistic World Views

“Genetic reductionism” is used to refer to the evaluation of individuals with reference only to their genetic inheritance. Western science has frequently sought to explain the whole by a greater knowledge, by a part that is deemed to be most fundamental. Some researchers, pursing Darwinian theory, propose an explanation of human beings in their origins as well as their evolution by reference only to DNA. Individuals have been categorised according to specific markers of inherited susceptibilities. Whatever the theoretical and scientific benefits of such categorisations, research scientists must always have regard to a more holistic appreciation of human beings, considered both as individuals with an inherent dignity, and as communities living in a given environment and culture.

It is precisely at this point that the objections of some population groups to population genetics have been most forcefully articulated. It is a mistake to imagine, for example, that opposition to certain research projects is based upon misunderstandings and confusions about scientific aspirations, and how the scientific information will be used. It is much more fundamental than that. It is a clash of philosophy and cultural insight concerning our understanding of the origins of humanity, the responsibility of individuals and the safety of the community in terms of past, present, and future generations. For many indigenous peoples, the dignity of their ancestors are “in our blood, our hair, our mucus, our genes”, accordingly some research projects are seen as an unwelcome interference “in a highly sacred domain of indigenous history, survival and commitment to future generations”.

Optical Character Recognition (OCR) document. WARNING! Spelling errors might subsist. In order to access the original document in image form, click on "Original" button on 1st page.
The categories of populations that are chosen include those that can answer specific questions related to contemporary "ethnic groups", language groups and cultures. Populations that are anthropologically distinct, that are linguistic isolates, and those in danger of losing their genetic identity will be chosen, as well as populations that are dominant in particular regions. The dominant population groups have nothing to fear, however some members of minority groups are already at risk of ethnic attacks and are therefore sensitive to any information that could be misused against them. For example, if the genetic knowledge can be used to classify them as distinct, e.g. French have a gene to make them good wine-makers and drinkers, it could become a point by which they are ostracised - though, the information could also be used for admiration. The usual cause for loss of genetic identity is not racial cleansing but the genetic admixture caused by intermarriage between different population groups. We could also expect concern from those groups who are also physically threatened by attempts to eradicate them, such as Kurds in Iraq, Tutsi in Rwanda.

If genetic reductionism derives from a misunderstanding of science and is suggestive of discrimination against a “genetic underclass”, it also represents a threat to those mythologies or cosmogonies which are different from the dominant world cultures. The sensitivities and legitimate cultural and social norms of particular population groups have to be respected and honoured in any population genetics research. One of the ways to address the concerns of groups of persons at risk of eugenic discrimination, or at risk of racism, is to have good communication with disability support groups and ethnic communities. For example, Australian aborigines have suffered racism since European colonisation of Australia, and they have expressed concern that decisions about the research were made independently of them - largely in the United States of America or Europe. The planners of population studies in general could counter these concerns and the risk of actual abuse, by including the indigenous peoples in the planning stages as well as in the ethical discussions of these studies. “The human rights of people in populations should be respected”, and these people should be seen as “partners in the work rather than merely subjects of it” (Cavalli-Sforza, 1994).

One of the fundamental points of opposition of indigenous groups towards genetic studies of human history is that the results may contradict indigenous people’s views of oral and traditional history, and the meaning of genes and genealogy. For example, Maori people have two words to describe the human gene, one meaning “life spirit of mortals” (Iratangata) and the other genealogy (Whakapapa), which connects Maori with themselves and others (Mead, 1995). The gene and genome are not the property of individuals but rather are part of the heritage of families, communities, tribes and entire indigenous nations. In this regard, the UNESCO position on the human genome being part of the common heritage of humanity is more compatible with the views of indigenous persons, than the view discussed in the patent section of those seeking patents on genes.

One response to the opposition has been to place some distance between population genetics research and patents by asserting that patenting is not the primary purpose of such research, and that, in the event that genetic products of the research are commercialised, financial benefits would be shared with the people from whom the genetic material originated. Although some have found this acceptable, others have pointed out that this only serves to incorporate indigenous peoples into a system that views living organisms and community knowledge as commodities which can be patented, “owned”, and traded.

The discussion on the ethical, legal, and social issues arising from human genome research reflects a particular world-view, which has arisen in the context of a world economy that is dominated by the multi-national corporation’s drive for profits. The wrangle over patents, for example, reflects this world view. Yet, an alternative world view is evident when researchers gather germ material from peasant farms and tropical rain forests, and acquire knowledge and expertise from indigenous peoples and peasants, without being asked a single cent in remuneration.

Indigenous peoples’ organisations have begun expressing their own value systems and discussing ways of conserving and protecting indigenous knowledge and culture. In the process, they have opposed the patent system as being fundamentally in conflict with their own value system. One analysis refers to the indigenous value system as the “co-operative
innovation system”, and that of modern science as the “institutional innovation system”, and calls for the recognition of the contribution and value of the former toward the world’s food supplies, farming systems, and medicinal needs (RAFI/UNDP).

III.2 Bioethics and Genetics Education

Public understanding of population genetics requires bioethics and genetics education. Such education has universal support. The questions are: what? by whom? to whom? and who pays? Bioethics and genetic education has been called for also in the Report on genetic screening and testing of the IBC, and is consistent with the founding goals of UNESCO. Population genetics research involves contact with and sampling of different populations. This presents opportunities to involve researchers and participants in a two way process of education.

As discussed above, the researchers should involve local participants in the research. This presents a chance for advanced genetics training, and training in taking consent and consultation from participating groups of people, not a concept currently found in the local scientific or legal environment! Researchers should also develop collaboration in the international context. Indeed, the process of anthropological research actually involves education of the researchers in the local customs and beliefs, which can then be shared with the rest of the world in efforts to help understanding among peoples. In this way all can learn through research.

The people participating in the research will be able to learn of the reasons why the sampling is sought and of the research goals. They may be interested to meet people from out of their community, though the contact should not create expectations which cannot be fulfilled. There is the need to share results. Some representatives of indigenous populations, however, have expressed concern that they do not want to know the results of scientific studies that challenge their local understanding of history. There is also the education of researchers during the process of their search negotiations and of the results of any investigations, of the attitudes of local groups and populations. The process of anthropological research actually involves education of the researchers of the local customs and beliefs, which can then be shared with the rest of the world in efforts to help understanding among peoples.

In this way all can learn through research that is entered into with a willing spirit to learn. There are further issues that need special attention for population genetics, especially those discussed in the ideology section above. Racism and eugenics are deep-seated attitudes, often related to a desire to protect the power of “my group”, rather than rationally arrived at positions. It is generally believed that the misuse of genetics also depends to some extent on the level of education of genetics that people have. If education of genetics, as well as the bioethical issues it raises, is increased, many hope this would reduce the tendency for racism. Contrary to this, however, in the first part of this century most educated biologists supported eugenic thinking (Paul & Spencer, 1995). Some would maintain that social eugenic programs of that time were based on false genetic knowledge, however, either interpretation of history illustrates the power of education.

There is a need for public and student education. Advances in biology and medicine have generally led to pressure upon educators of how students can be prepared to face the ethical dilemmas that the technology often raises. In school and university education during the 1960s to 1990s, in many countries, science has been taught independent of social or ethical values. However, science educators have discovered during the last two decades that the most efficient way to educate science is to discuss the science together with examples of technology and put the facts into the social context. This method of teaching is generally called the Science, Technology, and Society (STS) approach (Ramsey, 1993). Bioethics is one part of the approach of STS. There are a diversity of views on how to effect efficient education of social issues and even the science itself (Waks & Barchi, 1992), however, the point is that students learn more science when it is combined with practical applications. The problem is that value education has also been abused in the past to promote discrimination, and the weight of the word “scientific” can make people believe that such a value is also scientific. There is a need to work on what can be taught, and to promote decision-making, and recognition of human diversity.
The finding of educational efforts obviously cannot be absorbed totally in the budgets of the population genetics research. Therefore, there should be some commitment of the funds to education found in the Human Genome Project research programs for ethical, legal, social impact and educational issues.

IV. Conclusions

IV.1 Summary

Recently research involving human subjects has become more regulated. In addition to international bodies such as UNESCO or HUGO, and national finding agencies, there are already national laws in many countries to involve local research ethics committees, such as Institutional Review Boards (MacKay, 1993). Current population genetics research is under the oversight of different layers of control which vary widely around the world. Some research is only under the discretion of individual researchers, most seek consent from the persons who provide the tissue samples, and the international regulations on research involving human subjects are clear that informed consent is needed. Some finding agencies demand ethical review, such as NIH-funded research in the United States of America. Some universities in the world also demand ethical review, and the trend is to have more review. The HGDP being an international project will demand international standards of consent and confidentiality, which when appropriately implemented in the local situation will be at least as good as ethical guidelines for existing research.

In addressing the ethical, legal and social issues of human population genetics research, several points of principles need to be considered. The body entrusted with the responsibility of overseeing such research should include substantial and legitimate representation of the target populations. Indeed, a wide representation of people’s groups should be included in all stages of population genetics research projects. Considering that the protection of the intellectual and cultural property rights of the sampled populations is a legitimate concern, specific mechanisms on how to protect these rights ought to be formulated. Furthermore general statements of possible benefits flowing from research projects to local populations, such as the HGDP’s claims that it will lead to the development of scientific laboratories in local areas, should be formulated concretely and specifically so that it becomes obvious how this will happen.

The International Bioethics Committee of UNESCO needs to consider whether they should outline some principles of ethical guidance, and give further explanation of practical measures and procedures. As has been pointed out by Majumder (1995), member of HGDP Executive Committee from India, in some countries the positive image of a United Nations body such as UNESCO would ease the concerns of local politicians and groups if they were to take a direct interest in the oversight of the HGDP. In fact as we observed during the consultation process during the drafting of this report, some researchers and some population groups have asked UNESCO to review the ethical issues, and to establish a committee to continue the ethical review of the research, and proposals. However, this would require the development of more detailed guidelines addressing the ethical and commercial issues raised by the HGDP. Such guidelines would also be useful for general population genetics research. In any case, detailed guidelines should involve local authorities (communitarian as well as national) at first, to ensure that communitarian and national concerns, interests and conditions are fulfilled and respected.

The broad involvement of UNESCO, WHO, CIOMS, HUGO, ICSU, and possibly other bodies within the regulatory committee is important. There is a need to include representatives of people’s groups in all stages of population genetics research projects, and in the oversight committee. In North America the HGDP committee has included two representatives of indigenous peoples groups, and this should happen in a global sense, though we must ask who are suitable representatives. The answer to this may depend on the locality and situation, and should be flexible.
Regarding the HGDP, the scientific goals are generally valid, and the HUGO HGDP Committee has produced a good introductory report on the reasons for the HGDP (HGDP Summary Document, 1994). The North American HGDP regional ethical committee has produced detailed guidelines, which has progressed the ethical review of future population genetics studies conducted within their auspices (Greeley, 1995). The ethical guidelines do take account of the critiques of most writers, however, we can say that the organisers would have received less critique if they had more actively involved leaders of indigenous people’s groups in the planning of the project. Indigenous people’s organisations have opposed the HGDP on several bases, a fundamental one being that, while many groups of indigenous peoples face physical and cultural extinction, the project has not expressed concern about their eventual disappearance, but has instead expressed urgency in collecting tissues from these groups before they disappear as separate entities. The ethical oversight committee of the HGDP should address this issue in concrete ways.

The goal of population genetics to understand human history is controversial because of feared misuse, but the possible medical goals seem to be universally accepted except for the fact that the medical techniques may be patented. The possible patenting of products from the material collected from sampled populations has given rise to concerns that financial benefits are derived from them but will not benefit them in anyway. These concerns are based upon their past experience in having had their plant seeds and their knowledge of medical plants appropriated by outside parties. Cell lines and DNA collected during population genetics projects can be a potential target of commercial research, as shown in several patent cases. Although some researchers and the HGDP have committed itself to protecting the intellectual property rights of the sampled populations, the mechanisms for doing so are not clear and need to be specified.

The claim that the HGDP will reduce racism is debatable since it will be impossible to provide any proof that it will or will not happen until after the event. However, the misappropriation of population genetics to support racism has always been strenuously resisted by L.L. Cavalli-Sforza, one of the principal architects of the HGDP (e.g. Bodmer & Cavalli-Sforza, 1970). Nevertheless fears about the possible uses to which information gathered in the HGDP could be put have been expressed which cannot be ignored. At an early stage in the project’s planning, several groups speaking for indigenous peoples called for a halt to the Project. However, it would seem to be impossible to stop the general progress of this project, and it is not within the mandate of UNESCO to call for a moratorium on such a project or on population genetics research. The response of UNESCO has been to ask other groups to join in the regulation of population genetics, and the HGDP. Invitations to join the ethical oversight committee of the HGDP should be formally extended to indigenous communities who could select their own representatives. These principles apply to population genetics in general.

The use of research results should in no way harm persons and not result in possible discrimination of the individual and population concerned. Future increased ability to identify people genetically at risk for genetic and common diseases, needs to be accompanied with the measures to protect the individual from stigmatisation and misuse of information by a third party. (Note: we rely on the 1994 UNESCO IBC Report on Genetic Screening and Testing, and the 1995 UNESCO IBC Report on Genetic Counseling).

IV.2 Sanctions

While as described earlier, regulatory oversight usually foresees a certain degree of scientific and ethical review prior to acceptance of a research protocol, once accepted, ongoing monitoring and surveillance usually are not assured. Even less certain is the possibility of sanctions in whatever form. Disciplinary measures including for example, suspension, withdrawal of privilege and fines, constitute the usual avenue of professional measures. In addition, where research subjects have been harmed, civil and criminal sanctions are also possible. Funding bodies may withdraw funds and sometimes even retroactively. The latter is rare however. In any event, unless involving great numbers as in the HIV blood testing scandals and the recent breast cancer trials, cases of research fraud or of failure to respect basic ethical norms are usually not brought to public attention.
If researchers are to become more accountable and actual practices more transparent, other forms of sanctions, or at least of publicity, should be envisaged. Stricter, standardised reporting requirements, on a regular basis, and publication of such reports are one such avenue. We consider the latter to be a basic ethical obligation that should be universally applied.

If researchers are to be subject to greater scrutiny, the same holds true for the media whose duty of honest, scientific reporting and preservation of privacy needs to be underscored. Whole populations, communities and the researchers themselves have often been wrongly depicted and wrongly represented with the resulting unjust labelling and discrimination. Such practices only serve to undermine public confidence and participation in research.

**IV.3 Conclusions**

The scientific and philosophical traditions that have long permeated research are also present in population genetics. The prevailing attitude in science is that research is in and of itself a good. Therefore, if properly explained and understood, participation should be forthcoming. Communities and populations, however, have their own cultural traditions and histories that need to be understood and respected. Moreover, population genetics is not simply a multiplication of the individual ethical and legal issues already raised by genetic research. There are different concerns and traditions in each group under study, and even among individuals within any group. The degree of information, consultation and co-operation must reflect such differences in participants. Likewise, the role and responsibilities of the researchers and of the local and national authorities, as well as the societal implications, will differ.

Having examined then, the ethical issues particular to population genetics, their philosophical basis, their research methodologies and possible utilisation of research results and most importantly, the need for education because of fears of identification and stigmatisation through selection, of discrimination through participation, and, of possible eugenics through interpretation, we have recommended in this report the following issues as crucial to ethical review of population genetics research at institutional, and regional or global levels:

1) accessibility to populations;
2) consultation with populations;
3) individual and group consent mechanisms;
4) ongoing ethical review;
5) inclusion of representatives of populations in decision-making;
6) communication, education, benefits, and feedback strategies at the population level;
7) confidential data and sample banking;
8) continual scientific review and monitoring; and finally,
9) appropriate sanctions.

At its Second Session, the IBC was requested to consider establishing a committee on the ethical questions that might arise in the HGDP. This proposal has been supported by WHO, CIOMS, ICSU, and HUGO. We recommend that such a committee should be more broadly conceived so as to be available for ethical consultation for all human population genetic research projects, and not only the HGDP. Given the concern shown about population genetics and in particular for the HGDP by indigenous peoples’ organisations, we strongly recommend their inclusion in such a committee. While there is a negative side to a centralised population genetics project, there is some merit to the idea that co-ordination and review may help ensure ethical practice of individual researchers.

We suggest that a paragraph could be added to the preamble of the future UNESCO declaration on the human genome and human rights, for example: “Bearing in mind that human cultural and genetic diversity is an intrinsic value of the human species, which should be recognised in all communities”.

References

- Chadwick R. et al., “Ethical Implications of Human Genome Analysis for Clinical Practice in Medical Genetics with Special Reference to Genetic Counseling”. Cardiff: Centre for Applied Ethics, 1993
• Greely H.T., "Personal communication, comments of 24 February 1995 on the draft report of D. Macer oh 10 February 1995".


• Kahn P., "Genetic Diversity Project Tries Again". Science 266 (1994): 720-2

• Kevels D.J., "In the Name of Eugenics". New York: Knopf, 1985

• Knoppers B.-M., Hirtle M. and Lormeau S., "Ethical Issues in International Collaborative Reserach on the Human Genome: The HGP and the HGDP", draft version prepared for HUGO Ethics Committee, 1995

• Lock M., "Interrogating the Human Diversity Genome Project". Social Science & Medicine 39 (1994): 603-6

• Lucotte G. & Hazout S., "Y-chromosome DNA Haplotypes in Basques", a report on population genetics sent to UNESCO, 1995

• Macer D.R.J., "Bioethics for the People by the People". Christchurch: Eubios Ethics Institute, 1994


• Macer D.R.J., "Whose Genome Project?". Bioethics 5 (1991): 183-211


• Majumder P., "Personal communication, comments on the draft report of D. Macer of 10 February 1995"


• McCarrick P.M., "Genetic Testing and Screening". Kennedy Institute of Ethics Journal 3 (1993): 333-54


Declarations against the HGDP include: Karioca Declaration (June, 1992, Brazil); Mataatua Declaration (June 1983, Aotearoa New Zealand); UN-Working Group on Indigenous Populations, 10th Session (July 1993, Geneva); Maori Congress (1993, Aotearoa New Zealand); National Congress of American Indians (3 December 1993, Resolution NV-93-118); Maori Congress Indigenous Peoples Roundtable (June 1994); Guaymi General Congress (1994, Panama); Geneva IPR Workshop (August 1994); Latin and South America Consultation on Indigenous Peoples Knowledge, Santa Cruz de la Sierra, Bolivia (September 1994); Asian Consultation on the Protection and Conservation of Indigenous Peoples Knowledge, Sabbath, Malaysia (February 1995), Pan American Health Organisation Resolution (15 April 1995); Pacific Consultation on the Protection and Conservation of Indigenous Peoples Knowledge, Suva Statement (May 1995)

• Morell V., "Who Owns the Past?". Science 268 (1995): 1424-6


• RAFI, "Immortalizing the (Good?) Samaritan. Patents, Indigenous Peoples and Human Genetic Diversity". RAFI Communique, 1993b

• RAFI, "Patents, Indigenous Peoples and Human Genetic Diversity". RAFI Communique, 1993a

• RAFI/UNDP, "Conserving Indigenous Knowledge: Integrating Two Systems of Innovation", an independent study by the RAFI commissioned by the UNDP

• Roberts L., "Anthropologists Climb (gingerly) on Board". Science 258 (1992): 1300-1

• Science and Technology Committee of the House of Commons (UK), "Human Genetics: The Science and its Consequences". Third Report, 1995, xxix


INTERNATIONAL BIOETHICS COMMITTEE

Working Group on population Genetics

Members:

Mrs Chee Heng Leng (Malaysia)
Mrs Laïïla El-Hamamsy (Egypt)
Mr John I. Fleming (Australia)
Mr Norio Fujiki (Japan)
Mrs Genoveva Keyeux (Colombia)
Mrs Bartha Maria Knoppers (Canada)
Mr Darryl R.J. Mater (New Zealand)
Chapter 4

THE TEACHING OF BIOETHICS IN THE AMERICAS

- Teaching of Bioethics in Latin America
  (Lidia Vidal-Rioja and Rubén Lisker Y.)

- Bioethics Education in the United States: A Commercial Turn
  (Daniel Wikler)
I. Introduction

The extraordinary progress of human genetic research during the last years, fuelled in part by the international Human Genome Project, has made many people and organizations worry about the use that society will give to the results of the above project. Bearing this in mind, in September 1993 UNESCO created the International Bioethics Committee, to analyze the impact of “new genetics” on society and to issue a document by its Legal Commission for the protection of the human genome. All members of society should be engaged in this discussion and one of the questions that arises is how much bioethics is being taught in different parts of the world and to whom this teaching is addressed.

We were asked to explore this point, the teaching of bioethics in Latin America, for which purpose we developed a questionnaire and sent it to bioethics centres and educational organizations of different levels. What follows is the result of this survey.

II. Methods

Some centres contacted were listed in the directory of the UNESCO Bioethics Unit as leading institutions in teaching, advising, spreading and researching bioethics in different regions of Latin America. The questionnaire was also sent to universities and institutions to which one of us was linked or which were referred to us by some others. A total of 51 questionnaires were sent to institutions distributed across Argentina, Bolivia, Brazil, Colombia, Chile, Ecuador, Mexico, Peru and Uruguay. Table I summarizes the number of questionnaires sent to each country and the response rate. The survey sent by mail included a presentation letter which also stated the overwhelming scientific progress operating nowadays particularly in the medical genetics field and the bioethical issues raised by some biomedical applications. When the first sending was not answered, reminders were sent to some of the institutions forty days later. The questionnaire comprised two parts. One aimed to learn the organization of bioethic studies and the other to assess to what extent institutions were involved in the education of the general public.
## Table I. BIOETHICS TEACHING: SURVEY IN LATIN AMERICA

<table>
<thead>
<tr>
<th>Country</th>
<th>Surveys Sent</th>
<th>Response Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Argentina</td>
<td>24</td>
<td>13 (54.2%)</td>
</tr>
<tr>
<td>Bolivia</td>
<td>2</td>
<td>2 (100.0%)</td>
</tr>
<tr>
<td>Brazil</td>
<td>5</td>
<td>3 (60.0%)</td>
</tr>
<tr>
<td>Colombia</td>
<td>5</td>
<td>4 (80.0%)</td>
</tr>
<tr>
<td>Chile</td>
<td>2</td>
<td>2 (100.0%)</td>
</tr>
<tr>
<td>Ecuador</td>
<td>2</td>
<td>1 (50.0%)</td>
</tr>
<tr>
<td>Mexico</td>
<td>5</td>
<td>3 (60.0%)</td>
</tr>
<tr>
<td>Peru</td>
<td>2</td>
<td>1 (50.0%)</td>
</tr>
<tr>
<td>Uruguay</td>
<td>4</td>
<td>3 (75.0%)</td>
</tr>
<tr>
<td>Total</td>
<td>51</td>
<td>32 (62.7%)</td>
</tr>
</tbody>
</table>

## III. Results and Discussion

The survey was answered by 32 institutions (62%); 13 were chairs or centres affiliated to public universities, 7 corresponded to private universities, 4 to public health State departments and 1 to the Commerce Commission of the South America Common Market (MERCOSUR). From the 7 institutions remaining, 2 were branches of private foundations, 1 of a scientific academy and the last 4 were autonomous or under the patronage of professional associations. The first part of the questionnaire also explored the scope of action of each organism contacted. Thus, we learned that, in addition to centres belonging to the university, a number of unrelated ones also participate in the teaching of Masters (licentiate for most countries) and postgraduate courses at different schools (Figure 1 shows these data). At both stages of education the teaching of bioethics at medical schools far exceeds the number of other disciplines. This finding was not unexpected because medical ethics has been for centuries the concern of world-wide civilizations. Moreover, in the view of Chilean, Mexican, Argentine, Brazilian and other Latin American institutions, bioethics as a discipline of thinking, reasoning and morals, is well related to medical practice so it must be taught at the very outset of the biomedical career. This study also revealed the growing mention of bioethics within classical careers such as biology, law, philosophy, economy and technology. On the other hand, the data were explicit about Argentine and Brazil both having already instrumented health care postgraduate courses with a strong content of bioethic issues in their syllabus and yet others addressed to a postgraduate specialization in bioethics. We have information about other countries teaching similar courses but they were not registered in this survey.

During Master’s and postgraduate studies of different disciplines the time dedicated to courses of bioethics may vary from less than four weeks to more than a year. These data are depicted in Table II.

On scoring the bioethic professors we found that medicine showed the largest number (Fig. 2). The survey, however, did not make clear their qualifications nor those of philosophers, lawyers, and other professionals in charge of bioethics teaching in different faculties.
To achieve their goals, professors may employ a variety of approaches: lectures, seminars, courses, publications, TV media and others being the most frequently quoted (Figure 3 summarizes these data).

Bioethics, as understood by most current societies deals with ethical facts frequently raised by the rapid progress of life sciences. More recently, astonishing genetic breakthroughs and allied biomedical applications became a discussion focus of bioethics. Accordingly, each and every individual might be enlightened about the benefits of new technologies; everyone should also become aware of the social, medical, legal and economic effects these advances may produce on present and future generations. Which personal values and human freedoms should be protected or even enhanced? It can be realized that, upon inquiring about medicine and social sciences topics preferably discussed during bioethic classes, respondents were able to choose from a wide list of subjects with major bioethical impact. Although the religious enrolment of the institutions was not asked directly we could assume the Catholic Church dependence of some of the centres and infer its influence on several others. Figure 4 shows that among 28 possible answers, those on genetic manipulations and biotechnology were selected in different combinations to give 51 positive answers. Bioethics related to medical ethics and human welfare were cited in a cross manner in 46 opportunities, and reproductive technologies and abortion in 35. Other topics like quality of life and euthanasia are discussed together since in several centres each amounts 17 responses. Concerns about sexual education, sexually-transmitted diseases and drug and alcohol abuse are reflected in about a dozen of positive answers each. Discussions on ecology and environmental ethics were also quoted together 13 times and those on legal and commercial ethics 11 times. The high impact of organ transplantation in different societies is well known. It seems then justified that 18 institutions had included in their curricula the repercussions that these technologies are having in their own society.

A broad range of articles, bulletins, reports, books and other type of written information on bioethics, has been released by the participants surveyed, during the last five years. The information depicted in Figure 5 compiles these data and others from attached references sent by authors. These pieces of supplementary knowledge revealed the interdisciplinary character of some of the groups surveyed as well as the studies specificity covered by others. Moreover, the data reported knowledge on bioethic journals of regional circulation such as *Bioética* from Brazil which expresses the thinking and attitudes of the community towards universal issues.

As mentioned above, a section of the questionnaire was aimed to assess bioethic education for the general public. In this point, our perception indicates that a number of activities addressed to people are performed by public and private organizations. The last two years have been very productive, particularly in Brazil, Argentina, Chile and Mexico, where well attended meetings on bioethics, genetics, philosophy and law with sessions dedicated to bioethics, have been held. In addition to these reunions, conferences, courses, seminars, etc.

### Table II. DURATION OF POSTGRADUATE COURSES

<table>
<thead>
<tr>
<th>Discipline</th>
<th>1 month</th>
<th>1 to 6 months</th>
<th>1 year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicine</td>
<td>14</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Philosophy</td>
<td>10</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Law</td>
<td>5</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Biology</td>
<td>2</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>See. Sciences</td>
<td>1</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Others</td>
<td>1</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>
are organized at social institutions, professional and neighborhood associations, churches and parliament sessions. In every case, the respondents quoted the educational level of the audience which usually attend these meetings. Figure 6 shows that a high number of positive responses include people with third level of instruction. In most Latin America education systems this group comprises students with specialized jobs like grade-school teachers, musicians, nurses and other paramedical professionals, as well as language professors, librarians and others graduated from polytechnic institutions. Within university graduates we included those professionals with Master titles (which in most Latin America systems are referred to as Licentiate) and doctoral degree. By secondary school instruction we meant those that completed 5-6 years studies after the elementary schools. Currently, this group is constituted by employees from either State organizations or commercial bodies and less frequently by political, social and religious leaders, or police officers. In most cases, common people attending bioethic classes have completed the seven years studies of grade school and in many cases, particularly women, accredit having attended training courses for hairdresser, pastry, handicraft, etc.. Finally and unfortunately, only two respondents informed about activities addressed to children and teenagers from elementary school.

The final points assessed by the survey dealt with the availability of resources to teach bioethics in Latin America. The question whether universities possessed appropriate finding for bioethics was negatively answered by all respondents. Nevertheless, 63% remarked on the growing interest for the subject and the high perspectives of setting up new bioethic courses in medicine, philosophy, law, psychology, biology, health care and others by 1996 or proximate (Table III). Furthermore, in order to improve bioethics education in the region, opinions which outline the basic needs demanding attention were requested. According to the results of Figure 7 support for journals subscription and books purchasing seems the most imperative, though help to appoint professors and scholarships to grant attendants are also required. The desire of less provided centres of getting a computer to organize their records and the interest of others to exchange information with their partners in the region was also posed.

<table>
<thead>
<tr>
<th>Table III. PROSPECTS OF BIOETHIC COURSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discipline</td>
</tr>
<tr>
<td>Medicine</td>
</tr>
<tr>
<td>Philosophy</td>
</tr>
<tr>
<td>Biology</td>
</tr>
<tr>
<td>Law</td>
</tr>
<tr>
<td>Sot. Sciences</td>
</tr>
<tr>
<td>Others</td>
</tr>
</tbody>
</table>

**IV. Conclusions**

These results show that following universal tendencies a number of bioethic institutions have been created in Latin America during the last years. Most frequently, these centres are closely related to medical affairs such as university chairs, professional associations, public health bodies, academies, etc.. Nevertheless, bioethic issues concerning philosophy, law or social sciences have also set up. In all cases the role of these institutions in the teaching of bioethics is clearly perceived.
In general, at the university level, bioethics is preferentially taught to advanced students complementing classical disciplines. Teaching addressed to novel students is a more recent undertaking of some medical faculties from a few Latin America countries that should be imitated by many more.

A growing "protagonist" of bioethics itself is nevertheless indicated by regional settings as the Latin America School of Bioethics, the Regional Programme of Bioethics of the Pan-American Health Organization and the University of Chile, the first UNESCO Chair of Bioethics at the University of Buenos Aires and the Ph.D. in Bioethics at the University of Mar del Plata. All these aimed to make teachers and the general public aware of bioethical issues associated to science and technology developments, and enable them to take decisions based not only on practical benefits but on moral principles also.

It seems, at least in urban areas, that the general public possesses opportunities to become informed on the multiple technologies that scientific progress offers to society and the myriad of related situations on which they might have to make choices.

The survey is clear regarding the subjects preferably discussed during bioethic forums. Also it is clear about the imbalance between bioethic educational demands and the budgets that different bodies assign to it. This indeed is a critical point which we consider a challenge for future debate.

Acknowledgements

The secretarial help of M. Silbestro, the English correction by B. Tosti and the figures drawing by J. Lopez-Camelo are highly appreciated. Our thanks also go to all institutions who answered the questionnaire and made possible this investigation. This survey was carried out with the aid of A. Carnevale from Mexico and of the CIC and CONICET from Argentina.
Fig. 1 Teaching of Bioethics in the University.
Stage of Education and Schools

Fig. 2 Professors of Bioethics.
Number and Disciplines
Fig. 3 Teaching of Bioethics.
Approaches Employed

![Bar chart showing different approaches to teaching bioethics]

Fig. 4 Life Science Issues with Bioethical Impact Preferably Discussed.

![Bar chart showing life science issues with bioethical impact]

A: Genetics - Biotechnology  F: Social Diseases - Addictions
B: Bioethics  G: Organ Transplantation
C: i.v. Fertilization - Abortion  H: Genetic Diseases - Therapy
D: Quality of Life - Euthanasia  K: Ecology - Environment
E: Sexuality - Birth Control  L: Scientific Research
O: Commerce - Law  P: Aging
Q: Theology
Fig. 5 Publications on Bioethics.
Fig. 6 Public Information on Bioethics.
Education Level of the Audience

Fig. 7 Supplies Needed for Improving Bioethic Education in Latin America.
BIOETHICS EDUCATION IN THE UNITED STATES: A COMMERCIAL TURN

(Daniel Wikler*)

I. A Success Story

Twenty years ago, courses in bioethics in American Medical Schools were relatively rare. Today they are ubiquitous. This year’s Curriculum Directory of the Association of American Medical Colleges reveals that ethics courses are taught in every one of the schools comprising the Association of American Medical Colleges. In the majority of cases, the ethics course is required, not merely elective. The American Medical Association’s Accreditation Council for Graduate Medical Education, which accredits residency programs in the medical specialties, requires all residency programs to include bioethics education (compliance, however, is uneven). Similar trends have been supported by the nursing profession and even in schools of dentistry. Courses in bioethics are taught also to undergraduates and to scientists in training. These courses are supplemented by countless conferences, symposia, and journal articles which continue bioethics education for the duration of the health care professional’s working career.

Bioethics education is carried out by a small army of bioethicists - a group defined by what its members do rather than by any common credential or training program. Physicians, who once were uniquely trusted to teach bioethics to new generations of medical students, have been joined by professional philosophers, theologians, lawyers, social scientists, and psychologists. Only a small number of these teachers have degrees from an academic bioethics program. Moreover, no professional society has set standards for bioethicists, and there exist no formal qualifications for teaching bioethics in American Medical Schools and schools of allied health professions. Moreover, there is no consensus on whether this state of affairs should be regarded as a problem or as a strength.

* Professor of Medical Ethics, University of Wisconsin Medical School.
Serious attempts to measure the effectiveness of medical ethics courses have been few. This is not surprising, if only because bioethicists do not agree on why bioethics should be taught nor on the intended effect of their courses. For many lay people as well as physician-educators, bioethics education is understood as a response to a perceived deficit in the willingness of today's doctors to treat their patients as autonomous human beings. On this understanding, courses in bioethics would instruct students in listening sympathetically to patients and in ridding themselves of any tendencies toward arrogant or unfeeling bedside manner. More often, however, these “human skills” are taught in courses on interviewing and patient management and are not regarded as part of the bioethics curriculum.

A different understanding of the point of bioethics education views these courses as the occasion to instruct students on the substance of medical duties, such as confidentiality and informed consent, and to impress on students the necessity of acting according to professional standards of conduct(s). Still another view emphasizes “ethical process, not answers,” citing the multiplicity of ethical viewpoints in American medicine and the American public; and a variant of this position views bioethics courses as the occasion for combating the student’s tendency to accept conventional wisdom and to enhance his or her ability to think critically and act independently.

Since these goals are quite different, and in some cases are even at odd with each other, there is little hope for a criterion of success in bioethics teaching beyond the standard yardstick of student approval. Besides, it is widely acknowledged that bioethics teachers are not the most powerful teachers of bioethics; these are, instead, the clinicians who act as role models and whose behavior toward patients, sense of integrity, and devotion to the calling of medicine impress on students a living example of what they might aspire to become. This “hidden curriculum” is taught throughout the working day and probably swamps any specific effect of bioethics teaching on medical student behavior.

To date, however, the lack of proven benefit of bioethics teaching has not impeded its acceptance. It has become standard and routine. To idealists, the embrace by medical schools of bioethics teaching is a sign that health care professionals care deeply about human values and seek rational solutions for the ethical dilemmas they face in the clinic. To skeptics, their enthusiasm for bioethics can best be explained as a sop to the public, an inexpensive way of promising that physicians will be caring and reflective people who have their patients’ interests at heart.

II. Clouds on the Horizon

Is it possible to forecast the further development of bioethics teaching in the United States? Since its growth so far has been a surprise to nearly all observers, there is little reason for confidence in predicting what will happen in the years to come. I will take note of two trends, one of social importance, the other rather mundane, which are likely to have some influence.

Bioethics remains a “growth industry” in the United States. Newspapers and television compete to carry the latest stories of medical breakthroughs and the ethical issues that often attend their use, whether these be genetic tests or new methods of reproduction or advances in other medical specialties. Some bioethicists have become familiar public figures, and the current Vice-President, Al Gore, was an informed and interested participant during his years in the United States Senate. At the same time, government agencies at both state and local levels have increased their activity in bioethics. The National Institutes of Health, for example, is currently expanding its bioethics unit, and a new National Bioethics Advisory Commission is being formed in the White House. The Human Genome Project is generating as many ethical issues as it is genetic markers, and is also supplying some of the finds needed to investigate them. The Institute of Medicine, part of the National Academy of Sciences, studied the great variety of forums and methods used by our society to debate on bioethical dilemmas and called for still further strengthening of our deliberative capacities. This upward curve of societal interest can be expected to continue.
The mundane development which could have a significant impact on bioethics education stems from the large-scale changes now occurring in the organization and financing of American health care. Our health care system is funded by a blend of public and private dollars. Both kinds of payers have been plagued by costs which are far higher than those of any other country, and cost containment has become the central objective of health policy. The system has rapidly turned toward privately-owned prepaid health plans, which strive constantly to reduce costs so as to lower prices and to deliver profits. In many parts of the country, price competition has become severe.

Why does this bear on the teaching of bioethics? Because bioethics has been taught in academic medical centers, and these entities are having serious trouble in the current medical marketplace. Employers and others who pay for health care are buying health care services on the basis of price, and are increasingly reluctant to pay higher prices to academic hospitals so that the latter can engage in such good works as research, teaching or bioethics. The academic medical centers are competing with investor-owned chains which have bought local clinics and brought in efficient management. As Arthur Caplan recently noted in his presidential address to the American Association of Bioethics bioethics in “overhead”, a cost borne by the academic health center with no prospect of earning patient revenue. As these centers’ financial losses mount, all overhead, including bioethics, is likely to be targeted by accountants as a means of cost-saving for the sake of survival in the marketplace.

One might expect that bioethics, like teaching and research, would be financed independently as a public good. Until very recently, the government permitted higher charges by academic health centers, and private insurers as well were willing to tolerate cross-subsidization from their payments to support these activities. Because of the changed political mood of the country, however, along with the single-minded attention to lowering the costs of care, these finds are disappearing. A number of leading teaching hospitals are currently facing the choice of merger with another institution or locking their doors, and they will probably be joined by many more. It will be difficult for bioethicists to maintain their current level of activity, since hours spent in bioethics cannot be billed to patients and insurers (though, to be sure, some have proposed to try).

One outgrowth of these economic conditions is the effort of some bioethicists to market their services to the corporate entities now gaining control of the trillion-dollar health care system. Bioethics may not generate revenues, but it has the virtue of being inexpensive, and these corporations have a lot of money. What is less clear is what this kind of salesmanship will do to bioethics.

III. A Structural Agenda for Bioethics?

Even if the level of bioethics does not decrease, however, the privatization and corporatization of American health care will have a profound effect on bioethics and bioethics teaching.

Fifteen years ago, the philosopher Daniel Callahan, in a widely-noted address to the Massachusetts Medical Society called on his colleagues in bioethics to shift their attention from the individual to the structural. Up to the time of Callahan’s address, the substance of bioethics was targeted on the relationship of a doctor and his or her patient. Whether the subject was end-of-life treatment, genetic counseling, or human experimentation, bioethics offered advice to individuals and counseled them to adopt high standards of personal conduct. Yet the choices faced by individuals in these clinical dilemmas, Callahan argued, were determined by the health care system in which doctor and patient found themselves. Bioethicists who remained ignorant of the workings of this system, and who never looked up from the clinical encounter to understand how it is shaped and influenced by the structure and financing of the health care system, might miss the most important ethical questions.

Following Callahan’s address, increasing numbers of American bioethicists began writing on such topics as access to health care, rationing, and ethics of health insurance. Though some of this material began to be included in bioethics texts, and hence taught to
medical students, it was not clear at first who its audience might be. The individual medical student was unlikely to be in a position to determine health policy on a national scale. The bioethical work on these topics seemed better addressed to the government official or health care executive.

In the wake of the rapid corporatization of American health care, however, the relevance of this kind of bioethics to everyday health care is no longer in doubt. One aspect of the large-scale changes now under way is that individual physicians are losing some of the control they have enjoyed over the conditions of their work. They are increasingly required to ask the permission of an agent of the business side of the clinic before making a decision about a patient’s care. If they step too far outside a clinic’s guidelines, or ask too often for an extra measure of care for more than the occasional patient, they are likely to be told “no” and their continued participation in the clinic - indeed, their livelihood - can be put in jeopardy. Anecdotes have appeared in the literature about so-called “gag rules”, in which physicians working in a corporate prepaid health plan are forbidden to let patients know that they are critical of the health plan and its cost-saving rules which tie the doctor’s hands when they would like to provide an extra measure of care. There is also a prospect of “proletarianization” of some doctors, particularly younger ones just entering the field, with control centered in the hands of investors and senior physician-partners, and with junior physicians making the best deal they can in a time of threatened doctor surplus.

At the same time, these new corporate entities are experimenting with financial arrangements which reward doctors for increasing company profits. A portion of a doctor’s pay can vary up or down depending on whether the doctor has managed to curb his or her patients’ appetites for expensive care. Similarly, corporations seek out doctors willing to invest in jointly-owned radiological or surgical units, for example, to which the doctor might refer a patient.

These arrangements obviously have a potential for influencing health care. A doctor’s insight into ethical dilemmas of individual patient care is of less utility if that doctor’s freedom to act on conscience is constrained. Incentives and penalties can influence not only behavior but even the doctor’s own perception of what a patient might need and what might be omitted.

Virtually every bioethical issue discussed in American medical schools over the past two decades needs reexamination in light of these considerations. When bioethics began to be taught in American medical schools, the research their faculty conducted was largely government-funded. Physician-researchers used grants for equipment and to buy their time, but their salaries were not affected. Today, universities encourage physician professors not only to emphasize what can be immediately sold but also to take a financial stake in the outcome; research dollars increasingly flow from private companies, with the professors on the boards of directors. The ethics of human experimentation are very different from what they had been.

The same is true of reproductive medicine. Where once the central debates were over the welfare of the offspring and the autonomy of the mother, the headlines as of this writing tell of possible financial misconduct in a leading fertility clinic, one which had won the eager participation of a well-known public university. The university is alleged to have paid large sums to employees who threatened to publicize the misconduct and malpractice.

In the field of genetics, the major researchers and the leading corporate executives are in numerous cases one and the same. It is becoming increasingly difficult to obtain advice on public policy in genetics which is both informed and unconflicted.

Even the most basic bioethical concepts may need to be re-thought. Informed consent, for example, is a complex transaction in traditional fee-for-service medicine. Much research and long hours of training have been expended in making consent efficient and valid. In the new era in American medicine, however, the financial incentives are for under-treatment rather than over-treatment. The concept of informed consent for a treatment which a physician does not raise as a possibility, lest an assertive patient be prompted to demand expensive care, is still more elusive.
Though none of these developments is entirely new, their cumulative weight during a time of rapid transition puts into question the relevance of much of what has been taught in bioethics courses for the past two decades in the United States. Ezekiel Emanuel, of the Division of Medical Ethics at Harvard, has recently noted that the important ethical rules in the new American health care system may be rules for corporations rather than for individuals. For example, he has proposed that at least 80% of a physician’s salary be paid independently of whether he or she has saved or cost the health plan money by limiting the intensity of a patient’s health care or failing to do so, respectively. Emanuel’s point is that even physicians with great integrity will find it difficult to withstand financial incentives and penalties after a certain point.

Indeed, bioethicists are even beginning to question whether the individuals to whom bioethical duties apply in the future will be the physicians. In his 1995 Pyle Lecture at Harvard Community Health Plan, Bradford Gray noted the decreased ability of doctors under management control to act in the traditional role of advocate for the patient. The ethical duty of the physician, in this case, might be full disclosure - very different from the traditional fiduciary role. Who, then, would be the advocate? Gray reports that the candidate often mentioned in health policy circle is the patient’s employer, more specifically the employing corporation’s “benefits manager”, or executive in charge of employee health insurance. In this view, it would fall to this person to monitor the quality and conscientiousness of health care provided to employees under contract to the corporation, and to take steps to protect employees from under-service and exploitation. Do employee and employer interests coincide so neatly that executives can take on this once-hallowed physician role? Karl Marx would not approve.

If Emanuel and Gray are right, the teaching of bioethics will look very different in years to come. For one thing, bioethicists will have to learn a lot about finance and management, and will have to transmit this learning to medical students. Bioethicists will have to work alongside economists and policy experts to imagine a new set of bioethical responsibilities and rights which will protect the values worth upholding in traditional medicine. And they will have to avoid ethical conflicts of their own when searching for a pay check.

IV. Conclusion

The need for continued teaching in bioethics is, in my view, even more apparent in the current era than before. Bioethics in the United States has been concerned with two kinds of dilemmas. One sort is posed by new techniques and technologies, where the science has outpaced the ethics. The other represents conflicts between society and medicine, often over the most intimate and commonplace aspects of medical practice, when society changes faster than medical tradition. Both of these kinds of challenges remain. To these we must now add, in the United States, the quite uncertain ethics of the corporate marketplace, a set of moral standards once thought foreign to health care but now potentially affecting every medical encounter. The task has never been more important. Whether bioethics teaching will receive the support it will need in order to play a significant role in helping tomorrow’s medical students find a path through these obstacles is one of society’s own ethical dilemmas.


(3) Iserson Kenneth V. and Stocking Carol, “Requirements for Ethics, Socioeconomic, and Legal Education in Postgraduate Medical Programs”. The Journal of Clinical Ethics 4 (3), 225-229, Fall 1993


(9) Miles Steven, Lane Laura, Bickel Janet, Walker Robert and Cassell Christine, “Medical Ethics Education: Coming of Age”. Academic Medicine 64 (12): 705-714, 1989


(12) Bulger et al., op. cit.


(15) Emanuel Ezekiel, “Rules for Managed Care Ethical Conflicts”, Address to the American Association of Bioethics, Philadelphia, September 1995

Chapter 5

PREPARATION OF
A Universal Declaration on
the Human Genome and Human Rights

- Fifth Meeting of the Legal Commission of the IBC
  (Christine de Masson d’Autume)

- Results of the Discussion on Bioethics at the Twenty-Eight Session of the General Conference of UNESCO and Resolutions Adopted

- Preliminary Draft of a Universal Declaration on the Human Genome and Human Rights
  (6 March 1996)
I. Introduction

1. The purpose of the fifth meeting of the IBC Legal Commission was to consider the initial results of the international consultation on the “Outline of a declaration on the protection of the human genome” and to examine how the main comments received could be followed up.

2. To that end, the file handed to each participant contained the following documents: material on the consultation on the “Outline of a UNESCO declaration on the protection of the human genome”, the Report of the fourth meeting of the Legal Commission of the IBC, a text by the President of the Legal Commission on the concept of a common heritage of humanity, the comments of three members of the IBC on the outline of a declaration, and the Report of the Director-General on the possibility of drawing up an international instrument on the protection of the human genome (28 C/38).

3. Mr Hector Gros Espiell, the President of the Legal Commission, pointed out that in view of the wealth and diversity of contributions received the UNESCO Secretariat had grouped the comments according to subject matter in order to facilitate their analysis.

II. Analysis of the Initial Results of the Consultation Carried out on the Outline of a Declaration

4. In his introductory remarks, the President of the Legal Commission said he wished to stress the unquestionable quality and substance of the comments which had been sent in both by members of the scientific community and by legal experts, members of academies and many other institutions. The comments thus presented were, in his opinion, both relevant and stimulating for the reflection of IBC members.
5. An initial issue, already brought up in the comments made by the representative of the International Federation of Philosophical Societies to the Legal Commission on 27 April 1995, was raised by the President. Should it not be more clearly underlined that the essential purpose of the future declaration was to guarantee respect for human dignity and human rights with regard to the human genome? The President proposed that the title of the declaration be modified to that effect to take account of this concern.

6. With regard to the qualification of the human genome as the “common heritage of humanity”, the President considered that the objections raised stemmed perhaps from an inadequate understanding of this legal concept. The term did not in fact apply only to material assets that could be exploited economically. Nowadays, international law made use of this term in the field of culture, for example in the UNESCO Constitution, and in human rights. In the latter case, the Preamble to the European Convention for the Protection of Human Rights and Fundamental Freedoms of 4 November 1950 referred to the “common heritage of political traditions, ideals, freedom and the rule of law”. The term “common heritage of humanity”, which was attributed to the human genome, should therefore be maintained in the declaration in view of the need to guarantee respect for human dignity and human rights and the need for a balance between the protection of individual rights and the common interest of humanity. The rights of the individual and the common interest of humanity were indivisible in this context and mutually reinforced one another. It was proposed that Article 1 be expanded in order to express more clearly in the declaration what was implied by the use of the concept “common heritage of humanity”.

7. Several comments reflected the wish that a definition of the human genome should be given in the declaration. Although it was standard practice to define the terms used in a legal instrument, it would be preferable to refrain from doing so in the declaration in view of the risk of scientific definitions becoming obsolete due to the rapidity with which new discoveries were made.

8. The question of liability regarding interventions affecting the genome, which was addressed in particular in Article 10, raised a number of issues. That article, which laid down the principle of civil, rather than criminal, liability, asserted a general principle of liability without going into the details of how it was to be implemented.

9. In further pursuit of the matter, the requirement of the prior, free and informed consent of every person undergoing an intervention affecting his or her genome was raised. Article 8, which was intended to provide a guarantee in that context, did not take account of the difficulty of obtaining such consent and in particular of all the factors, especially cultural factors, which could impair the validity of the consent given.

10. Lastly, the President of the Legal Commission did not consider it appropriate to take up the proposal aimed at prohibiting interventions affecting germ-line cells, despite the fact that he was of the opinion that such interventions should not be allowed. The purpose of the declaration was to assert principles intended as a guide for the action of the persons and professionals concerned. It was not designed to regulate scientific or medical practice.

III. General Debate

III.1 The Human Genome, the Common Heritage of Humanity

11. With regard to the qualification of the human genome as the common heritage of humanity, it was suggested that the declaration should emphasize the fact that before being part of the common heritage the human genome was first and foremost the property of the individual. The reference in Article 2 to the evolutive nature of the genome should be offset by a reference to the need to protect the genetic identity of the individual.

12. The President of the IBC pointed out that it would be difficult to state in a declaration that the individual was the “owner” of his or her genome, since that would run counter to the legislation of certain countries, including France, which did not recognize ownership of the human body. It would be desirable, on the other hand, to assert more firmly that every individual had a genetic identity and that no operation affecting that identity might be carried out against the wishes of the person concerned.
13. Since the patentability of the genome was not dealt with in the declaration, should there be a reference in the preamble to the international instruments concerning the protection of intellectual property rights? Similarly, should a new article be added to the declaration making provision for the prohibition of all forms of appropriation or marketing of the results of genome research? Any prohibition of the possibility of patenting the results of research in the field of human genetics would have a significant impact on research itself, since prohibiting all possibility of gaining commercial benefits would be liable to discourage research work.

14. It would be difficult to address the important and complex issue of the patentability of human genetic sequences in the UNESCO context alone, particularly in view of the economic interests at stake. The need for a balance between the imperative of free access to the results of genome research and the investment essential for developing that research must be borne in mind. Reflection on the conditions for protecting research results should be pursued in greater depth. It would seem difficult at all events to advance much further on this subject within the context of a general document such as the declaration on the human genome.

15. The President of the IBC stated that the concept of the “common heritage of humanity” was not incompatible with the prospect of the patentability of the human genome. The common heritage concept simply aimed to assert the principle of freedom of access to the results of genome research. She was of the opinion that UNESCO could not go any further in the declaration with regard to the question of patentability in view of the many interests at stake. She proposed, on the other hand, that in-depth examination of the matter be continued in the context of the IBC’s work on ethics and genetic data banks.

III.2 Interventions Affecting Human Genome

16. A debate developed on the principle of liability in the event of injury sustained as the result of an intervention affecting a person’s genome. It was considered preferable to replace the right to reparation by the right to compensation, and to state in the relevant article that it was impossible for children to sue their parents for damages. Care should be taken not to assert “genetic rights” as a result of which children would be able to take legal action against their parents for genetic injury. With regard to the question of causality, if, in order to establish liability, the person concerned must be able to provide proof of a causal link between the injury he/she claimed to have suffered and an intervention, it would seem desirable that the onus of proof should not be on the victim. As to the question whether Article 10 made it possible to render the persons performing the intervention liable, it was pointed out that by law liability could be incurred on grounds of negligence or risk. A more open formulation was suggested with regard to the right to compensation, since, while the right to reparation could result in compensation, it was not limited to that.

17. Mrs Noëlle Lenoir, President of the IBC, considered that Article 10 set forth a major innovatory principle, which could be exercised in a universal context. Specifically, it laid down a principle whose purpose was to ensure the protection of individuals in the event of an intervention affecting their genome, particularly in the case of relocated experiments carried out in the countries of the South. The wording of the article should be revised to that effect.

18. The participants were reminded of the conclusions regarding free and informed consent which had been reached at the meeting in Santiago, Chile, organized by Professor Gonzalo Figueroa Yañez. It was stressed that it was desirable that the declaration exclude any possibility of performing an operation affecting a person’s genome unless for scientific, therapeutic or diagnostic purposes. A further condition for performing an operation on a person’s genome must therefore be added to Article 8: that of the assessment of the risks and advantages for the person concerned. Furthermore, despite the possible drawbacks of the excessive protection of persons who were de jure or de facto incapable, the possibility of carrying out research from which they might benefit must be left open.

19. It was pointed out that the condition of the free and informed consent of the individual concerned was not always appropriate in situations where the group (family, community, etc.) played a predominant role. Article 8 should be reworded to that effect in view of the importance of this issue.
III.3 Rights and Obligations of Researchers

20. It was suggested with regard to the regulation of genetic research that the declaration be confined to entrusting this responsibility to the researchers themselves, urging them to comply with special obligations of meticulousness, caution, etc.

21. The President of the IBC pointed out that the declaration contained another article which invited States to regulate genetic research. She stressed that it would be desirable for the declaration to contain a new article recommending that States set up independent ethics committees, which would have the effect of stimulating public debate on the issue of the applications of genetics. This draft article was approved, subject to certain clarifications that might be added, such as the independence of these committees, the multidisciplinary and pluralistic nature of their composition, their means of action, etc. An effort should be made to take advantage of existing structures in this area: ethics committees functioning at the national or local level, bodies set up on the initiative of governments or private entities.

III.4 Standardization of Terminology

22. With regard to the terminology used in the declaration, attention was drawn to the advisability of certain formulas such as “States shall undertake”. It was stressed that it was standard practice in international law to use wording in declarations that was binding upon States. The purpose was not to create legal constraints, but to commit States morally.

23. The terminology of the declaration, in which the terms “person”, “human being”, “individual” or “no one”, “everyone”, and so on, were used, should be standardized, except in cases where there was a logical reason for such diversity. The matter would be taken up again at the sixth meeting of the Legal Commission.

IV. Conclusion

24. At the conclusion of the discussion, Mr Mohammed Bedjaoui said that he wished to stress that, in his opinion, the draft declaration on the human genome was a text of great quality, even though there was still room for improvement. He underlined its two strong points: the concept of the human genome as the common heritage of humanity, and the statement of the rights and obligations of researchers.

25. The President of the Legal Commission thanked the participants and stated that a new draft reflecting their comments and any new elements arising as a result of public debate would be presented at the sixth meeting of the Legal Commission, which was scheduled for 25 January 1996.
RESULTS OF THE DISCUSSIONS ON BIOETHICS
AT THE TWENTY-EIGHTH SESSION OF THE
GENERAL CONFERENCE OF UNESCO
AND RESOLUTIONS ADOPTED

(25 October -16 November 1995)

I. General Policy Debate

1. The Director-General presented a report on the possibility of drawing up an
international instrument on the protection of the human genome (document 28 C/38), under
Item 7.5 of the Agenda of the twenty-eighth session of the General Conference.

2. Document 28 C/38 presents the results of the reflections undertaken in 1994-1995 by
the International Bioethics Committee (IBC), its Bureau and its Legal Commission, as well as
the recent changes observed world-wide, at national, regional and international levels, in the
field of bioethics. It also reviews the preparation by the IBC of a possible international
instrument on the protection of the human genome. The draft Outline of the Declaration,
which is annexed to this report, is provided for information only, and is still the subject of a
wide consultation amongst the international intellectual community.

3. In his introduction to the general policy debate, Mr Federico Mayor stressed the ethical
mission of UNESCO, which should constitute “a meeting-place where ethical analysis that is
both free and global in its approach can develop, involving political leaders, intellectuals in
all fields and other individuals and institutions in society”.

4. In underlining the role of UNESCO in this field, the Director-General emphasized “the
movement launched with the establishment of the International Bioethics Committee, whose
work, on account of its quality and vision, provides . . . cause for hope. I believe, however, that
beyond the questions linked to advances in the biomedical sciences UNESCO must henceforth
pursue a path of much broader analysis of the ethics of scientific knowledge. Such an
analysis, which could cover all the areas of scientific progress, including the relevant
applications and technologies, should give rise to a broad debate on the challenges to society
now represented by the growth of knowledge and the powers it gives rise to”. 
5. Indeed, during the debate in the plenary meeting, numerous delegates stressed the importance of the ethical mission of UNESCO, in all fields of its competence, to develop international intellectual co-operation and to build a peace founded on the intellectual and moral solidarity of humanity.

6. Where scientific progress is concerned, bioethics, as an awareness of the implications of the advances made in the life and health sciences, in particular genetics and molecular biology, is the basis of an ever-growing debate on the choices that will direct the future course of humanity. Bearer of hope as well as fear, this progress spreads, particularly through biotechnology, to other fields of activity, and the concerns it expresses have an increasing international dimension. In this respect, UNESCO constitutes a place where different views can be expressed and exchanged between all countries of the world.

7. In particular, the International Bioethics Committee constitutes a forum which, in a transdisciplinary perspective, keeps abreast of progress in biomedical sciences, particularly genetics, whilst at the same time taking care to ensure respect for the values of human integrity and dignity in view of the potential risk of irresponsible attitudes in this field.

8. Moreover, in his reply to the general policy debate, the Director-General highlighted "the many references made to the Organization’s, ethical mission and to the leading role assigned to it in this connection, as an international forum", and he referred to "the example of the International Bioethics Committee, which has led to the initiation of an intercultural dialogue - dispassionate, but searching - on the problems in society that arise from the application of the findings of research on the human genome".

9. Finally, UNESCO should strengthen ethical discussions in all the sectors of competence of the Organization. As Mr Mayor stated, "It will be for UNESCO to initiate a more wide-ranging discussion on the use of scientific knowledge and the resulting technological innovations within the broadest possible multicultural context and on the basis of the principles of the freedom and dignity of the human individual". The emphasis placed by several delegates on the educational, scientific, cultural and ethical challenges of the new technologies of information and communication is without doubt an expression of the need for analysis of the ethical and legal aspects of present knowledge.

II. Debate in Commission III (The sciences in the service of development)

10. All the interventions during the debate stressed the need to keep abreast of advances in knowledge, particularly scientific knowledge, through ethical discussion and analysis. The status of our scientific knowledge and the powers conferred on us by our technologies bring us, more than ever before, face to face with our responsibilities - responsibilities towards ourselves, our communities and humanity as a whole. Ethics - which the Director-General has often qualified as “ethics of responsibility” - concern all aspects of our daily lives, private and public, related to the scientific or social and cultural fields.

11. Where bioethics is concerned, delegates recognized the importance of such a discipline which would reconcile the needs of scientific research with the universal principles of human rights and respect for human dignity, and emphasized the quality of the work carried out by the IBC. The interest expressed by certain States as to what is at stake in research in genetics, and the activities of UNESCO in this field, is witnessed by their active involvement in the work of the IBC, particularly during its Third Session in September 1995. At the opening of this Session, a round-table discussion involving several parliamentarians afforded the occasion for a dialogue between different points of view on the subject of bioethics.

12. The IBC has been invited to strengthen its efforts in disseminating information concerning its work, in particular by using new methods of communication and information. Ever since its creation, the Committee has been considered as a place for debate and the exchange of information and ideas. In this respect, its discussions and analyses have always
been associated with various National Ethics Committees which also receive its publications and reports on a regular basis. The publication of a Directory listing information collected with the co-operation of National Commissions is planned for 1997. It should also be noted that numerous non-governmental international organizations and academies of sciences follow the activities of the Committee with great interest and make active contributions to its work through suggestions and propositions.

13. In the same vein, the Committee has striven, through a number of initiatives, to encourage the exchange and dissemination of information. Firstly, the publication of the Proceedings of the IBC, the 1995 edition of which has been largely diffused; so too Spotlight on Ethics, the Committee’s newsletter. Furthermore, UNESCO produced the film Genome: Odyssey of the Species. Produced for television and used as a means of communication, it has been disseminated in German, English, Spanish and French, in particular through the National Commissions. Finally UNESCO, in its will to having the press more closely associated with its bioethics programme, has seen numerous Press Reviews prepared by the Bioethics Unit throughout the past year. These are just some examples of numerous initiatives which will continue, particularly through the use of new methods of information and communication such as Internet.

14. Special emphasis should be placed on public awareness and the teaching of bioethics which should be conceived on a transdisciplinary level. Observing its pedagogical mandate, UNESCO intends to promote public awareness and understanding of bioethics, especially by young people and even the establishment of teaching programmes in this field.

15. To this effect, the Committee is reviewing the teaching of bioethics in all regions of the world - a report concerning the Americas was submitted to the Third Session. A further illustration is the creation of the first UNESCO Chair in Bioethics at the University of Buenos Aires in June 1994. In collaboration with the “Académie de Paris” and the “Association Descartes”, a pilot project of teaching bioethics in high schools began a few months ago in France. It is appropriate to mention here that during the debate in Commission III, the Delegation of Kenya expressed its wish for the creation of a UNESCO Chair in Bioethics in Nairobi, which would facilitate dissemination of information and promote co-operation between African universities.

16. In reference to the drawing up of an international instrument, all speakers who intervened on this subject expressed their support for the preparation of a future declaration which would affirm the priority of the dignity, the rights and the liberties of each individual with regard to the human genome.

17. As to the form this instrument should take, the choice of a declaration seems to be the most appropriate one for an instrument dealing with this subject. A declaration allows flexibility but does not exclude a legal sense being conferred to its content. Given the current burgeoning of research in genetics and the applications arising from it, the format of a declaration is most suited to define the major guidelines.

18. With regard to the content, some delegates stressed the innovative aspect of the text which proclaims, for the first time in international law, the human genome “common heritage of humanity”. By so doing, the future declaration could underline the signal responsibility of humanity with regard to the human genome as a constituent element of the individuality of each person and the very identity of humanity.

19. Whilst the principle of freedom of research - recognized by constitutional law in various States - has been affirmed, it must in no way impinge upon the respect of human dignity. Other interventions raised the question of commercialization and exploitation of genetics for monetary gain, for example intellectual copyright of biotechnology’s and genetically-modified organisms.

20. It should be added that the Outline of a declaration, annexed to 28 C/38 is given for information only as explained in paragraph 107. Before drawing up a draft declaration, the IBC has circulated the Revised Outline of 7 March 1995 for observations amongst international and regional inter-governmental and non-governmental organizations, and major
scientific and cultural organizations (academies of sciences, faculties of law) and ethics institutions (particularly national ethics committees). In its present preliminary form, the Outline is still the subject of extensive consultation within the international intellectual community.

21. The Legal Commission of the IBC will examine suggestions still forthcoming from numerous organizations - inter alia the World Health Organization (WHO), the International Labour Office (ILO), the United Nations Environment Programme (UNEP) - and several academies of sciences (Belgium, China and Sweden, to name but a few).

III. Conclusions

22. Based on the examination of the Report of the Director-General and on the debates in plenary and in Commission III, the General Conference has adopted the 28 C/Resolution 2.2 “Drawing up of an international declaration on the human genome and the protection of human rights” (see Annex).

23. It should also be indicated that 28 C/Resolution 2.1, to which in fact the above resolution refers, invites the Director-General:

“to facilitate the establishment of an international bioethics network, to encourage exchanges of information, bioethics teaching and the setting up of ethics committees, and to develop the awareness of decision-makers and the public at large;

to prepare a preliminary draft declaration on the human genome and to convene, in 1997, a committee of governmental experts (category II) to finalize the draft declaration with a view to its adoption by the General Conference at its twenty-ninth session”.

24. Finally, it is important to note that the General Conference, by 28 C/Resolution 0.12 “Medium-Term Strategy for 1996-2001” in considering it indispensable for UNESCO to fulfil its specifically ethical calling:

“Reaffirms in this connection the urgent need to strengthen the moral solidarity of mankind in order to safeguard its common heritage - natural and cultural, tangible and intangible, intellectual and genetic”.

And further it:

"Recognizes the quality of UNESCO’s contributions to those debates, and welcomes the fact that, through such forums as the ad hoc Forum of Reelection of the Executive Board, “Audience Africa”, the International Commission on Education for the Twenty-First Century, the World Commission on Culture and Development and the International Bioethics Committee, it has lent fresh impetus to international intellectual co-operation".
The General Conference,

Bearing in mind the Universal Declaration of Human Rights (1948), the international covenants on human rights (1966) and the international conventions on the protection of human rights,

Reaffirming the importance of the ethical mission of UNESCO, in accordance with its Constitution, and the role that UNESCO must play in strengthening international intellectual co-operation within its fields of competence,


Recognizing that progress in the life sciences, and particularly molecular biology and genetics, holds out great hopes of benefits to individuals and to the whole of humanity, but anxious to preserve, in this context, the dignity of individuals and their rights and freedoms,

Having examined document 28 C/38 entitled “Report by the Director-General on the possibility of drawing up an international instrument on the protection of the human genome”,

1. Congratulates the International Bioethics Committee (IBC), and particularly its Legal Commission, on the high standard of its work;
2. Considers that it is necessary for the Organization to prepare a declaration on the subject;
3. Invites the Director-General to draw up a preliminary draft declaration along these lines, which he should communicate to the Member States for their comments, and to convene, in 1997, a committee of governmental experts (category II) to be entrusted with the finalization of this draft declaration, with a view to its adoption by the General Conference at its twenty-ninth session pursuant to paragraph 2, B.(e) of 28 C/Resolution 2.1;
4. Further invites the Director-General to provide assistance to those States which may request it for the creation of national bioethics committees to be concerned with the protection of universally recognized rights and freedoms.

PRELIMINARY DRAFT OF A UNIVERSAL DECLARATION ON THE HUMAN GENOME AND HUMAN RIGHTS

(4 March 1996)

The present version stems from the debate which took place at the Third Session of the International Bioethics Committee of UNESCO (IBC), held from 27 to 29 September 1995, It takes also into account the amendments proposed subsequently by the Legal Commission of the IBC.

This version will be examined by the IBC at its Fourth Session, in October 1996.

The General Conference,

Recalling that the Preamble of UNESCO’s Constitution refers to “the democratic principles of the dignity, equality and mutual respect of men”, rejects “the doctrine of the inequality of men and races”, stipulates “that the wide diffusion of culture, and the education of humanity for justice and liberty and peace are indispensable to the dignity of men and constitute a sacred duty which all the nations must fulfil in a spirit of mutual assistance and concern”, proclaims that “peace must be founded upon the intellectual and moral solidarity of mankind”, and states that the Organization seeks to advance “through the educational and scientific and cultural relations of the peoples of the world, the objectives of international peace and of the common welfare of mankind for which the United Nations Organization was established and which its Charter proclaims”,


Bearing in mind the international instruments which could have a bearing on the applications of genetics in the field of industrial property, inter alia, the Bern Convention for the Protection of Literary and Artistic Works of 9 September 1886 and the UNESCO Universal Copyright Convention of 6 September 1952, as last revised in Paris on 24 July 1971, the Paris Convention for the Protection of Industrial Property of 20 March 1883, as last revised at Stockholm on 14 July 1967, and the Budapest Treaty of the WIPO on International Recognition of the Deposit of Micro-organisms for the Purposes of Patent Procedures of 28 April 1977,

Bearing in mind also the United Nations Convention on Biological Diversity of 2 June 1992 and emphasizing in that connection that the recognition of the biological diversity of humanity should not give rise to any interpretation of a social or political nature which could call into question the fundamental principle of equal dignity inherent in all members of the human family,

Recalling 22 C/Resolution 13.1, 23 C/Resolution 13.1, 24 C/Resolution 13.1, 25 C/Resolutions 5.2 and 7.3, 27 C/Resolution 5.15 and 28 C/Resolutions 0.12, 2.1 and 2.2, urging UNESCO to promote and develop ethical studies, and the actions arising out of them, on the consequences of scientific and technological progress in the fields of biology and genetics, within the framework of respect for human rights and freedoms,

Recognizing that:

a) research on the human genome and the resulting applications open up vast prospects for progress in improving the health and well-being of individuals and of humankind as a whole,

b) the applications of genetic research must, however, be regulated in order to guard against any eugenic practice that runs counter to human dignity and human rights,

c) the results of research on the human genome should in no case be used towards military or bellicose ends,

d) the human and social situations generated by advances in biology and genetics require that there should be a very open international debate, ensuring the free expression of the various shades of socio-cultural, religious and philosophical opinion,

Considering that the principles relating to the human genome and the protection of the individual based, in accordance with the preamble to the Universal Declaration of Human Rights, on “recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family (which) is the foundation of freedom, justice and peace in the world”,

Proclaims that the human genome is the common heritage of humanity and hereby adopts the principles set forth in the present Declaration.
A. THE HUMAN GENOME

Article 1
The human genome is a fundamental component of the common heritage of humanity.

Article 2
a) The genome of each individual represents his or her specific genetic identity.
b) An individual's personality cannot be reduced to his or her genetic characteristics alone.
c) Everyone has a right to the respect of their dignity and of their rights regardless of these characteristics.

Article 3
The human genome, which is by nature evolutive and subject to mutations, contains potentialities that are expressed differently according to the environment, education, living conditions and state of health of each family and each individual.

B. RESEARCH ON THE HUMAN GENOME

Article 4
The protection of the individual with respect to the implications of research in biology and genetics is designed to safeguard the integrity of the human species, as a value in its own right, as well as the respect for the dignity, freedom and the rights of each of its members.

Article 5
a) Research, which is an essential activity of the mind, has the function, in the fields of biology and genetics, of advancing knowledge, relieving suffering and improving the health and well-being of the individual and of humankind as a whole.
b) Everyone has the right to benefit from advances in biology and genetics, with due regard to his or her dignity and rights.

Article 6
No scientific advances in the fields of biology and genetics should ever prevail over the respect for human dignity and human rights.

C. INTERVENTIONS AFFECTING THE HUMAN GENOME

Article 7
No intervention affecting an individual’s genome may be undertaken, whether for scientific, therapeutic or diagnostic purposes, without rigorous and prior assessment of the risks and benefits pertaining thereto and without prior, free and informed consent of the person concerned or, where appropriate, of his or her duly authorized representatives, guided by the person’s best interests.
Article 8
No one may be subjected to discrimination on the basis of genetic characteristics and that aims or has the effect of injuring the recognition of human dignity or the enjoyment of his or her rights on the grounds of equality.

Article 9
The confidentiality of genetic data associated with a named person and stored or processed for the purposes of research or any other purpose, must be protected from third parties.

Article 10
Every individual has the right to just reparation for any injuries sustained as a direct result of an intervention affecting his or her genome.

D. RIGHTS AND OBLIGATIONS OF RESEARCHERS

Article 11
States shall ensure the intellectual and the material conditions favorable to research on the human genome, in so far as this research contributes to the advance of knowledge, the relief of suffering and the improvement of the health and well-being of the individual and of humankind as a whole.

Article 12
States shall provide a framework for research with due regard for democratic principles, in order to safeguard the dignity and rights of the individual, to protect public health and the environment.

Article 13
In view of its ethical and social implications, research in biology and genetics entails special responsibilities as regards the meticulousness, caution and intellectual honesty required of researchers.

E. DUTIES AND RESPONSIBILITIES TOWARDS OTHERS

Article 14
States must guarantee the effectiveness of the duty of solidarity towards individuals, families and population groups that are particularly vulnerable to disease or disability linked to anomalies of a genetic character.

Article 15
States shall recognize the value of promoting, at various appropriate levels, the establishment of independent, multidisciplinary and pluralist ethics committees to identify ethical, social and human issues raised by research and interventions affecting the human genome.
F. INTERNATIONAL CO-OPERATION

Article 16
States shall undertake, with due regard for democratic principles, to foster the international dissemination of scientific knowledge concerning the human genome and to foster scientific and cultural co-operation, particularly between industrialized and developing countries.

Article 17
States shall undertake to promote specific teaching and research concerning the ethical, social and human foundations and implications of biology and genetics.

Article 18
States shall undertake to encourage any other form of research, training and information conducive to raising the awareness of society of its responsibilities regarding the basic choices entailed by advances in biology and genetics.

G. IMPLEMENTATION OF THE DECLARATION

Article 19
States shall undertake to ensure that the principles set out in this Declaration are respected.

Article 20
The principles set out in this Declaration shall guide all authorities and other persons responsible for their implementation.

Article 21
States shall undertake to promote, through education, training and information, respect for the aforementioned principles, based on human dignity and human rights and to foster their recognition and effective application.

Article 22
The International Bioethics Committee of UNESCO shall monitor observance of the principles set out in this Declaration. For this purpose, it may make recommendations and give advice.

Article 23
No provision of this Declaration may be used by any State, group or person to ends contrary to the principles set forth herein.
Chapter 6

THIRD SESSION OF THE IBC

(Georges B. Kutukdjian)

I. Introduction

The International Bioethics Committee of UNESCO (IBC) held its third session at UNESCO Headquarters, Paris, from 27 to 29 September 1995. Four working groups had been set up to prepare reports on the topics chosen for the annual sessions of the IBC. In fact, the working groups had already met twice in Paris in 1995, once on 26 and 27 April and then again on 25 and 26 September. These two meetings provided for consultation between the Rapporteur and the members of the working groups before the topical reports were presented to the plenary committee.

The subjects examined at the third session were:

- ethics and neuroscience;
- genetic counseling: for a new physician/patient relationship;
- population genetics; and
- the teaching of bioethics in the Americas.

The IBC also devoted two meetings to presenting and discussing the Outline of a declaration of UNESCO on the human genome prepared by the Legal Commission of the IBC during 1995. This project was in response to the 27 C/Resolution 5.15, adopted by the General Conference on 15 November 1993, inviting the Director General to pursue “the preparation of a possible international instrument for the protection of the human genome”.

Several parliamentarians also took part in a Round Table on the topic “Bioethics: what role for Parliaments?” at which there was a debate on the scope and limits of national and international legislation in this field. The Round Table continued the discussions of the 93rd Interparliamentary Conference (Madrid, Spain, 27 March - 1 April 1995) on bioethics and the protection of the rights of the human person, at which UNESCO had participated.
II. Opening of the Third Session

The solemn opening ceremony of the third session was marked by the presence of Mr Philippe Séguin, President of the French National Assembly.

Mrs Noëlle Lenoir, President of the IBC, emphasized three points in her opening speech. Firstly, she highlighted the IBC’s originality as an institution of dialogue dealing with different subjects from a transdisciplinary perspective, with a view to universality, while taking differing cultural realities into account. Secondly, she pointed out that the IBC’s specifically legal approach had led it to prepare a draft declaration on the human genome based on universally recognized rights and freedoms. Finally, she said that the pedagogical scope of the IBC’s activities implied the fostering of education in bioethics and the creation of national ethics committees.

For his part, Mr Federico Mayor, Director-General of UNESCO, stressed the IBC’s place in the programme of UNESCO, at the very heart of the Organization’s ethical mission. As for the preparation of the future declaration, he recalled its importance inasmuch as it responded to mankind’s need to shoulder its responsibilities in the face of progress in biology and in genetics. At the same time, he laid emphasis on the great hopes that have been created for mankind by the advances being made in these sciences. He made a vigorous appeal for a sharing of scientific knowledge between North and South, and East and West, and affirmed the Organization’s attachment to freedom of scientific research.

Mr Philip Séguin dwelt on the spectacular growth of the life sciences and underlined the need to reconcile this growth with respect for constitutional values and above all with respect for the dignity of the human person. The legislator, while being aware of the primarily open-ended nature of progress in the life sciences and the complexity of the subject, must ensure respect for the individual as well as for the interests of society. He welcomed the role played by UNESCO in the field of bioethics where the issues need to be addressed at the national as well as the international levels.

The speeches made at this ceremony will be found in Volume I of these Proceedings.

III. Bioethics: What Role for Parliaments?

The Round Table on “Bioethics: what role for Parliaments?” was presided over by Sir John Maddox, Editor-in-Chief of the journal Nature. Several parliamentarians and former ministers participated in the Round Table, among them Mrs Sigrun Lömissch and Mrs Marina Steindor, Mr Wolf-Michaël Catenhusen, Mr Claude Evin, Mr Claude Huriet, Mr Jean-Yves Le Déaut, Mr Jean-François Mattéi and Mr Alain Pompidou.

In his preliminary address, Sir John Maddox referred to the prospects opened by the extraordinary advances being made in genetics. He also stressed the challenges to be met by parliaments in adopting laws that are all the more necessary as the field is a complex one.

The Round Table unanimously acknowledged the fact that contemporary societies are characterized by the importance of the role of science and technology at all levels of life, whether economic or cultural, public or private. In particular, the progress of the life sciences is leading parliaments to make choices that are based on respect for rights and freedoms and imply new responsibilities for individuals and society. Parliaments play a key role of mediation here between scientific institutions and society, the prime beneficiary of the results of scientific research.

The participants at the Round Table unanimously felt that it is indispensable to legislate in the field of bioethics. The approach must be one of humility, given the technical and moral uncertainties, and it has to be properly buttressed by scientific arguments.

The advisory role, whether direct or indirect, of national ethics committees was frequently stressed. Indeed, in this respect, the national ethics committees were seen to fulfill an essential threefold function. They analyze problems in the light of the most up-to-date scientific knowledge. They take account of the viewpoints of the scientists and the main actors
in the economic sphere and of the clearly perceived interests of society. They define rules of action, evolve principles that are both rooted in the universality of rights and freedoms and based on the diversity of sensibilities existing throughout a given society. This function may be complemented by the services of a Parliamentary Office for Technological Assessment of the kind that is now being set up in many countries, to examine issues pertaining to the life sciences and health as well as to the environment and communications.

However, whereas it was felt by some that the legislator has to demarcate the boundaries between what is possible and what is permissible while at the same time preserving (or even strengthening) the freedom of research, others on the contrary thought that the legislator should not hesitate to prohibit certain types of research or practices in the field of genetic engineering. At the same time, in view of the constant development of knowledge in this field, parliaments have a duty to be vigilant in order that the laws may take account of the new situations created by scientific discoveries and adapt to them.

In any case, the task of parliaments in this field was considered to be of prime importance, the fact being that they represent the aspirations and concerns of citizens and guarantee the protection of the basic freedoms and rights of the human person.

IV. Ethics and Neuroscience

As this meeting, which was chaired by Mr Jean-Pierre Changeux, Professor at the “College de France” and President of the French Consultative Committee of Ethics for Life Sciences and Health, two reports were presented by Mr David Ottoson, Secretary-General of the International Brain Research Organization (IBRO) and Mr Jean-Didier Vincent, Professor of Neurobiology, Director of the Alfred-Fessard Institute (see Volume I of these Proceedings).

The neuroscience are constantly increasing our knowledge of the human brain, especially through advances in the science of imaging (tomography, nuclear magnetic resonance techniques, etc.). In the perhaps not distant future, they will shed light on the function and activity of each region of the brain. Scientific knowledge of the brain will very probably modify the way in which man sees himself.

In the meantime, today, the neuroscience occupy an exceptional position not only at the scientific and symbolic levels but also at the political and social levels. After all, many countries have proclaimed the ’90s to be the “Decade of the Brain”, for the neuroscience have the capacity to contribute to mankind’s well-being inasmuch as, according to current estimates, about fifty million people are presently suffering from brain disorders. However, since the neuroscience are capable of finishing new instruments of hidden coercion and thus creating new forms of dependence, they sometimes give rise to misunderstanding and may be used for ideological ends.

Indeed, the brain which is considered to be the seat of thought and even, in many cultures, the seat of consciousness, symbolizes the identity of a human being in his innermost depths. The brain, both before and after Freud, has been seen to be the site of the formation of subjectivity, the place where exchanges take place between the somatic and the psychic. Thus, the very idea of “brain transplants”, setting aside the unlikelihood of its becoming a reality, has produced a body of novels which, by their very proliferation, point to the emotional and symbolic significance that is attached to this organ.

It is perhaps at the level of the brain that genetics is opening up pathways to the most spectacular developments in the future while at the same time prompting the greatest disquiet over the possibility of genetic manipulation. In many monogenic diseases (such as Huntington’s choreas or Tay-Sachs disease), it is generally in the brain or the nervous system that the genetic anomalies causing these illnesses are expressed. It is also to the brain that a large part of research in gene therapy (especially research on brain cancer) is devoted.
Mr Vincent’s report presented above all a record of the present state of research in this field. Pharmaceutical research, he said, was going through a period of stagnation: despite the considerable efforts being made by the pharmaceutical industry, no genuinely new family of molecules has emerged in the past decade. The achievements of the past few years relate to the marketing of products rather than to any therapeutic originality.

He stressed the fact that although it is becoming increasingly less difficult, technically speaking, to introduce genes into a nerve cell, gene therapy for its part is coming up against unexpected immunological obstacles. Finally, the transplantation of embryo nerve cells does not appear to constitute a major step forward in the treatment of certain disorders such as Alzheimer’s disease.

However, the advances of the neuroscience have had an impact which is firstly “instrumental” so to speak and, secondly, social, raising several ethical questions.

With regard to the instrumental impact, several possibilities were examined. While it is true that the pharmaceutical industry has not made any substantial progress, the fact is that biochemical research and molecular biology have become the providers of new molecules enabling progress in the knowledge of vital human mechanisms. This was the case in the ‘70s with the discovery and cloning of morphine receptors. The existence in the brain of these receptors, which are capable of recognizing exogenous molecules, has led to the discovery of natural morphines (endorphins, enkephalins or dinorphins) which are neurotransmitters directly produced by the neurons. In the ‘90s, the discovery and cloning of the receptor of tetrahydrocannabinol, the active principle of cannabis, was followed last year by the discovery of its endogenous ligand, anandamide.

Besides, data processing is based on binary logic, which is also the basis of modern linguistics and semiotics and is considered by certain scientists to be at the very roots of human thought. At the technical level, it is opening up new prospects, in particular through robotics and studies on artificial intelligence. The introduction of prostheses, for example cochlear and retinal implants, are enabling the replacing of a sensory or motor system in modifying not only the relationship of the brain with the exterior but also the relationship between the living and the machine.

Finally, the advances of genetics applied to the brain will enable the neuroscience, in the coming century, to deal with questions pertaining to the development of the brain. Thus, molecular biology will probably provide for an understanding and therefore make it possible to intervene in the constitution and development of the brain itself. Research workers have furthermore begun controlling these processes through the discovery of molecules such as the growth factors or cell adhesion molecules (CAM), or again electrine which is both a growth factor and a factor of “guidance” in the building of the brain. This early knowledge points to the remarkable plasticity of the brain resulting from the conjunction of a specific genetic component and a wide degree of epigenetic freedom. It also suggests disturbing possibilities of intervention in the process of the constitution and development of the brain.

With regard to the social impact of the neuroscience, a primary area of concern relates to the possibility of intervention in and control over the behaviour of an individual. Medicines, developed as it happens with the best intentions, could themselves become addictive substances, drugs far more dangerous than those known up to the present time. A new molecule, capable for example of acting on one form or another of “social pathology” (such as drug addiction, alcoholism, etc.) could be used on an individual considered to be “normal” for purposes other than therapeutic ones. Furthermore, there is a great temptation to link the different forms of behaviour to a variety of deterministic genetic factors.

The debate highlighted the difficulty of an issue, the medical and social scope of which is equaled only by the scale of the ethical questions that it raises and that are far from being answered.

It has to be clearly acknowledged that advances in this field are leading, at present, to temptations of a eugenic nature rather than to genuine therapies. However, while the possibilities of detecting an illness at the foetal stage are numerous, the fact remains that progress in the treatment of these illnesses is still the exception.
Thus, respect for the rights and freedoms of the human person in the face of these new dangers is a matter of crucial importance. The question is how to ensure that the work of scientists will not be diverted from its primary goal, towards eugenic deviations or deviations seeking to push back human limits by enhancing the mental performance of human beings. Is it necessary to formulate ethical principles relating specifically to the neuroscience? What is the information that must be provided to society so that it can gauge the scope and limits of the genetic component of behaviour?

While it is true that the neuroscience are in full spate of development with consequences that cannot yet be wholly measured, there can be no doubt that it is premature, at the present time, to examine their effects on legal systems, especially in the context of penal law. In this respect, a consensus appears to have emerged on the need to stress the unique character of each individual and to combat any form of genetic determinism, for the behaviour of an individual cannot be seen as a mechanical process.

Certain “studies” and “theories” of behaviour, such as those on aggressiveness linked to the XXY genetic structure or on the intelligence quotient, or again on the behaviour of twins, have encouraged a deterministic view of human behaviour among the public and are sapping the ethical principles of freedom and autonomy of the human person as well as his responsibility as something to which he is committed by his actions.

It is probably necessary to identify the genetic component of behaviour. Behavioral problems (pharmaceutical dependence, eating disorders, deviant behaviour, etc.) are perhaps linked to genuine organic dysfunctioning. Genetics could provide new approaches to social problems such as those related to serial killers, rapists, etc. Thus, studies carried out on a family of criminals over several generations seem to indicate a correlation between the endogenous production of serotonin and their criminal behaviour.

However, man continues to be the subject of his history. The behaviour of the individual cannot be determined genetically since any dysfunctioning is influenced by various factors in his life, his education, his family and social environment, and his choices. Epigenesis is therefore an essential part of the formation of the brain and personality of the individual.

In conclusion, the debate asserted the directive principle of attaching importance to the equality of individuals, in dignity and in law, as enshrined in the Universal Declaration of Human Rights. However, care has to be taken not to deny human genetic diversity, the positive aspect of which must always be further emphasized. While diversity is acquiring the status of a given fact, “individuation” - namely the formation of an individual’s personality - as the product of epigenesis, belongs to the realm of acquired characteristics. Diversity may take the form of inequalities, in terms of capabilities or potential, but the extraordinary power of epigenesis and of human cultures enables each and every individual to blossom by his own resources and, through education, to develop his capabilities to the utmost extent.

V. Genetic Counseling: For a New Physician/Patient Relationship

The meeting on genetic counseling was chaired by Mr Jean Bernard of the “Académie française”. Mr Michel Revel, Professor of Molecular Genetics at the Weizmann Institute of Sciences, and Mr Arthur Robinson, Professor Emeritus at the Faculty of Medicine, University of Colorado, presented reports on this subject (see Volumes I and II of these Proceedings).

Mr Xavier Emmanuelli, French State Secretary in charge of Emergency Humanitarian Action, opened this meeting by raising the basic question of the new physician/patient relationship entailed by the development of genetic counseling. He stressed the asymmetrical character of this relationship which gives rise to a power-based relationship between the physician who “prescribes” and the patient who “undergoes”. To temper this relationship based on force, as well as to safeguard the integrity and dignity of the patient, the medical relationship requires that the physician should make sure of the informed consent of his patient.
He indicated the example of France where the new situations brought about by genetic medicine have prompted action by the public authorities to assert the principles and rules guiding medical dialogue and specify the contents of genetic counseling. He emphasized the concern that might be aroused by the applications of fundamental research in genetics and hoped that the IBC would play an active role to help control possible deviations and social ill-effects if any.

Mr Harold Edgar had prepared a questionnaire which had served as the basis for individual papers by members of the working group on genetic counseling. The questionnaire was intended to prepare a status report for each country. The following were some of the questions asked. What does genetic counseling consist of? How many counselors are there? Is their work governed by a body of rules? To whom is the information given? What is the code of ethics followed by genetic counselors in the field of information? What is the role of the public authorities?

The greater number of genetic tests now available is giving genetic counseling an increasingly important place in medical practice. In particular, these tests could have considerable repercussions on individuals in both public and private life. These repercussions were the subject of a previous Report of the IBC, prepared by Mr David Shapiro and published in the 1995 Proceedings of the IBC. It is clear that the discussion on genetic counseling was a continuation of the IBC’s work of reflection on genetic screening and tests.

The report, presented by Mr Revel, presented a general picture of genetic counseling in the world. It is clear that the planning and organization of genetic counseling greatly depends on the health systems and policies of each country as well as on cultural traditions and religious convictions. Thus, relations between the physician and the patient differ not only from one country to another but also according to whether they are placed in an urban or a rural context. Similarly, free and informed consent in certain cases cannot be obtained without the agreement of the family or even that of the community.

Furthermore, the framework of genetic counseling also defines its contents, depending on whether it is carried out by public sector establishments or private centres or again by physicians (whether these are geneticists or gynecologists/obstetricians), by specialists organized in the para-medical professions or by voluntary workers in charities (patients’ associations or associations of patients’ relatives and friends).

Genetic counseling is at the very core of the relationships between the physician and the patient, in a process of communication between two or more persons. This is a process at times difficult for it can put family cohesion to the test (for example when a paternity test has to be carried out). This process is always a singular one, for each case is unique and the physician has to lead the consulting party, depending on his individual history and his environment, to make a choice that is in keeping with his convictions and can be lived with.

While genetic counseling is now at its very beginnings, it is destined to extend and become widespread owing to the increasing use of genetic testing for diagnostic, predictive and preventive purposes. Indeed, genetic tests, which previously concerned primarily single-gene illnesses, now cover multifactorial illnesses as well as the detection of the genes establishing a predisposition or susceptibility to certain disorders.

Genetic counseling has to take account of the characteristics proper to each illness, especially as genetic illnesses do not form a homogeneous group. A primary difference lies in their seriousness. A distinction has to be made between often incurable illnesses such as Tay-Sachs disease or cystic fibrosis and illnesses such as phenylketonuria or hemophilia for which there presently exists therapeutic or preventive treatment. The second difference relates to the time of their appearance in the life of an individual. Here again, a distinction has to be made between illnesses appearing at birth and illnesses that appear later, such as Huntington’s chorea or Alzheimer’s disease which on the contrary are illnesses typical of adulthood.

Finally, genetic counseling will in all likelihood have to confront questions relating to the confidentiality of genetic data, the furnishing of information to the consulting party (whether or not it is the patient) and the autonomy of his/her free choice. While all are agreed
on the need for genetic counseling to ensure that the approach should be non-directive, the way in which a counselor may influence the decisions of the consulting party, even in spite of himself, is clear.

This latter point was particularly illustrated by Mr Robinson, whose report relied on several longitudinal studies on families having had recourse to genetic counseling. The question is whether the counselor must consider himself to be a simple “agent” of information transmission. Must he give whole-hearted consideration to the interests of public health? Could he be truly non-directive? In interpreting the results of a test, does he not communicate his own moral precepts and cultural values, whether consciously or unconsciously?

The discussion first of all drew a distinction between individual genetic tests and large-scale screening. Although genetic counseling could be associated with screening programmes, the discussion related above all to genetic counseling proposed to individuals, couples and families. In any case, genetic counseling has been done by an adequately trained professional. This practice must be placed in the context of the work of a team consisting of geneticists as well as psychologists.

The discussion saw a review of the most salient aspects of genetic counseling from the pre-testing to the post-testing stages. In the pre-testing stages, a counselor might have before him an individual or a couple expressing some concern or even anxiety. He has to be capable of analyzing the request expressed and responding to it appropriately. Furthermore, before a test is carried out, it is up to the counselor to inform the consulting party about the illness that might be detected and explain all the implications of the test conducted. Thus, the counselor must provide him with an assessment of the risks as compared with the benefits, as the case may be, of existing treatment or the advantages that may be derived by a heterozygotic carrier of a recessive mutation (for example the resistance to malaria that seems to exist in healthy carriers of sickle-cell anemia) or again advantages arising out of certain types of genetic predisposition (for example a high level of cholesterol appears to protect an individual from certain forms of cancer).

In the post-testing stages, it is up to the counselor to emphasize the statistical and probabilistic nature of the results of a genetic test. It is therefore for a professional to present and interpret these results which moreover must be tempered. It was acknowledged by all that genetic tests, even if they are likely to become widespread, are not innocuous examinations. However, the question is whether it is possible to conceive of these tests without genetic counseling. Are the two actions intrinsically related? Might it not be hazardous to envisage over-the-counter genetic testing outside a clinical context that defines its scope and limits. In any case, the consulting party’s free will must be respected without any economic, social, cultural or psychological pressure being exerted.

The consulting party’s consent, however awkward the problems that it may entail, is nevertheless an essential element of the process. The question is whether a distinction must be drawn between consent given to genetic testing and consent given to receiving genetic counseling. It has to be admitted that the use of molecular genetics, by modifying the medical environment, could lead to the preparing of “genetic profiles” on individuals. Or again, it could lead to genetic tests becoming commonplace, or to their being made compulsory, which is not generally the case (except for certain tests which are compulsory at birth in some countries, such as for example tests for phenylketonuria). The question is whether it should be necessary to obtain specific consent for each test performed, once such a test is considered to be a routine examination (as in the case of a blood test).

The data obtained from genetic tests raises the issue of the confidentiality, processing and storage of this information. The question is whether this information must be given solely to the consulting party. What about the couple? How are cases of divergence to be taken into account? What will be the place of the family if this information relates to a matter of possible concern to relatives? From another viewpoint, is it for the counselor to be the depository of the genetic data collected or rather should provision be made for data banks? If so, who will manage these data banks?
The long-term social repercussions of genetic counseling were the last topic to be dealt with in the discussion. Genetic counseling could appear to be a tool of “hygiene” or genetic “cleansing” or again be the subject of concern related to health policies. Thus it is indispensable for genetic counseling to form part of an approach to educating and informing the general public that would highlight the genuine possibilities of genetics and its applications without raising false hopes or unnecessary fears. Indeed, it would be dangerous to allow the development of a view of man as being determined solely by his genes.

VI. Population Genetics

During this meeting, which was chaired by Mr Maurice Godelier, Director of Research at the “Ecole des hautes etudes en sciences sociales”, the Report on this question, which was drafted by a Working Group, was presented by Mr Darryl Mater, Foreign Professor at the University of Tsukuba (see Volume I of these Proceedings).

The members of the group had prepared a paper on the most salient aspects of population genetics, namely:

- the practical experience of studies on population genetics and medical genetics in isolated communities;
- the values and basic principles to be followed in research on population genetics and the risk of eugenics;
- the informed consent of the persons concerned, and the confidentiality of the genetic data collected;
- the financial and commercial exploitation of the results of research on population genetics as well as their repercussions on international scientific cooperation;
- the examination of scientific criticism of the “Human Genome Diversity Project” (HGDP) as compared with other research on population genetics.

In addition, the Working Group had associated both specialists in the field and representatives of the populations concerned by this research with the drafting of its report.

Population genetics consists of the study of the variation of frequencies of genetic characteristics within a population or between populations. It is based on the existence of human genetic polymorphism. Research of this kind pursues scientific goals relevant both to genetics and anthropology. This research is often carried out by multidisciplinary teams (of geneticists, physicians, anthropologists, linguists, demographers, geographers, etc.). Samples, for example of blood or saliva, are taken from volunteers belonging to various population groups with a view to making comparative studies. The samples are then stored in the form of collections of cells and the data is entered in genetic data banks.

At the anthropological level, these surveys on population genetics can reveal, for example, successive waves of migration in a given geographical zone with very valuable information on the population groups that have migrated. Studies on population genetics, for example, have confirmed that the Americas were populated by migrations of Asiatic populations through the Bering Straits. Other studies conducted in Melanesia have provided useful information on linguistic exchanges. In the Mediterranean basin, they have revealed a significant frequency of a common genetic trait in the populations of Lebanon and Tunisia, thus corroborating the view that there were migrations by Phoenicians into Tunisia. It has to be acknowledged however that certain anthropologists believe that these studies will not give the results anticipated, especially because of the fact that, throughout history, alliances have been contracted between ethnic groups assumed to have been isolated.

At the scientific level, these surveys could provide important information on the evolution of the human species, its origins and the syntax of the human genetic code. They could also shed new light on many questions relating especially to the relationships between genetic mutations and the environment. They could also reveal the prevalence of an illness in a given population or the existence of genetic resistance to such and such an illness in a
community. This research in the long term could lead to therapeutic applications whose scope would not be negligible. One of the incidental dangers here would lie in the possible use of this genetic information on a given community for purposes of repression or even to limit the exercise of fundamental rights and freedoms.

Research on population genetics has given rise to concern on the part of the population groups that have participated in it, especially indigenous peoples. Practical experience has shown that it is necessary for such research to be planned with respect for religious, cultural and social traditions so that they are accepted by the concerned population. This is so especially with the vast research project that has been under way for many years and is known as the Human Genome Diversity Project (HGDP). In the discussion, representatives of the Amerindian nations stressed the relevance of the problems touched on in the report. They expressed their opposition to the filing of patents on DNA sequences from samples taken during surveys on population genetics concerning their communities. While it is true that the genome of an individual, as a whole, cannot be patented since it identifies this person, the question remains whether a DNA sequence is a sequence identifiable with that of an individual or whether it is a generic piece of information that can be patented.

The ethical questions raised by surveys in population genetics are of several orders. First of all, it would appear that it is sometimes difficult to obtain free and informed consent from certain persons inasmuch as the goals of the research in which they agree to participate cannot be immediately apprehended. Appropriate forms of consent need to be available so that projects on population genetics can be pursued with respect for each person’s freedom of choice, whether in a context where the individual enjoys a large degree of autonomy or in a context where the voice of the community prevails or yet again in a context where a signature is not the most appropriate form of consent.

Secondly, the anonymity of genetic data has to be ensured and computerized encoding to protect this data has to be strictly controlled.

It is also necessary to ensure that the results of these surveys are conveyed to the persons participating in the research, and that this is done with a two-fold aim: firstly, that these persons will derive benefit, especially in terms of health, and secondly, that the result of this research will not be able to harm them, whether individually or in terms of the population group to which they belong.

Finally, it was felt that the economic spin-off, if any, of such research whether through the commercial use of genetic data banks or the exploitation of certain individual or collective genetic properties, might perhaps require the setting up of a system of a *sui generis* legal protection.

**VII. The Teaching of Bioethics in the Americas**

Mrs Helene Ahrweiler, President of the Science Ethics Committee at the “Centre national français de la recherche scientifique”, who chaired this meeting, gave the floor successively to Mrs Lidia Vidal Rioja, Head of the Department of Molecular Cytogenetics at the Multidisciplinary Institute of Cellular Biology, La Plata, and Mr Ricardo Cruz-Coke, Director of the Genetics Unit at the J.J. Aguirre Hospital, University of Chile, Mr Rubén Lisker Y., President of the Mexican National Committee on Genetics and Ethics, and Mr Daniel Wikler, Professor of Medical Ethics, Faculty of Medicine at the University of Wisconsin and President of the International Bioethics Association (IAB) (see Volume I of these Proceedings).

In order to prepare a “status report”, the Rapporteur for Latin America had sent a questionnaire to the main universities and teaching and research institutions. The questionnaire has two parts, The first part is aimed at getting general information on the status and activities of the organizations considered. The second part, intended solely for graduate and post-graduate institutions was used to draw up a list of doctoral and post-doctoral courses in bioethics.
Few universities in Latin America include required courses in bioethics in the general curriculum. However, seminars and specialized lectures are often proposed. Moreover, students at the medical faculties of most of the universities are required to take classes in medical ethics (or professional ethics) forming a part of the various stages of their training.

The inquiry highlighted the factors that could foster the teaching of bioethics in this region. First of all it is necessary to marshal all the resources, both human and material, namely teachers available to participate in transdisciplinary training, financial resources, access to publications and to specialized information sources, etc.

With regard to North America, Mr Wikler stated that bioethics is in fact widely taught on that continent. In addition to required courses in ethics, there are many seminars and lectures. However, there is no specific qualification for the teaching of bioethics which is imparted by physicians and philosophers as well as by jurists and theologians. The privatization of the health system in the United States of America will have significant repercussions on the teaching of bioethics which is done above all in the medical college hospitals. Indeed, since these medical college hospitals are financed no longer by public funds but by private enterprise, they attach less importance to bioethical questions and instead are promoting activities that might be profitable.

The speaker felt that the teaching of bioethics in the United States has already taken a new turn. Bioethics, long limited to questions of individual biomedical ethics, dealing in particular with dilemmas in the relationships between the physician and the patient, is now concerned more broadly with structural and institutional aspects.

The debate highlighted the importance of teaching bioethics in a way that would be both transdisciplinary and pluralistic, imparted not only in the faculties of medicine and pharmacology but in all faculties, especially those of the sciences, literature, legal sciences and social and human sciences. This teaching is all the more urgent as the life sciences are advancing at an unprecedented pace. It also has to be recalled that in 1994, at the initiative of the IBC, UNESCO created a Chair of bioethics at the Law Faculty of Buenos Aires. This is a faculty that is essentially transdisciplinary in its design and, by vocation, regional in its character.

Bioethics furthermore is a matter of great interest to young people, from the secondary school stage onwards. It is already present in the teaching of other subjects in various forms and now lies at the interface between several subjects ranging from biology to history and from philosophy to the economic and social sciences. In order to ensure a quality of teaching that will not belie expectations, special attention must be paid to the training of the educators.

Finally, the importance of informing and educating the public was stressed on several occasions. In this respect, the work of the ethics committees appears to be crucial. Through the meetings, conferences and seminars organized by these committees, the general public will be able to become familiar with concepts that it does not always fully understand.

VIII. UNESCO Draft Declaration on the Human Genome

His Excellency Mr Hector Gros Espiell, President of the IBC Legal Commission, presented the conclusions of the discussions of the fifth meeting of the Legal Commission, on 25 September 1995 (see Volume I of these Proceedings). In particular, he outlined the modifications proposed, at this meeting, in the text of the draft declaration dated 7 March 1995.

Many written comments had been sent to UNESCO in response to approaches made by the IBC to consult international, intergovernmental and non-governmental organizations as well as national institutions. These comments led the Legal Commission to include a specification in the title of the future declaration stating its vocation to protect the rights of the human person. The results of this international consultation are available in French and English with the UNESCO Bioethics Unit (Document CIB/BIO/96/COMJUR.6/4 dated 5 April 1996).
The Legal Commission also deemed it necessary to specify the contents of the Articles 1, 6, 7, 8, 10 and 16. Furthermore, two more articles were added to the Draft, respectively after Articles 14 and 21. The first article pertains to the need to create ethics committees in countries that do not have them. The second prohibits the use of the provisions of the declaration for ends contrary to the rights and freedoms stated therein.

The debate highlighted the interest of the international community in UNESCO’s undertaking and the wide support shown for such a declaration. The specialized institutions of the United Nations system, especially the World Health Organization (WHO) and the United Nations Food and Agricultural Organization (FAO) expressed their support for the Draft presented. This was also the case with several international non governmental organizations, especially the World Medical Association (WMA), the Council for International Organizations of Medical Sciences (CIOMS), the International Council of Scientific Unions (ICSU) and Inclusion International. However, the representatives of the last-named organization felt that the formulation of several articles needed to be reviewed in order that the document might in no way be used for purposes of discrimination against genetically handicapped persons.

Several participants felt that the title of the normative text, as it appeared in the Draft, did not sufficiently highlight the primacy of the rights and freedoms of the human person, which is the “raison d’être” of the future declaration.

The concept of humanity’s common heritage as extended to the human genome was stressed as being one of the most innovative aspects of the legal document under preparation. Necessary clarifications were made concerning this concept inasmuch as it cannot dispossess the individual of his or her rights to his or her own genome any more than it can permit a State to refer to it in order to lay down a coercive policy.

The human genetic diversity that some consider it essential to emphasize has to find its place in a revised version of the legal document. While it is true that genetic diversity is a given fact, it has nevertheless been shown that it is a reservoir of possibilities enabling living species to adapt under the pressure of the evolutionary process.

Although some participants would have liked the future instrument to make explicit reference to experimental practices in human genetics, it is clear that the specific feature of a declaration is that it must proclaim values and lay down principles and not regulate practices, this being the responsibility of the legislator and depending on the legal framework and the traditions of different States.

The suggestions that came up during the discussion were examined by the Legal Commission at its sixth meeting on 25 January 1996. The report of all the work and discussions leading to the preparation of the future declaration on the human genome and human rights, especially the work and discussions of the Legal Commission, will be published in 1997.

IX. Closing of the Third Session

In his closing speech, Mr Federico Mayor first of all stressed the role of parliaments in the protection of rights and freedoms of the human person in the face of scientific advances. Expressing satisfaction at the quality and range of the debate, he emphasized two aspects that had marked the discussions in this third session. First of all, he stressed the need to avoid genetic reductionism which could deprive human beings of their freedom as well as their responsibilities. Secondly, referring to the richness that constitutes human diversity, whether genetic or cultural diversity, he recalled at the same time the fact that bioethics is striving to enhance the idea of universality by basing itself on the values of dignity and freedom of the human person as proclaimed by the Universal Declaration of Human Rights.

Mr Roland Dumas, President of the French Constitutional Council, praised the initiative taken by the Director-General in creating the IBC and the eminent role of Mrs Noëlle Lenoir, President of the IBC. Recalling the experience of France, which has recently
adopted a legal framework in the field of bioethics, he emphasized the co-operation that has arisen between Parliament, which creates the legal rules, and the constitutional judge who derives the standards of constitutional values to which these rules must conform. The novelty of the situation has made it necessary to seek standards in accordance with the prevailing spirit and the state of technology and in keeping with fundamental rights. He affirmed the view that the primacy of the human person is the principle that must guide legislators, jurists and constitutional courts in any action pertaining to the conscience and to the existence of each and every individual.

In his speech, Mr Mohammed Bedjaoui, President of the International Court of Justice, referred to the progress of science that is today affecting both mankind’s destiny and its purpose. He stressed the challenges to ethics and law raised by the new-found control over genetics which is a harbinger of both the best and of the worst. It is absolutely necessary to reinvent the basic principles of ethics and buttress them with an appropriate panoply of laws. The current genetic revolution cannot be dissociated from the binomial entity constituted by freedom and responsibility if this revolution is not to be accompanied by the perverse consequences that would arise out of a potential recourse to eugenics. Furthermore, to meet the aspirations of the greatest number, the notion of solidarity must imperatively be taken into account. The widening technological gap between the North and the South in terms of the applications of biology and genetics, must not give rise to new forms of exploitation of vulnerable populations or to new forms of injustice as regards access to these applications. The dignity of the human person and respect for his inalienable and immanent rights must remain one of the major goals of scientific progress. Finally, he stressed the pre-eminent role that must be played in this respect by the universal declaration on the human genome which has no purpose other than that of protecting the human person.

After praising the work of the IBC, Mr Jacques Toubon, French Minister of Justice, stressed the importance of the role that the IBC must play in the normative field. Emphasizing the fact that scientific advances in human genetics could not take priority over respect for the dignity and freedom of the human person, he called for vigilance with respect to applications derived from research into the human genome. He also stressed the fact that, in bioethics, the emergence of an international legal order is eminently desirable both to supplement the efforts being made by States to adopt appropriate legal frameworks and to provoke such efforts. He emphasized the major role that the IBC has to play in this respect by following the progress of the universal declaration of the human genome under preparation.

Finally, Mrs Noëlle Lenoir, President of the IBC, thanked all the eminent persons who had taken the floor at the third session of the IBC as well as all the participants and especially all the members of the Committee whose reports, by virtue of their scientific relevance, their breadth of views and the cultural diversity that they expressed, were a source of richness and inspiration to every country.
Chapter 7

**Speeches at the Third Session of the IBC**

- **Mrs Noëlle Lenoir**, President of the IBC
- **Mr Federico Mayor**, Director-General of UNESCO *(opening speech)*
- **Mr Philippe Séguin**, President of the National Assembly of the French Republic
- **Mr Xavier Emmanuel**, French State Secretary in charge of Emergency Humanitarian Action
- **Mr Federico Mayor**, Director-General of UNESCO *(closing speech)*
- **Mr Roland Dumas**, President of the Constitutional Council of the French Republic
- **Mr Mohammed Bedjaoui**, President of the International Court of Justice
- **Mr Jacques Toubon**, French Minister of Justice
I. Speech by Mrs Noëlle Lenoir, President of the IBC

Mr Director-General,
Mr President of the French National Assembly,
Your Excellencies,
Presidents,
Ladies and Gentlemen,

“No testament precedes our inheritance”, wrote French poet René Char upon the ruins of the First World War. The idea he was expressing was that of mankind’s responsibility in the eyes of history.

Ethics, and more especially bioethics, insofar as they develop principles for “guiding human action” - to quote the phrase used in this very place last year by Jean-Pierre Changeux, President of the French National Ethics Advisory Committee - strike me as demonstrating our societies’ concern to equip themselves for assuming the responsibilities that arise in various circumstances from technological and scientific discoveries.

The creation four years ago at your instigation, Mr Director-General, of the International Bioethics Committee (IBC) therefore met an urgent need. One has only to look at the world-wide response to its work - largely owing, it must be said, to the active participation of all its members - to be convinced of this. We moreover have the pleasure today of welcoming among us Mr Albie Sachs, constitutional judge in South Africa, who will describe the progress of bioethics in his country.

In the North as in the South, an awareness of the importance of bioethics is spreading to a growing number of countries. A product of fear - “man’s most faithful companion”, in the words of President Mohammed Bedjaoui - bioethics, since it keeps us in a constant state of alert, enables us to overcome present anxieties in order better to control the future.

Human beings, despite being more conscious today of the two-edged character of scientific and technological progress, are unlikely to abandon their continuing search for knowledge.

As its role implies, the IBC hopes to further this collective “awakening”, and thereby reduce the disharmony caused by cultural differences.
Time is too short for presenting a full report on the IBC’s activities since last year. I should nevertheless like to stress three points:

first, the uniqueness of the IBC’s mode of operation as a forum for dialogue;

second, the specificity of its approach to the task of reflecting on the law;

third, the educative dimension of its practical work.

In conclusion, I shall briefly refer to the agenda of the present Session, which is honoured by the presence of eminent world personalities, such as Mr Philippe Séguin, President of the French National Assembly, this morning.

The International Bioethics Committee, Forum for Dialogue

Mr Director-General, your choice of a broadly-based International Bioethics Committee has given us the opportunity of fully assuming our vocation as a forum for discussion.

The Committee is composed of fifty members from forty different countries. It is not an assembly of experts, but it strives to reflect the various shades of thinking and sensitivity to be found across the world.

It does not, in the normal course of events, issue ad hoc recommendations or opinions. What it does do is tackle the most technical and advanced subjects so as to keep abreast of the ethical issues which they raise, with a view to informing and alerting the international community in general. At our September 1994 Session, for example, we examined the scientific status and prospects of gene therapy and genetic testing. This afternoon and tomorrow, we shall deal successively with the ethical problems attached to the neuroscience and genetic counseling, a new medico-social activity whose features are still undefined.

The Committee’s goal is to ensure that open debate takes place on techniques and practices that are quite obviously liable to induce major social changes.

The challenge facing the Committee where these discussions are concerned is considerable, since:

it must reconcile the two UNESCO principles of universality and respect for pluriculturalism;

it must provide the conditions for a fruitful exchange between all the disciplines represented on it, ranging from biology, medicine, law, philosophy, sociology, demography and nutrition to anthropology, and more.

Our special objective continues to be the North-South dialogue, given that the globalization of the ethics debate is a necessary corollary of the globalization of science and economics, and that this dialogue has become a prime driving force in that process.

The IBC, in Connection with its Task of Legal Research

Following the UNESCO General Conference’s Resolution of 15 November 1993 inviting you, Mr Director-General, to proceed in 1994-1995 with the preparation of an international instrument on the protection of the human genome, you entrusted us with a mandate for researching into the law.

We have now concluded the first stage in our deliberations on the instrument which could, as we see it, take the form of a declaration. For us, this constitutes a decisive step, a turning-point.

The paper drawn up by the IBC’s Legal Commission under the supervision of His Excellency Hector Gros Espiell, an eminent jurist, of course does not have force of law. Its purpose is solely to provide an indication and suggestions.
In preparing this outline declaration on the protection of the human genome, we ourselves wished to take an approach consistent with ethics, that is to say, one which was both transparent and interactive. The outline was distributed, along with a questionnaire, to some two hundred correspondents: academic bodies, ethics committees, relevant international organizations and UNESCO National Commissions. The replies are, I think, of exceptional interest. You will be able to judge this for yourselves when they come up for discussion later in this Session.

Three key concepts underlie the guidelines contained in the outline:

- the first is that the human being and his rights and freedoms, that is to say, the dignity of the human person, must be the focus of the ethics of genetics. The “sense of what is human”, to use Professor Jean Bernard’s expression, is the cornerstone of ethics;
- the second refers to the special social responsibility incumbent on scientists in today’s world, even though the freedom of scientific creation is a basic human right;
- the third, which I should no doubt have placed first, is that scientific ethics are necessarily based on solidarity, the intellectual and moral solidarity of mankind to which the preamble to UNESCO’s Constitution refers. As you stressed, Mr Director-General, in your address at the opening of our 1994 Session, “scientific progress and knowledge are universal; as such they should be considered to be common heritage and, consequently, should be shared equally”.

The IBC and the Educative Dimension of its Practical Work

Among the various activities of the IBC outside of its annual Sessions, three have special relevance to the educational mission of UNESCO. They are indeed intended to have educational value.

The first concerns the teaching of bioethics, as a new academic discipline. A UNESCO Chair in Bioethics was created last year at the University of Buenos Aires.

This year, a sweeping survey on the teaching of bioethics in North, Central and South America was launched under the leadership of different members of the Committee. Its conclusions, which will be presented tomorrow, are interesting and promising. The survey is due to be followed up by co-operation efforts with certain countries, Mexico being one of them.

I may also report that the Rectorate of Paris has agreed, in conjunction with the IBC, to launch an experimental bioethics course in several lycées and colleges. Bioethics seems destined to become a central feature of general culture in the next century.

Our second activity, conducted with a view to education, or ever to monitoring, relates to the methodological follow-up to surveys concerning populations genetics. A study group in which CIOMS, ICSU and HUGO participate has been set up under the chairmanship of a member of the Committee. It is a fact that such research can stir up controversy, since it raises difficult ethical questions.

In conclusion, let me mention our co-operation projects for furthering the creation of ethics committees. We are already seeing growing numbers of bodies of this kind, which are considered as fora for democratizing the ethics debate. Not so long ago, a National Committee was set up in Tunisia; there will perhaps soon be one in Germany. Our international Committee is ready to help with the planning, and even the organization, of ethics committees in the countries of the South. A first step in this direction has been accomplished in Uruguay, at the urging of His Excellency Hector Gros Espiell. A Bill providing for the creation of a National Ethics Committee in Uruguay has been drafted. Other initiatives of this kind are planned in our programme for 1996.
As regards the present Session, you will have noticed the symbolism of its being opened by the President of the French National Assembly who will moderate a round table discussion on the role of national parliaments with regard to bioethics.

The Session, as you will also have noticed, will be closed by representatives of some of the world’s foremost legal institutions: Mr Mohammed Bedjaoui, President of the International Court of Justice, Mr Roland Dumas, President of the French Constitutional Council, and Mr Jacques Toubon, French Minister of Justice.

This is a clear indication, I feel, of the law’s central position as the expression of the basic choices of society.

National parliaments are becoming more and more involved in bioethics. Last March, the Interparliamentary Union itself adopted a solemn motion acknowledging the international dimension of bioethics as a factor in the protection of human rights.

The conclusion to be drawn from all contemporary thinking about ethics is that it is for every one of us to determine the conditions under which the tool of genetics should be used. It is also important, in my opinion, to avoid treating genetics, as is the trend nowadays, as the master blueprint for all human ailments and behavioral patterns. Human dignity requires that the individual be considered as free and responsible.

“People have lost sight of a truth. But you must never forget it. You become responsible ever afterwards for what you have tamed”, says one of the characters in Saint-Exupéry’s “The Little Prince”. These words apply very appositely, I think, to the principle of responsibility which is the foundation of ethics.
II. Opening Speech by Mr Federico Mayor,  
Director-General of UNESCO

Mr President of the National Assembly,  
Madam Chairperson of the International Bioethics Committee, 
Your Excellencies,  
Ladies and Gentlemen,

It is with great pleasure that I welcome you here today to the third session of the International Bioethics Committee.

I should first of all like to welcome Mr Philippe Séguin, President of the National Assembly of the French Republic, who is honouring us—with his presence on our rostrum today, and express to him my warmest thanks for his sustained efforts to encourage the formation of the new partnerships that are essential to the establishment of a culture of peace.

It is also a pleasure to greet Mrs Noëlle Lenoir, who chairs UNESCO’s International Bioethics Committee with remarkable skill and vision.

Without going back to describe the circumstances surrounding the creation of this International Committee, the purpose and relevance of which is more strongly confirmed with each session, I should like to remind you that it responds to two obligations: the need to reflect and the need to inform.

Humanity now has the power to exert a direct influence on its own biology and, for the first time, is piercing the secrets of its own workings. With genetic engineering, we can now modify the human genome, in other words we have the power to transform our own species. The increasing pace and scale of research breakthroughs in this area have overturned humanity’s perceptions of its own nature and called into question our relationship to science. When limitations disappear - the same is true in other fields - and everything seems possible, then we start to ask ourselves questions. Whether such questions take the form of the Nietzschean aphorism or of a discussion between specialists in the biomedical sciences, there is always a sense of moral concern. 

In a scientific context in which research programmes and their findings require a new collective awareness and sense of responsibility, an international committee was clearly needed.
Ethics dictates respect for human dignity in new, science-generated situations. It was my wish that UNESCO should articulate this concern, a concern shared by all societies whatever their economic, social and cultural priorities, by assisting, through its committee, in the vital collective effort to provide information at the international level. Is it not one of UNESCO’s most important purposes to reconcile the cultural diversities so precious to humanity with the universal character of human rights? Knowing what is at stake should not be the privilege of an élite: all individuals, whatever their community’s level of development, should benefit equally from scientific progress and its applications. The sharing of knowledge has been a key aspect of the work of the committee over the past two years. It is even more necessary in an international context presenting new threats to the cohesion of societies - inter-ethnic conflicts, civil wars encouraged by poverty and ignorance, increasing social inequalities and the erosion of social ties.

Should not UNESCO, being an international forum, not be prepared to suggest angles from which a subject could be approached and markers for the debate, based on the shared values which it is its duty to defend?

As the only international body in the world concerned with bioethics, the International Bioethics Committee, unique both in its membership and in its functions, responds to precisely these concerns. It is by definition a place where different views can be expressed and exchanged, where the various aspects of genetic research and its applications can be discussed in a transdisciplinary perspective. It has a duty to keep abreast of progress in research while taking care to ensure respect for the values of human integrity and dignity where there might be a risk of irresponsible attitudes in biomedical research. The Committee hopes to arouse the conscience of the international community and public attention to the ethical problems involved. At a time when the acceleration of scientific progress is increasing the gap between those with access to such knowledge and the rest, bioethics could be regarded as a prolegomenon to the culture of science. This is why the International Bioethics Committee has taken the initiative, in liaison with the Paris education authority, and starting this year, of launching a pilot scheme for the teaching of bioethics. The course will be given by teachers of biology, philosophy or history to the first year of some lycées in Paris and the Paris region.

At the same time the committee is continuing the task, entrusted to it under Resolution 5.15 adopted by UNESCO’s General Conference at its twenty-seventh session, of preparing an international instrument on the human genome designed to safeguard the principles of human dignity and freedom in new situations arising from advances in genetics, to involve governments and to foster awareness of society’s responsibilities.

As the first international instrument on the human genome, the aim of this Declaration will be to combine ethical imperatives with those of human rights to the freedom of the individual, freedom of research and respect for the integrity of the human person where research is concerned.

Scientific progress is a source of hope, especially for those suffering from hitherto incurable diseases and handicaps of genetic origin. As you know, research on the human genome is advancing in leaps and bounds and genes responsible for genetic diseases are constantly being identified. But such research and its applications could open the door to excesses that undermine respect for the individual and place human dignity, integrity and freedom in jeopardy. There is an additional risk that the benefits of such research will not be divided equally, developing countries in particular losing out. Throughout the twentieth century, so prolific in scientific discovery, we have been able to see just where the misuse of science can lead. In itself, knowledge is always positive; it is its application that can be dubious or even harmful. There are important lessons to be learned in this respect from recent history and important precautions to be taken to avoid the perversion of “progress”.

On the other hand, our awareness of the dangers should not lead us to question freedom of research, a vital facet of freedom of thought and an expression of human dignity. We need to strike a balance between human dignity, freedom of research and human solidarity. For their part, governments should foster democratic debate on advances in human genetics and the issues they raise and actively promote scientific and cultural co-operation.
At the same time, it is for all of us to be aware of the risks that we maybe laying in store for our own species and to shoulder our responsibility for safeguarding its rights. One illustration of this concern is the idea of adopting internationally a framework of guiding principles - as yet non-existent - that would protect the physical and moral integrity of humanity.

Ladies and Gentlemen,

The issues at stake in bioethics are of equal concern to the State, the scientific community and civil society, which must be involved in this reflection. The human community needs to stand together to face the uncertainties weighing over its future.

The future of our democracies could depend on our refusal to allow scientific progress to take precedence over human dignity, and on our insistence on the right of all to benefit equally from any spin-off from such research in all societies. We must see this as another aspect of the injunction in the Preamble to UNESCO’s Constitution, to secure that “intellectual and moral solidarity of mankind” upon which peace must be founded.
III. Speech by Mr Philippe Séguin,  
President of the National Assembly of the French Republic

Mr Director-General,  
Madam Chairperson,  
Your Excellencies,  
Right honorable Deputies and Senators,  
Ladies and Gentlemen,

It is a great honour for me to open with you, Mr Director-General and Madam Chairperson, this Third Session of the International Bioethics Committee. It is an honour whose importance I measure from the weight and seriousness of the issues to be dealt with during the three days of your proceedings.

Let me also measure this honour by another standard. Only two or three years ago, it might not have seemed so obvious that the President of a parliamentary assembly should find a place naturally in this eminent circle of yours. If he had been invited, it would probably have been only to restrict himself to the most formal aspects of your opening session, and to a few broad considerations, not to say generalities, while leaving the heart of the subject to the other contributors.

At best, he would have gone so far as to share the doubts, and possibly fears, of a growing number of men and women faced with problems which are often nearly insoluble, at least at their level of responsibility - doctors obliged to act far beyond the limits of their traditional calling to treat and make well; researchers torn between their eagerness to follow leads that take them outside their initial fields of research and their equally understandable apprehension at venturing into unexplored territories; judges puzzled by contradictory jurisprudence since, for want of clear legal guidelines, courts have handed down totally different rulings on broadly similar cases; lastly, philosophers and other moral leaders bereft of easily recognizable signposts indicating what society can accept and what it should refuse.

Yet, ladies and gentlemen, it is possible for me to say more today than I could have done two or three years ago. As you know, the French Parliament, like some others, has made a notable breakthrough in this area which was long considered to be inaccessible, and which you will be discussing within a short space of time. I can therefore say something on at least the fringes of the subject, if not on its core!
I am sure you will excuse me if I take as my example the framing of my country’s legislation on bioethics to illustrate what I believe is the role that parliaments can play in this field. Please view this as testimony and not as presumptuousness. It is testimony to what national representatives can achieve when they tackle a question in earnest. It must be said that our National Assembly took the time it needed - it spent months consulting, studying and conducting hearings on the subject. Let me from my own experience bear witness to the valuable support that lawmakers can receive from ethics committees. The advice received from the French National Advisory Committee on Ethics enabled our Parliament to gain a clearer idea of the ethical, cultural, economic and social issues involved in the life sciences. The creation of this Committee has moreover been a source of emulation; many countries have since set up bodies of a similar kind.

Our legislators had to do more, however, than establish a compendium of the views expressed by the experts and moral leaders. Their task was to give legal form to these views. The results were our Acts of 1994.

The three Acts on bioethics of July 1994, presented in the National Assembly by Professor Mattéi, deputy for the Bouches-du-Rhône, and in the Senate by Mr Chérioux - both of whom did what was universally acknowledged to be a superb job - provide clear directives in several fields. The principles were established of forbidding the transfer for gain of all or part of the human body, and of the dignity of the human person in regard to any form of subjection or degradation. I may remark in passing that both of these principles have been given constitutional status. The Acts also prohibit agreements for procreation and childbearing on behalf of another person; and they protect the confidentiality of personal data used in health research. The protection of such data is, as we know, threatened by the spread of computerized records. I might also quote the banning of foetal research and the prevention of new forms of exclusion based on an individual’s genetic characteristics.

It has to be admitted that many areas have not been satisfactorily dealt with. The law has been content to set different, and sometimes contradictory, principles side by side. Examples are the limits to experimentation - you will remember Jean Bernard’s elegant phrase that experimentation is “morally necessary, but necessarily immoral” - the inviolability of the human person, and the still-open debate on whether the law should regard the body as subject or object.

This action proved that a representative assembly is capable of addressing any issue, no matter how delicate. In other words, there are no subjects which cannot be tackled and handled by the most democratic institutions, often decried as being poorly equipped for such a task.

What must absolutely be avoided is the temptation to skepticism which leads to doing nothing, equivalent to allowing anything be done, or - the other side of the same error - stopping everything. There is another approach possible and that is to hem innovations within a veritable “rampart” of principles, to order what can be ordered, and remain watchful as regards that which cannot yet be ordered.

It is therefore fortunate and encouraging that a number of countries have, like France, set out over the last decade to equip themselves with bioethics laws. This trend illustrates a growing awareness around the world that legislators must, despite the difficulties, act to ensure that science develops with a respect for human dignity and fundamental human rights, and in line with national democratic traditions.

If they fail to do so, the new areas of freedom opened up by advances in the life sciences could well, in the absence of ground rules, lead to aberrant developments with disturbing implications for the future and cohesion of our societies. Thousands of persons and families place great hopes in gene therapy and genetic testing for conquering the genetic diseases with which they are afflicted. Yet cannot the spectre of eugenics be descried lurking in the background of these promising applications? And can we be certain that genetic engineering techniques will not one day serve as a platform for abominable experiments that impugn the integrity of the human race?
We can be sure that, without ground rules, private interests will prevail. Firms will be able to choose new staff on the basis of genetic tests. The traffic in organs will prosper. Parents will be able to have blue-eyed babies and, who knows one day, children who do as they are told.

In the face of these perils, it is obviously the lawmaker’s job to frame the rules. It may be wondered why legislatures have taken so long to devise a framework fixing appropriate limits to biomedical applications.

I think the explanation lies in two sets of considerations:

the complex and constantly changing nature of the subject and, even more,
the type and scope of the prohibitions to be enacted, since these touch on the most intimate depths of individuals, their bodies, their procreative freedom and their biological identity. In these circumstances, the law cannot help but carry a charge of meaning that goes beyond its stated terms.

Is it not, however, the legislator’s duty to come to terms with uncertainty, be it technical or moral, to take a stand and make choices, without any assurance that the future will prove them right? What nobler task is there for a country’s elected representatives than to draw the path towards a civilization that acts responsibly towards its present and future generations and shows its concern for the dignity of humankind?

No, it is unthinkable for the people’s representatives to shirk their responsibility concerning the risks with which progress in genetics confronts our societies. The world’s nations are today embarked upon the adventure of the human genome, so that politicians have more than ever before a duty to look ahead to the future. They must refuse the temptations of non-intervention and permissiveness. Laws providing answers to the questions raised by bioethics must be enacted, and these laws must be precise in their formulation. For, as the famous dictum of Portalis puts it, the law “permits, orders and forbids”.

It is furthermore evident that standard-setting in bioethics must be grounded in national history and democratic traditions. It is striking, if we compare French, German and Spanish bioethics legislation, to note their differences, which are, of course, tied up with their respective history and traditions. What better vehicle for these can there be than parliament?

All national laws endeavour to arbitrate - I use this verb deliberately, since it is at the heart of the policy-makers’ mission - among three of a democratic society’s basic principles:

respect for human dignity,
individual freedom,
the interest of society, that is to say, “the public interest” which is itself twofold: on one side, the progress accruing to the nation from scientific research and, on the other, the need for social cohesion.

It follows that the treatment of bioethical issues cannot be reasonably confined to a purely national or even continental framework. Each one of their component parts - research, application, reflection, legislation - has a universal dimension. Why labour the point? We all know that the proximity of more permissive neighbors saps the effectiveness of purely national statutes. A case in point is medically assisted procreation, which is more freely available to single women in the United Kingdom and Spain than in France. Many other differences can be found as regards the sale of organs or foetal research.

This is the sort of problem with which you shall be dealing, I imagine. May I just warn you against the natural tendency to line up with the most permissive faction. It is a tendency that appeals as much to states as to private individuals; they are always tempted to push research to its farthest limits so as not to let someone else have an exclusive claim on discoveries.
In this area, as in many others, countries are no longer “lone rangers”. They do and must stand together in order “to promote social progress and better standards of life in larger freedom” as the Preamble to the Charter of the United Nations declares. Such solidarity, in the matter of research on living organisms, must find international expression. It should allow all countries, and not only the wealthiest ones, to have access to the therapies derived from genetic research. Disease knows no boundaries. The most elementary ethics dictates that countries should pool their efforts and combine their action to prevent glaring inequalities in the ability to treat disease from developing.

Exclusion, whether at the national or international level, is a grave danger to democratic regimes. It undermines social cohesion, since those excluded cannot recognize or project themselves in a society which leaves them by the wayside. It impairs the essential awareness of a common destiny which binds together the members of any national or international community.

This is why from now on it is essential that the United Nations system, UNESCO in particular, should occupy itself with all these issues. Doing so is not only normal; it is also welcome. It is proof of the increasing need we have for a universal framework to accompany developments in science and technology.

I personally should very much like to see a new universal declaration of human rights to supplement the 1948 Declaration, which would lay down at least some principles, such as the non-remunerability of organ donations, a principle which is unfortunately contravened every day. Other solutions are, of course, possible, for instance along the lines of the Resolution adopted last April by the 93rd Interparliamentary Conference held in Madrid - I note in passing the participation there of Professor Huriet - suggesting that member parliamentarians should formulate some universal principles without delay.

UNESCO, by creating the International Bioethics Committee two years ago, expressed its wish to see the debate on biological research and applications conducted at world level. In doing so, UNESCO demonstrated its concern for promoting a development of the life sciences and their applications which would be internationally compatible with humanist values.

This venture will be able to draw strength from the work of those parliaments in the world which have tried to find answers to the questions raised by bioethics.

I am hence grateful to you, Mr Director-General, for having wished to confer a parliamentary dimension on the programmes of the international organizations. Allow me to pay particular tribute to you and all your associates for the role you are playing in the development of the International Bioethics Committee.

I should also like to thank all the personalities from abroad, and they include the most eminent, whose presence in Paris to discuss some of the most delicate issues of our day is perceived by France as a compliment. France is proud to have been one of the laboratories of modern law, and especially of what we call “human and citizens’ rights”, just as it is proud to have been home for several centuries to some of the most outstanding advances in scientific research, notably in the fields of medicine and biology. This is the legacy which it intends unremittingly to develop and which places an obligation on us. It is this legacy which meetings like yours seem to honour, and that is why we must thank you.

Likewise, I feel I must congratulate those who had the idea of stimulating this reflection, beginning with you, Madam Chairperson. You show tireless energy in taking the measure of questions as they arise and in the necessary labour of translating them into legal terms.

It is this labour which brings together scientists, philosophers, jurists and politicians, all convinced that men are capable of influencing the course of events, convinced that nothing is inevitable, either in technology or economics.

Yes, bioethics is a political issue, in the noblest sense of the term.
I insist on this deliberately, so as to exclude a confusion of ideas of which we have all been guilty at one time or another and which the distinguished biologist and philosopher, Jean Rostand, identified thirty years ago: “In the larger human politics which will increasingly call for choices on our part, these choices will have less to do with politics properly speaking than with biology and morality”. This is something which has become obvious: the connection between scientific progress and political choice has grown much closer. This fact prefigures a constant extension of the responsibility of democratic institutions. Science and technology will present a host of problems that, without debate and arbitration, will remain insoluble - insoluble, that is to say, without parliaments.

The representatives of the people, bred in their respective traditions, will have to learn how to rise above these traditions in order to meet the new challenges.

Let us have the clarity of vision to realize with the philosopher Hans Jonas that: “There is no traditional ethics to instruct us in the standards of ‘good’ and ‘evil’ which must be applied to entirely new systems of power and its possible creations. The new world of collective practice to which high technology has introduced us is still virgin territory for ethical theory. It is in this vacuum (which is also the vacuum of the present relativity of values) that the search for a new principle of responsibility is being undertaken”. So you see, we are only just beginning to fill the vacuum, and I am persuaded that the proceedings of this third Session of the International Bioethics Committee will make a decisive contribution to this vast enterprise.
IV. Speech by Mr Xavier Emmanuellli,
French State Secretary in charge of
Emergency Humanitarian Action

Madam Chairperson,
Mr President,
Ladies and gentlemen,

I am most happy to be taking part in the proceedings of the International Bioethics Committee. Its mission strikes me as being exciting and important, since it has the task of keeping abreast of progress in genetics, while being careful to see that the use of the new knowledge remains under control and does not pose a threat to human dignity and freedom.

I know that your discussions today are devoted to a fundamental issue, namely the doctor-patient relationship, or rather the “new” doctor-patient relationship in the context of genetic counseling.

Allow me, as a doctor, to recapitulate briefly the main features of the relationship between a practitioner and his patient.

The therapeutic relationship can, it is true, be described in a multitude of ways. It is admittedly different according to whether the doctor is a general practitioner, the family doctor, or a specialist in a hospital. Whatever the case, there can be no hiding the fact that the relationship is a dissymmetrical one.

While the patient is defined by his pain, ignorance or fear, the doctor represents knowledge. There is an inevitable power situation created, a bond of subordination. The doctor “diagnoses” and “prescribes”. The relationship is also extreme, in the sense that it alone gives a person the right to “invade” the integrity of another. The patient asks the doctor to do something which he would not allow from anyone else. The criterion of violence is suppressed.

The medical relationship demands - and this notion is essential - the patient’s knowing and willing consent. This is something which all the national and international provisions concerning medical experimentation have repeated constantly for many decades. Professor Savatier, in his “Treaty on Civil Liability” written in 1951, drew attention to this fundamental notion: “The nature of medical treatment is such that the patient, a human being, puts
himself in many cases entirely at the mercy of the doctor”. This contract must nevertheless remain, inasmuch as the nature of things does not absolutely forbid it, a flee one between two human beings of equal dignity. The patient’s freedom is in this respect all the more sacrosanct in that he is the weaker party.

We must, I think, remember, before closing this description of the doctor-patient dialogue, that it always involves a gamble, a risk, a decision and an uncertainty. Technological and scientific progress will never rid the doctor of this uncertainty.

Does this mean that progress bears no influence on the therapeutic relationship? And, since this is the issue which you are going to discuss, is it possible that the growth of genetic counseling might forge a new type of relation between the person treating and the person treated?

Where the basic constituents of the relation are concerned, I tend to think that the answer is largely negative. Its deeper features continue to exist.

Progress of whatever sort must never let it be forgotten that - if I may quote President Jean Bernard - ‘Medicine is a solitary enterprise: it concerns man, it concerns one man’.

All the same, we must obviously adapt, without renouncing our traditions, habits and customs - which come down to us from Hippocrates as well as from the Declaration of Human Rights - to new situations.

Genetic medicine confronts us with numerous new situations, especially since it is a basis for foretelling:

- in the short term, an affection which will manifest itself shortly after birth;
- an ailment, like Huntington’s chore, which will set in at an advanced age;
- or merely a predisposition to a particular condition.

In France, both medical circles and public opinion are in broad agreement that the government should fix rules and declare principles. The legislature took action in the shape of the “Bioethics Acts” of 29 July 1994, making genetic counseling compulsory before any prenatal diagnosis or act of preventive medicine.

It is interesting to note that the government has thought fit to “signpost” the medical dialogue and define with precision the contents of a genetic counseling. In the case of a prenatal diagnosis, the Decree of 6 May 1993 very much tells the doctor what he must say in order to allow the pregnant woman to give her informed consent regarding any tests that might entail the taking of critical decisions. The woman must be told of the risks to the foetus, the signs of the suspected disorder, the chances of detection, and possible methods of treatment.

The lawmakers also considered it necessary to set rules of good technological and therapeutic practice for governing the exercise of predictive medicine. A reading of these texts makes it clear that the relationship between doctor and patient is indeed modified, at least partially:

- greater involvement is required from the patient, who becomes a genuine and clear-sighted partner in the fight against disease;
- the patient is not necessarily ill, at least for the time being;
- the diagnosis may apply not only to the patient but also to his family and offspring.

The cornerstone of this relationship, I notice, is the quality of the information imparted by the physician to the patient and, where appropriate, to families. I believe that medical schooling should be changed to take account of this fact.

It seems to me that two factors require emphasis.
First, should not the type of dialogue propounded here serve as an example for doctors confronted with other sorts of medical situation and, when all is said and done, is it not very close to the requirement in the recent medical code of ethics that information given to the patient must be “honest, clear and appropriate”?

Second, I should like to return for a moment to the government’s very precise and defining incursion into the medical relationship. It is, of course, right to see this as a consequence of the anxieties fostered by the applications of genetic research.

The speed at which exploration of the human genetic heritage is progressing opening fascinating vistas for the prevention, and even cure, of a certain number of disorders.

It is nonetheless evident that it can give rise to the most fearful developments, and it is precisely these, Madam Chairperson, that your Committee has the task of controlling.

Please allow me, after having spoken at length in my capacity as doctor, to return to my position as State Secretary for Emergency Humanitarian Action. My field experience in humanitarian aid and my present experience as State Secretary lead me to conclude that a sizeable part of the population is becoming increasingly vulnerable. If so, may we not fear that these technologies could be used to create even greater discrimination?

The new medicine could clearly have nefarious social consequences. Doctors must, in my view, be clearly aware of such possible effects. In their relations with their patients, they should therefore act with even greater respect for medical ethics.
V. Closing Speech by Mr Federico Mayor, 
Director-General of UNESCO

Mr Minister,
Mr President of the International Court of Justice,
Mr President of the Constitutional Council,
Madam Chairperson of IBC,
Excellencies,
Ladies and Gentlemen,

“Responsibility is concern, recognized and accepted as the duty to be other than oneself”, wrote the philosopher Hans Jonas. At the dawn of the twenty-first century, the status of our scientific knowledge and the powers conferred on us by our technologies bring us, more than ever before, face to face with our responsibilities towards ourselves, our communities and humankind as a whole.

The world-wide growth of the ethical movement that has marked the last few years is without doubt the most eloquent expression of this new awareness. Born in a context in which scientific and technological progress is challenged as a source of benefits in itself, this movement has assumed such dimensions that it is no longer confined to issues pertaining to the revolution that is still unfolding before our eyes.

Indeed, an ethic of responsibility is now taking shape as a new requirement of society. All aspects of our daily lives, private and public, scientific and cultural, raise ethical questions that prompt us to seek, or revert to, principles and guidelines that can inform decision-making and action. Where scientific progress is concerned, bioethics, as awareness of the implications of the advances made in the life and health sciences, is at the centre of the ever-growing debate on the major choices that will direct the future course of humankind.

UNESCO’s mission embraces all ethical and legal aspects of research conducted in the life sciences and must promote an enlightened and dispassionate debate on their consequences. Indeed, these consequences will increasingly influence the way in which our societies are organized and managed. All the more so since progress in the biological sciences extends,
particularly through biotechnology, to other fields of activity, such as agriculture, food and the biotechnology environment. Hence, the necessary choices involve several sectors that are essential to the world's future equilibrium and can be neither shunned nor rejected. Elucidated by the knowledge of scientists, the courage of jurists, the wisdom of philosophers, these choices should be the concern of all and sundry.

Parliaments play a vital role here, for they give voice to the needs, hopes and anxieties of the societies they represent. This role is most visible in the preparation of legislation that may result from ethical soul-searching and grows in importance as its responsibilities transcend national frontiers and enter the realm of international affairs, where shared knowledge and the dissemination of research findings are prime concerns. This is why I would especially like to thank the parliamentarians from many countries who have readily come to UNESCO to share their ideas on the opportunities afforded us by science and technology to contribute to the greater welfare of humankind. Their presence here attests to the elected representatives’ resolve to ensure that human rights and freedoms are protected in this regard.

This session of the Committee has been marked by three themes that certainly raise fundamental ethical questions. Firstly, neuroscience. While the brain is still largely terra incognita, the advances made in this domain could open up new paths on the road to both relieving pain and altering behaviour by enabling us to explore the depths of thought, will and consciousness. There is no doubt that the question of consent is central here, since the subjects are usually either vulnerable or debilitated by a host of problems. Neuroscience is being increasingly invaded by neuro-technology, whose advances certainly include the use of electronics in the human body; in other words creation of those “hybrids” to which science fiction has already introduced us. We see, then, that the fascinating and delicate ethical problems on the horizon are legion. Gene therapy, yes. Electronic therapy, certainly. But with concern for the patient’s welfare and respect for scientific standards. Only within the framework of these absolute principles does the treatment have meaning and justification.

Secondly, genetic counselling. Your discussion followed on from what was said at your second session on genetic screening and testing. Thanks to the abundance of available tests, genetic counseling is becoming more and more widespread in medical practice, especially in predictive medicine.

Lastly, the ethical questions raised by population genetics, which have been addressed for the first time from a multicultural viewpoint and with an eye to the anthropological dimension of this research field.

Allow me, today, as this session draws to a close, to say a few words about two aspects of bioethics that I consider fundamental to the democratic future of humankind and that I think underlie your deliberations.

Over the last few years, the human being’s genetic component has acquired vital importance. Whether through the study of genetic diseases or of the biological mechanisms at work in behaviour, we might well start imagining that genetic knowledge will one day tell us all there is to know about the human species. This reduction of human beings to “a collection of genes”, which scientists are the first to denounce, poses a dual risk. In the first place, it mythifies genetics: science can never completely account for our destiny. Secondly, it robs us not only of our freedom but also of our responsibility. There is no such thing as genetic determinism, because epigenesis plays and will perforce continue to play an undeniable role in the singularity of the individual. Human beings are still the product of their history. Even their gene expression is actually a function of permanent interaction with their environment, their way of life, their hygiene, their education - in short, their entire culture.

This brings me to my second reflection, which, you will not be surprised to hear, concerns human diversity. The applications of science and technology must not reduce this rich diversity that inheres in us. For instance, genetic counseling - above all a space and time for communication between doctor and patient - should accord a specific place to the facts of the case in question and the sensibilities of the individual patient. It is the unique individual, this person in the here and now - seeking a consultation, with his or her own history, fears and expectations - that should be at the centre of the concerns of genetic counseling.
However, where I consider the recognition of diversity - genetic or cultural - to be most justified is in research on population genetics. You have highlighted this in your discussions: respect for each population group’s social standards, acknowledgement of their symbolic representations and consideration of their religious convictions are indispensable components of such research. You also stressed, and rightly so, the need to involve the communities that participate in surveys in the definition of the objectives, the conduct of research and the use of the findings of such research in population genetics.

Be that as it may, over and above the diverse cultures and perceptions of the peoples of the world, bioethics sets out to uphold the principle of universality. It is founded on the values enshrined in the Universal Declaration of Human Rights: those of the dignity and liberty of the human person. This awareness of our responsibilities should persuade us to adopt general guiding principles that will compel national and international respect for those values.

At the national level, alongside the effort of parliaments to define bioethics legislation, the role of ethics committees is becoming ever more firmly established. Even though these are often consultative bodies they prepare texts for the legislator’s guidance and inspiration; they also boost awareness of the issues by alerting and informing the public and political circles.

On the international front, the International Bioethics Committee has from its inception joined forces with the national ethics committees and international, intergovernmental and non-governmental organizations.

Great store has been set by bioethics education both for its intrinsic merits - it admirably illustrates the force of learning dispensed by and through several disciplines - and for the overall education and greater awareness of individuals in regard to bioethical matters. Yesterday the Committee made an appraisal of this type of learning in the Americas, and it will do the same for other regions of the world at subsequent sessions.

Lastly, you have just studied the outline for UNESCO’s declaration on the protection of the human genome prepared by the Committee’s Legal Commission. As you are aware, for you made your own contribution, it was the subject of broad consultation among the intellectual community. This initial text, enhanced by the observations and conclusions of your work this morning, will be useful to the Legal Commission in its preparation of a new draft.

The General Conference, whose twenty-eighth session will begin in Paris in a few weeks’ time, will study the report based on your work that I will be presenting to it. I would suggest in particular that the States be consulted on the new text, with a view to the preparation of a preliminary draft declaration. A committee of governmental experts could be convened early in 1997 and a draft declaration prepared for the General Conference session to be held in October/November 1997.

Ladies and Gentlemen,

Before I conclude, I should like to thank Mr Mohammed Bedjaoui, President of the International Court of Justice in the Hague, for so clearly outlining the importance of the future UNESCO Declaration. My thanks also to Mr Roland Dumas, President of France’s Constitutional Council, who has been kind enough to share with us his ideas on bioethics from the perspective of constitutional law.

I should like to express UNESCO’s profound gratitude to Mr Jacques Toubon, Minister of Justice of the French Republic. Mr Toubon was present at the installation of the International Bioethics Committee and has followed its progress. I am touched by the fidelity and constancy of his personal interest in bioethics. His presence here today and his very apposite remarks have added even more distinction to this third session and evinced the great importance that the French Government places on bioethics. The opening address by Mr Philippe Séguin, President of the National Assembly, and yesterday’s address by Mr Xavier Emmanuelli, the Prime Minister’s Secretary of State for Emergency Humanitarian Action, also demonstrate the host country’s support.
Apart from this, I have noted with great satisfaction the non-governmental organizations’ attentive and dynamic participation at this session, and my fervent wish is for the consolidation of this partnership that holds so much potential.

Allow me to express my thanks to you all for your outstanding co-operation and availability, a token of the selfless mobilization of the intellectual community. My thanks go out in particular to the members of the Legal Commission for its work throughout this year and especially to its Chairman, Mr Hector Gros Espiell.

In conclusion, I wish to pay special tribute to the Chairperson of the Committee, Ms Noëlle Lenoir, who day after day puts her intelligence, competence, fine judgement and dynamism at the service of this body. Without them, much of the road already travelled would still lie ahead of us.
VI. Speech by Mr Roland Dumas,
President of the Constitutional Council
of the French Republic

Mr Director-General,
Mr President,
Right Honorable Minister,
Your Excellencies,
Madam Chairperson,
Members of the Committee,
Ladies and Gentlemen,

UNESCO, when creating the International Bioethics Committee four years ago, had the intention of involving itself with the new issues generated by the development of biomedical technology.

What organization could better stimulate international debate on these issues than yours, Mr Director-General? The nature of the Committee reflects the image of this house - multicultural and pluridisciplinary.

It is a remarkable tool for thoughtful analysis and initiating action. The proceedings of this Third Session are proof of that.

The Committee is chaired by Mrs Noëlle Lenoir. Everyone knows the role she played in launching and bringing to fruition the public debate which preceded the adoption in France of the legislation of July 1994. Thanks to that legislation, our country occupies a leading position where the legal expression of bioethical imperatives is concerned.

I have no doubt that her experience, legal knowledge and intellectual curiosity are fully recognized and much appreciated within your Committee.

May I say a few words now on your proceedings, Ladies and Gentlemen? On Wednesday, you raised the subject of the role of parliaments in the field of bioethics.

Allow me, as President of a constitutional court, to share some thoughts with you, drawn from France’s experience, on what the collaboration in this field can be between parliament and the constitutional judge, the judge of the law. In so doing, I shall not wander outside of my own domain.
France, as you know, recently passed three Acts, one of them dealing with “the donation and use of human body elements and products, medical assistance, procreation and prenatal diagnosis”. Another concerns “the respect for the human body”.

Through these texts, the legislator imposes on all the protagonists a set of severe requirements and strict rules, designed to prevent medical progress from being diverted from its purpose.

The Constitutional Council examined the conformity of these Acts with the Constitution and pronounced them to be in conformity on 27 July 1994.

Its decision reflects an original approach to the verification of constitutionality.

First of all, the Acts submitted to the Constitutional Council were somewhat special in the sense that they had been drafted by one parliamentary majority and passed by a different one at the start of the new session.

Parliament, in other words, was able to rise above party divisions and adopt texts that by their nature related to the personal convictions of each deputy. It seems to me that this conduct can only be commended.

The President of the National Assembly referred the question to the Constitutional Council in the same spirit - that is to say, co-operation rather than confrontation - with the aim of seeking standards that are consistent not only with current mores and technology but also with our fundamental rights and freedoms. The purpose of the referral was, in his own words, “having regard for the determining scope of these texts...”, to ensure that “their conformity with the Constitution suffers from no uncertainty” and that the “reference value of the main rules set out therein be solemnized through the most appropriate channels”.

Mr Philippe Séguin did not advance any complaint of unconstitutionality in support of his referral. He presented it rather to have confirmation or extra comment for the present and the future as to the conformity of the Acts in question with rules and principles of constitutional value.

It is usually the parliamentary minority which submits cases to the Constitutional Council in the hope of obtaining condemnation of a text it dislikes. As it happened, the Council and Parliament showed that - when the seriousness of the subject warrants it - they could work together in harmony, one creating the rules of law, and the other defining the standards of constitutional value with which these rules of law must comply.

Where such essential texts are concerned, I would recommend speakers of parliament to adopt unhesitatingly a similar approach in order to “consecrate” the work accomplished by the legislature.

I should like also to share some thoughts with you on the substance of the July 1994 decision.

When taking this decision, the Constitutional Council elevated the “safeguarding of the human person against all forms of subjection and degradation” to the level of a principle with constitutional value, as a natural extension of the Preamble to the 1946 Constitution, which begins as follows:

“Following the victory of the free peoples over the regimes which attempted to subjugate and degrade the human person, the French people proclaims anew that every human being without distinction of race, creed or religion possesses inalienable and inviolable rights.”

This principle, formulated very soon after the discovery of the ghastly reality of the concentration camps, and particularly the eugenics experiments carried out in them, finds fill application in the field of bioethics.

The Constitutional Council held that the Acts referred to it respected this principle from the moment that they tended to ensure “the primacy of the human person, respect for the human being as from the beginning of life, . . . the inviolability, integrity and non-patrimonial character of the human body, and the integrity of the human race”.


The constitutional judge thus once again demonstrated his ability to correlate with new realities the standards which it is his duty to apply.

The principle of dignity is certainly not the only one to be applied in this field where other rights and freedoms - such as freedom of conscience or individual liberty - must be respected. It is the task of Parliament to achieve the appropriate reconciliation between these different requirements.

On the other hand, everyone noticed that the Constitutional Council refused to consider “protection of humankind’s genetic heritage” as a principle with constitutional value, it is not the Council’s business to create such principles out of nothing.

This should not be construed as censuring in advance the work of your Legal Commission on the protection of the human genome. I pay tribute to the value of this work and to the remarkable progress made.

It is probable that these issues have rather to do with parliamentary choices and the promulgation of international standards, in accordance with the mandate conferred by the UNESCO General Conference in 1993 on the Organization’s Director-General.

To conclude, I should like to quote Nobel prize-winner Jérôme Monod:

“No society can survive without a code of morality grounded in values that are understood accepted and respected by the majority of its members. Will modern societies indefinitely manage to control the fantastic powers that science offers them? Will they succeed in easing their unbearable strains?”

Ladies and Gentlemen,

The legislator, the jurist and the constitutional judge must, each in his station, help towards providing their answers, founded on the principles of freedom and law.

The task ahead, in other words, remains formidable. Your work, ladies and gentlemen, will surely be of the utmost importance in this respect.

It bears on issues which concern the conscience and existence of us all. Allow me to wish your young Committee all the success that the quality of its work deserves and the seriousness of the questions under discussion demands.
VII. Speech by Mr Mohammed Bedjaoui,  
President of the International Court of Justice

“Every individual is a universe carrying  
the memory of humanity in his genes”  
(Paul Auster, quoted by Mrs Noëlle Lenoir)

Mr Director-General,  
Madam President,  
Mr Minister,  
Mr President of the Constitutional Council,  
Your Excellencies,  
Colleagues and Friends,  
Ladies and Gentlemen,

For only a few decades, biological and medical science and technology have been the scene of tremendous upheaval. Man is beginning to understand the secret of life and to learn the language of genetics. Our world today is in labour in the anticipation of major births. Births which concern both the destiny and the purpose of man. There is scarcely anything grander than that! Man is now able to recompose plant or animal species and, above all, to transform the human race - a fact which is causing quite some anxious concern.

As Professor and Deputy Jean-François Mattei pointed out, humanity has made much more progress in the last four decades than it has done in the last four thousand years. But that progress is the cause of essential questioning relating in particular to the meaning of life, of death and of physical suffering and also to the predestination of all existence.

What is more, faced with this science which knows everything and can do anything, we are like children. We ask triumphant science where we have come from and how we were born, just as every child in the world asks its mother. But our world can no longer content itself with the flowery reply of the mother who would delight in explaining that she found her offspring in a rose or under a cabbage leaf. The child’s question has now been taken over by the adult. It has become the primary enigma of the human condition. But the answer we are able to give today, thanks to bio-genetics, has neither the fragrance of roses nor the flavour of the cabbages of bygone days.
So science, ethics and law have been convened to a permanent emergency session to take up the absolute challenge of the formidable conquests of technology. Confronted with the headlong advance of the bio-sciences, legislations of the world are hastening to catch up with the unbridled thrust of development.

The fundamental changes in man’s knowledge, which are taking place before our eyes as we marvel in apprehension, are bringing to our present age a novelty more intense than anything ever experienced at any major turning point in the course of human history. The invention of the printing press or the steam engine, the industrial revolution, wireless telephony, radioactivity and the use of the atom undoubtedly left a profound mark on the human adventure on earth. But how can these powerful moments bear comparison with man’s breath-taking power to recompose his own species? This power of man over himself is taking on dimensions which in theory know no bounds. As is stated very appropriately in one of the leaflets distributed at this meeting, the knowledge of the human genome constitutes an unprecedented scientific revolution.

I would quote the French psychoanalyst Monique Vacquin, who has said that:

"Like Pythia in Delphi, bent over the bowels of the earth, like the Sibyl drawing knowledge from the grotto . . . . our contemporary world in its fever is breaking down the barriers of ethics to decipher life and death with the colossal and disturbing powers “it now possesses” (1)."

Control of genetics gives man the power not only to remodel himself but also to recompose - for better or for worse - the family, the marital relationship, the parental or filial relationship, the human group, society, the State, democracy - in short, the social, political and legal organisation of interpersonal relationships. We must actually think of the social body as a whole and of the structures and ultimate aims of political power itself

Medicine, biology and genetics perhaps do not disintegrate or decompose the human body entirely, but they at least “externalise” it in its functions and organs. This creates relationships between the subject man and his objects, between the subject man and his social environment. In our everyday language we now talk about “recomposed man”, “artificial man”, and when we discuss assisted procreation we not only hear about the now common lace “test-tube babies”, but we visit, for example, the “child shop” with Jacques Testard(2). A “child market” with its law of supply and demand is potentially forming. The human body is dissected into pieces. In pieces, too, the medicine of our childhood, which can no longer be or remain a science of the body alone; now, more than ever before, it must become a science of man. Man, family, society, time. Kinship relationships are being affected. Individual identity is being distorted by the anonymity of the donor. The constellation of the family is changing. Societal equilibrium is losing its centre of gravity. The cohesion of society is beginning to crack.

The range of man’s potential powers is expanding daily. Organ transplants, the array of means of antenatal diagnosis, human genome mapping, predictive medicine, gene therapy, various forms of action on man’s genetic heritage, action on his brain, genetic manipulation, methods of eugenic selection, start-of-life medicine and end-of-life medicine - all have now become commonplace.

"Practices aiming here to promote birth, there to prevent it, here to promote death, there to prolong survival, here to tranform the organic being, there to modulate the psyche.” (3)

---

(3) Labrusse-Riou Catherine, “De quel droit”. Autrement, n°93, “Ethique, corps et âme”, p. 125
To cite again the technologies of artificial insemination alone, we are now confronted with the perturbation of generation links, the break-up of parenthood, surrogate mothers, requests for the sperm of a deceased husband with a view to fertilizing his widow, the insemination of a virgin tormented with the “desire for a child” but claiming the right to refuse all relations with a man, the status of supernumerary embryos, eugenic temptations and even genetic manipulations.

Marvel or malediction? Producing man, creating man as a pure social transparency, making the “perfect” man, the convivially gentle man relieved of all of his urges, the economically profitable, politically disciplined, socially pliable man? What would then become of human relationships? Exchange would be meaningless, dialogue pointless, words vain, debate absent, freedom captive and democracy empty. But conquering, thanks to genetics, the cancers which strike us down, AIDS which terrifies us, Duchenne’s disease, cystic fibrosis, Huntington’s choreas, Turner’s syndrome and other appalling diseases which I, as a layman, cannot even describe? What a tremendous feat of science!

Genetic science thus has the potential for better and for worse. And man has the power to avoid that worse. Let us consider the typicality of the lyrical works of the British poet Percy Shelley, the poet of fire and water, whose life was so short and so turbulent. Let us consider in particular the typicality of his “Prometheus Unbound” as well as that of the works of his wife, Mary Shelley Wollstone Craft, who left us a “Frankenstein” in 1818 and then in 1826 “The Last Man”, a science fiction novel giving a striking description of the destruction of the human species, a nightmarish horror story of the reconstruction of a human body which was alive but had no soul, no “divine spark”. Once again, man, preoccupied with the myths of Prometheus and Frankenstein, is seeking to “fabricate” himself by his own devices by attempting to escape his human condition and to transgress the laws of the transmission of life within the natural limits of sexual reproduction and death. The myths of Prometheus and Frankenstein thus predate by far recent technological discoveries.

But in other respects, far removed from all of these myths, do we reflect sufficiently on that singularity of the life in that being whom we call man and who is always and essentially the fruit of chance? Kierkegaard said quite rightly that the origin of life is a lottery or a throw of the dice, since of the 300,000 or 400,000 sperm which besiege the ovum, only one will be the first to succeed in penetrating and fertilizing it, thus causing all of the others to retreat. What is therefore disturbing is the fact that there is a sort of genetic lottery in insemination. I exist thanks to the elimination of other existences which were superfluous in the “noble seed” of my parent. But what difference is there then in artificial insemination, since I exist thanks to another lottery, which functions on identical principles but in which the selection is performed by the hand of a professional rather than by Mother Nature?

Before the current explosion of genetic science, all of the ethical codes in this world were based on two intangible factors: life and death. Life was one factor, and death was another. Man was well aware of his own limits. He could not influence life: life was received. Nor could he influence death: death was endured. Today, with the tremendous advances in genetic science, predictive medicine, antenatal diagnosis, gene therapy, etc., man has become Promethean and he can influence both life - which he can modulate as he pleases or prevent from being born - and death, whose decree he can postpone. Consequently, entire areas of our former moral code are collapsing and are having to be rebuilt. The genetic challenge must be met with more appropriate ethics. Law must also be added which, as an expression of those ethics, can exercise a regulating power in society.

Thus, faced with biology and genetics, we must reinvent the major fundamental principles of our ethics and must consolidate them with an appropriate new legal arsenal. We must base research on a platform of incontestable values which correspond to our concept of man and to the meaning we see in his life on this earth.

(4) Shelley Mary, “Frankenstein or the Modern Prometheus”. 
Formerly, several decades ago, the relations between patient, doctor and researcher were fairly clearly defined under the vigilant eye of the jurist, the legislator and the philosopher. The professional, as he was called, and his patient entered into and entertained a controlled relationship without major risks or surprises. Today, however, the set is changing. The curtain is rising on an unfamiliar scene. We are waiting expectantly for something to appear on that scene, something which we hope for and dread at the same time. The actors - doctor and patient - have been joined by the legislator, who has come quickly to the scene to catch up with events, the philosopher, who has come to reconcile science and conscience, and the jurist, who has been mobilised to harmonise in order the various interests at stake and the law. All of these actors are called upon to act in a singular drama, none having any idea of how it will end. They are trying to improvise the “happy end” smoothly, with no prompter behind the scenes and no stuttering on stage.

The scenes to be acted without a hitch are called the mutations of modern medicine, the status of the researcher, the consent of the patient, and the freedom, responsibility and solidarity of all.

Formerly, the doctor brought relief, repaired damage, prolonged life when he could and helped the patient who was ill. And of course he continues to do so. But the function, and even the nature, of medicine has changed before our very eyes. Medicine now has the power to modify, alter or improve the life processes. We are entering a world of medicine which responds not to suffering but to needs, and which is able to satisfy them, such as the “desire for a child”, for example, in a sterile couple or a single woman. This means that medicine is liberating hopes, building up happiness, forging new human rights. This new medicine is in the process of becoming a tremendous and real power, whose roles must be defined urgently. Looming beside the political power, the power of the administrative management of public health and that of the media, which are also involved in the debate, there is now the power of the technology which has pioneered the progress in genetics and of the new medicine through which these conquests of science are applied.

In many respects, our legal frames of reference are behind the times when it comes to providing guidelines for these new or unprecedented acts. This new form of medicine needs a new field of law with appropriate ethical rules. Medicine has never left responsibility for making ethical choices in the case of certain acts to the inspired or less inspired reasoning of the professional. Ever since Hippocrates, the medical world has provided itself with a code of ethics. Today it is tuning in to public opinion and is seeking the advice of ethics committees or commissions, which have been multiplying in many countries for several years. It must be pointed out that doctors and researchers in general are now feeling the need to share the responsibility of all ethical problems involved in their acts rather than to continue to bear it alone. It is doctors and researchers who are calling on the legislator and public opinion to lay down clear guidelines for their acts. We must redefine the researcher’s eminently strategic position in society from a new angle, and we must redefine in particular the responsibility of the scientist in the modern world.

As for the status of knowledge and of the researcher, we must meet the expectation which has been expressed. First, the status of knowledge. Back in the early 17th century, Francis Bacon, in his “Novum Organum”, sought the origin of human error and of the misconceptions which obstruct man’s judgement in what he called “the idols of the tribe, the cave, the market and the theatre”, meaning primarily that knowledge suffers above all from the overcautious conservatism of societies. It is patently obvious today that idols and temples have been ruthlessly overthrown, that the theatre is recomposing a new decor, and that the market is opening up to the promising new boost brought by genetics. But be this as it may, knowledge per se clearly cannot tolerate any limitation set by principle, which, moreover, would be impossible to enact, if only due to the difficulty in determining the threshold above which it should apply. Knowledge is always good. It alone cannot constitute a danger. It is more the use of knowledge without any appropriate ethical reference that can be perverse. Efforts must therefore be focused on defining the guidelines which must form the framework for the use of knowledge. One cannot, one must not set limits on human knowledge which are reminiscent of the fears and interdicts of mediaeval times. How can one close the door to knowledge - and on the basis of what criteria? - without subjecting civilisation to dark eclipses? Research must be openly proclaimed free.
But I must hasten to add that the spurious rule that “anything that technology can do is licit” must be banned. In actual fact, in order to place restrictions on the validity of scientific research the correct answer to two essential questions, clearly phrased by the theologian Michel Demaison, must be found. First: “What is man?” - that is to say, how are we to conceive of man? And then: “What is his destiny?” - that is to say, does not man have a “finitude” marked by two phenomena: his sexual differentiation and his death?

So, what is man first of all? Blood, sperm, tissue, and organs are elements which cannot be dissociated. Man is made up of all of these elements, plus something else. He is a whole. Let us not reduce the subject that he is to a conglomeration of detachable objects. The “human subject” is more than a “biological individual”. Which means, incidentally, that the marketing of these elements must be utterly banned. And also that the freedom which the biologist might request to use “human material” must also be rejected. Man cannot serve as “material” when he is an eminent subject.

It also means examining intently the question put by Dr François-Dominique Charles of Strasbourg University:

“Is not technological progress (....) leading us to adopt a unidirectional approach to man, which reduces and transforms him into an ‘object’ of analysis and care? Is not man liable to become dehumanised, fragmented, defined by what is accessible to technical exploration? Is the biological, or indeed the genetic, approach sufficient for defining man, for saying everything there is to say about him?

(...) Where the human being is a ‘mass of cells’, man cannot be reduced to that: he is also a being who speaks and lives in relationships with others, a cultural being who has a history, a being who thinks and reflects, who produces works of art, who sings and dances and narrates, a being capable of exercising his freedom and of making choices which orient his existence, a being capable of love and hatred, a being whose face lights up with joy and is drawn and tormented with suffering.”

After many other learned assemblies or gatherings involved with human society, the 93rd Interparliamentary Conference in Madrid adopted a resolution on 1 April 1995, which summarises the conduct of the actors in the drama of the genetic revolution when it proclaims the reconciliation of the imperative of freedom of research with that of the primacy of the protection of the individual and the preservation of humanity.

It is the indissociable binomial of freedom and responsibility which must govern the genetic revolution more than ever before.

Take antenatal diagnosis, for example, where that freedom and responsibility are clearly involved. The freedom, and therefore the choice, to decide whether or not to accept the arrival in the world of a human being which is already alive. Posed in this way, that freedom cannot be dissociated from responsibility. It is also here, in this antenatal diagnosis, in the embryo or in the foetus, that the germ - one might well say - of the problem of potential eugenics appears.

With predictive medicine we are now able to decipher the destiny of a human being through his genes and to make an *ex ante* prediction of his future. But does this not then involve tremendous problems?

First of all, a psychological and social problem: is man capable of coming to terms with a destiny which is revealed to him in advance? He will wonder first of all if there is any point in diagnosing a disease predictively if, for example, science does not have the means of treating it. It is of course a good thing to know the risks to which one is exposed so that one can organise one’s life accordingly. But is not the burden of that secret which has been snatched from the mists of the future at all events too heavy? And if the subject is entitled to know, does the same apply to the employer, the insurer and/or society as a whole?

---

But we have merely touched upon the problems, however serious they may be. There are others - philosophical problems, and they are important. If our predictive ability is certain, does this not mean that we are prisoners of our genes? Are we not then predetermined? What of our freedom? Predictive medicine thus poses the tremendous problem of the innate and the acquired, a problem which is still under debate. As Professor Jean-François Mattei puts it, “are we doomed to be what the genetic heritage we have received has destined us to be, or can we believe in the possibility of being remodeled by our environment?”

Is not the issue at stake in all of these questions then no more and no less than the human condition? And then one is strongly tempted to proceed from the discovery of the gene to its utilisation by means of gene therapy, which is still in the experimental stages, to treat cancers in particular, thanks to the possibility of placing “genetic material” in the diseased cells in order to correct their defect. But this being so, what limits are to be placed on this new science, which is so fascinating but so widely exposed to genetic manipulation?

Freedom and responsibility. These two categorical imperatives cover all of their field of action when one adds the necessary dimension of solidarity. One of the aspects of that solidarity calls for the proper handling of the aspirations of the countries of the South. All members of the human race must benefit from scientific progress and its applications. The human community as a whole must participate in the sharing of knowledge throughout the world and in the results deriving from it.

In his 1987 Encyclical “Sollicitato rei socialis”, His Holiness Pope Jean-Paul II said the following:

“At the international level, the level of relations between States or, as they are commonly termed, relations between the various ‘worlds’ there must be full respect of the identity of each people, with its historical and cultural characteristics... Peoples, just as much as individuals, must enjoy the fundamental equality on which, for example, the Charter of the United Nations is based - the equality which forms the basis of the right of all to participate in the entire development process”.

Debates developed in the sixties on scientific research, debates which were fostered by what was known as “the technological gap” between North and South. Thirty years have meanwhile passed and the gap has now become a chasm. We must take care to prevent that chasm from becoming an abyss between South and North to the extent that one day one will no longer be able to speak of humanity and humanity will cease to be a subject in which every individual can feel involved. When he inaugurated the proceedings of our session, Mr Philippe Séguin, the President of the French National Assembly, emphasised that exclusion is a major danger for democracies. Humanity can only exist in solidarity, that is to say, there must be the same rights for all.

However, due to the technological backwardness in the so-called developing countries, to their inadequate level of education, to their financial destitution and to many other structural factors, genetic research is geared more to satisfying the needs of rich countries - at least in the medical field. This is not surprising. It is a tendency which is observed in every field. We are all familiar with what is known as the “Saint Matthew effect”, where “the rich get richer and the poor get poorer.”

It is often said that bioethics concerns only rich countries, the only ones that can afford high-tech biomedical applications. To refer to the issues at stake in artificial insemination techniques, genetic diagnosis, or euthanasia would in some respects amount to intolerable provocation in countries which are battling painfully with problems of survival - the population explosion rather than sterility, infantile mortality rather than the prolongation of life, the decay of the fabric of society and the abandonment of minors to their own devices rather than surrogate mothers. For those underdeveloped countries, bioethics would be like a ridiculous quarrel about the sex of angels.

Mattéi Jean-François, “L’espèce aux limites de son savoir”. La Rencontre du Club de Marseille (The Meeting of the Club of Marseille), Marseille Chamber of Trade, 24-26 November 1994
But until such time - alas, still a long way off - as developing countries can manage to “get their heaven and earth together” - i.e. to flourish while respecting their values in a mutually profitable exchange - until this time, the North should at least curb a certain tendency to take excessive advantage of the vulnerability of the populations of the South. There are researchers, we are told, who conduct research on populations of the underdeveloped hemisphere without the consent of the subjects included in the study. That is against the whole philosophy of the International Bioethics Committee.

Africa, for example, possesses what specialists say are the most numerous and the most varied of genetic resources. I like to think that population genetics programmes, a particularly sensitive field of research, will be able to avoid any deviations. I like to think that this continent up for auction will not become a mere reservoir of organs and genes for surgery and research. I am not trying to minimise the gravity of the scourges which are weighing on developing countries, but I think we must cultivate a certain amount of optimism as to the favorable effects of genetic research on the development of those countries.

Quite apart from the more or less questionable practices in which bio-genetic research may engage in those vulnerable regions, it involves human dignity and fundamental human rights, which must be protected there probably to a greater extent than elsewhere. Like the god Janus of ancient times, scientific progress has two faces: the advantages being reserved for developed countries and the harmful effects for the others. Trade in organs, not to speak of organ theft, is flourishing in a steady South-to-North flow. The 93rd Interparliamentary Conference in Madrid was took right direction when it laid down the following principle in its Resolution of 1 April 1995: “The obligation to define rules which protect vulnerable populations, more specifically in developing countries”, and called for action to “ensure the fair sharing of the knowledge and advances resulting from scientific research and the new medical practices, particularly for the benefit of developing countries, with a view to remedying the imbalances observed in this field between those countries and developed countries”. And the Conference added the following significant statement: “(This Conference) urges parliamentarians and governments in developing countries . . . to bear in mind the risk of local knowledge being exploited by non-local societies”.

If there is resolute solidarity and vigilance, the global genetic revolution can have some beneficial effects on the underdeveloped world.

While health problems in Africa are tragically worrying, those of hunger cause equal concern in that plagued continent. Yet man has long discovered how to transform nature, and vegetal nature in particular, by means of hybridisation, cross-breeding and grafts. New biotechnology thus offers man considerable possibilities for new “foodstuffs”, and, as a result, can certainly play a beneficial role in the African environment and in African agriculture.

Ladies and Gentlemen,

I am not sure that human societies can be formed perfectly without reference to science construed as rationality. But I do believe, however, that no society can be built without normative principles - I mean, without law.

Where technological activity and, more specifically, biology and genetics are concerned, it is clearly dangerous to expect self-regulation to be secreted by that activity itself or by the market it creates. Medicine, biology and genetics now, at the very request of their servants, stand before the legislator, the jurist and public opinion by virtue of the phenomenal issues at stake.

The upheavals which, in the grip of technological advances, are today affecting the living conditions of men and women more than ever before, are confronting humanity with unequaled threats. Is it conceivable for the international community to disregard those threats, which are calling in question the integrity of the species and the perpetuity of humanity, with its experience and fundamental values? With the rapid development of genetics, which, as I have already said, confer on man the Faustian power to become his own engineer, the international community cannot afford spectacular progress at the price of unprecedented perils.
There are always loopholes in the law, whether it be national or international. Law is constantly striving to keep abreast with novelties in order to subject them to rules in its organisation of things. This essentially lacunary law sometimes fails to define even the most ordinary of events. It was Vercors who remarked in his work “Les animaux denatures” (Denatured animals) that “universal law gives no specific definition of the human person”. Law can advance bioethics within a salutary framework without drift or deviation. Technological advances must be followed step by step; they must be accompanied, fostered, and guided by legal standards for conduct which is in conformity with human rights and human dignity. As our President, Mrs Lenoir, has said, whether it is a matter of sperm or ovum donation, artificial insemination, the donation of blood, tissue or human organs, genetic testing or gene therapy, a legal framework for potential new practices or those already engaged in which concern the human body is absolutely essential in that it protects man in his freedom and dignity. But it is by no means an easy task. It is preceded by moral choices which are always delicate. And even when those choices have been made they still have to be translated into law, and that is often difficult.

Take, for example, the concept of the respect of “human dignity”. It is an expression which seems simple: one immediately apprehends its prospective import, if not its exact meaning. But, paradoxically, it is also an expression full of fragility, for in the name of the same argument of “human dignity” some refute the legitimacy of euthanasia, whilst others claim it as the ultimate right of those who wish to “die in dignity”! Concerned with their dignity as they construe it, men and women today are drawing up what are known as “biological wills”, that is to say, declarations of the wish to die in “dignity”, refusing in advance the prolongation of life by medical means, physical or mental degeneration, hopeless suffering, and degrading dependence. “Manifesto for a gentle death” are thus in circulation in our world. It is a sign of the times.

The declaration on the human genome is now making an essential - indeed, I would say historic - contribution to the freedom-responsibility duo and to the solidarity-human rights binomial.

First and foremost, because it makes the human genome a component part of the common heritage of humanity - and that is its most remarkable contribution. As I have already underlined, the introduction of this concept above all a question of expressing the fact that the primary common heritage of humanity is first and foremost man himself with his fundamental and universally recognised rights. Whatever his origin, his environment or his social circumstances, whatever his genetic characteristics, man is the owner of a number of rights which are inherent in his person and which it is impossible to transgress without at the same time attacking the human essence.

The sole purpose of protecting the human genome is to protect the person and his inalienable and immanent rights. I think that this still has to be clarified for, as our debates have shown, some fear that the idea of genome as the common heritage of humanity may be detrimental to the recognition of the rights of the individual over his genome. They must be entirely reassured, for the very objective of the declaration is precisely to protect the rights of the individual over his genome. For the concept of common heritage has the function of asserting a right, the right of humanity, and consequently of every individual to enjoy that heritage in conformity with his dignity and his fundamental rights. In the case of the human genome, this means that every individual has the right to the protection of his genome against any form of experimentation or exploitation which is contrary to his human dignity and to the fundamental rights accompanying it.

This of course implies that every individual is entitled to that protection with regard to his own genome, but also with regard to the genome of any other human being. In short, it is a matter of asserting that the protection of the human genome can only be the business of all humankind, for any interference with the genome of any one individual and, as a result, any violation of his dignity and his rights, is considered at the same time to be a violation of humanity as a whole and of the dignity of the entire human race. Thus, the interests of the individual and the interests of humanity are two sides of the same coin. I believe that the
The major contribution made by this declaration is to underline, with this concept of common heritage of humanity, that interdependence of the individual and humanity. Whether individual or collective, in the final analysis the only person to whom that right to the protection of the genome can be directed is man himself.

Moreover, in just a few articles and with remarkably restrained wording, this draft declaration sets out the essential principles which are intended as a guideline for conducting genetic research with a view to guaranteeing first of all that it is harmless before counting on its favorable effects.

And finally, there is the question of the form of this draft. It is true that a declaration of this nature is not directly binding for States. But neither is it merely a flash in the pan. I can but point here to the precedent of the 1948 Universal Declaration of Human Rights to express the hope that our declaration may also gradually gain effective legal force through the moral force it certainly possesses.

In the West, we talk about respecting human dignity, but one also speaks of the sacred in all forms of life, both animal and vegetal, in ancient India, in particular, and in cultures based on the unity and unicity of nature.

"Man, that needless passion", as Jean-Paul Sartre put it. That man is today at the parting of the ways, the cross-roads of destinies. If he succeeds in steering the genetic revolution clear of irreparable and tragic deviations and in making it a continuous benefit, man will most certainly not be that “needless passion”. Nor will he be that “recent invention destined for imminent death”, which Michel Foucault so amiably predicted. He will remain what he has always been: the marvel of creation.
The inauguration of the International Bioethics Committee in September 1993 gave me my first opportunity to take part in one of your sessions. Your invitation to me to participate in the closing of your Third Session is a token of interest which I particularly appreciate.

I am conscious of the extent of your work on behalf of the teaching of bioethics across the world and of your concern to make the general public aware of the issue. I know how many ties you maintain with other international organizations having an interest in bioethics. I perceive your Committee’s efforts to gather a maximum of information on the subject areas created by modern biology and genetics.

Your concern for the protection of the genome has remained a constant factor in the activity of your Committee since it was set up. I should like to hail the important step you have taken towards framing a political and legal instrument tailored specifically to the need for this protection.

Your line of action considers the human being from the angle of his biological existence as revealed by the latest advances of science. This standpoint has led you, in a most instructive text, to highlight the specific risks inherent in that approach.

The genome, which is a vital element in the conservation of the human race, is today widely vulnerable to deciphering and all the dubious developments that use of such knowledge or speculation based on it can produce.
Your human genome project thus lies at the heart of the bioethical concerns of our age. Your action also bears witness to a firm intention to confer an international legal dimension on bioethics. In the world in which we live, such a development seems to me to be absolutely essential.

Your work explicitly postulates that no scientific advance in human genetics can take precedence over respect for the dignity and freedom of the human person. In this respect, you have many points in common with French law:

- protection of the integrity of the human race;
- need for a person’s free and enlightened consent concerning any interference with his genome;
- obligation not to reduce the human individual to his genetic characteristics;
- requirement that personal genetic data capable of being stored or processed be treated as confidential with respect to third parties.

It behoves us to be particularly vigilant as to the applications, technologies and medical practice stemming from fundamental research on the genome.

Forecasting of pathological indications in certain individuals could, if we are not careful, result in the development of sinister tools for selection and discrimination in certain contractual relations.

The promotion of the principles referred to above can only be applauded.

I note that your draft declaration, unlike the positions recently adopted by the Council of Europe, does not contain a ruling on human genome research and manipulation aimed at modifying a person’s offspring.

The prospects for implementing germ-line gene therapy seem still to be far-off. France’s bioethics legislation has taken a stand on this point. The new Article 16-4 of the Code Civil unambiguously forbids “any eugenic practice tending to organize the selection of individuals”. Its final sub-paragraph is, however, more tolerant towards research. It states that “without prejudice to research seeking to prevent or treat genetic diseases, no alteration can be made to genetic characteristics with the aim of modifying a person’s offspring”.

This qualified position is, I feel, appropriate to the complex nature of the problem. It combines caution and open-mindedness. It forbids eugenics, yet does not, behind this ban, lock the door to all possibility of research.

It is now up to States themselves, as you ask, to put these principles into practice by adopting the required normative measures.

This strikes me as being a necessity. What effect can bioethical principles have if their implementation at national level is not defined by actual legislation?

What can their role be in a country which does not possess protective legal instruments capable of prosecuting and putting an end to every illegal aggression committed on the human body?

Further to the contents of your draft protocol, allow me to stress the interest and importance in my view of developing international instruments in the field of bioethics.

“Science has no fatherland”, wrote Pasteur. In bioethics, it is highly desirable that a legal order transcending national borders should emerge.

Medical and pharmaceutical research is certain to become even more international in the years to come. Citizens’ and patients’ rights, like the obligations of doctors and researchers, will be less and less demarcated by frontiers.

The globalization of population movements, as of health policies, will result in greater numbers of biomedical forms of treatment which will in turn require consultations and operations performed successively on the territories of several countries.
The same will apply to the cross-border movement of donated human body parts or constituents.

A wider dissemination of bioethical principles is essential so that these procedures and operations can benefit from a maximum of guarantees concerning the ethical, legal and health conditions in which they are conducted.

The dissemination of bioethical notions and standards, far from being a hindrance to successful research, can be one of its preconditions. Unless a sufficiently general rule of law is established, bioethics runs the risk of remaining enmeshed in the contradictory opinions which surround it.

This observation applies as much to the opinions of ordinary citizens as to those of doctors and researchers. It is also true for senior advisory bodies.

For want of legal guidelines, judges themselves tend to hand down contradictory opinions when they are required to rule in a new and shifting subject area such as biotechnology.

France, by adopting comprehensive and universally-intended legislation, has already made progress in this connection. Thanks to the action of organizations such as the one from which you have received your mandate, a framework of general principles such as that of the dignity of the human person should become a reality at international level.

A number of countries, currently at a remove from bioethical concerns, should thereby discover the impetus and reference points that will enable them to acquire legislation in this field. They will no longer find themselves excluded from the concert of nations called upon to choose for the whole of humankind.

The incentive provided by a declaration or international convention would hence be extremely valuable.

For this to happen, States must be conscious of the need for possessing a legal framework capable of promoting the rules of bioethics, which goes beyond a simple wish-list of principles.

At any event, your Committee, the end of whose draft declaration provides for a follow-up of its observation by the various States, would have just as vital a role to play here as the one it has just assumed in composing the draft.

The law’s duty is to familiarize itself with advances in knowledge in order to respond to the demands made on it by society.

The biological and genetic revolution which we are witnessing carries with it a threat to human freedom. This freedom, which is axiomatic, will always win over strict determinism. The law is precisely the guardian of this freedom. It is therefore the law’s task to set universal standards fixing the thresholds of what is acceptable and what is not in regard to the powers of men and of technologies.

This idea has been summed up as follows by one of our foremost jurists: “A definition is needed of the obligations of man towards man”.

This is what I wished to say to you, in the name of the President of the Republic and the Government. I also wish to assure you that France will accompany UNESCO, the International Bioethics Committee and all the Member States, in their efforts on behalf of the progress of humankind.
LIST OF PARTICIPANTS

I. Members of the Committee

Mr Mohammed BEDJAoui
President of the International Court of Justice
International Court of Justice
Palais de la Paix
Carnegieplein
2517 KJ THE HAGUE - The Netherlands

Mr Mohammed BENNOUNA
Director of the Arab World Institute
1, rue des Fossés Saint-Bernard
75005 PARIS - France

Mr Adriano BOMPIANI
Professor of gynaecology at the Catholic University of Rome
Via delle Tre Madonne, 12
00197 ROME - Italy

Mrs CHEE Heng Leng
Department of Nutrition and Community Health
Faculty of Human Ecology
Universiti Pertanian Malaysia
43400 SERDANG
SELANGOR - Malaysia

Mr Ricardo CRUZ-COKE
Director, Genetic Unit
J.J. Aguirre Hospital
Universidad de Chile
Santos Dumont 999
SANTIAGO 7 - Chile
Mr Jean DAUSSET
President
"Centre d'étude du polymorphisme humain"
27, rue Juliette-Dodu
75010 PARIS - France

Mr Harold EDGAR
Director
Julius Silver Program in Law, Science and Technology
Columbia University School of Law
435 West, 116th Street
NEW YORK, NY 10027 - United States of America

Mrs Laila EL-HAMAMSY
Professor Emeritus
Social Research Centre
The American University in Cairo
113 Kasr Aini Street, P.O. Box 2511
CAIRO - Egypt

Mr John I. FLEMING
Director
Southern Cross Bioethics Institute
P.O. Box 206
PLYMPTON, S.A. 5038 - Australia

Mr Gonzalo FIGUEROA YANEZ
Director, "Escuela de Graduados"
Facultad de Derecho, Universidad de Chile
Avda Santa Maria 076
SANTIAGO - Chile

Mr Norio FUJIKI
Vice-President of the IBC
Department of Internal Medicine & Medical Genetics
Fukui Medical School, Shimoaizuki
MATSUMOKACHO
Fukui Prefecture 910-11 - Japan

Mr Guido GERIN
President
International Institute for the Study of Human Rights
President, International Bioethics Centre
Via Cantù, 10
34127 TRIESTE - Italy

Mr Santiago GRISOLIA
Director
Fundacion Valenciana de Investigaciones Biomedicas
Amadeo de Saboya, 4
46010 VALENCIA - Spain

Mr François GROS
Professor at the "Collège de France"
Secrétaire perpetuel à l'Académie des Sciences
Institut de France
23, Quai de Conti
75006 PARIS - France
H. Exc. Mr Héctor GROS ESPIELL  
Vice-President of the IBC  
Ambassador  
Permanent Delegation of Uruguay to UNESCO  
Maison de l'UNESCO  
1, rue Miollis  
75732 PARIS CEDEX 15 - France

Mrs Genoveva KEYEUX  
Associate Professor of Genetics  
Instituto de Genética Humana, Facultad de Medicina  
Pontificia Universidad Javeriana  
Carrera 7a. No 40-62  
Apartado Aereo 56710  
SANTAFE DE BOGOTA, D.C. - Colombia

Mr George KLEIN  
Professor of Biology  
Department of Tumor Biology  
Karolinska Institutet  
104 01 STOCKHOLM - Sweden

Mrs Bartha Maria KNOPPERS  
Professor of Law  
University of Montreal  
Faculty of Law, Private Law Research Centre  
3101, Chemin de la Tour  
C.P. 6128, succursale centre-ville  
MONTREAL, Quebec H3C 3J7 - Canada

Mr Georges B. KUTUKDJIAN  
Secretary-General of the IBC  
Director, Bioethics Unit  
UNESCO  
1, rue Miollis  
75732 PARIS CEDEX 15 - France

Mr Peter LACHMANN  
Vice-President of The Royal Society  
Molecular Immunopathology Unit  
Medical Research Centre  
Hills Road  
CAMBRIDGE CB2 2QH - United Kingdom

Mrs Noëlle LENOIR  
President of the IBC  
Member of the French Constitutional Council  
Conseil Constitutionnel  
2, rue de Montpensier  
75001 PARIS - France

Mr Rubén LISKER Y.  
Deputy Director-General  
Departamento de Genética  
Instituto Nacional de la Nutricion Salvador Zubiran  
Calle Vasco de Quiroga 15  
Delegacion Tlalpan  
14000 MEXICO DF - Mexico
Mr Darryl MACER  
Foreign Professor (New Zealand)  
Institute of Biological Sciences  
University of Tsukuba  
TSUKUBA, IBARAKI 305 - Japan

Mr Kéba M'BAYE  
Former Vice-President of the International Court of Justice  
Rue "G" Angle Rue L.G. Damas  
B.P. 5865  
DAKAR-FANN - Senegal

Rev. Jean-Marie MPENDAWATU  
Pontificio Consilium de Apostolatu pro Valetudinis Administribus  
00120 Vatican City

Mr David OTTOSON  
Secretary-General of the International Brain Research Organization (IBRO)  
Department of Physiology  
Karolinska Institutet  
10401 STOCKHOLM - Sweden

Academician Rem V. PETROV  
Vice-President of the Russian Academy of Sciences  
Leninsky Avenue, 14  
117901 MOSCOW, V-71 - Russian Federation

Mr QIU Renzong  
Director  
Program in Bioethics  
Institute of Philosophy  
Chinese Academy of Social Sciences  
5 Jianquomenei Avenue  
BEIJING 100732 - China

Mr Michel REVEL  
Professor of Molecular Genetics  
Department of Molecular Genetics  
Weizmann Institute of Science  
Box 26  
76100 REHOVOT - Israel

Mr Albie SACHS  
Justice of the Constitutional Court of South Africa  
Constitutional Court  
Private Bag X32  
BRAAMFONTEIN 2017 - South Africa

Mr Hans-Martin SASS  
Professor of Philosophy  
Institüt für Philosopachie  
Ruhr Universität  
Postfach 102 148  
4630 BOCHUM - Germany
Mr Daniel SERRAO  
Professor of Pathology and Bioethics  
Faculdade de Medicina, Laboratorio de Anatomia Patologica  
Rua de S. Tomé, 746  
4200 PORTO - Portugal

Mr David SHAHIRO  
Executive-Secretary  
Nuffield Council on Bioethics  
28 Bedford Square  
LONDON WC1B 3EG - United Kingdom

Mrs SHEN Yucun  
Director, Institute of Mental Health  
Beijing Medical University  
BEIJING 100083 - China

Mrs Lidia VIDAL RIOJA  
Head of Molecular Cytogenetic Department  
Instituto Multidisciplinario de Biologia Celular (IMBICE)  
Casilla 403  
1900 LA PLATA - Argentina

II. Partipants in Round Table:  
Bioethics: What Role for Parliaments?

Mr Wolf-Michaël CATENHUSEN  
Member of Parliament  
Bundestag  
53113 BÖNN - Germany

Mr Claude EVIN  
Former Minister for Social Affairs and Health  
Deputy  
National Assembly  
126, rue de l'Université  
75700 PARIS - France

Mr Claude HURIET  
Senator of Meurthe-et-Moselle  
Palais du Luxembourg  
75291 PARIS CEDEX 06 - France

Mr Jean-Yves LE DEAUT  
Deputy of Meurthe-et-Moselle  
Maire adjoint de Pont-à-Mousson  
14, rue Victor Hugo  
54706 PONT-A-MOUSSON CEDEX - France

Mrs Sigrun LOWISCH  
Member of Parliament  
Bundestag  
53113 BÖNN - Germany
**III. Liaison Officers**

### III.1 International Intergovernmental Organizations

**World Health Organization (WHO)**

**Mrs Geneviève PINET**  
Chief, Health Legislation  
20, Avenue Appia  
CH-1211 GENEVA 27 - Switzerland

**Food and Agricultural Organization (FAO)**

**Mr José T. ESQUINAS-ALCAZAR**  
Secretary  
Commission on Plant Genetic Resources  
Via delle Terme di Caracalla  
00100 ROME - Italy

**United Nations Fund for Population Activities (UNFPA)**

**Mr Richard OSBORN**  
Senior Technical Officer  
Maternal and Child Health and Family Planning Branch  
Technical and Evaluation Division  
220 East 42nd Street  
New York, N.Y. 10017-5880 - United States of America
III.2 International Non-Governmental Organizations

Council for International Organizations of Medical Sciences (CIOMS)

Mr Zbigniew BANKOWSKI
Secretary-General
c/o World Health Organization
20, rue Appia
1211 GENEVA 27 - Switzerland

European Working Group on Human Gene Transfer and Therapy

Mrs Odile COHEN-HAGUENAUER
Scientific Secretary
EWGT Central Office - Scientific Secretariat
Institut d'hématologie
Hôpital Saint-Louis
75475 PARIS CEDEX 10 - France

International Council of Scientific Unions (ICSU)

Mr G. BERNARDI
Laboratoire de génétique moléculaire
Institut Jacques Monod
2, place Jussieu
75005 PARIS - France

Organization for Economic Cooperation and Development

Mr Mark CANTLEY
Principal Administrator
Unit of Biotechnology
Directorate of Science, Technology and Industry
2, rue André-Pascal
75775 PARIS Cedex 16 - France

The World Medical Association, Inc. (WMA)

Dr Ian T. FIELD
Secretary-General
B.P. 63
O1212 FERNEY-VOLTAIRE Cedex - France

III.3 Private Foundations and National Organizations

Belgian Society of Xenotransplantation

Mr Georges BINAME
Parliamentary Adviser
Chambre des représentants
Maison des parlementaires
21, rue de Louvain
1000 BRUSSELS - Belgium
Fondation Mérieux (Lyon)

Mr Charles MERIEUX
President
17, rue Bourgelat
B.P. 2021
69227 LYON CEDEX 02 - France

Fondation Sandoz

Mr René BASDEVANT
President of the Administrative Council
SANDOZ France
14, Boulevard Richelieu
92506 RUEIL-MALMAISON CEDEX - France

Foundation for International Studies

Dr Emmanuel AGIUS
Coordinator of the Future Generations Programme
University of Malta
St Paul Street
VALLETTA - Malta

IV. Representatives of Organizations of the United Nations System

United Nations Organization (UNO)

Mr Hassen FODHA
Director
United Nations Information Centre
UNESCO House
PARIS

World Health Organization (WHO)

Mr V. BOULJENKOV
Responsible Officer
Human Genetics Programme
Division of Noncommunicable Diseases, and
Mr Sev. S. FLUSS
Adviser on Health Legislation to the Director
Division of Publishing, Language and Library Services
World Health Organization
CH-1211 GENEVA 27 - Switzerland

Pan American Health Organization (PAHO)

Dr Julio MONTT MONBERG
Director, Regional Program on Bioethics
Casilla 9459
Paul Harris
9041 Las Condes
SANTIAGO - Chile
V. Observers of Intergovernmental International and Regional Organizations

Commission of the European Communities

Mrs Isabelle ARNAL, and
Mrs Christiane BARDOUX
General Secretariat
Rue de la Loi 200
1049 BRUSSELS - Belgium

Council of Europe

Mrs Johanna H.W. KITS NIEUWENKAMP
President/Chair
Steering Committee on Bioethics
Head of Section Medical Ethics
Ministry of Welfare, Health and Cultural Affairs
Postbus 3008
2280 MK RIJSWIJK - The Netherlands

Andean Parliament

Mr Leonardo ESCOBAR B.
President
Comision de Salud
Carrera 7a. N° 13-58-Ofc. 401
BOGOTA - Colombia

VI. Observers of International Non-Governmental Organizations

Consultative Council of Jewish Organizations (CCJO)

Mrs Diane MEHREZ
9, rue Parent de Rosan
75016 PARIS - France

Council for International Organizations of Medical Sciences (CIOMS)

Mr Sev S. FLUSS
World Health Organization
20, rue Appia
1211 GENEVA 27 - Switzerland

The Human Genome Organization (HUGO)

Mrs Jaume BETRANPETIT
HUGO's European Committee for the Human Genome Diversity Project
University of Barcelona
BARCELONA - Spain
International Catholic Centre for UNESCO

Mr Jean LARNAUD
Director
9, rue Cler
75007 PARIS - France

International Council of Scientific Unions (ICSU)

Mr Matthias KAISER
Member of the ICSU Working Group on the Ethical Responsibility of Scientists
Director
National Committee for Research Ethics in Science and Technology
Gaustadalleen 21
The Research Park
N-0371 OSLO - Norway

International Council of Women

Mrs Monique LEVESQUE
Secretary-General
75, rue Saint-Charles
75015 PARIS - France

International Christian Union of Business Executives

Mr Gabriel SCHMIDT
Secretary-General
Representative to UNESCO
56, rue Cambronner
75015 PARIS - France

International Federation of Training Centres for the Promotion of Progressive Education

Mr Cheikh DEM
President
29, avenue Georges Mandel
75116 PARIS CEDEX - France

International Federation of University Women

Mrs M. GERLACH-NIELSEN
19, rue Saint-Saens
75015 PARIS - France

International Federation of Women in Legal Professions

Mrs Claire JOURDAN
President
26, avenue Kléber
75116 PARIS - France

Mrs Juliette VALENTIN
20, rue du Cardinal Lemoine
75005 PARIS - France
International League of Societies for Persons with Mental Handicap (ILSMH)

**Dr Marcia RIOUX**
G. Allan Roeher Institute  
Kinsmen BLDG. - York University  
4700 Keele Street  
DOWNSVIEW - Ontario M3J 1P3 - Canada

**Mr Kees VAN DE VATE**
Julianweg 17  
2042 ZANDVOORT - The Netherlands

International Social Science Council (ISSC)

**Lord Wayland KENNET**
LONDON SW1A 0PW - United Kingdom

Pax Christi international

**Mrs Colette PETIT**
58, avenue de Breteuil  
75007 PARIS - France

Pax Romana

**Mr Jean LEROY**
91, avenue du Général Leclerc  
91190 GIF-SUR-YVETTE - France

Women's International League for Peace and Freedom

**Mrs Suzanne THIBERT**
19, avenue du Général Leclerc  
75014 PARIS - France

Working Group on "Science and Ethics" of the Standing Committee of NGOs

**Mrs Gabrielle VOIGNAC**
14, avenue Fernand LEBEVBRE  
78300 POISSY - France

**Mrs Susan VIDAL-NAQUET**
17, rue Condorcet  
75009 PARIS - France

World Federation of Scientific Workers (WFSW)

**Mr André JAEGLE**
Secretary-General  
155, rue du Château des Rentiers  
75013 PARIS - France

World Federation of UNESCO Clubs, Centres and Associations

**Mrs Anastasie N'GUETTA**
26, rue Mollet  
75017 PARIS - France
Mrs Josée TISSOU KOSSIWA
17, rue des Pêcheurs
77360 VAIRES-SUR-MARNE - France

World Federation for Mental Health (WFMH)
Mrs Madeleine RIVIERE
Psychiatrist/Psychoanalyst
11, rue Bertin Poirée
75001 PARIS

The World Medical Association, Inc. (WMA)
Mrs Elisabeth VILLETTE
17, avenue du Président Wilson
75006 PARIS - France

World Organisation for Early Childhood Education
Mrs Madeleine GOUTARD
President
17, avenue du Colisée
94100 SAINT-MAUR-DES-FOSSES - France

VII. Observers from Member States, Permanent Missions of Observation and National Commissions for UNESCO

H. Exc. Mr Abdul Aziz Nasser Rahma AL SHAMSI
Extraordinary and Plenipotentiary Ambassador of the United Arab Emirates in France
Permanent Delegate to UNESCO
UNESCO House

H. Exc. Doctor Abdul-Amir Ali AL-ANBARI
Ambassador
Permanent Delegate of the Republic of Iraq to UNESCO
UNESCO House

Mrs Elodie BERNARD
Administrative Attaché
Permanent Delegation of Paraguay to UNESCO
Embassy of Paraguay
113, rue de Courcelles
75017 PARIS

Mrs G. BRIANZONI
Chief of Paris Bureau
Liaison Officer with UNESCO
Council of Europe
55, Avenue Kléber
75784 PARIS Cedex 16
H. Exc. Mrs Sybil CAMPBELL
Ambassador
Permanent Delegate of Jamaica to UNESCO
UNESCO House

Mr Alessandro CANDEAS
Second Secretary
Permanent Delegation of Brazil to UNESCO
UNESCO House

Mr Peter CANISIUS
President, and
Mr Wolfgang REUTHER
Deputy Secretary-General
German Commission for UNESCO
Colmanstrasse 15
53115 BONN - Germany

H. Exc. Mr Carlos Antonio CARRASCO
Extraordinary and Plenipotentiary Ambassador of Bolivia in France
Permanent Delegate to UNESCO
UNESCO House

H. Exc. Mr Etzer CHARLES
Ambassador
Permanent Delegate of Haiti to UNESCO
Embassy of Haiti
10, rue Théodule-Ribot
75017 PARIS

H. Exc. Mrs Maria Saledad CRUZ GUERRA
Ambassador
Permanent Delegate of Cuba to UNESCO
UNESCO House

H. Exc. Mr Christoph DERIX
Extraordinary and Plenipotentiary Ambassador
Permanent Delegate of Germany to UNESCO, and
Mrs Rose LASSING
Counsellor, Deputy Permanent Delegate
UNESCO House

Mrs Lil DESPRADEL
Director of the Latin Union Bureau
Permanent Representative to UNESCO
UNESCO House

Mrs Maria Manuel DURAO
First Secretary, Embassy of Portugal
Permanent Delegation of Portugal to UNESCO
UNESCO House

H. Exc. Mr Jorge EDWARDS
Ambassador
Permanent Delegate, and
Mr Jaime CONTRERAS
First Secretary
Permanent Delegation of Chile to UNESCO
UNESCO House
H. Exc. Mr M. Alexandrovitch FEDOTOV
Extraordinary and Plenipotentiary Ambassador
Permanent Delegate, and
Mr Valérie SAKAROV
Counsellor
Permanent Delegation of the Federation of Russia to UNESCO
UNESCO House

H. Exc. Mr Sverrir Haukur GUNNLaugSSON
Extraordinary and Plenipotentiary Ambassador of Iceland in France
Permanent Delegate to UNESCO
8, avenue Kléber
75116 PARIS

Mrs Soheir HAFEZ
Second Secretary
Mission of the Arab League
114, boulevard Malesherbes
75017 PARIS

H. Exc. Mr Claude HAREL
Ambassador
Permanent Delegate of France to UNESCO
UNESCO House

H. Exc. Mr Dan HAULICA
Ambassador
Permanent Delegate of Romania to UNESCO
UNESCO House

Mr David HAY-EDIE
Permanent Observer of the United Kingdom to UNESCO
British Embassy
35, rue du Faubourg St. Honoré
75383 PARIS Cedex 08

H. Exc. Mr Azusa HAYASHI
Ambassador
Permanent Delegate of Japan to UNESCO
UNESCO House

H. Exc. Mr Jacob IMBE
Ambassador
Permanent Delegate of Madagascar to UNESCO
Embassy of Madagascar
4, avenue Raphael
75016 PARIS

Mrs Natalia JILEVITCH
Counsellor
Permanent Delegation of Belarus to UNESCO
UNESCO House

H. Exc. Mr Tleoukhan KABDRAKHMANOV
Extraordinary and Plenipotentiary Ambassador of Kazakhstan in France
Permanent Delegate to UNESCO
UNESCO House
Mr Taner KARAKAS
Counsellor
Permanent Delegation of Turkey to UNESCO
UNESCO House

H. Exc. Mrs Ugne KARVELIS
Extraordinary and Plenipotentiary Ambassador of Lithuania
Permanent Delegate to UNESCO
UNESCO House

Mrs Mariane KOPPER ORLICH
Counsellor
Permanent Delegate of Costa Rica to UNESCO
UNESCO House

Mrs Athena KOTSOULOS
Programme Specialist
Permanent Observation Mission of the United States of America to UNESCO
Embassy of the United States of America
2, Avenue Gabriel
75008 PARIS Cedex 08

H. Exc. Mr Sami KRONFOL
Ambassador
Permanent Delegate of Lebanon to UNESCO
UNESCO House

Mrs Anne LAMMILA
Counsellor
Permanent Delegate of Finland to UNESCO
UNESCO House

Mrs Dominique LEVASSEUR
Political Assistant
Permanent Delegation of Canada to UNESCO
UNESCO House

H. Exc. Mr Ingemar LINDAHL
Ambassador
Permanent Delegate of Sweden to UNESCO
UNESCO House

H. Exc. Mr Petr LOM
Extraordinary and Plenipotentiary Ambassador of the Czech Republic in France
Permanent Delegate to UNESCO
UNESCO House

H. Exc. Mr Piergiorgio MAZZOCCHI
Ambassador
Permanent Representative of the European Commission to OECD and UNESCO, and

Mr Hubert PETIT
First Secretary
12, avenue d'Eylau
75116 PARIS

H. Exc. Mrs Sonia MENDEITA DE BADAROUX
Extraordinary and Plenipotentiary Ambassador
Permanent Delegate of Honduras to UNESCO
UNESCO House
Mr Daoud Mohammed MIR
Minister Counsellor
Acting Chargé d'Affaires of Afghanistan in France
Permanent Delegate to UNESCO
Embassy of Afghanistan
32, avenue Raphaël
75016 PARIS

Mrs Radhia MOUSSA
Counsellor
Permanent Delegation of Tunisia to UNESCO
UNESCO House

Mr Saad NASRI
Counsellor
Permanent Delegation of Algeria to UNESCO
UNESCO House

H. Exc. Mr Alphonse NIANGOULA
Extraordinary and Plenipotentiary Ambassador of the Congo in France
Permanent Delegate to UNESCO
Embassy of the Congo
37bis, rue Paul Valéry
75116 PARIS

Mr Gilles NOGHES
Minister Counsellor
Deputy Permanent Delegate
Permanent Delegation of Monaco to UNESCO
Embassy of Monaco
22, boulevard Suchet
75116 PARIS

Mr Vincenzo PALLADINO
Deputy Delegate
Permanent Delegation of Italy to UNESCO
UNESCO House

H. Exc. Mr Hugo PALMA VALDERRAMA
Extraordinary and Plenipotentiary Ambassador of Peru in France
Permanent Delegate to UNESCO
UNESCO House

Mr Pal PATAKI
Plenipotentiary Minister
Permanent Delegate of Hungary to UNESCO
UNESCO House

Mrs Maria Susana PATARO
Minister,
Deputy Permanent Delegate, and
M. Eduardo GONZALES PLAZA
Counsellor
Permanent Delegation of Argentina to UNESCO
UNESCO House
Mrs Viera POLAKOVICOVA  
Deputy Permanent Delegate  
Permanent Delegation of the Slovak Republic to UNESCO  
UNESCO House

Mrs POVATONG Siinoi  
Deputy Permanent Delegate  
Permanent Delegation of Thailand to UNESCO  
UNESCO House

H. Exc. Mr Anton PROHASKA  
Extraordinary and Plenipotentiary Ambassador  
Permanent Delegate of Austria to UNESCO  
UNESCO House

Mr Heni QUINTERO  
Second Secretary  
Permanent Delegation of Colombia to UNESCO  
UNESCO House

Mr RI Kyong Il  
Third Secretary  
Delegation of the Democratic People's Republic of Korea to UNESCO  
UNESCO House

Mrs Jolanta ROSTWOROWSKA  
Plenipotentiary Minister  
Permanent Delegate of Poland to UNESCO  
UNESCO House

Dr Abd Elkarim SAOUD  
Plenipotentiary Minister  
Permanent Delegate of the Syrian Arab Republic to UNESCO  
UNESCO House

H. Exc. Dr Ahmed Saleh SAYYAD  
Ambassador  
Permanent Delegate of the Republic of Yemen to UNESCO  
UNESCO House

Mrs Leila SHAHID  
General Delegate of Palestine in France  
Permanent Observer to UNESCO  
Permanent Observation Mission of Palestine  
UNESCO House

H. Exc. Mrs Nina SIBAL  
Ambassador  
Permanent Delegate of India to UNESCO  
UNESCO House

Mr Janis SILIS  
Second Secretary  
Embassy of Latvia  
14, boulevard Montmartre  
75009 PARIS
Mr Jean SIRINELLI  
President, and  
Mr Georges POUSSIN  
Secretary-General  
Mrs Anne LEWIS-LOUBIGNAC  
Legal Counsellor  
Commission of the French Republic for Education, Science and Culture  
36, rue La Pérouse  
75775 PARIS Cedex 16

Mr Jan Helge SOLBAKK  
Representative of the Norwegian National Commission for UNESCO  
Director  
National Committee for Medical Research Ethics (NEM)  
Gustadalleen 21  
0371 OSLO - Norway

H. Exc. Mr Mohsen TAWFIK  
Extraordinary and Plenipotentiary Ambassador  
Permanent Delegate of Egypt to UNESCO  
UNESCO House

H. Exc. Mr Bakari TIO TOURE  
Extraordinary and Plenipotentiary Ambassador  
Permanent Delegate of the Ivory Coast to UNESCO  
UNESCO House

Mrs Tanya VELLA  
First Secretary  
Embassy of Malta  
92, avenue des Champs-Elysées  
75008 PARIS - France

H. Exc. Mr José Ramiro ZEPEDA ROLDAN  
Extraordinary and Plenipotentiary Ambassador of El Salvador in France  
Permanent Delegate to UNESCO  
UNESCO House

VIII. Guests from the Host Country

Mr Georges ABADIE  
Member of the French Constitutional Council  
Conseil Constitutionnel  
2, rue de Montpensier  
75001 PARIS

Mrs Hélène AHRWEILER  
Ethics Committee for Sciences  
CNRS  
3, rue Michel-Ange  
75794 PARIS CÉDEX 16
Mr André ALBERT  
Magistrate  
Bureau de Droit civil  
Ministère de la Justice  
13, Place Vendôme  
75001 PARIS

Mr Michel AMELLER  
Member of the French Constitutional Council  
Conseil Constitutionnel  
2, rue de Montpensier  
75001 PARIS

Mr Mohamed ARKOUN  
Member of the "Comité consultatif national d'éthique  
pour les sciences de la vie et de la santé" (CCNE)  
71, rue Saint-Dominique  
75007 PARIS

Mr Charles AUFFRAY  
Director  
CNRS UPR 420  
Génétique moléculaire et biologie du développement  
19, rue Guy Moquet  
94801 VILLEJUIF CEDEX

Mrs Michèle BARZACH  
Former Minister for Health  
Michèle Barzach Santé International  
99, boulevard Raspail  
75006 PARIS

Mr Serge BATUSANSKI  
Ministère de la Santé  
Direction des hôpitaux/ SI  
8, avenue de Ségar  
75007 PARIS

Mr Patrick BAUDRY  
Chef du Secrétariat de la Commission  
des affaires Sociales  
Senat  
Palais du Luxembourg  
75291 PARIS CEDEX 06

Mrs Etienne-Emile BAULIEU  
Director of Research - INSERM 433  
Hôpital Bicêtre  
80, avenue du Général Leclerc  
94276 LE KREMLIN BICETRE

Mr Jacques BENHAMOU  
Notary  
122, rue de la Boétie  
75008 PARIS
Mr Grégory BENICHOU
Université de Paris-Sorbonne
Philosophie morale et politique
96, avenue de Suffren
75015 PARIS

Mr Jean BERNARD
Honorary President
"Comité consultatif national d'éthique pour les sciences de la vie et de la santé" (CCNE)
71, rue Saint-Dominique
75007 PARIS

Mr Alain BERTHOZ
Professor, "Collège de France"
11, Place Marcelin Berthelot
75231 PARIS CEDEX 05

Mr Jean-Pierre BLOCH
Chief, Division de la coopération interparlementaire
Service du protocole et de la coopération
Assemblée nationale
126, rue de l'Université
75007 PARIS

Mrs Martine BOITEUX
Chargée de mission
Ministère de l'Education nationale, de l'Enseignement supérieur,
de la Recherche et de l'Insertion professionnelle
1, rue Descartes
75231 PARIS CEDEX 05

Mr André BOUÉ
Member of the "Comité consultatif national d'éthique pour les sciences de la vie et de la santé" (CCNE)
71, rue Saint-Dominique
75007 PARIS

Mrs Odile BOURRE
Chief, Secrétariat particulier du Président
Commission nationale Informatique et Libertés
21, rue Saint-Guillaume
75007 PARIS

Mr Christian CABROL
Deputy, European Parliament
Hôpital la Pitié
83, bld de l'hôpital
75013 PARIS

Mr Jean-Pierre CAMBY
Legal Service
Conseil Constitutionnel
2, rue de Montpensier
75001 PARIS
Mrs Marie-Madeleine CANCE
Avocat à la Cour
4, boulevard Saint-Michel
75006 PARIS

Mrs Nicole CATALA
Deputy
Assemblée nationale.
126, rue de l'Université
75700 PARIS

Mrs Catherine CHADELAT
Assistant Director General
Bureau de droit civil
Ministère de la Justice
13, place Vendôme
75042 PARIS

Mr Jean-Pierre CHANGEUX
President
"Comité consultatif national d'éthique pour les sciences de la vie et de la santé" (CCNE)
71, rue Saint-Dominique
75007 PARIS

Mrs Janine CHANTEUR
Professor, Université de Paris IV Sorbonne
39, boulevard Saint-Michel
75005 PARIS

Mr Jean CHERIOUX
Senator
25, quai André Citroën
75015 PARIS

Mrs Claire CSERNEL
Ministère de la Santé (DRI)
8, avenue de Ségur
75007 PARIS

Mr Thierry DAMERVAL
Assistant to the Director
Direction des sciences du vivant
Commissariat à l'énergie atomique (CEA)
31-33, rue de la Fédération
75752 PARIS CEDEX 15

Mr Jean-Pierre DELPEUCH
Legal Director
Conseil supérieur du notariat
31, rue du Général Foy
75008 PARIS

Rev. Olivier de DINECHIN
Member of the "Comité consultatif national d'éthique pour les sciences de la vie et de la santé" (CCNE)
71, rue Saint-Dominique
75007 PARIS
Mrs Paulette DOSTATNI
Director
Centre de documentation et d'information
en éthique de l'INSERM
71, rue Saint-Dominique
75007 PARIS

Mr Jean DREANO
President
Académie nationale de pharmacie
4, rue de l'Observatoire
75270 PARIS CEDEX 06

Mrs Renée DUFOURT
Honorary Professor
Former Member of the "Comité consultatif national d'éthique pour les sciences de la vie et de la santé" (CCNE)
47, cours de la Liberté
69003 LYON

Mr Alain DUPAS
Director of Protocol
Assemblée nationale
Palais Bourbon
126, rue de l'Université
75005 PARIS

Mrs Isabelle ERNY
Ministère de la Santé publique
Direction générale de l'assurance santé
8, avenue de Ségur
75007 PARIS

Mr Jacques FAUVE
President
Commission nationale d'informatique et Libertés
21, rue Saint-Guillaume
75007 PARIS

Mrs Odile FICHOT
Member of the "Comité consultatif national d'éthique pour les sciences de la vie et de la santé" (CCNE)
35, rue Michel-Ange
75794 PARIS CEDEX 16

Mrs Françoise FICHTER
Mairie de Paris
Bureau de Mme. I. de Kelviler
15, rue de Paris
75008 PARIS

Mr Jean-Louis FUNCK-BRENTANO
Professor of Nephrology
Hôpital Necker-Enfants Malades
161, rue de Sèvres
75743 PARIS CEDEX 15
Mr Hervé GARRAULT  
Director-General  
Association française de lutte contre la mucoviscidose  
76, rue Bobillot  
75013 PARIS

Mrs Marthe GAUTIER  
Former Director of Research, INSERM  
6, rue de Douai  
75009 PARIS

Mr Claude GIBEL-DEBURGE  
Director of International Affairs Service  
Assemblée nationale  
126, rue de l'Université  
75007 PARIS

Mr Maurice GODELIER  
Director of Studies  
Ecole des hautes études en sciences sociales  
54, boulevard Raspaïl  
75006 PARIS

Mr Claude GRAILLOT  
Assistance publique de Paris  
Direction de la prospective et de l'information médicale  
4, avenue Victoria  
75004 PARIS

Mrs Danièle GUILLAT-DEMONCHY  
Maître de conférences  
Faculté des sciences pharmaceutiques et biologiques  
4, avenue de l'Observatoire  
75270 PARIS CEDEX 06

Mr Philippe HOUILLON  
Deputy of Val d'Oise  
Assemblée nationale  
233, boulevard Saint-Germain  
75007 PARIS

Mr Pierre JOUANNET  
CECOS Paris-Bicêtre  
Centre hospitalier Bicêtre  
94270 KRÉMLIN-BICETRE

Mr Léon JOZEAU-MARIGNE  
Former Member of the French Constitutional Council  
38, rue de Lille  
B.P. 116  
50301 AVRANCHES CEDEX

Mrs Colette KOUCHNER  
Scientific Secretary  
Fondation Fyssen  
194, rue de Rivoli  
75001 PARIS
Mr Emmanuel de LA LANDE de CALAN
Direction générale des relations culturelles, scientifiques et techniques
Ministère des Affaires étrangères
Mission multilatérale
23, rue La Pérouse
75116 PARIS

Mrs Catherine LABRUSSE-RIOU
Professor, Université de Paris I
1, rue Michelet
75006 PARIS

Mr Yves LAPORTE
Professor, "Collège de France"
11, Place Marcelin-Berthelot
75231 PARIS CEDEX 05

Mr Pierre LAROCQUE
Member of the "Comité consultatif national d'éthique pour les sciences de la vie et de la santé" (CCNE)
71, rue Saint-Dominique
75007 PARIS

Mrs Marie-Jacqueline LAURIAU
Chief, Bureau des structures
Direction générale de la recherche et de la technologie
Secrétariat d'État chargé de la recherche
1, rue Descartes
75231 PARIS CEDEX 05

Mr Philippe LAZAR
Director-General
INSERM
71, rue Saint-Dominique
75007 PARIS

Mr Dominique LE VERT
Conseiller d'État
Conseil d'État
Place du Palais Royal
75001 PARIS

Mr Gilles LECOQ
Direction générale de la santé
124, avenue Sadi Carnot
92170 VANNES

Mr Dominique LECOURT
President
Association Diderot
2, place Jussieu
75005 PARIS

Mrs Soheila LEGER
Ministère de la Santé
8, avenue de Ségur
75700 PARIS
Mr Joseph LELLOUCH
Member of the "Comité consultatif national d'éthique pour les sciences de la vie et de la santé" (CCNE)
16, avenue Paul Vaillant Couturier
94807 VILLEJUIF CEDEX

Mrs Sylviane LEMONNIER TEREYGEOL
Chargée de mission
Conseil Constitutionnel
2, rue de Montpensier
75001 PARIS

Mrs Laurence LEPINNE
Parliamentary Assistant to Mr A. Pompidou
Faculté de médecine Cochin, Département d'anatomie-pathologie
24, rue du Faubourg Saint-Jacques
75014 PARIS

Mrs Marie-Hélène LHUGUENOT
Secretary-General
"Comité consultatif national d'éthique pour les sciences de la vie et de la santé" (CCNE)
71, rue Saint-Dominique
75007 PARIS

Mrs Ariane LOZACHMEUR
Direction générale de la santé, Bureau Ethique et Droit
Ministère de la Santé publique et de l'Assurance maladie
1, place de Fontenoy
754350 PARIS CEDEX 07

Mrs Hélène MARTEL
Marketing Director
SOCIÉTÉ LEICA
86, avenue du 18 juin 1940
92534 RUEIL-MALMAISON

Mr Robert NAQUET
Emeritus Director of Research
"Centre national de la recherche scientifique" (CNRS)
3-5, rue Michel-Ange
75794 PARIS CEDEX 16

Mr Jean-Claude PECKER
Honorary Professor, "Collège de France"
Collège de France, Annexe
3, rue d'Ulm
75231 PARIS CEDEX 05

Mr Louis-Edmond PETTITI
Judge, European Court of Human Rights
4, square La Bruyère
75009 PARIS
Mrs Nicole QUESTIAUX
Former Minister for Social Affairs
Member of the "Comité consultatif national d'éthique pour les sciences de la vie et de la santé" (CCNE) 
Conseil d'Etat- Président de Section
Place du Palais Royal
75001 PARIS

Mrs Janine RAULIN
Director of Research
Université Denis-Diderot et Bibliothèque inter-universitaire scientifique Jussieu (BIUSJ)
4, Place Jussieu
75005 PARIS

Mr Emmanuel RENE
Chef de service adjoint
Clinique des maladies de l'appareil digestif
Hôpital Bichat Claude-Bernard
46, rue Henri-Huchard
75877 PARIS CEDEX 18

Mr Franck SERUSC LAT
Senator
Sénat 
Palais du Luxembourg
15, rue de Vaugirard
75006 PARIS

Mr Jacques SEYLAZ
Member of the "Comité consultatif national d'éthique pour les sciences de la vie et de la santé" (CCNE)
71, rue Saint-Dominique
75007 PARIS

Mr René Samuel SIRAT
Grand Rabin de France
52, rue des Vignes
75016 PARIS

Mrs Juliane STROOGO
Ministère de la Solidarité (Mission Pékin)
8, avenue de Ségur
75007 PARIS

Mr Bruno STURLESE
Chief
Bureau du droit international et de l'entraide judiciaire internationale
Ministère de la Justice
57, rue Saint-Roch
75042 PARIS CEDEX 01

Mrs Gwen TERRENOIRE
CNRS - IRESCO
59, rue Pouchet
75849 PARIS CEDEX 17
Mr Maurice TREVOUX  
President  
Académie nationale de chirurgie dentaire (R.U.P.)  
57, Boulevard Murat  
75016 PARIS

Mr Pierre TRUCHE  
Attorney General  
Cour de Cassation  
5, quai de l'Horloge  
75055 PARIS RP

Mr Jean-Didier VINCENT  
Director  
Institut Alfred-Fessard  
Avenue de la Terrasse  
91198 GIF-SUR-YVETTE

Mr François VITTECOQ  
President  
Association des centres de rééducation pour déficients mentaux (A.C.R.)  
55, boulevard de la Villette  
75010 PARIS

Mrs Sophie VULLIET-TAVERNIER  
Chargée de mission, Legal Service  
Commission nationale Informatique et Libertés  
21, rue Saint-Guillaume  
75340 PARIS CEDEX 07

Mr Pierre ZEMOR  
Conseiller d'Etat  
Président de "Communication publique"  
19, rue Raspail  
94230 CACHAN

IX. Guests

Mr Ali ABDELFATTAH  
President  
Association internationale des recherches en psychiatrie  
B.P. 11  
003360 AINAY LE CHATEAU - France

Mrs Nicole ALBY  
Chargée de mission  
La Ligue  
1, avenue Stephen Pichon  
75013 PARIS - France

Mrs Maria del Consuelo ALDANONDO  
56, rue de la Pompe  
75116 PARIS - France
Mr Aleandro ARGUMEDO  
Coordinator  
Indigenous Peoples' Biodiversity Network  
200 Isabell St. - suite 304  
OTTAWA, Ontario - Canada

Mrs Irma ARNOUX  
Professor  
Université de Bordeaux  
22, rue de Sauteines  
33800 BORDEAUX - France

Mrs Farked Zok ASSI  
Professor, Faculté de Santé publique  
Centre national de recherche scientifique  
Université Libanaise  
BEIRUT - Lebanon

Mr Nicolas AUTET  
16, rue des Ecoles  
75005 PARIS - France

Mr Jean BACOU  
Institut des sciences de la santé  
86, rue du Bac  
75007 PARIS - France

Mr Emmanuel de BAILLON  
Editions législatives  
Dictionnaire permanent Bioéthique et Biotechnologies  
80, avenue de la Marne  
92546 MONTROUGE CEDEX - France

Mr Noël BARAG  
Docteur of Medicine  
57, rue Notre-Dame des Champs  
75006 PARIS - France

Mr Pedro BAUSERO  
"Centre national de la recherche scientifique" (CNRS)  
107, avenue Simon Bolivar  
75019 PARIS - France

Mrs Marie-Louise BEAUMONT  
106-108, boulevard Pereire  
75017 PARIS - France

Mr Denis de BECHILLON  
Secretary-General  
Association française d'anthropologie du droit  
Domaine des Vences  
13122 VENTABREN - France

Ms Karin BENGTSSON  
Department of Clinical Genetics  
East Hospital  
41685 GOTEBERG - Sweden
Mr Jacques BIOT
Consultant, J.N.D. Developpement S.A.
65-67, avenue Victor Hugo
69160 TASSIN-LA-DEMI-LUNE - France

Mrs Cécile BLANDY
Chargée de recherche
INSERM
Unité de génétique oncologique
Institut Curie, Section médicale
26, rue d'Ulm
75231 PARIS CEDEX 05 - France

Mr Dominique BLOIT
3, rue du Carouge
95760 VALMONDOIS - France

Mrs Myriam BLUMBERG-MOKRY
17, rue Michel-Charles
75012 PARIS - France

Mrs Bénédicte de BOISCHIEVALIER
Responsable de la bibliothèque
Centre de documentation et d’information
en éthique de l’INSERM
71, rue Saint-Dominique
75007 PARIS - France

Mr Jacques Roger BONNEAU
Jurist
47, boulevard du Lycée
92170 VANVES - France

Mr Julien BOUKAMBOU
Institut de la vie
Tour Maine-Montparnasse
B.P. 142
33, avenue du Maine
75755 PARIS CEDEX 15 - France

Mrs Catherine BOURDON
C4, rue V. Lacaille d’Esse
71100 CHALON-SUR-SAONE - France

Mr Jacques BRUNSCHWIG
Stomatologist
3, rue Notre Dame
55000 BAR LE LUC - France

Mr Pascal BUFFETEAU
20, rue de Lancre
60200 CAMPPIEGNE - France

Mr Jean-Claude BUXTORF
Assistant Director, CDEI - INSERM
Faculté de médecine, Hôpital Necker-Enfants malades
156, rue de Vaugirard
75015 PARIS - France
Mr Christian BYK  
Secretary-General  
Association internationale Droit, Ethique et Science (IALES)  
62, Boulevard de Port-Royal  
75005 PARIS - France 

Mrs Mady CAGEL  
Teacher  
10, rue Suger  
75006 PARIS - France 

Mr José-María CANTU  
President  
Programme latino-américain du génome humain  
Sierra Mojada 800  
GUADALAJARA, Jalisco - Mexico 44340 

Mrs Hélène CARTERON  
INSEMr  
Département du partenariat pour le développement économique et social  
101, rue Tolbiac  
75654 PARIS CEDEX 13 - France 

Mr Luigi Luca CAVALLI-SFORZA  
Professor  
Stanford University School of Medicine  
Department of Genetics  
STANFORD, CA 94306-6120 - United States of America 

Mr Yves CHAMPEY  
President  
Rhône-Poulenc Rorer Fondation  
20, avenue Raymond Aron  
92165 ANTONY CEDEX - France 

Mr Laurent CHATELIN  
216, rue Saint-Jacques  
75005 PARIS - France 

Mr Abram COEN  
Psychiatrist, Hôpitaux de Saint-Denis  
Consultation spécialisée pour enfants et adolescents  
Hôpital Casanova  
11, rue D.-Casanova  
93200 SAINT-DENIS - France 

Mr Pierre-Yves COURSIMAULT, and  
Mrs Rolande COURSIMAULT  
32, chemin des moluex  
95430 ANVERS-SUR-OISE - France 

Mrs Marie-José COUTEAU  
CNRS  
Centre de recherche Sens, Ethique, Société  
59, rue Pouchet  
75849 PARIS CEDEX 17 - France
Mrs Mireille DELMAS-MARTY
Institut de droit comparé
28, rue Saint-Guillaume
75007 PARIS - France

Mrs Sandra DETRIE
37, rue Scheffer
75116 PARIS - France

Mr Pape DIMUF
INED
24, rue Rothschild
C.P. 136
1211 GENEVA 21 - Switzerland

Mrs Marie-Claude DOCK
Vice-President
Association française des juristes démocrates
4, rue Auguste Vitu
75015 PARIS - France

Mrs Thomaïs DOURAKI
Legal Counsellor
28, rue Achaias
ATHENS - Greece

Mr Raphaël DRAI
Professor
Université d'Amiens
Faculté de droit et de sciences politiques
Campus
rue Salomon Mahlangu
84000 AMIENS - France

Mr Luc DRUART
Hôpital Robert Debré
48, boulevard Séurier
75019 PARIS - France

Mr Jean DUFFAR
Doctor of Law
16 bis, rue Edouard-Jacques
75014 PARIS - France

Mrs Caroline DUPUY
Fondation Marcel Mérieux
17, rue Bourgelat
B.P. 2021
69227 LYON CEDEX 02 - France

Mrs Brigitte ECKERT
Hôpital Lariboisière
Laboratoire central d'histologie, embryologie et de cytogénétique
2, rue Ambroise Paré
75010 PARIS - France
Mr François EWALD
Director of Public Affairs
Fédération française des sociétés d'assurances
26, boulevard Haussmann
75311 PARIS CEDEX 09 - France

Mr Robert EXPERT
Professor of Biology
32, avenue Corentin-Cariou
75019 PARIS - France

Mr Robin FEARS
Director, Science Policy Analysis
SmithKline Beecham Pharmaceuticals
Coldharbour Road, The Pinnacles
HARLOW, Essex CM19 5AD - United Kingdom

Mr Pierre FEDIDA
Director
Centre d'études du vivant
Université Paris 7 - Denis Diderot
2, Place Jussieu
Tour 16, 3ème étage
75251 PARIS CEDEX 05 - France

Mr Bernard FIEVET
Chief, Service santé personnes agées dépendants
Secours catholique
106, rue du Bac
75341 PARIS CEDEX 07 - France

Mrs Barbara FISCH
22, allée Jomde / aprt. 206
92000 NANTERRE - France

Mrs Ursel FUCHS
Documentation of Research in Medical Ethics
Kaiser-Wilhelm-Ring 19
40545 DUSSELDORF - Germany

Mrs Nathalie GAK
10, rue Jean Mermoz
94210 LA VARENNE - France

Mrs H. GAUMONT-PRAT
Doctor of Law
Maitre de conférences
Université Versailles Saint-Quentin
11, rue du Repos
78600 LE-MESNIL-LE-ROI - France

Mr Jean GAYON
Université de Bourgogne
Faculté de lettres et philosophie
2, Boulevard Gabriel
21000 DIJON - France
Mrs Michelle GOBERT
240, rue Saint-Jacques
75005 PARIS - France

Mr Fernand GOFFIOUL
Maître de conférences
Avenue du Luxembourg 11
4020 LIEGE - Belgium

Mr Alain GOMIS
CERSES/CNRS
59, rue Pouchet
75849 PARIS CEDEX 17 - France

Mr Antonio G. GONZALES
International Indian Treaty Council
Information Office
54 Mint Street #400
SAN FRANCISCO, CA 94103 - United States of America

Mr Pierre GOUBE de LAFORET
CERPH
Université de Poitiers
CHU La Milétrie
B.P. 577
86021 POITIERS CEDEX - France

Mrs Michèle GOUVERN
Conservateur en chef à la Bibliothèque inter-universitaire scientifique Jussieu
11, rue W. Saint-Lambert
92360 MEUDON - France

Mrs Laurence GUIBELEGUIET
FG Associés (Avocats)
50, avenue Victor Hugo
75016 PARIS - France

Mrs Fatima HAMAR
24, avenue du 29 août 1944
51000 CHALONS-SUR-MARNE - France

Ms Debra HARRY
International Indian Treaty Council
Information Office
54 Mint Street #400
SAN FRANCISCO, CA 94103 - United States of America

Mr Jacques HAVET
41-45, rue Galilée
75116 PARIS - France

Mrs Claire HONIGMAN
Fédération de la voix de l'enfant
17, boulevard Picpus
75012 PARIS - France
Mr Gérard HUBER
General Delegate, Association Descartes
1, rue Descartes
75231 PARIS CEDEX 05 - France

Mr Ram ISHAY
Chairman
The Israel Society for Medical Ethics
2 Twin Towers
35 Jabotinsky St.
RAMAT-GEN 52511 - Israel

Mrs JONG
23, rue Louis Pouey
341, Tour 2000 La Défense
92800 PUTEAUX - France

Mrs Marie JOZEAU-MARIGNE
Doctor of Medicine
8, rue de la Fontaine
94470 BSSY-SAINT-LEGER - France

Mr Emmanuel JULIEN
Cité des sciences et de l'industrie
Département Science Actualités
30, avenue Corentin-Cariou
75930 PARIS CEDEX 19 - France

Mr Georges JUNOSZA-ZDROGIEWSKI
Avocat, Institut des droits de l'homme
24, avenue de Suffren
75015 PARIS - France

Mr Noumadi KAMARA
Parliamentary Attaché
Parlement européen
Avenue de l'Europe
67000 STRASBOURG - France

Mr Bernard KANOVITCH
Professor, Chaire d'éthique Rothschild
30, boulevard du Port-Royal
75014 PARIS - France

Mr Max KAUFMANN
Secretary, Directorate of the "Groupe Sandoz"
Sandoz International S.A.
CH-4002 BALE - Switzerland

Lord Wayland KENNET
House of Lords
LONDON SW1A 0PW - United Kingdom

Mrs Navia KOSSIAKOV
22, avenue de Suffren
75015 PARIS - France
Mrs Fanny KOWAL
105, rue de Grenelle
75007 PARIS - France

Mrs Isabelle de LAMBERTERIE
CNRS, Cellule Science et droit
27, rue Paul Bert
94204 IVRY SUR SEINE - France

Mr Philippe LAURENT
42, rue de Grenelle
75343 PARIS CEDEX 07 - France

Mrs Chantal LE BATARD
Union nationale des associations familiales (UNAF)
28, place Saint-Georges
75009 PARIS - France

Mrs Sonia LE BRIS
CRDP
Faculté de droit, Université de Montréal
C.P. 6128
Succ. Centre-ville
MONTREAL, Quebec H3C 3J7 - Canada

Mrs Roseline LETTERON
Agrégée des Facultés de droit
Professeur à l'Université de Paris-Nord
24, rue Spontini
75116 PARIS - France

Mr Pierre LOTIRON
Psychiatre honoraire des hôpitaux
4, place Violet
75015 PARIS - France

Mr Peter W. MAIN
Associate Director
International Federation of Institutes for Advanced Study
39 Spadina Road
TORONTO, Ontario M5R 2S9 - Canada

Mrs Marie-Cécile MASURE
COPE - Département des sciences de la vie
CNRS
3, rue Michel-Ange
75016 PARIS - France

Mr Bertrand MATHIEU
Professeur agrégé des Facultés du droit
Icarie
21560 REMILLY-SUR-TILLE - France

Mr Romain MBIRIBINDI RUKEBEKA
President, Afrique Avenir
Mission intérieure de l'Eglise évangélique luthérienne
22, rue des Archives
75004 PARIS - France
Mr Marco MILANI-COMARETTI
"La Miralunga"
Arsina
55100 LUCCA - Italy

Mr Jacques MONTAGUT
Secretary-General
Institut francophone de recherche et d'études appliquées
à la reproduction et à la sexologie
20, route de Revel
31400 TOULOUSE - France

Mrs Danielle MONTEAUX
Chargée des relations internationales du Barreau de Paris
Ordre des avocats
4, boulevard du Palais
75004 PARIS - France

Mrs Nicole MORGAN
Visiting Professor
McGill Centre for Medicine, Ethics and Law
McGill University
3690 Peel Street
MONTREAL, Quebec - Canada H3A 1W9

Mrs Pierrette NEAUD
8, rue Rosa Bonheur
75015 PARIS - France

Mr Pascal NOUVEL
Director of Programme
Association Diderot
20bis, boulevard de la Bastille
75012 PARIS - France

Mr Jiro NUDESHIMA
Research Scientist
Life Science and Society Programme
Mitsubishi Kasei Institute of Life Sciences
11, Minamioooya
Machida-shi
TOKYO - Japan

Mr Victor B. PENCHASZADEH
Chief, Division of Medical Genetics
Beth Israel Medical Centre
First Avenue at 16th Street
NEW YORK - 10003 N.Y. - United States of America

Mr Pascal PEREAULT
204, boulevard Saint-Germain
75007 PARIS - France

Mr Dominique PLANCHENAUT
Centre de coopération internationale en recherche agronomique
pour le développement (CIRAD)
10, rue Pierre Curie
94700 MAISONS-ALFORT - France
Mr Rio D. PRAANING  
European Haemophilia Consortium  
c/o Rue Franklin 108  
1040 BRUSSELS - Belgium

Mr Octavi QUINTANA TRIAS  
INSALUD  
Alcala 56  
MADRID 280 71 - Spain

Mrs Suzanne RAFFLE  
Doctor of Medicine  
15, rue Erlanger  
75016 PARIS - France

Mrs Chantal RAMOGIDA  
President  
Association Pauline et Adrien  
920 chemin du Pré Seigneur  
78670 VILLENES SUR SEINE - France

Mr David REVCOLEVSCHI  
27, route de la Reine  
92100 BOULOGNE - France

Mr Guy RIEUTORD  
President  
Comité d'action pour la communauté universelle  
22, rue François Bonvin  
75015 PARIS - France

Mr Arthur ROBINSON  
National Jewish Center for Immunology and Respiratory Medicine  
DENVER, Colorado 80206 - United States of America

Mr Carlos Maria ROMEO-CASABONA  
Director  
Chair in Law and Human Genome  
University of Deusto  
BILBAO - Spain

Mr Emmanuel ROUKOUNAS  
Professor  
Département d'études internationales  
Facultés des sciences juridiques, économiques et politiques  
Université d'Athènes  
33, rue Hippocratous  
10680 ATHENS - Greece

Mr François ROUSSEL  
Chercheur en sciences politiques Paris I  
23, rue Melingue  
75019 PARIS - France

Mrs Danièle ROUSSELIER  
Writer  
11, rue aux Ours  
75003 PARIS - France
Mrs Jacqueline RUBELLIN-DEVICHI  
Professor, Université Jean-Moulin (Lyon 3)  
Director, Centre de droit de la famille  
1, rue de l'Université  
BP 638  
69239 LYON CEDEX 02 - France

Mrs Jacqueline RUSS  
Professor of Philosophy  
37, rue Ribéra  
75016 PARIS - France

Mr Nadji SAFIR  
Consultant  
196, rue de Belleville  
75020 PARIS - France

Mrs Monique SCHINDELMAN  
Director  
Bibliothèque inter-universitaire scientifique Jussieu  
4, place Jussieu  
75005 PARIS - France

Mrs Virginie SCHMIT  
240, rue de Charonne  
75012 PARIS - France

Mr Alexander SCHRAMM  
Department of Legal Science  
Research Centre on Biotechnology & Law  
University of Lüneberg  
Scharnhorstrasse/Campus  
21332 LUNEBERG - Germany

Mr Dirk SCHULZ  
Federal Foreign Office  
Ref. 410  
Postfach 1148  
53001 BONN - Germany

Mr George P. SMITH  
Professor of Law  
The Catholic University of America  
Columbus School of Law  
Office of the Faculty  
WASHINGTON, D.C. 20064-8030 - United States of America

Mrs Dominique SONET  
Consultant  
Grande Rue  
70000 MAILLEY-CHAZELOT - France

Mr Claude SUREAU  
President, Comité pour l'étude des aspects éthiques de la reproduction humaine (FIGO)  
Hôpital américain de Paris  
9, boulevard du Château  
92200 NEUILLY-SUR-SEINE CEDEX - France
Mrs Sylvie SZPIRO-TAPIA
Laboratoire CERBA
95066 VAL D’OISE - France

Mr Frédéric TRIERZ
Avocat au Conseil d’Etat
62bis, rue Charles Laffitte
92200 NEUILLY-SUR-SEINE - France

Mrs Sandy THOMAS
Science Policy Research Unit
Sussex University
BRIGHTON BN19RF - United Kingdom

Mr Michel TIBON-CORNILLOT
52, rue du Faubourg-Poissonnière
75010 PARIS - France

Mrs Marine TOULLIER
Stagiaire
Conseil Constitutionnel
27, boulevard Saint-Germain
75005 PARIS - France

Mrs Françoise TOURNAINE MOULIN
Biologist
Laboratoire d’immunologie
Hôpital Pierre Wertheimer
B.P. Lyon Montchat
69394 LYON CEDEX 03 - France

Mrs Marie-Françoise VALETTE
Maître de conférences
Faculté de droit de Poitiers
93, avenue du Recteur Pineau
86021 POITIERS - France

Mrs Sandrine VALSESIA
UCB Lyon 1 - CGMC
CNRS UNR 106
43, boulevard 11 novembre 1918
69622 VILLEURBANNE CEDEX - France

Mrs Thérèse VATURE
Professor
132, boulevard de Clichy
75018 PARIS - France

Mrs Jocelyne VAYSSE
Doctor of Medicine and Psychology
20/22, rue Lantiez
75017 PARIS - France

Mr Etienne VERNET
ECOROPA France
24, rue de l’Ermitage
75020 PARIS - France
Mrs Nelly VEROTTE
Institut Gustave Roussy
19, rue Camille Desmoulins
94805 VILLEJUIF CEDEX - France

Mr Patrick VERSPIEREN
Director
Département d'éthique biomédicale
Centre Sévres
12, rue d'Assas
75006 PARIS - France

Mr Jan VESTING
University of Lüneberg
Department of Legal Science
Research Centre on Biotechnology & Law
Scharnhorststrasse/Campus
21332 LÜNEBERG - Germany

Mrs Maria Dolores VILA-CORO
Docta en Derecho
Asociación de Biojurídica y Bioética
Plaza de la Castellana, 111
28046 MADRID - Spain

Mr Maurice A.M. de WATCHER
Director
Institute for Bioethics
P.O. Box 778
6200 AT MASTRICHT - The Netherlands

Mr Karl-Heinz WEHKAMP
Member of the "Akademie für Ethik in der Medizin"
Institut für der Medizin der
Georg-August Universität
Humboldtallee 36, 37073 GÖTTINGEN - Germany

Mr Daniel WIKLER
Professor of Medical Ethics
Program in Ethics and the Professions
Harvard University
79, J.F.K. Street
CAMBRIDGE, MA 02138 - United States of America

X. Communication Media

Mr Jean-Michel BADER
RTL
PARIS

Mr Marc BERTHIAUME
Radio Canada
PARIS
Mr Peter BUCHER
*Vision*
BERN

Mr Declan BUTLER
*Nature*
PARIS

Mrs Isabelle CELERIE
*Le Quotidien du médecin*
LEVALLOIS-PERRET

Mrs Pia DAIX
Attachée de presse
Comité consultatif national d'éthique pour les sciences de la vie et de la santé (CCNE)
PARIS

Mr DESORREAUX
*El Mercurio*
SANTIAGO DE CHILE

Mrs Lyliane DEVEZE
*Les actualités biologiques*
PARIS

Mrs Sophie GIDEL
*Arabies*
PARIS

Mr Cyril EGNER
*Le Courrier du Parlement*
SAINT-DENIS

Mr Siegfried FORSTER
*Radios allemandes*
PARIS

Mr Jack GEE
*Daily Express*
PARIS

Mrs Marianne GOMEZ
*La Croix*
PARIS

Mr Claude JEROME
*Radio France*
PARIS

Mr F. KAZIZ
*Le Concours médical*
PARIS

Mr André KRASNOCKTCHEKOU
*Agence ITAR-TASS*
PARIS
Mrs Géraldine LANGLOIS
Impact médecin quotidien
NÉUILLY-SUR-SEINE

Mr Philippe LAURENT
Civiltà Cattolica
PARIS

Mrs Marie-Gaëlle LE PERFF
Impact médecin hebdo
NÉUILLY-SUR-SEINE

Mrs Marie-Geneviève LEMOINE
TFI
BOULOGNE

Mrs Michèle LEONARD
La Vie
PARIS

Mr Philippe COSTE
AFP
PARIS

Mrs Sylvie MATTHIES
A.R.D. (Television Section)
MUNICH

Mr Jean-Michel MOLINS
Panorama du médecin
PARIS

Mrs Marielle MORGEAN
Impact médecin hebdo
NÉUILLY-SUR-SEINE

Mr Martial PENICAUD
Eurêka / Esprit Libre
PARIS

Mrs Ada PRINCIGALLI
Agence ANSA (Italie)
PARIS

Mrs Francine QUENTIN
RFI
PARIS

Mr Charles RAV
Free-lance journalist
PARIS

Mr Stéphane RENAULT
Science et Vie Junior
PARIS
Mr Etienne RICA  
*Univers Santé*  
PARIS

Mr Jean-Claude RONOD  
*Survival International (France)*  
PARIS

Mrs Anne SEYS  
*News Family Global*  
PARIS

Mrs Tara PATEL  
*New Scientist*  
LONDON

Mrs Catherine TASTEMAIN  
*Nature Médicine*  
PARIS

Mrs Catherine VINCENT  
*Le Monde*  
PARIS

XI. UNESCO

Mr Federico MAYOR  
Director-General

Mr Daniel JANICOT  
Assistant Director-General, Directorate

Mr Henri LOPES  
Assistant Director-General for External Relations

Mme Sabiha SYED  
Principal Programme Specialist  
Transdisciplinary and Inter-agency Project  
Environment and Population Education and Information for Development

Mr Malcolm HADLEY  
Programme Specialist  
Division of Ecological Sciences

Mrs Alya SAADA  
Programme Specialist  
Consultative Committee on Women

Mrs Graciela V. SAMUELS  
Liaison Officer  
Relations with parliamentarians  
Division of National Commissions and UNESCO Clubs
Mr Alex MAALIW  
Population, Communication and Research Specialist  
Transdisciplinary and Inter-agency Cooperation Project  
"Environment and Population Education and Information for Development"

Mrs Magdalena LANDRY  
Liaison Officer  
Intergovernmental Organizations Section  
Bureau of External Relations

Mrs Marie-Ange THEOBALD  
Division of Philosophy

Mrs Jeanne GRUSON  
Consultant  
50th Anniversary of UNESCO

Mrs Muriel BEAUVAL-TACCONIS  
Consultant  
Division for the renovation of educational curricula and structures

Mrs Christine de MASSON d'AUTUME  
Legal Adviser to the IBC  
Bioethics Unit

Miss Sabina COLOMBO  
Assistant Programme Specialist  
Bioethics Unit

Miss Laurence LISSAC  
Press Officer  
Bioethics Unit

Mrs Chantal GLADIEUX  
Administration  
Bioethics Unit

Mrs Léonie TREGUER  
Documentation  
Bioethics Unit

Mrs Christina BILLAUD  
Secretary  
Bioethics Unit