PROCEEDINGS

Fifth Session

Volume I

INTERNATIONAL BIOETHICS COMMITTEE
OF UNESCO (IBC)
Division of the Ethics of Science and Technology of UNESCO
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INTRODUCTION

At the kind invitation of the Government of the Kingdom of the Netherlands, the Fifth Session of the International Bioethics Committee of UNESCO (IBC) was held in Noordwijk, the Netherlands, from 2 to 4 December 1998. The opening ceremony was honoured by the presence of Her Majesty the Queen of the Netherlands. H. Ex. Mrs Vígdís Finnbogadóttir, Former President of the Republic of Iceland and Chairperson of the World Commission on the Ethics of Scientific Knowledge and Technology of UNESCO (COMEST), Mr Federico Mayor, Director-General of UNESCO, and Mr Stephen Schwebel, President of the International Court of Justice (ICJ), took part in the opening ceremony.

The topics on the agenda of this session were ‘Bioethics and Women’s Rights’ and ‘Ethics and Preventive Medicine’. The IBC devoted a session to the presentation of the results of the working group, established in 1996, in particular concerning to the status of the report entitled ‘Women’s Health, Bioethics and Human Rights’ which gives an assessment of the situation of women and the discriminations to which they are subjected with regard to health. Another session afforded the opportunity to examine the impact, from both a short and long term perspective, of the application of new technologies in the biomedical field.

Moreover, in accordance with article 24 of the Universal Declaration on the Human Genome and Human Rights, the IBC devoted a working session, chaired by H. Ex. Mr Héctor Gros Espiell, to the implementation of the Declaration.

Finally, as with the previous sessions, a round table was organised. Representatives from the pharmaceutical and agro-alimentary industries as well as members of the IBC gathered together around the theme ‘Ethics and Uses of Genetic Engineering in Industry’. On this occasion, the discussions underlined the increasing importance given by industry to ethical reflection and the role it can play in the promotion of public debate.
Volume I of these Proceedings contains the report of the fifth session of the IBC, the speeches delivered and the list of participants. Volume II contains all the contributions, especially by members of the International Bioethics Committee, on the topic ‘Ethics and Preventive Medicine’, as well as the contributions of participants at the Round Table.

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I. Introduction

At its 154th Session on 7 May 1998, the Executive Board of UNESCO adopted the Statutes of the International Bioethics Committee of UNESCO (IBC) (see pag. 99). By an innovative procedure, these Statutes set up, first of all, an International Bioethics Committee of 36 members, appointed by the Director-General in their personal capacity, and, secondly, an Intergovernmental Committee, constituted by 36 Member States, elected by the General Conference of UNESCO. The Statutes also provide for the possibility of joint sessions between these two bodies.

At the invitation of the Government of the Netherlands, the Fifth Session of the International Bioethics Committee of UNESCO was held in Noordwijk, the Netherlands, from 2 to 4 December 1998, and brought together more than 200 participants.

At an informal meeting, in accordance with its Statutes, the IBC adopted rules of procedure with a rewording of Article 10.1, suggested by the Director-General of UNESCO. It then elected its Bureau on the basis of proposals made by the Director-General (see pag. 111). The newly elected Chairperson, Mr Ryuichi Ida, emphasised the responsibility of the present generation towards future generations, as regards the ethical issues raised by scientific progress. The Committee also discussed its working methods and stressed the importance of obtaining a multidisciplinary composition of the working groups of the Committee set up to deal with specific topics.

The topics on the agenda of the fifth meeting were:
- ‘Bioethics and Women’s Rights’ and
- ‘Ethics and Preventive Medicine’.
Moreover, in accordance with Article 24 of the Universal Declaration on the Human Genome and Human Rights and on the basis of a document prepared by the Secretariat, the IBC devoted a working session to the follow-up of the implementation of the Declaration.

Finally, in the light of the increased importance being attached by industry to ethical reflection and in order to give industry a greater role in its work, the IBC decided to hold a round table on ‘Ethics and Uses of Genetic Engineering in Industry’ which brought together several personalities from both the private and the public sectors.

II. Opening of the Fifth Session

Her Majesty the Queen of the Netherlands honoured the opening ceremony of the Fifth Session.

After some words of welcome by Dr (Mrs) Els Borst-Eilers, Vice Prime-Minister, Minister of Health, Welfare and Sports of the Netherlands, Mr Federico Mayor, Director-General of UNESCO, thanked the Government of the Netherlands for hosting the Fifth Session of the IBC. He then recalled that the adoption of the Universal Declaration on the Human Genome and Human Rights was a historic moment for the Organization: the Declaration, he said, is indeed the first international instrument in this field and represents a significant contribution to the celebration of the fiftieth anniversary of the Universal Declaration of Human Rights. Lastly, after referring to the topics on the agenda of the meeting, Mr Mayor underlined the priority that was being given to the ethical mandate of UNESCO in all its fields of competence.

Mr Stephen Schwebel, President of the International Court of Justice, The Hague, recalled the contribution of the Court to the promotion of human rights. He stressed the crucial role played by the Court especially in inter-State disputes on human rights. He also pointed out that the Court had been requested by several organizations, among them UNESCO, to render opinions and recommendations on human rights.

Mrs Vigdís Finnbogadóttir, former President of the Republic of Iceland and Chairperson of the World Commission on the Ethics of Scientific Knowledge and Technology of UNESCO (COMEST), referred to the main topics to be dealt with by the COMEST at its first meeting: energy, fresh water resources and the information society. Recalling the coexistence of the COMEST and the IBC within UNESCO, she emphasised the importance of the reflection being carried out by these bodies in order to
develop an ethical framework and a system of values with which to face the challenges of scientific and technological progress.

Mrs Els Borst-Eilers rendered homage to the IBC as a focal point for the development of ethical reflection on a world-wide scale, in keeping with full respect for individual cultural sensitivities. The independence of the Committee’s members means that it can formulate opinions and recommendations that reflect the views of the international intellectual community. She also stressed the fact that the Universal Declaration on the Human Genome and on Human Rights, by encouraging scientific progress in keeping with respect for the rights of the individual, formed a rightful part of UNESCO’s goals. Finally, the Minister, mentioning the organization of the round table on industry, stressed the importance of fostering open debate on issues requiring ethical reflection such as gene therapy, cloning, embryo research, organ transplants and the theme of termination of human life.

The Chairperson of the International Bioethics Committee, Professor Ryuichi Ida, began by taking stock of the Committee’s work since its creation. He then drew attention to the fact that the IBC, which had now been endowed with Statutes, had entered a new stage, especially in regard to the implementation of the Universal Declaration and in its reflection on present and future questions of bioethics. In this respect, he drew attention to some issues such as transgenesis and xenotransplantation, genetic data banks in relation to the principle of confidentiality or, again, the latest advances in human reproduction.

The speeches made during this ceremony are reproduced in these Proceedings.

III. Bioethics and Women’s Rights

Within its framework of ethical reflection, the IBC has always taken account of the impact of progress in the sciences of the living on the status of women. Technological advances are opening up major prospects for improving the welfare and health of women. However, they could also give rise to new forms of discrimination and constraints.

At its Fourth Session in October 1996, the IBC organized a round table on the topic ‘Bioethics and Women’. Following this round table, and in the light of the need for a study on women’s health within the perspective of human rights and within the framework of bioethics, a working group was asked to prepare a report on this topic. The members of this group were:

- Dr (Mrs) Attiya Inayatullah (Pakistan), Chairperson
- Professor Lorraine Dennerstein (Australia), Rapporteur
The Working Group, which met in Paris in May 1997 to analyse the various sections of the report, prepared a draft report entitled ‘Women’s Health, Bioethics and Human Rights’ which was presented at the Fifth Session of the IBC by Dr Attiya Inayatullah (Pakistan), former Chairperson of the Executive Board of UNESCO and Chairperson of the International Planned Parenthood Federation, and Professor Lorraine Dennerstein (Australia), Director of the Key Centre for Women’s Health in Society, University of Melbourne.

Mrs Michèle Jean (Canada), Former Deputy Minister of Health, Special Advisor to the Canadian Minister of Foreign Affairs at the European Union, chaired the session on this topic. She opened the session by referring to the way in which women, during the last decades of the 20th century, have committed themselves to the liberation of body and mind. While recalling that the feminine condition and women’s rights are different from those of men in a very wide variety of fields, especially in health and reproduction, she pointed out that the task of the Working Group on ‘Women’s Health, Bioethics and Human Rights’ was to review the current situation and to contribute to shedding light on future prospects.

Mrs Inayatullah thanked the members of the Working Group for their contributions. She then presented the goals of the Working Group set up in 1996, and stressed the importance of the theme of study which had been chosen after careful reflection. In choosing the topic of ‘Women’s Health, Bioethics and Human Rights’, the IBC recognised that the feminine condition raises problems regardless of a woman’s place of residence, social status and culture.

Mrs Inayatullah pointed out that the Working Group had tried to draw up a list of possible avenues without losing sight of several requirements. It was necessary first of all not to repeat work already done on the same subject. Moreover, the reflection needed to be contained within the framework of human rights and bioethics.
At the end of its study, the Working Group had arrived at the following conclusions.

- The health experiences of women are different from those of men, at all ages and in all societies.
- Women’s health should be understood through an interdisciplinary and inter-sectoral approach. The life and health sciences, social sciences, education, law and economic sciences need to be associated in order to provide the benefit of maximum knowledge and reliable methodology.
- While women’s health appears to raise problems especially in the developing countries, the same observations can be made about the industrialised countries.
- Women’s reproductive health, far from being merely the absence of disease or infirmity, should be defined positively as a state of physical, mental and social well-being.

The report is organised into 10 chapters. Each one of them has been drafted more particularly by one of the members of the Working Group. In addition, five case studies on various subjects accompany certain chapters: their purpose is to illustrate the relevant chapter in order to focus on a particularly important aspect raised in the document or to place the chapter in question in a broader context. These five case studies are the following:

- Sex Selection in India (K. Kusum);
- Female Circumcision (Nahid F. Toubia);
- The South African Decentralised Education Programme in Advanced Midwifery (Christa Mary-Jones);
- Women as Victims of War (Berit Schei, Amira Frjjak, Mihr Pjshic and Monika Hauser);
- The Impact of Widowhood on Elderly Women’s Health and Well-being (Susan Feldman and Rosie Beaumont).

The report begins by placing the subject in perspective, in the context of the United Nations conferences and of the Commonwealth initiatives of the last decade, especially the eleventh Commonwealth Health Ministers Meeting in 1995, which discussed the topic of ‘Women and Health’.

Chapter 2 is based on a 1996 study by Murray and Lopez, *The Global Burden of Disease and Injury*, which is probably the most complete and ambitious attempt to study health and mortality levels in every region of the world.
Chapter 3 on ‘Infants, Children and Adolescents’ seeks to show how institutions influence the development of women and men unequally, from the very first years of the individual’s life. Three steps have been identified: early childhood (0-5 years), childhood (6-11 years) and adolescence (12-17 years). Two case studies broaden the scope of this chapter: one relates to sex selection in India and the other to female excision.

Chapter 4 begins by emphasising the influence of numerous cultural, social and medical factors on the reproductive health of women. In the absence of any international code in this field, the principles defined by the Women’s Voices Group in 1994 are used as terms of reference. Other references are constituted by the principles that emerged at the Fourth World Conference on Women in Beijing (Policy, Services and Quality of Care). The chapter then examines four questions: fertility and family planning; infertility and childlessness; motherhood, maternal mortality and morbidity; sexually transmitted diseases, including AIDS. This chapter also contains a case study on the Decentralised Education Programme in Advanced Midwifery in South Africa, which aims at the improvement of the health care available for women living in isolated areas.

The Working Group felt it appropriate to complete the report by examining four additional questions: men’s participation in reproductive health; family relations and gender roles, especially in North Africa; violence against girls and women, taking the example of South America; and occupational health. Each one of these questions is the subject of a chapter of the report.

The report concludes with Chapter 10 which deals more particularly with adolescents aged 10 to 19 throughout the world. The question of the right to reproduction is dealt with in this chapter under the international law of human rights.

Mrs Inayatullah concluded by stressing that the report is both realistic and optimistic. It contains reflection that is universal inasmuch as, in its report, the Working Group has tried to cover every region of the world; balanced in that it deals with the health of the woman throughout her lifetime; and relevant because it tries to chart pathways for the future.

Professor Lorraine Dennerstein (Australia), who co-ordinated the preparation of the various chapters of the report, presented the broad outlines of reflection of the report.
She first of all emphasized the need to deal with the issues of bioethics in taking account of the cultural and social context of countries concerned. Indeed, the case studies presented in the report on ‘Women’s Health, Bioethics and Human Rights’ could serve to place the general debates within a specific framework.

She then recalled that, in the field of women’s health, different forms of behaviour can be influenced by local conditions, political and religious factors, and human emotions, all at the same time. The report examines the influence of gender and gender-based inequalities in the field of health. However, gender is not the only factor to influence the health conditions of individuals: race, social class and poverty also play a decisive role. For example, women live longer than men in most countries with the exception of those where the female sex is under-valued. If life expectancy is a function of the level of development of a country, it may also vary according to ethnic origin: thus the Australian aborigines lives shorter lives than the other members of the population. Such inequalities deserve more thorough study.

One of the fundamental principles of bioethics is autonomy, namely the capacity of an individual to determine a destiny that is his own. However, the question is how to invoke such a principle for women who cannot make autonomous decisions on health and whose property rights are denied. Even when a law guarantees the autonomy of women, the exercise of this right is impossible if they do not have access to relevant and clear information on their health.

It must also be acknowledged that although the debates on the ethics of health have dealt extensively with the impact of new technologies, especially in the field of reproduction, nevertheless they do not consider the differentiated impact of these technologies on men and women. The use of these technologies can raise serious ethical issues insofar as it can even be an instrument of discrimination, as can be seen from the case study on gender selection.

Mrs Dennerstein then reviewed the various chapters of the report.

Chapter 1. Women’s Health: Context, Recent Recommendations by United Nations Conferences and Commonwealth Initiatives (Lorraine Dennerstein)

As mentioned by Mrs Inayatullah, Chapter I recalls the principles that emerged in the five United Nations conferences of these past ten years. It relates especially to the last three conferences held in Cairo, Copenhagen
and Beijing. In particular, the Fourth World Conference on Women in Beijing brought out five strategic goals:

- supporting lifelong access by women to health care and information;
- strengthening prevention programmes;
- supporting initiatives in favour of the female sex designed to resolve the problem of sexually transmitted diseases;
- promoting research and disseminating information on women’s health;
- increasing the necessary resources for monitoring women’s health.

In order to achieve these goals, it is necessary first of all to define the concept of ‘good practice’ as referred to by the Commonwealth Health Ministers Conference. This concept needs to be considered according to the following criteria.

- The issue of women’s health is not limited to the problems of reproduction but to the whole life cycle. The concept of women’s health covers specifically female diseases and disorders, those more commonly occurring in women or again those that are influenced by risk factors that are different for men and for women. Health needs to be apprehended within the broadest possible framework, both negatively and positively, and it is necessary to include the physical, mental, social and spiritual aspects.

- Women’s health is directly affected by socio-cultural, physical and psychological factors. Women have specific gender roles and responsibilities that directly affect their access to health care and their control of the resources allowing them access to this care (in terms of money, time, absence of violence, self-esteem, etc.). The diversity of feminine conditions (according to age, social class, religion, etc.) may lead to inequalities that adversely affect their health.

- Priority should be given to issues that have been identified as important by women themselves, especially women from the communities concerned and those who suffer discrimination in a given society. In the same way, information on projects designed to improve their health should be accessible to all women and must be provided in a way that is suited to different educational levels.

- An interdisciplinary and intersectoral approach is essential. This approach should involve the collaboration of specialists in various disciplines as well as representatives of States, non-governmental organizations and the private sector. The data on the projects must serve as a basis for the deliberations and work of governments, researchers and health professionals. There should be a sharing of experiences.
Chapter 2. **Women’s Health across the Life-Cycle** *(Penny Kane)*

According to a study by the United Nations Development Programme (UNDP), the annual number of infant female deaths exceeds the figure for male infants by one million. The case study on gender-based selection as well as the manifest worsening of attitudes of neglect towards girls elucidate these statistics.

The risk of death among women aged 15 to 44 is far greater than it is among men, especially in the developing countries. Tuberculosis is the leading cause of death among women aged 15 to 44 in the developing countries. Other factors, such as nutritional deficiencies and AIDS (even if it is mainly men who are the victims of this illness, apart from sub-Saharan Africa) are often associated with tuberculosis.

Suicide is another significant cause of death among women. In the same way, cultural practices may also be the cause of these deaths. This is the case, for example, with the Indian practice of *sati*, the self-immolation by fire of a deceased man’s wife.

Complications, related especially to childbirth, also represent the cause of death of almost half a million women each year throughout the world.

Chapter 3. **Infants, Children and Adolescents** *(Lucile Newman)*

In Chapter 3, the author reviews the questions of bioethics and human rights in relation to female children. Various discriminatory practices are examined: these may be gender-based selection in abortions, food habits and customs, or again negligence in the provision of health care to children (the refusal to nurse female infants to the benefit of male infants, for example). The life expectancy of girls is in fact directly linked to the value attached to the woman in society.

Even when the Constitution of a country guarantees education for all, girls have more limited access than boys to schooling. This discrimination in education has long-term consequences on the size of the family, the capacity of the women to gain access to health care for themselves and their families, the economic status of women and their autonomy in society. It is also recognised that education has consequences on demographic growth: there is a direct relationship of cause and effect between limited access to education and a high fertility rate. Conversely, the fertility rate drops if there is easy and widespread access for women to education.
Chapter 3 also examines various problems relating to the health of adolescent girls, with consequences that adversely affect the growth of the individual in society: these are malnutrition, sexual experimentation, pregnancies, early marriages and abortions, the risk of sexually-transmitted diseases, rape, etc. In addition, one problem of growing seriousness is nicotine addiction: a recent report made in the United Kingdom shows in this connection that cancers to which adolescent girls are exposed through smoking are more aggressive in nature than those affecting boys in the same age group.

Two case studies illustrate these chapters. The first examines gender-based selection in India: a study in 1984 in the city of Bombay has shown that, out of 8,000 abortions performed, 7,999 were on female foetuses. Gender determination has thus become a very lucrative business in India: a majority of the women who have such abortions come from the poorest social classes. The author of this case study shows that the legislation in force is not enough to remedy the problem of gender-based selection: what is needed particularly is a cultural change designed to enhance the role of women in Indian society.

The second case study concerns traditional practices in some societies: excision and the genital mutilation of girls. It is estimated that these practices - often based on the principle of the inequality of the sexes in social and sexual relations - affect approximately 130 million women and girls throughout the world, and that this figure is increasing each year by about two million. These practices have serious consequences on the reproductive health of women. The case study provides details of various types of sexual mutilation, their effects on morbidity and mortality as well as their implications in terms of human rights and ethics.

Chapter 4. Reproductive Health (Atiya Inayatullah)

The statistics which appear in this chapter show in particular that a large majority of female deaths in the developing countries are due to factors linked to reproduction. In Laos for example, the proportion is of 600 deaths out of 1,000. The impossibility for women to exercise the right to make their own decisions on sexuality and reproductive health affects 120 million people throughout the world. The number of abortions carried out under difficult conditions amounts to approximately 20 million a year. The chapter contains many other statistics on perinatal mortality, fertility, the weight of new-born infants, HIV infections, AIDS cases, sexually-transmitted diseases, sexual mutilation, etc. Information and access to family planning or methods guaranteeing healthy sexual relations would make it possible to effectively combat most of these problems.
One case study is on the South African Education Programmes in Advanced Midwifery. The purpose of this initiative in the Commonwealth countries is to improve the qualifications of midwives working in remote areas where the presence of doctors is rare. Its objective is thus to teach nurses how to resolve the problems that the female community might be confronted with. These midwives have also taken part in works of general utility such as the building of roads and bridges to alleviate the isolation of entire regions.

Chapter 5. Towards Men’s Participation in Reproductive Health (Roland Eddie Mhlanga)

The role of men in various issues related to women’s health has often been overlooked. However, it is of primary importance in the improvement of women’s health. The author believes that men need to be implicated in fields as diverse as those of access to contraception, the type of sexual relations practised, the protection of sexual relations, access to care and decision-making in health matters, access to education, violence against women, family planning and the education of children.

It is important to provide men with the information they need to assume their responsibilities in reproductive health.

Chapter 6. Family Relations and Gender Roles: The Example of North Africa (Laila El-Hamamsy)

The author examines health-related issues in the specific context of North Africa. She examines family relationships and the role of the male and female sexes in society, showing that there are major differences from one country to another. The Constitutions of the countries in the region proclaim equality in voting, education and employment. However, the majority of the laws on the family and the status of the individual do not conform to these constitutional principles.

In several countries, it is in fact cultural traditions that have the most decisive role in freedom of choice in reproduction. In particular, in societies where the family has a preponderant role in the life of the individual, as is the case in several African countries, efforts to improve women’s health and promote family planning must necessarily take account of the influence of the family environment on decision-making in the health and welfare of the individual.

The study shows that the average marriage age is tending to increase even if it is still low in rural communities and among less-educated women. Family planning services exist, but women often have no access to them.
or are not encouraged to use them. Again, the question of ownership rights can be a source of problems in the event of divorce or widowhood.

Chapter 7. Violence Against Girls And Women In Latin America (Genoveva Keyeux and Silvina Ramos)

Violence against women and girls is a problem in every country of the world and it persists despite the United Nations Declaration on the Elimination of Violence Against Women. It is of unquestionable importance in the developing countries.

It is estimated that a third of the women of Latin America are victims of sexual abuse, generally within the home itself, before reaching adult age. This abuse has serious consequences on the physical, sexual and mental health of these women. Violence against women includes sexual abuse, rape, incest, the lack of health care, violence in school and in the home, homicide, psychological abuse, forced prostitution, sexual harassment as well as the fact of women being prevented from having recourse to family planning services. It would appear that, in South America, this violence originates firstly in a marked separation between public action and the private sphere and, secondly, in a high threshold of social tolerance towards violence.

This chapter furthermore contains a case study of institutional violence in wartime Bosnia-Herzegovina. Women there were victims of systematic rape, ‘ethnic cleansing’ forced prostitution and the psychological, physical and social consequences of rape, torture and humiliation. For all these reasons, post-traumatic symptoms are frequent. The Vienna Declaration states that human rights violation against women in wartime constitutes a violation of the fundamental principles of the international law and of humanitarian law.

Chapter 8. Women’s Health in Mid-Life and Later Life (Margaret Baltic and Elisabeth Steinhagen-Thiessen)

Biological factors (menopause), psychological factors and social factors (access to resources) play a role in the quality of life of women in old age. The study shows how the attitudes of societies are negative towards elderly women.

These questions are examined in detail in the case study on the consequences of widowhood. The negative image of widowhood is common to many societies and cultures. A significant part of the population of elderly women is constituted by widows whose living conditions decline because of the poverty or ostracism of which they are the victims.
Chapter 9. Women and Occupational Health (Penny Kane)

This chapter examines the health of women in relation to their professional lives, in the industrial and private spheres as well as in rural life. The environmental risks at the workplace can have disproportionate consequences for the health of women because of their susceptibility to the toxic effects of certain chemicals. The author also studies questions of justice and equity, especially with regard to access by women to work.

Chapter 10. Duties to Implement Reproductive Rights: The Case of Adolescents (Rebecca Cook and Rika Pretorius)

The sexual exploitation of adolescents, which is examined in this last chapter of the report, is a major problem in certain countries. From the viewpoint of human rights, the duties towards adolescents are the following: to respect and protect the rights of adolescents, make governments accountable, list violations committed by States or permitted by discriminatory practices, find remedies to guarantee the reproductive rights of adolescents and even adults.

In conclusion, Mrs Dennerstein stressed the possible role of the International Bioethics Committee in developing an innovative approach to improving the feminine condition throughout the world.

How can bioethics contribute to improving women’s health? A pluridisciplinary and intersectoral approach is needed. It will bring together specialists from the health sciences, social sciences, education, exact sciences, law and economy.

Discussion

While recognising the quality of the information contained in the report on ‘Women’s Health, Bioethics and Human Rights’, the discussion underlined the idea that certain parts of the report deserved to be developed more thoroughly: this is the case for example with the differences in condition between Aboriginal and non-Aboriginal women in Australia. The section of the report dealing with the condition of marginalized women would thus be made more extensive.

The discussion also identified issues that should be added to the report before it is drafted in its final form. Two topics were then highlighted: the link between the conditions of women’s health and bioethics, and the question of the dissemination of the report.
Prostitution

Prostitution - which is one of the leading causes of the spread of sexually transmitted diseases, not only in Asia, but also in the countries of Eastern Europe East - has assumed such proportions that it is important for the report to give special attention to this issue.

A report by the International Labour Office (ILO) on the subject was indeed published in Spring 1998. Five Asian countries were studied in particular. It is striking to note that the authors of this report were unable to come up with any conclusions that might remedy this scourge. The reason for it is simple: prostitution is a significant part of the gross national product of these States and is thus assumed to be supported by Governments. Eradicating it will require special measures of financial solidarity.

The World Health Organization (WHO) will also publish a report on women and occupational health containing a case study on prostitution. It is perhaps desirable to include a case study of this kind in the IBC report.

The Religious Question

Religions can have considerable influence on the condition and status of women. However, it would seem to be more appropriate to remove all references to any particular religion in the report and rather to use the generic expression, 'religious and traditional beliefs'.

Recent Developments in the Industrialized Countries

All the case studies in the report are from the developing countries. It would be desirable also to have a case study relating to an industrialized country.

Three case studies were suggested. The first could relate to the theme of single-parent families, a model that is becoming widespread throughout the industrialized countries. The second could be on the age of first pregnancy in the Netherlands. Indeed, the average age at which a woman has her first child in the industrialized countries is tending to increase rapidly for complex reasons that need to be studied in detail. The third study could highlight the example of a woman who has been particularly distinguished in the scientific or medical fields.

Three observations were also made about the development of biotechnology in the industrialized countries. First of all, there is the question of whether women have a specific viewpoint on the use of new biotechnology? Secondly, it would seem that the impact of modern technologies on the fertility and sterility of women in the industrialized
countries has not been explored in sufficient depth by the rapporteurs. The social pressure is so strong, for example as regards in vitro fertilisation (IVF), that a woman for whom this technique fails could well be seen by society not only as sterile but also as someone incapable of making ‘proper use’ of modern technologies.

Thirdly, it seems necessary to reassert that scientific progress should not be used to promote the practice of choosing a child’s sex and other discriminatory practices, all the more so as certain diagnostic practices are geared towards an obviously lucrative purpose. In this respect, the Rapporteurs have specified that this point will be mentioned in the last chapter of the report which will deal with bioethics and the conditions of women’s health.

Bioethics and Women’s Rights

The debate provided an answer to the question: what is the ultimate aim of this work and how can it be attached to genetics and bioethics? The report shows that bioethics is not limited to the individual consequences of the application of modern science and technology, but also encompasses the problems raised by collective choices.

The final chapter which will place the question of women’s rights in the context of bioethics will be useful. It will make it possible, for example, clearly to give the lie to the opinion according to which male violence might be present in a male gene. It ought to be recalled, indeed, that violence does not have a genetic basis and that the problem is above all social and cultural. Another theme of this final chapter could be that of justice and of access to health care. It could be necessary to identify the principles of distributive justice in this field.

Finally, this chapter could contain quantitative data and summary tables enabling comparisons of the conditions of the different age groups. In addition, the rapporteurs should consider the question of the confidentiality of genetic information on the foetus and that of the status of the unborn child.

The Dissemination of the Report

The report, which will be published in English and French in UNESCO’s Ethics series, deserves to be very widely disseminated. This dissemination will most probably be facilitated by the simplicity of its vocabulary. Its publication will moreover contribute to the 50th Anniversary of the Universal Declaration of Human Rights.
Increased co-operation with other international, inter-governmental and non-governmental organizations, governments, health professionals, or researchers, will in all likelihood promote the dissemination of the report at various levels, especially among committed non-governmental organizations in the field, which would be best placed to sensitize the general public to the questions dealt with in the report.

It must also be recalled that UNESCO is now preparing the World Conference on Science which will be held in June 1999 in Budapest (Hungary). It will perhaps be timely to make the IBC’s work known to this Conference - especially its working group on women, science and technologies.

The Implementation of the Recommendations

Certain countries could co-operate by informing the Committee of the new tools available for assessing health programmes or effective policies for the protection of women’s rights. In this manner, the other States would benefit from specific examples which could be used as models for the implementation of the principles spelled out in the report. For the recommendations to be applied at the national level, political action will in any case be essential.

A thorough study of the rules of international law on women’s rights would be useful. At the legal level, the feminine condition is indeed highly variable. However, an effort to bring the laws into harmony with one another can be seen. It would be appropriate, however, to strengthen existing rules in this field, at the international level, and to obtain their application.

IV. Ethics and Preventive Medicine

Professor Michel Revel, Professor of Molecular Genetics at the Weizmann Institute of Sciences (Israel), chaired the meeting on ‘Ethics and Preventive Medicine’ in which many specialists, in particular IBC members, participated.

In his introduction, he said that bioethics and preventive medicine could not be dissociated from what Professor Jean Dausset has called predictive medicine. Indeed, the advances of genetics, especially within the framework of the Human Genome Project, are perhaps heralding a period in which medicine will not only be preventive but also predictive: the physician will be able to predict what happens to his patient with a definite degree of certainty. At present, a constantly increasing number of genetic tests are making it possible to plan a therapeutic or diagnostic
approach designed to make an early diagnosis or prevent a disease from developing. These tests may relate to known genetic diseases, as well as to multiple-factor illnesses such as cancer and, in future, to cardiovascular diseases.

However, it is important to take account in this field of the interaction between genetics and the environment. Indeed, even in the case of genetic tests indicating the presence of a predisposition to a disease, the penetrance of the gene in question is not necessarily total and the environment plays a fundamental role in this respect.

While prevention can be envisaged, especially for diseases of genetic origin for which there are specific treatments or lifestyles, in no case should screening be made compulsory for all diseases. It would therefore seem to be preferable to speak of the right of a person to decide if he/she can bear the idea of knowing that he/she is carrying a disease or, in the case of the antenatal diagnosis, is carrying a sick child.

Professor Revel spoke of the cost of certain diagnostic methods (the diagnosis of breast cancer, for example) and the financial responsibility of States in this respect. This high cost also warrants reflection on the question of equal access of all individuals to these methods.

Professor Adriano Bompiani (Italy), Professor of Gynaecology and former Chairperson of the Italian National Bioethics Committee, spoke of predictive genetic tests in paediatrics. In predictive medicine, the situations of risk in which an individual will find himself during his existence are determined at birth or even as early as conception. A current classification divides genetic tests into preclinical or presymptomatic tests and tests for the assessment of genetic susceptibility.

Preclinical or presymptomatic tests predict the many genetic diseases - in particular those of dominant autosomic type - which, while they are present at birth in the form of genetic anomalies, become clinically manifest later on, sometimes even at an advanced age. The result of the genetic test may make it possible to reduce morbidity and/or mortality if appropriate forms of secondary prevention or therapies are available. In paediatrics for example, a conventional example of presymptomatic tests is that of the phenylalanine-hydroxylase deficit. The tests enable the recognition of positive phenotypes at birth itself and ensure the prevention of cerebral damage through the administering of a low-phenylalanine diet.

The predictive tests for their part detect a situation of susceptibility to a disease, greater than that of the general population (for example, BRCA1 and the risk of breast cancers). The tests that measure susceptibility are
of indisputable biological value, but their large-scale implementation remains controversial at the present stage. Indeed, hopes for a truly predictive branch of medicine in this great chapter of human medical knowledge, capable of achieving effective prevention, prove to be less well-founded than was originally assumed.

From an ethical point of view, the prime justification for genetic testing in paediatrics should be the direct benefit to the child, both short-term and long-term, as decided by the parents or the doctor. The indications that enter this concept of utility are, for example, hypertrophied family cardiomyopathy, a disease associated with an increased risk of sudden death, which can be prevented by an anti-arrhythmic pharmacological therapy, or again, family hyperlipidemy which can benefit from appropriate dietary restrictions.

On the other hand, where effective preventive treatment does not exist, the use of predictive or even presymptomatic tests would appear to be debatable. Tests that reveal an increased susceptibility to tumours in children have proved, for example, to be useful in the presymptomatic diagnosis of retinoblastoma but are far less useful for other types of tumours.

The associations of patient’s families also underline the risk of a kind of genetic determinism that would further the stigmatising of individuals and discrimination against them. On the contrary, it is important to guarantee respect for differences between individuals and promote the integration of handicapped persons by providing them with suitable social support.

In conclusion, Professor Bompiani insisted on the need to enhance the doctor’s role at a time when there is a risk that molecular biology might override other fields of medicine. Genetic tests will play a major role in the medicine of the third millennium provided that they are correctly interpreted and explained to patients.

Professor Odile Cohen-Haguenauer (France), Co-ordinator of the Programme Regulation of Gene Therapy in Europe and Professor at the Saint Louis Hospital, Paris, first of all pointed out that even if research generates innovations and even if it raises new issues for doctors, the rules of medical ethics remain the same and must be followed. The doctor’s role is always to measure the risk/benefit ratio, but also to place medical progress in an ethical context, where it can be managed on a case-by-case basis. The patient should be considered not as an object of experimentation, but rather as an individual to be looked after.
Medical expert opinion is fundamental in the field of predictive testing. It makes it possible, instead of blindly applying genetic testing to entire populations, to define specific populations on which genetic tests will be made and for which therapeutic provisions will be considered.

Predictive medicine thus encourages reflection in three distinct dimensions:

- the aim of scientific and experimental research is to make knowledge go forward;
- the development of medical expert opinion should flow from the advances of scientific knowledge;
- the fields of application of predictive medicine must be clearly distinguished. In the case of a monogenic disease, for example, a positive test corresponds to a near certainty of the future onset of the disease. It is then advisable to adopt preventive measures. On the other hand, the detection of a mutation in the case of multigenic diseases does not result in certitudes. It is for the doctor to manage this risk: the question is which type of medical cover should be proposed for it.

It is important to stress the fact that medical practice must be the object of careful evaluation. Adopting principles of preventive medicine means ensuring the effectiveness of these principles in a field that is tolerable both for the patient and in economic and social terms. Indeed, the economic, social, psychological and moral consequences concern society as a whole and bring many actors into play: the patient, his close relations, health professionals, industrialists, lawyers, insurers and employers.

Professor Cohen-Haguenauer concluded her paper by underlining the need, especially in a field such as predictive and preventive medicine, of preserving a form of medical practice attuned to the needs of each specific individual and of creating large networks for the education, training and evaluation of medical practices and their adaptation to the development of scientific knowledge.

Professor Ricardo Cruz-Coke (Chile), Professor of Medicine and Clinical Genetics, presented a review of preventive medicine and medical genetics in Chile, which is presently one of Latin America’s most advanced countries in the field of medicine.

Although the country has attained very high levels in health conditions, there are still problems to be resolved, especially in the field of equitable access to health care. Chile’s epidemiological profile rather resembles
that of an industrialized country, but the arrival of new technologies continues to be confronted with that of a medical organization that is old and often insufficient in certain areas.

In the last two decades, genetics and ethics have been a major part of the training of Chilean doctors. In addition, a programme of bioethics has recently been launched within the framework of ‘post-diploma’ training. The departments of genetic medicine will continue to grow with the economic development of the country. The debates will undoubtedly concentrate on ethical questions, such as reproduction choices, a sphere in which the cultural, religious and political conceptions of Chilean society are very much present (the Chilean Medical Code, for example, prohibits abortion and embryo manipulation).

From an ethical point of view, Professor Cruz-Coke drew attention to the necessity of not translating genetic prevention into a form of eugenics. Eugenics denies human freedom, degrading the status of the human person while artificially elevating certain human characteristics. In this sense, genetic prevention should retain a voluntary character: a compulsory approach could perhaps reduce the number of births of sick children, but would run counter to respect for human dignity.

Professor Maurice S. Fox (United States of America), Lester Wolfe Professor of Molecular Biology, centred his talk on the utility of screening women for breast cancer. By the end of 1998, breast cancer had affected approximately 178,000 new female victims in the United States. Public opinion constantly hears it said that treatment can succeed provided that cancer is diagnosed sufficiently early, that treatment is becoming increasingly effective and that screening can ‘save lives’. It is therefore commonly accepted that women must undergo regular mammography examinations for the early detection of breast cancer.

In order for screening to be effective, the treatment must be effective too. If there is no such treatment, then the risk of arriving at falsely positive diagnoses - i.e. identifying individuals as ‘patients’ when, in fact, they are not - will result in an apparent improvement of the statistics of successes in the treatment in question. Since 1960, the statistics of breast cancer patients surviving 5 years would appear to have been precisely the object of such an error. Does the trend towards an increase in the survival rate result from more effective treatment or is there not an alternative explanation?
Epidemiologists regularly provide data on the incidence of breast cancer and the mortality rate associated with it according to age. While the US mortality rate has remained stable in the last 60 years, data on breast cancer for the same period shows a relatively stable incidence in the 1930s, 1940s and 1950s followed by an average increase of 2.8% during the 1960s. This increase has continued up to the present time, so that the incidence measured in 1994 is twice that of 1960.

Indeed, the fact that there is an observed increase in the incidence of breast cancer without any consequent increase in the mortality rate can lead to either of two assumptions. It is indeed possible that there was a spectacular increase in the incidence of the disease in the 1960s but that the treatments were effective and allowed the mortality rate to remain stable. On the other hand, it is also possible to imagine that increase in the frequency of the diagnosis of breast cancer, resulting from the great increase in the number of mammography check-ups in the 1960s, uncovered cases of predisposition that were not life-threatening and would not have previously warranted treatment.

So long as the question raised by the existence of these two concurrent assumptions has not been answered, generalised screening will be the subject of debate. On the one hand, the partisans of screening point out that the mortality rates are lower in the screened populations. But, on the other hand, it must not be forgotten that the mortality rate in the Eastern United States has remained stable for 60 years, namely during a period when screening has expanded, treatment is becoming increasingly effective and access to health care has become widespread.

Indeed, even if certain doctors feel that ductal carcinoma in situ (DICS) inevitably leads to clinical disease, several studies have shown that three quarters of the women having this symptom do not suffer from any clinical disease 15 or 20 years after the detection. In the same way, the presence of carcinoma of the breast amounts to 15% in autopsies of women aged 20 to 54. This is far superior to the theoretical cumulative result of the past 20 years.

In this respect, it can therefore be imagined that the increase in the incidence of breast cancer in the United States is the result of the development of screening which identifies situations that do not necessitate treatment. These patients are deemed to be breast cancer patients and undergo unnecessary treatment.
In conclusion, the question is whether routine screening for breast cancer is relevant from a medical point of view. Is such screening of any benefit to women?

Professor Hans Galjaard (The Netherlands), Professor of Human Genetics, drew attention to the fact that public decision-makers, such as the general public, are very often preoccupied by local health problems or the announcement of the development of new technologies, especially in reproduction and genetics. However, even if these scientific advances should not be overlooked, the debate on other aspects of the development of human genetics, which could entail major social implications, should not be concealed.

Medicine in the industrialized countries is currently developing at a very fast pace: diagnostic methods and genetic tests are likely to predict the health risks and the corresponding forms of treatment will very quickly be put into application. Examples of this development can be seen in the neonatal field or for breast cancers.

Gene mapping has provided much greater knowledge of diseases of all kinds. Predictive tests are already in use for breast cancers, for example: the risk of developing breast cancer is far greater among carriers of the BRCA1 mutations than in the general population. Another example is that of colorectal cancer: the risk of developing such a cancer is indeed 80% for individuals carrying an HNPC mutation. In such cases, regular coloscopy can be recommended, providing for the speedy detection of the tumour.

It remains difficult to answer the questions raised by these practices. Do these predictive tests have a limit? When and for what risk can it be agreed to carry out the tests? What is the aim of these tests? Can these tests be conducted also in the absence of all treatment?

The last question seems to have been answered already since predictive tests are often carried out for Huntington’s disease in a situation where there is no preventive treatment. In the Netherlands, 10% of potential patients chose to undergo a genetic test, in particular so as not to live in uncertainty. This also means that 90% of patients refuse to carry out this test because they do not want to know. It should be recalled that Article 5 of the Universal Declaration on the Human Genome and Human Rights recognises the right of individuals to be informed or not to be informed of the results of a genetic examination.
Even in a homogeneous population, the perception of the risks or severity of a disease are extremely varied. In a heterogeneous society then, the following question arises: who can assume the right to decide for the whole population? Would it not be preferable to educate individuals so that they can make autonomous and fully informed decisions?

In this case, how will future generations be able to preserve concern for the general interest? How are we to ensure the solidarity which alone can combat inequality? The fact is that concern for the general interest and solidarity are essential to educating individuals and giving them the means of making autonomous decisions.

Many social and ethical problems would be resolved if effective preventive measures were available. Nevertheless, although industry invests colossal sums in the development of new drugs and vaccines, this research is often oriented towards diseases specific to the industrialized countries, to the detriment of the rare diseases or the medical problems of the developing countries.

Professor Jens Reich (Germany), Professor of Genetics, for his part also felt that predictive diagnosis would undoubtedly become widespread in years to come, within the framework of individual medical treatment or with a view to methodical screening. Scientific progress, in this field, will make it possible to forecast a significant number of diseases at reasonable cost and on a large scale, before even the conception and birth of a human being, and a fortiori before the onset of the disease.

Prediction can be divided into two categories: prediction with 100% certainty and the prediction of a heightened risk affecting an individual or category of the population. It is also possible to distribute predictions according to illness: serious illness, benign illness, illness for which there is curative or preventive treatment, etc.

Ultimately, screening programmes for the whole population would become possible. This is leading, especially in Germany, to a reaction on the part of the public opinion which is opposed to all forms of official diktat related to genetics.

The question of antenatal diagnosis too is crucial insofar as abortion seems to eliminate the carrier of the disease rather than the disease itself. Many people emphasise the right of the embryo to be born; others feel that it is for the woman to decide whether or not she wishes to have a child. It is generally impossible to find a solution to the conflict between these two concepts of human rights.
Preimplantation diagnosis may be considered as an alternative practice although, in Germany, it appears to run counter to prevailing legislation on the embryo, which prohibits the creation of an embryo for purposes other than to cause a pregnancy. Whereas, in the case of abortion, there is ‘a conflict’ between the rights of two beings, the mother and the unborn child, in the case of preimplantation diagnosis, the selection of the embryo can be perceived as an act of aggression against the embryo, without an implication for the rights of the mother. Thus, even this solution raises ethical and cultural opposition.

In conclusion, Professor Reich stressed the need for genetic tests to remain an individual act. In any case, routine screening should be planned only if there are effective preventives measures in existence.

Lastly, Professor Huanming Yang (China), Professor of Genetics, placed the question of preventive medicine within the framework of Chinese social and cultural conceptions.

Health will probably be a crucial factor in the 21st century for China which is a developing country with the world’s largest population. The health professionals and the Chinese authorities have already made extensive contributions to the improvement of public health and the country will undoubtedly be one of the first beneficiaries of scientific advances in the field of human genetics and preventive medicine.

Professor Yang recalled that the concept of preventive medicine was not new and that it corresponds to the doctor’s wish to prevent illness rather than to cure it. Besides, this conception is central to traditional Chinese medicine. A Chinese proverb says that a good physician is able to cure illnesses; still better is he who treats his patients before the onset of the disease. Unlike predictive medicine, preventive medicine makes it possible to reach a precise goal. It also has the merit of showing that the predictive approach should not be initiated without direct benefit to the health of the individual or without the existence of preventive treatment.

The difference between the traditional idea of prevention and the new concept of preventive medicine lies in the use of genetic information. While modern preventive medicine is based primarily on genetic information, the use of this information should follow principles already recognised by the international instruments existing in the field such as the fundamental principle of the free and informed consent of the patient and that of respect for privacy.
Discussion

The discussion first of all highlighted the differences existing between countries as regards clinical practices. Whereas in countries like France, the confidentiality of genetic data is protected at an individual level, in other countries, respect for this confidentiality is subjected to the influence of the family circle on decision-making by the individual. Similarly, preventive surgery for gynaecological cancers is very rare in France and doctors prefer to propose complementary tests such as magnetic resonance imagery or ultrasound whereas in other countries, such as the Netherlands, the doctors have more extensive recourse to surgery as a form of prevention of these cancers.

Cultural differences, as much as the concept of medicine, can thus justify different medical practices. However, it would seem to be appropriate to define directive principles, at an international level, to be used as references common to all countries.

It seems, moreover, to be obvious that the application of new technologies to medicine, while it may give rise to new forms of discrimination, is undoubtedly an unequalled tool for the improvement of health.

In this sense, while these technologies may perhaps tend to increase the gap between the developing countries and the industrialized countries, the dissemination of new therapies will also tend to reduce its cost so that more significant numbers of individuals will be able to benefit from these new therapies.

Similarly, it was recalled that, in certain cases and beyond all expectations, antenatal and preimplantation diagnoses had resulted in an increase in the number of births. Before the existence of predictive tests, for example for Huntington’s disease, 50% of couples at risk did not wish to have a child. Since the tests have been in existence, 85% of the couples wish for a child.

In any case, it is advisable once again to stress the importance of the interaction of education and the environment in the expression of the human genome. The expression of the genes can never be considered to be uniform: in a field like preventive medicine, providing the patient with enlightened information and appropriate medical advice prove to be essential.
V. Follow-up of the Universal Declaration on the Human Genome and Human Rights

His Excellency Mr Héctor Gros Espiell, Professor of International Law, former Minister for External Relations, former President of the Inter-American Court of Human Rights, chaired the session on the follow-up of the Universal Declaration on the Human Genome and Human Rights.

In his opening speech, Mr Gros Espiell emphasising the moral commitment undertaken by the Member States when they had adopted the Declaration, pointed to the transparency of the IBC’s deliberations which had led to the drafting of the Declaration. He recalled that all nine versions of the document had been the subject of much consultation: advisory opinion had been obtained from international, governmental and non-governmental organizations, academies of science and medicine, law faculties, national ethics committees, patients’ associations, etc. The drafting of the Declaration had furthermore been based on a review of research into genetics and the applications of this research.

The Universal Declaration on the Human Genome and Human Rights is innovative in that it entrusts the IBC with a role in the monitoring of its implementation. It is, indeed, the first document of a declarative nature that stipulates the existence of a system of follow-up and implementation. Mr Gros Espiell recalled that the Declaration, in Section G pertaining to the ‘Implementation of the Declaration’ establishes the norms pertaining to the duties of the States (Art. 22 and 23), a provision on the deliberations of the IBC (Art. 24) and a final article, directly inspired by the Universal Declaration of Human Rights, on the interpretation of the Declaration.

The importance of the follow-up of the Declaration has furthermore been established through the adoption by the General Conference of UNESCO of Resolution 29 C/17 entitled ‘Implementation of the Universal Declaration on the Human Genome and Human Rights’.

In accordance with Article 24 of the Declaration and Article 2 of the Statutes of the IBC - adopted on 7 May 1998 by the Executive Board of UNESCO - it is for the IBC to contribute to the dissemination of the principles set out in the Declaration and to the further examination of issues raised by their applications and by the evolution of the technologies in question. It should organise appropriate consultation with parties concerned, such as vulnerable groups. In accordance with UNESCO’s statutory procedures, it should make recommendations addressed to the General Conference and give advice concerning the follow-up of the Declaration.
Article 11 of the IBC Statutes also sets up the Intergovernmental Committee, responsible for examining ‘advice and recommendations of the IBC, including those concerned with the follow-up of the Universal Declaration’.

Mr Gros Espiell also noted the importance, for the future development of international law, of the provision of laying down that the IBC and the Intergovernmental Committee will be able to hold joint meetings. These meetings will foster dialogue on questions of common interest, especially the examination of any proposal to amend the Universal Declaration on the Human Genome and Human Rights or to adopt any other Declaration or other international instrument falling within the fields of competence of the IBC.

In conclusion, Mr Gros Espiell recalled the action undertaken by UNESCO since the adoption of the Declaration, namely the dissemination of the Declaration, the promotion of the principles of the Declaration by education, training and information, the setting up of national ethics committees, and the collection of information on the measures taken by Member States to implement the principles set forth in the Declaration.

Discussion

The discussion emphasised four points corresponding to an equivalent number of initiatives to facilitate the dissemination and implementation of the Universal Declaration on the Human Genome and Human Rights.

Disseminating the Declaration at the Local and Regional Level

The Declaration should be distributed as widely as possible, at the local and regional levels. It must be pointed out that the Declaration and the Resolution of Implementation - translated into the six working languages of the Organization, as well as into German, Catalan, Korean, Greek, Hungarian, Italian, Polish and Serbo-Croat - have been extensively disseminated by UNESCO in the form of brochures and posters, with the governmental and non-governmental international organizations concerned, the National Commissions for UNESCO, the regional offices, the associated schools, the UNESCO Centres and Clubs and with press institutions. Similarly, the Declaration has been reproduced in a number of specialised journals and has been very widely distributed at international, regional and national meetings.
Strengthening Co-operation between the Various International Organizations

The United Nations has concerned itself with bioethics since the Teheran Conference on Human Rights in 1968. The United Nations Organization (UNO), as also the Human Rights Commission and the World Health Organization (WHO) have dealt with questions such as the development of genetics, organ transplants, artificial insemination, neonatal diagnosis, etc., in order to promote the development of ethical guidelines.

An increase in information exchange between the various international authorities would unquestionably be beneficial. Thus, the WHO representative suggested the institution of collaboration with UNESCO in the collection and dissemination of legal information in the field of bioethics.

It must also be recalled that, since then, the United Nations General Assembly, at its Fifth Meeting on 9 December 1998, adopted Resolution A/RES/53/152 on the ‘Human Genome and Human Rights’ endorsing the Universal Declaration on the Human Genome and Human Rights.

Finally, emphasis was placed on the importance of associating parliaments with the ethical debate, especially through collaboration with the Interparliamentary Union. In the same way, national ethics committees and similar national institutions should be special partners of the International Bioethics Committee.

Better Knowledge of Institutions Specialising in Ethical Questions

The development of institutions specialising in ethical issues is coming about in a twofold process.

Firstly, numerous committees are being created at the national level: in certain countries such as the United Kingdom, several ad hoc advisory committees have emerged while other countries have set up national committees.

Secondly, at the international and regional levels, there seems to be a trend towards the federation of these various national authorities. This trend could be seen for example in the Summit of National Bioethics Commissions in San Francisco (United States of America) and Tokyo (Japan), or in the standing Conference of European Ethics Committees which recently met in Oporto (Portugal).
It is therefore necessary to obtain greater knowledge of the typology of these new institutions at the international level and their linkages, both horizontally and vertically. UNESCO is unquestionably the authority best placed to undertake an initiative of this kind and establish a network between institutions concerned by ethical questions.

It should also be recalled that UNESCO is working to set up a data base on the ethics committees, councils and commissions and similar institutions throughout the world, by means of a questionnaire that has been sent to all Member States and to more than 1,000 universities and research centres.

Encouraging the Debate on New Technologies

Article 24 of the Universal Declaration on the Human Genome and Human Rights specifies that one of the IBC’s task will be to make recommendations on practices contrary to human dignity. The necessity of an open dialogue on all new technologies was highlighted in order to single out topics and avenues of reflection for the future. To do this, discussion fora, for example with the participation of the general public, could be set up.

VI. Ethics and Uses of Genetic Engineering in Industry

Mr Steven van Hoogstraten, Director of the Public Health Department of the Ministry of Health, Welfare and Sports of the Netherlands, presided over the round table on ‘Ethics and Uses of Genetic Engineering in Industry’. In his speech, Mr van Hoogstraten raised some questions relevant to the debate on the use of genetic engineering in industry:

• Should ethical considerations guide the progress of genetic engineering?
• Does ethics have to be defined by governments and expressed in laws?
• Should genetic engineering come under patenting systems or should it remain free in the market?
• What is the role of industry? Should it define its own principles of bioethics or should it simply follow its commercial interests?
• When will industry and government authorities be in a position to say that the ethical dilemmas have been sufficiently debated in such a way as to foster acceptance by the consumer?
• What is the place of the developing countries in the ethical debate? Are they regarded by the industries as mere fields of experiment or are they put on an equal footing with the industrialized countries?
To quote only some examples, the use of BST in the production of milk, which is permitted in the United States of America and Canada, came under a moratorium in the European Union, for reasons both economic (the overproduction of milk in Europe) and ethical (it was not a natural product). The consumer here is divided between a government decision and the standpoint of the scientists who assert that there is almost no risk for human beings. The genetic modification of agricultural produce such as soybean and maize raises even sharper debate.

On the question of patentability, the European Union recently adopted a directive on the legal protection of biotechnological inventions. Thus most patents, except for those concerning human beings, can be filed as is the case in other countries such as the United States, Canada and Japan. However, although backed by industry, this system does not have unanimous support. For example, the Dutch Parliament has opposed this European Directive, in particular because of ethical arguments based on animal rights.

The situation is different for the pharmaceutical products resulting from genetic engineering. At present, fifty drugs have been authorised in Europe and public opinion does not seem to oppose the manufacture of these drugs, provided that it means a clear improvement in health.

Mr Van Hoogstraten concluded his intervention by singling out the issues raised by the use of animal genes. In the Netherlands in particular, the production of transgenic animals is strictly regulated and is the subject of a wide-ranging debate.

Mr Yves Champey, President of the Rhône-Poulenc Rorer Foundation, referred to the specific role that the pharmaceutical firms will be called upon to play. Society has indeed turned towards these firms and asked them to provide the therapeutic resources that it needs. The fact is that few drugs have been developed and made available to prescribers by organizations other than private firms.

The pharmaceutical industry is bound by an obligation of means. Unlike other industries whose activities are primarily regulated by competition, it must ensure that the means adopted by it take account of the most recent scientific knowledge. Moreover, genetics have produced a mass of significant knowledge representing a primary source of inspiration and feeding the work of the pharmaceutical industry. This industry thus cannot fulfil its mission without making use of the new tools proposed by science.
From an ethical point of view, Mr Champey first of all emphasised the issue of patentability. Here, there are two opposing positions. On the one hand, the biotechnological industries believe that they are entitled to guarantee their ownership of their inventions. On the other hand, various cultural and religious sensitivities see the gene as a modern representation of the human soul and oppose any form of patentability. It must also be recalled that the framework of the law, by guaranteeing the ownership of the invention to the researcher, can prevent others from having access to the fruits of this invention.

Mr Champey then referred to the novel situations created by advances in genetics, that is, firstly the rise of genetic testing and, secondly, the new possibilities of therapeutic intervention.

Can a genetic test be proposed if no treatment is available? How are we to inform the mother of a foetus in which a genetic mutation has been identified? How is the family to be informed? How are those who do not wish to have the information to be protected? How are genetic data banks to be managed? Will insurers have access to this genetic information? Will employers be able to ask for the information?

Pharmacogenetics, for its part, will make it possible to have a precise spectrum of a person’s genotype and to make a precise forecast of the effectiveness of a drug. There is a risk that this new situation might create a new group of orphan diseases and orphaned patients who will be told by doctors that a drug cannot be administered in their case. There is another question about rare parasitic diseases. While it is true that it is now possible to envisage the treating of diseases as serious as malaria and sleeping sickness, the question is whether the pharmaceutical industry will give itself the means to use these genetic tools?

Through gene therapy - which enables the introduction, into target cells, of a corrector gene capable of producing protein normally - it will be possible to act in hitherto inaccessible situations (by carrying out in utero interventions for example). That also means that to propose gene therapy is to transform the responsibility of the physician and of industry into a responsibility for results.

Lastly, it is possible to consider a situation where genetics will commit doctors and industry to action at the borderline of the realm of health: genetics could be used, for example, for the preventive treatment of wrinkles, freckles, etc. In this case too, medicine would commit itself to a responsibility for results.
In conclusion, Mr Champey pointed out that the ethical debate is not restricted to industry alone. In modern medicine, both science and politics come into play, the latter in a form where it is strongly marked by the ethical reflection. Which is why it is importance that public decision-makers, for their part, should also be educated and informed.

Mr Robin Fears, Director, Science Policy Analysis, SmithKline Beecham Pharmaceuticals, spoke of the way in which recent activities of research and development had transformed his company.

While SmithKline Beecham does not wish to develop techniques of genetic diagnosis where there is no treatment, it does take an interest in the development of new categories of tests designed to provide a better understanding of individual responses to the administration of a drug. These tests will make it possible to increase the effectiveness of drugs, target categories of patients for whom such and such a product will be the most effective and avoid exposing other categories of patients to undesirable side effects. In the same way, the researchers of SmithKline Beecham are working on new proteins and on the identification of relevant targets in diseases like osteoporosis and atherosclerosis. They are also taking an interest in the identification of microbiological targets to improve the effectiveness of antibiotics, vaccines and drugs in order to treat malaria, hepatitis B and sexually transmitted diseases.

Mr Fears drew attention to two important aspects of the activity of pharmaceutical firms. Firstly, given that the pharmaceutical laboratories are naturally interested in the developing countries where the potential patients are numerous, the question is how to develop a coherent policy in countries where the problems of health are far more acute than in the industrialized countries. The majority of the products that have been developed in the industrialized countries are already being sold at very low prices in the developing countries. However, it is also necessary to foster research and development as well as marketing approaches suited to the conditions of these countries.

Secondly, it would be useful to reflect thoroughly on the establishment of mechanisms of partnership between the public sector and the private firms. The purpose of such partnerships would be to optimise the use and the effectiveness of the new drugs. SmithKline Beecham, for its part, is already co-operating with WHO, and collaboration with the Rockefeller Foundation is making it possible to set up partnerships with many research and development laboratories, especially in the United Kingdom.
Mr Fears finally recalled that the pharmaceutical industry has a role to play in promoting the public debate on bioethics. It can be the catalyst of debate and contribute to the education of public opinion. SmithKline Beecham, for example, has created a bioethical institution oriented towards public policy. This organization brings together outside experts who are specialists in medicine, ethics and genetics. Moreover, it is a member, in Europe, of the Europabio Association, which is a group of forty transnational corporations and fourteen national associations. One of its most recent tasks was to draw up a Core Ethical Values in the fields of bioethics, health care and the environment. A specific advisory working group has worked on biodiversity, the use of genetic information, biotechnology, gene therapy, the sharing of experiences between the developing countries and the industrialized countries, etc. The results of these discussions, which were widely disseminated, have also been used to initiate a constructive dialogue and debate with the employees of the company itself who themselves also need to be as well-informed as possible.

Mrs Penelope K. Manasco, Vice-President, Worldwide Clinical Genetics, Communications and Education, Glaxo Wellcome Inc., pointed out that genetics is related to both of the principal activities of the pharmaceutical industry, namely, the discovery and the development of new drugs.

In the long run, genetics will enable the definition, with greater precision, of the targets of the drugs developed. It must be known indeed that, out of 10,000 molecules discovered, only one has led to the manufacture of a new drug. A better understanding of biology and metabolisms will make it possible, firstly, to develop new drugs more efficiently and, secondly, to identify the patients and the diseases on whom these products will have the most effect.

The identification of targets will thus make it possible, no longer to just treat the disease, but to prevent it and thus significantly reduce death and morbidity rates: preventive medicine will thus flourish. In this field, Glaxo Wellcome has set up a partnership with universities to study gene susceptibility in the context of several diseases.

In the short run, the approach favoured by the pharmaceutical industry is the pharmacogenetic one. Public opinion rightly believes that industry should be concerned with the reactions of patients to drugs: some of them react favourably to a treatment, while others do not. Research in this field is directed towards determining the metabolic profiles of the patients.
These profiles indeed often explain why side effects from drugs occur in certain patients. A recent study published in the *Journal of the American Medical Association* has moreover shown that undesirable effects occupy an important place among the causes of death.

The goal of the studies conducted by Glaxo Wellcome in pharmacogenetics has been to comply with the same ethical standards as in the case of clinical trials. However, the new questions raised by genetics have led the company to educate the members of each of its subsidiaries and partner companies in the bioethical issues underlying the programme. Through collaboration with various ethics committees and institutions the world over, it has been possible to determine if the processes implemented correspond to the major ethical guidelines, and also follow the development of each country in the field of bioethics. Moreover, a permanent team in the company is responsible for studying the discussions taking place within international institutions like the IBC.

Similarly, special attention is being paid to education and information, especially as regards changes in diagnostic methods, the understanding of diseases and their treatment. Pharma and Glaxo Wellcome have, for example, organized a seminar for the staff of the US Food and Drug Administration to explain how recent progress in biotechnology is leading them to adapt their methods of developing new products.

In conclusion, Mrs Manasco recalled the four trends that can be identified for the future. Diseases will be defined according to their genetic characteristics and not according to their symptoms. Drugs will be suited to the treatment of each disease, through a precise definition of target groups of patients. The economic efficiency of industry and the therapeutic effectiveness of treatment will be optimised.

*Mrs Elizabeth McGregor*, Co-ordinator of the National Biotechnology Advisory Committee of the Canadian Ministry of Industry, gave an account of an initiative launched by the Canadian Government to set up links, in the field of bioethics, between governments, Members of Parliament, public opinion, researchers and industry.

The report of the Biotechnology Advisory Committee, entitled *Leading into the Next Millennium*, raises essential questions such as intellectual property, competitiveness in a context of globalization, infrastructures, etc. One of the chapters also makes an in-depth examination of the social and ethical implications of the new technologies.
The composition of the Biotechnology Advisory Committee is pluridisciplinary and moreover it has a team of young students associated with its work. They assisted the members of the Committee in the research needed to draft each of the chapters of the report *Leading into the Next Millennium*.

Awareness of the urgent need for a national debate on bioethics has led to an essential recommendation: a nation-wide consultation of citizens should be undertaken in order to work out an ethical framework that could be used as guide for future regulations.

The creation of an Internet site ([http://www.strategis.ic.gc.ca/biotechethics](http://www.strategis.ic.gc.ca/biotechethics)) designed to sensitize public opinion on ethical questions has seen collaboration between several categories of participants: members of the Medical Research Council, the Ministries of agriculture, health, industry and of the environment, representatives of industry, teachers, Members of Parliament as well as participants from universities (McGill University in particular).

Four pages of the site are of particular importance:

- a page providing a short introduction on the main issues in bioethics;
- a list of products derived from biotechnology that seek to improve the quality of life and the environment;
- a page on career profiles enabling students to be informed about positions available in industry, the research agencies and the public sector and to send their *curriculum vitae*; this page also enables firms to advertise vacant positions;
- links between the site of the Canadian Government and external Internet sites.

The site has three characteristic elements. Firstly, the science section provides information that can be easily understood after a simple introduction on the major issues of the bioethics. Links to other sites enable those who so wish to go more deeply into the subject. Secondly, the legal section gives special importance to case studies: in order to avoid burdening the site with numerous texts, links are directed towards sites indicating proposed legislation in the Canadian provinces and at the national level. Thirdly, the chapter on bioethics of the report *Leading into the Next Millennium* has been put on line. Furthermore, the many links to the sites of national ethics committees and associations of industries make it possible to initiate a new form of collaboration between local, national and international institutions.
To give priority to simple and accessible information, the core of the site consists of scenarios and practical case studies. With a view to clarification and simplification, ‘histories’ have been written down in order to underline the bioethical issues of a real situation.

Mrs McGregor concluded by referring to the possibility that collaboration between the Canadian Government and the IBC might be conducted in the form, firstly, of mutual links between respective Internet sites, and secondly of a forum enabling an exchange of opinions with the members of the Committee.

Mr Ewald Wermut, Secretary General of Product Board for Margarine, Fats and Oils (MVO), focused his speech on the introduction of transgenic soybean in Europe, by way of an example showing how the agro-food industry and society as a whole are confronted with technological innovations that are inspired by supply rather than by demand.

The question of the responsibility of the agro-food industry here arises more particularly with respect to consumers: every firm should promote adequate information at different levels on the new technologies.

Soya is a very important agricultural product, of which 50% in the world is produced in the United States of America. The other producer countries are mainly located in South America. Europe is completely dependent on imports and the Netherlands is the main port of access for these imports. In addition, it is estimated that 60% of foodstuffs comprise soybean-derived ingredients. This means that the introduction of transgenic soybean is a major innovation of capital importance for both the consumer and the agro-food industry.

In a socio-cultural context that is unfavourable to biotechnological innovations, like that of the European countries, the agro-food industry has made every effort, especially in the Netherlands, to foster public debate on the introduction of transgenic soybean.

The policy of the food industry is based on a case-by-case analysis. For each innovation, it is necessary to assess whether the public authorities will approve the innovation in question by an official authorisation; verify the safety of this new product by risk analyses, and study its possible advantages to consumers and industry.

Indeed, while marketing authorisation is essential for the agro-food industry, ‘authorisation’ by public opinion - represented by non-governmental organizations, environmental associations, consumer associations and the consumer himself - is also necessary. In the case of transgenic soybean, the food industry devised a plan to introduce it on the
market, while trying to explain why it was favourable to it. It then entered into an open and transparent dialogue in order to forge a consensus on transgenic soybean. However, it came up against many problems.

A first question arose with regard to the free and informed choice of the consumer. While there is a necessary obligation to inform the consumer, it is also true that the concept of free choice cannot be established per se for an agricultural product that is in fact the raw material for many foodstuffs. Moreover, industry has at its disposal a complete line of unmodified agricultural products and, at the same time, a complete line of genetically modified agricultural products. Is it legitimate then to put products on the market for which it is quite difficult to adhere to the concept of free and informed choice of the consumer?

There is one last question on the distribution of the advantages of these new technologies. Firstly, do industry and the consumer derive equal benefit from the introduction of modified agricultural products? It would seem that it is above all the great biotechnological transnational corporations that benefit from them in Europe. Public opinion has the impression that it is impossible for it to influence the choices of such firms. Secondly, the benefits for the consumer may be found in prices, product quality or health. In the case of soybean, the environmental benefits are predominant, but are located primarily in the producing countries, namely in the United States (the use of pesticides is less necessary and less developed). In addition, the large non-governmental organizations for the defence of the environment question these environmental benefits.

In his paper, Mr. Gerald M.A. van Beynum, Vice-President, Corporate Communications ans Strategy, Pharming Group N.V., pointed out that the activities of the pharmaceutical industry raise many ethical problems with regard not only to human beings but also other animal and plant species as well as to micro-organisms. A part of the activities undertaken by Pharming relate, indeed, to the treatment of the orphan diseases and to the production of human proteins out of animal milk. In other words, transgenic animal milk is being converted into pharmaceutical products.

Mr van Beynum then underlined the point that industry is conscious of the problems raised by the use of genetic engineering. The Dutch Association of Biotechnology and Industry (NIABA), for example, has set itself the goal of introducing biotechnology into the public debate and, more generally, into society. The reflection that may be developed therein is varied: it concerns the application of innovations in the sectors of food, health and environment, as well as the right to competition, property rights, competitiveness and, of course, the major ethical issues.
The NIABA co-operates especially with the Europabio association, which recently drafted a charter of bioethical principles in the fields of health, environment, information, the treatment of the animals, exchanges of information between countries, etc., while laying particular emphasis on the following principles: respect for existing ethical codes, the confidentiality of genetic information, informed consent by individuals, the utility of genetic counselling as well as the rejection of human cloning and germline therapy.

For its part, Pharming has developed its own code of conduct, which is included in the annual report of the Company and stipulates compliance with a certain number of ethical rules. The Company supports the principle according to which it uses animals solely for the purpose of improving the health of human beings. The health and welfare of the animals are closely monitored and care is taken to avoid undesirable side effects in the experiments. Moreover, compliance with the regulations of the countries in which it develops its activities is always guaranteed, even though these regulations differ from one country to another.

In conclusion, Mr van Beynum stressed that, in general, the biopharmaceutical industry was facing five ethical dilemmas that took the form of five requirements, namely:

- complying with the rules on the use of genetically modified animals (a new law will establish new rules on the import of genetically modified animals into the Netherlands);
- taking account of the cultural and ethical sensitivities of the different countries;
- implementing an open and transparent policy as well as partnerships, even if this transparency may appear to be dangerous in some cases;
- resolving the problem of the selection of the patients who will form part of the experimentation groups, to the detriment of those which will not benefit from the treatment;
- accepting possible failures.

Professor W. Kilama, Chairperson and Co-ordinator of the African Malaria Vaccine Testing Network, refocused the thinking of the round table in the light of the situation of the developing countries. How can genetic engineering be used in the developing countries? Are the ethical debates raising questions proper to these countries?
In the field of transmissible diseases, the role of genetic engineering is central, especially in the development of diagnoses, drugs and vaccines. The introduction of these new tools into the developing countries must nevertheless fit the context in which they will be used. These areas are often characterised by high levels of illiteracy and poverty and by the pre-eminence of traditional cultures and religious convictions. In addition, the diversity of the causes of diseases makes this environment even more complex. The clinical studies conducted in these regions will thus have to take account of these specific human, social, medical and cultural characteristics.

Indeed, it is no longer possible for a new drug, useful to the developing countries, to be developed entirely, from beginning to end, in the industrialized countries. It has to be tested in the local context. However, the political decision-makers are not always conscious of the ethical issues at stake in these trials and tend to give authorization, even when there are no in-depth studies.

Another question is that of informed consent. How can information be effective and how can consent be truly informed, especially in the case of products derived from genetic engineering, in countries that are torn apart by social and cultural conflict, and where education is not widespread?

Similarly, questions relating to the effectiveness and safety of clinical trials on a new drug may be overlooked. This is the case for example with the new vaccines, which must be compatible with the immunisation programmes in force in the countries considered.

In addition, the subjects who participate in clinical trials must be informed of the results of this research. In the same way, it would be appropriate to plan for new action among reference populations that have received only placebos. However, the populations that participate in research are sometimes overlooked and neglected and are not always the direct beneficiaries of the product tested.

Professor Muhammad Kamil Tadjudin, Professor of Biology, cited a traditional Indonesian food, *tempe*, in order to illustrate two aspects of the use of genetic engineering that relate more specifically to the developing countries.

Tempe is a flat cake made from soybean flour, and is a major source of protein in Indonesia (it is ‘the meat of the poor’). While it is true that the introduction of transgenic soybean into the market by the great transnational corporations can affect the production of the small Indonesian farm-holdings, still the fact of prohibiting it would result in an
increase in the price of tempe - which would thus become inaccessible to the majority of the population - and, in the long run, it would lead to an increase in the rate of malnutrition.

Another question raised by the use of genetic engineering is that of the patentability of organisms and of traditional methods of manufacture. Perhaps in such cases, legal protection should be envisaged not only for genetically modified organisms but also for organisms traditionally used by local producers. To quote only one example, the possible patenting of the yeasts utilised by the local producers of tempe would, once again, lead to an increase in the prices of this foodstuff.

Professor Tadjudin concluded by stressing the importance of respecting the rights and welfare of local populations into account.

**Discussion**

The discussion centred on certain points raised by the speakers at the round table.

**The Passage from Ethics to Law**

Science is progressing at a very fast pace and it does not appear certain that freezing ethical principles in the form of legislation is the best way of responding to different ethical questions. On the contrary, citizens and political representatives should be educated and informed so that they can take fully informed decisions for the future.

**The Role of the Transnational Corporations**

The debate provided for an in-depth discussion of the role of transnational corporations in this field. It is true that European industry is dependent on their innovations. It would be desirable then for an international authority to succeed in regulating these innovations by examining their ethical consequences, even if such an idea is quite probably utopian.

**The Concept of Informed Consent**

It was pointed out that, in general, pharmaceutical industries are increasingly providing the patients who undergo programmes of clinical studies with large numbers of written documents that clearly explain the full implications of these studies. However, while it is true that, on the ethical level, patients are entitled to know the aims of the studies, it is also true that this is not always possible, given their possible long-term implications. This is why firms try to carry out these studies within a strict framework of confidence and caution.
The Production of Drugs and Vaccines for Developing Countries

The production of drugs and vaccines for developing countries has occurred at two specific historical moments: in the colonial period and during the Vietnam war. This attests to the fact that the conditions of production of drugs and vaccines are related to specific social and historical conditions. Besides, it is more difficult to develop drugs against the parasitic diseases of the developing countries than drugs against the diseases of the industrialized countries. Indeed, the former need to act very swiftly in order to be effective, properly tolerated and inexpensive. Lastly, nothing will be possible if the problem of the solvency of the patients in the developing countries is not dealt with through international co-operation between the public research organizations and the industrialists.

VII. The Closing of the Fifth Session of the IBC

On behalf of the Dutch Government, Mr Bart Wijnberg, Head of the Division of Medical Ethics of the Ministry for Health, Welfare and Sports of the Netherlands, thanked the participants for having come to the Netherlands from all over the world, to take part in the Fifth Session of the IBC. Referring to the transparency that has always characterised the discussions within the IBC, he underlined, firstly, the independence of the experts who were members of the Committee and, secondly, the importance for the IBC to maintain contact with the general public.

Closing this Fifth Session, the Chairperson of the IBC reviewed the discussions on the topics on the agenda. He recalled especially that the Universal Declaration on the Human Genome and Human Rights is not an end in itself, but the starting point of the reflection being conducted by the IBC, especially as regards the follow-up of the Declaration. He then described the broad outlines of the IBC’s working programme: first of all, the setting up of a working group on the follow-up of the Declaration, presided over by His Excellency Mr Héctor Gros Espiell; then, the possible creation of a second working group, whose tasks will have to be defined on the basis of suggestions by the members of the IBC. Finally, he announced that in order to enable the members of the Committee to go more deeply into the topics for discussion, the Sixth Session of the IBC would be divided into two parts: as far as possible, there would be two sessions reserved for the IBC and two others open to the public.
Mr Ryuichi Ida concluded by emphasising the importance of co-operation with other institutions. As the only institution within the United Nations system to be working in the field of bioethics, the IBC should take account of the possibility of being at the core of a new international co-ordination between the various national committees and ethics commissions.
I. Introduction

1. In 1993, the Director-General of UNESCO created the International Bioethics Committee of UNESCO (IBC) to encourage the debate, at a world-wide level, on the ethical, social and human consequences of the rapid development of the life sciences. At its 27th session, by Resolution 27 C/5.15 (15 November 1993), the General Conference of UNESCO approved the establishment of the IBC. The IBC, the only international consultative body in the field of bioethics, gathered together approximately 50 well-known people from all regions of the world acting in their personal capacity. The transdisciplinary composition of the IBC enables it to deal with the diversity of issues that advances in research and their application in the field of the life sciences give rise to.

2. By the same resolution, the General Conference of UNESCO invited the Director-General:

   - to continue in 1994-1995 the preparation of an international instrument on the protection of the human genome and to report to it at its twenty-eighth session on the implementation of this resolution.

3. The Director-General therefore gave the IBC a task of primary importance - to make an exploratory study of the conditions for the drafting of an international instrument for the protection of the human genome. The Legal Commission, established within the IBC, was entrusted with the task of making suitable proposals on the form and content of the possible international instrument. The first draft, examined by the IBC at its second session resulted in the drafting of an Outline of a declaration (7 March 1995) based on universally recognized rights and freedoms.
4. On the basis of the Director-General’s Report, the General Conference, at its 28th session, invited the Director-General, by Resolution 28 C/2.2, 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 ...

(par 2).

5. To carry out this resolution and taking into account Decision 150 EX/8.3 of the Executive Board taken during its 150th session (14-31 October 1996), the Director-General invited the Member States to be represented in a meeting of the Committee of Governmental Experts for the finalization of a declaration on the subject, which was held at the Organization’s Headquarters from 22 to 25 July 1997. On the basis of the work of the International Bioethics Committee of UNESCO (IBC) carried out between 1993 and 1997, the Committee of Governmental Experts drew up and adopted, by acclamation, the text of the ‘Draft of a Universal Declaration on the Human Genome and Human Rights’, which was presented to the General Conference at its 29th session.

6. At its 29th session, when adopting, unanimously and by acclamation, the Universal Declaration on the Human Genome and Human Rights (29 C/Res. 16), the General Conference also adopted Resolution 29 C/17 entitled ‘Implementation of the Universal Declaration on the Human Genome and Human Rights’ that laid the foundation for the modalities of the follow-up of the implementation of the Declaration.

7. The Universal Declaration on the Human Genome and Human Rights aims at ensuring the development of human genetics on lines which will fully respect the dignity and human rights of the individual, and be of benefit to humanity as a whole. The progress of research in human genetics, which holds great promise for the health and welfare of humanity, might also be used for harmful purposes contrary to human dignity, human rights, or respect for the integrity of the human race. It is incumbent on the international community to guard humanity against such risks by proclaiming the principles whose universal observance will forestall any departure from them.

8. The Declaration recalls three essential principles which are fundamental to the protection of humanity as regards the implications of biology and genetics: human dignity, freedom of research and human solidarity.
9. It also reaffirms the need for a democratic debate on the progress of genetics so as to enable society to fulfil its responsibilities. From this point of view, it stresses the importance of international co-operation in furthering the dissemination of knowledge, and the advantages of promoting bioethics teaching.

10. As a guide to its implementation, the Declaration stipulates in Section G, entitled 'Implementation of the Declaration', that in subscribing to the principles set forth in the Declaration: ‘... States should make every effort to promote the principles set out in this Declaration and should, by means of all appropriate measures, promote their implementation’. It is therefore incumbent on States to identify the most appropriate measures for the promotion of these principles, whether through the setting of standards or the provision of incentives. By adopting the Declaration, States give solemn recognition to the importance of these principles with respect to the need to promote and protect human rights. In addition, the terms of the Declaration assign to the IBC, *inter alia*, the delicate task to ‘... make recommendations, in accordance with UNESCO’s statutory procedures, addressed to the General Conference and give advice concerning the follow-up of this Declaration’.

II. Ways in which UNESCO’s Standard-setting Instruments are Monitored

11. It is interesting to recall here that no declaration adopted by the Member States of UNESCO has yet led to the establishment of a monitoring mechanism. One particular case, however, needs mentioning - that of the Declaration on Race and Racial Prejudice, adopted by the General Conference on 27 November 1978. When adopting this Declaration, the General Conference, in Resolution 20 C/3/1.1/3, also invited the Director-General to prepare a comprehensive report on the world situation in the fields covered by the declaration on the basis of information supplied by Member States. In the same Resolution, the General Conference also invited the Director-General to submit to it any comments and recommendations deemed necessary to promote the implementation of the Declaration.

12. In general, the procedures for monitoring UNESCO standard-setting instruments or instruments drawn up under its aegis aim to:

   (i) inform States on the way in which the instruments are applied;
   
   (ii) encourage States to apply these instruments;
   
   (iii) ensure that they are correctly applied;
(iv) identify any obstacles to their implementation so as to establish whether measures need to be taken by UNESCO to help Member States overcome these difficulties.

13. These procedures are defined:
   (i) in the Constitution adopted by the General Conference at its fifth session (1950) (Articles IV, paragraph 4, and VIII);
   (ii) in the Rules regarding recommendations to Member States and international conventions laid down by Article IV, paragraph 4, of the Constitution, which sets out the procedure for presenting and considering reports from Member States under Articles IV and VIII of the Constitution;
   (iii) in UNESCO’s standard-setting instruments, some of which make provision for special mechanisms (conventions for the protection of cultural heritage, 1954 and 1972, regional conventions on the recognition of higher education studies, diplomas and degrees, etc.);
   (iv) in Resolution 15 C/12.2, adopted by the General Conference at its 15th Session, concerning the procedure enabling the application of standard-setting instruments to be monitored, and the resolutions adopted by the General Conference concerning the implementation of certain specific instruments.

14. The mechanisms for monitoring UNESCO instruments are of three kinds:
   (i) mechanisms for which provision is made in the Constitution;
   (ii) implementation mechanisms for which provision is made in conventions;
   (iii) implementation mechanisms for which provision is made in specific General Conference resolutions.

III. Follow-up of the Implementation of the Universal Declaration on the Human Genome and Human Rights

15. The follow-up of the implementation of the Universal Declaration on the Human Genome and Human Rights comes under the last category mentioned above. According to Resolution 29 C/17:

   The General Conference,
   ...
   1. Urges Member States:
(a) in the light of the provisions of the Universal Declaration on the Human Genome and Human Rights, to take appropriate steps, including where necessary the introduction of legislation or regulations, to promote the principles set forth in the Declaration, and to promote their implementation;

(b) to keep the Director-General regularly informed of all measures they have taken to implement the principles set forth in the Declaration;

2. Invites the Director-General:

   ...

(c) to prepare for the General Conference a global report on the situation world-wide in the fields relevant to the Declaration, on the basis of information supplied by the Member States and of other demonstrably trustworthy information gathered by whatever methods he may deem appropriate;

   ...

(e) to submit his global report to the General Conference, together with whatever general observations and recommendations may be deemed necessary in order to promote the implementation of the Declaration.

16. The follow up of the implementation of the Universal Declaration on the Human Genome and Human Rights is at two levels.

A. At the International Level

17. As indicated above, Article 24 of the Declaration deals with the procedure for its follow-up and stipulates that:

   The International Bioethics Committee of UNESCO should contribute to the dissemination of the principles set out in this Declaration and to the further examination of issues raised by their applications and by the evolution of the technologies in question. It should organize appropriate consultations with parties concerned, such as vulnerable groups. It should make recommendations, in accordance with UNESCO’s statutory procedures, addressed to the General Conference and give advice concerning the follow-up of this Declaration, in particular regarding the identification of practices that could be contrary to human dignity, such as germ-line interventions.

18. In this regard, it is for the IBC to play a role in following-up the implementation of the Declaration. With this objective, the functions of the
IBC are clearly laid down in Article 2 of its Statutes adopted, on 7 May 1998, by the Executive Board at its 154th session, which read as follows:

1. The Committee shall have the following functions:
   
   (a) it shall promote reflection on the ethical and legal issues raised by research in the life sciences and their applications, as well as encourage the exchange of ideas and information, particularly through education;
   
   (b) it shall encourage action to heighten awareness among the general public, specialized groups and public and private decision-makers involved in bioethics;
   
   (c) it shall co-operate with the international governmental and non-governmental organizations concerned by the issues raised in the field of bioethics as well as with the national and regional bioethics committees and similar bodies;
   
   (d) in accordance with Article 24 of the Universal Declaration on the Human Genome and Human Rights, hereafter referred to as ‘the Declaration’:
      
      (i) it shall contribute to the dissemination of the principles set out in the Declaration and to the further examination of issues raised by their applications and by the evolution of the technologies in question;
      
      (ii) it shall organize appropriate consultations with parties concerned, such as vulnerable groups;
      
      (iii) it shall make recommendations, in accordance with UNESCO’s statutory procedures, addressed to the General Conference and give advice concerning the follow-up of the Declaration, and it shall identify practices that could be contrary to human dignity.

19. In addition, Article 11 of the Statutes of the IBC establishes an Intergovernmental Committee. In the terms of this article:

1. An Intergovernmental Committee, hereafter referred to as ‘the Intergovernmental Committee’, is hereby established within the United Nations Educational, Scientific and Cultural Organization (UNESCO).

2. The Intergovernmental Committee shall examine the advice and recommendations of the IBC, including those concerned with the follow-up of the Universal Declaration. The Intergovernmental Committee shall inform the IBC of its opinions. It shall submit its opinions to the Director-General for transmission, together with the advice and recommendations of the IBC, to the Member States, the Executive Board and the General Conference. It may transmit any proposals for the follow-up of the advice and recommendations of the IBC.
3. The Intergovernmental Committee shall be composed of 36 representatives of the Member States elected by the General Conference. Associate Members of UNESCO shall be invited to participate. When electing the members of the Intergovernmental Committee, the General Conference shall take into account cultural diversity, balanced geographical representation and the need to ensure appropriate rotation.

7. Where the Intergovernmental Committee or the Director-General so decides, a Joint Session of the IBC and the Intergovernmental Committee, hereafter referred to as ‘the Joint Session’, shall be convened. The Joint Session shall foster dialogue between the IBC and the Intergovernmental Committee on matters of mutual concern. Without limiting the generality of such matters, they may include consideration of any proposals to:
   (a) amend the Universal Declaration on the Human Genome and Human Rights; or
   (b) adopt any further declaration or any other international instrument within the field of competence of the IBC.

20. At its 155th session, on 19 October 1998, the Executive Board of UNESCO elected the following 36 Member States as members of the Intergovernmental Committee:

   Australia, Bangladesh, Belarus, Benin, Cameroon, Canada, Chile, Congo, Côte d’Ivoire, Cuba, Dominican Republic, Egypt, Finland, France, Gabon, Germany, Ghana, Hungary, India, Indonesia, Iran (Islamic Republic of), Italy, Japan, Lebanon, Lithuania, Morocco, Mexico, Netherlands, Nigeria, Peru, Republic of Korea, Russian Federation, South Africa, Tunisia, United Kingdom and Venezuela.

   The Intergovernmental Committee will be renewed at the 30th session of the General Conference (October-November 1999).

21. In addition, the implementation of the Declaration will be followed up regularly by the community of Member States of UNESCO. Indeed, in accordance with the Statutes of the IBC, the Director-General is invited to present an overall report on the implementation of the Declaration at the General Conference of UNESCO.

B. At the National Level

22. At its 28th session, in November 1995, the General Conference stressed the importance of ethics committees by adopting Resolution 28 C/2.2 which invited 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’.

23. The Universal Declaration on the Human Genome and Human Rights foresees the creation of bodies for study and counsel which are capable of promoting the principles laid out in the Declaration. Article 16 of the Universal Declaration stipulates that: ‘States should recognize the value of promoting, at various levels, as appropriate, the establishment of independent, multidisciplinary and pluralist ethics committees to assess the ethical, legal and social issues raised by research on the human genome and its applications’.

24. Furthermore, in Article 23, in the context of the promotion of the principles set out in the Declaration, special emphasis is put on the need to ‘encourage exchanges and networks among independent ethics committees, ... to foster full collaboration’.

25. To give effect to the principles set out, and in addition to possible standard-setting action, the Universal Declaration on the Human Genome and Human Rights stresses the importance of undertaking measures which would heighten the awareness of individuals that life sciences do not in themselves guarantee social and human progress, though they are called on to contribute to it, and that this is a matter to be ensured by States.

26. Apart from the setting up of national bioethics committees, the implementation of the Declaration should be accompanied by actions for training and information. Under the terms of Articles 20 and 23 of the Declaration, States undertake to promote, inter alia, education in bioethics and research associated with it, and encourage training in interdisciplinary fields. In addition to the professionals concerned (for example biologists, doctors and jurists), education in bioethics is intended for each one of us and its purpose is to make bioethics an intrinsic component of general knowledge of the future. Bioethics, as a multidisciplinary approach to the relations between man and the life sciences, should include the necessary scientific and technological bases to make it possible to raise fundamental questions and promote an ethic of freedom and responsibility. Teaching should therefore be developed at all appropriate levels according to specific features of national education systems.

27. The choices that advances in biology and genetics call for necessarily relate to a concept of the individual and his or her rights and duties. Far from being a matter for experts, they involve genuine choices of society in which all members of the community should be involved. In
addition to bioethics teaching, States should support all research, information or training activities which can foster public debate on these issues. For example, it would be useful to encourage nationally, theses, conferences and publications on bioethics.

IV. UNESCO’s Action

28. The adoption of the Universal Declaration on the Human Genome and Human Rights, a moral commitment by States, is a starting point and not an end in itself. If the Declaration encourages the Member States of UNESCO to take steps that can put the Declaration into practice and thus ensure its continued existence, it entrusts to UNESCO the tasks that have been set out to support the action by States, as stipulated, in particular, in Article 19, paragraph b) of the Declaration, or in paragraph 2 of Resolution 29 C/17, UNESCO’s action appears in various fields.

A. Dissemination of the Universal Declaration on the Human Genome and Human Rights

29. Upon adoption, the Declaration and the Resolution 29 C/17 for the ‘Implementation of the Universal Declaration on the Human Genome and Human Rights’ were widely distributed. On 11 November 1997, the Director-General addressed them to the Secretary-General of the United Nations, Executive Heads of Specialized Agencies of the United Nations system, the United Nations High Commissioner for Human Rights, the United Nations High Commissioner for Refugees, the Rector of the United Nations University, members of the International Committee of Bioethics (IBC), thanking the latter for their valuable contribution to the drafting of the Declaration, and to all the Permanent Delegations. The Declaration and the Resolution for the implementation were also sent to intergovernmental and non-governmental organizations concerned.

30. In addition, the Universal Declaration on the Human Genome and Human Rights, accompanied by the Resolution for its implementation and preceded by a preface signed by the Director-General, was published as a brochure in the six working languages of the General Conference. More than 60,000 copies were sent to Permanent Delegations, National Commissions, Parliaments, ethics committees and similar institutes, academies and universities, ombudsmen and numerous specialists. The Declaration was also distributed to specialized agencies of the United Nations, numerous intergovernmental and non-governmental organizations, UNESCO Offices, Associated Schools and UNESCO Associations, Centres and Clubs. It was also reproduced in specialized reviews such as: The UNESCO Courier, Diogène, the Dictionnaire permanent de
bioéthique (France), Derecho y Genoma Humano (Spain), the Chilean Medical Review, several Catholic reviews, etc.. The Declaration, which has been mentioned in a number of periodicals such as the International Law Journal, the American Medical Association Journal, etc., has also been translated into Catalan, German and Polish, and the brochure is now also available in Greek and in Italian. The text of the Declaration has also been produced as a poster - in English, French and Spanish - and has been widely distributed.

B. Promotion of the Principles of the Declaration through Education, Training and Information

31. Again to encourage the dissemination of the principles laid out in the Declaration, various tools have been conceived and thus the text of the Declaration together with the Resolution for its implementation can be found on the Internet site (http://www.unesco.org/ethics). It should be noted that many of the numerous sites devoted to biology and genetics (universities, centres and specialised institutes, etc.) refer back to the UNESCO site. In the framework of Article 11 of the Declaration, a kit entitled No to Human Cloning was prepared in English and in French making a statement on the debate on the problem of human cloning, at both the international and national level. This aid to the dissemination of the principles of the Declaration has been widely distributed, in particular to the Permanent Delegations, the National Commissions for UNESCO and to more than 600 journalists. The first publication in UNESCO’s new Collection Ethics, entitled Ethics of Life, has been published in English and in French.

32. In the framework of the promotion of the ethical debate, UNESCO has participated or collaborated in a number of national and international events, in particular in Colombia, Ecuador, France, Hungary, India, Italy, and the United Arab Emirates.

33. For the promotion of education and training in bioethics, a UNESCO Chair of Bioethics was created at the Egerton University at Njoro, Kenya. With a view to the creation of similar Chairs negotiations are underway in Madrid (Spain) and in Oran (Algeria). It is of interest to note that in the framework of the UNESCO Chair at the University of Buenos Aires (Argentina) a meeting of bioethics specialists in Latin America took place on 6 and 7 November 1998. Also, still in the field of education, UNESCO’s assistance has been requested for the setting up of a pilot project for teaching bioethics in training schools for secondary-school teachers. Finally, UNESCO participated in teaching and lectures at university level in France, Lebanon and Spain.
C. National Ethics Committees

34. Society is now measuring the consequences of these advances which lie midway between hope and fear. The decision-makers, in both the public and the private sectors, are becoming increasingly aware of the potential impact of this new form of power. All over the world, they are realizing that there is a need for ethical reflection to accompany scientific research and foresee its applications. The world of scientific research now considers ethical reflection to be an integral part of the development of this field. Similarly, the consortiums of the pharmaceutical industry recognize the fact that ethics has become an essential factor in their strategies for development, and are readily setting up ethics committees.

35. UNESCO’s experience in this field has led it to emphasize the threefold vocation of national bioethics committees:

(i) First of all, they must carry out ethical reflection on progress in the life and health sciences, and must take account of the arguments that might be put forward by research workers and practitioners as well as the various demands made by society. This reflection, which goes together with scientific progress, must also look ahead to issues that may arise in the future.

(ii) It is then up to them to fulfill an advisory role. Indeed, ethical reflection leads to the formulation of directive principles drawing inspiration from universally recognized rights and freedoms, and detailed advisory opinions. In this way, bioethics committees will enlighten the legislator and, in general, public and private sector managers in the decision-making process. Furthermore, by defining rules of conduct, they may also guide research workers and practitioners in their actions.

(iii) Finally, national bioethics committees should foster education, training and information in this field for specialist groups as well as for the public at large. They must encourage a broad public debate, with the participation of scientists. Thus they will reinforce the process by which society as a whole as well as its members individually become aware of the responsibilities incumbent on them in the face of issues raised by research in biology, genetics and medicine and their applications. This action is indispensable in order to enable informed participation by all the actors in the choices that society will have to make in these fields.
36. The establishment of bioethics commissions, councils and committees unquestionably marks the rise of ethical reflection which is now at the centre of the social concerns of our age. In general, these bodies are established at four different levels. The following typology could be established:

- **at the local level**: a committee attached for example to a hospital, which is consulted about questions raised in connection with hospital practices;

- **at the institutional level**: an ethics research review board, connected for example to a research funding institution, which is expected to examine research protocols from an ethical point of view;

- **at the professional level**: an ethics committee attached to a professional association expected to examine, for example at the request of the medical association, issues related to medical ethics;

- **at the national level**: an ethics committee or commission, which gives its opinion or formulates recommendations on topics which have been submitted to it by various governmental bodies or by non-governmental organizations.

37. In the framework of the last category, there are several long-established national commissions, councils and committees. UNESCO encouraged the creation of many of them, in particular in Cameroon, Côte d'Ivoire, Cuba, Ecuador, Egypt, Estonia, India, Jordan, Lebanon, Poland, and Tunisia, to mention but a few.

38. The structure, organization and functioning of these committees may differ greatly. Some of them were set up by presidential or ministerial order, others by parliamentary decision. At times they were created following national conferences or on the initiative of non-governmental organizations or even private institutions. Sometimes, they come under a medical council or are attached to a para-governmental institution.

39. The characteristic common to all these committees is their consultative nature. They furnish advice and opinions to the institutions that approach them. Their standpoints, even when they are non-governmental committees, have a definite influence on government and parliamentary decision-making bodies. Very often, they are empowered to take up and examine issues that they consider likely to raise ethical questions.
40. It is the charters constituting these committees that set their composition and the modalities of their functioning. In most cases, their composition is multidisciplinary, ensuring that they include at least doctors, researchers, jurists and philosophers. Some of them provide for the participation of representatives of different currents of thought, religious beliefs and forms of spiritual sensibility while others have a place for representatives of civil society. The way in which their members are appointed varies to a very great extent. It is related to the composition of the committee which may be mixed (for example with one third of the members being appointed by parliamentary decision, one-third by a Medical Council and one-third by a Bar Association) or it may stipulate statutory consultations. It may be of interest to note that the Division of the Ethics of Science and Technology is presently creating a database of the existing national committees.

41. It is important to recall that several international institutions have declared their support for the creation of bioethics committees. Thus, on UNESCO’s initiative, the 93rd Inter-parliamentary Conference in March 1995, attended by parliamentarians from more than a hundred countries, adopted a resolution asking States to establish national committees in order ‘to monitor protection and respect for the dignity, freedom, identity and integrity of the individual in biomedical research’, if they so wish, in co-operation with UNESCO.

42. Similarly, the Conference of Heads of State and Government of the Organization of African Unity (OAU), at its 32nd ordinary session (Yaoundé, Cameroon, 8-10 July 1996), adopted Resolution AHG/Res. 254 (XXXII) on bioethics, in which it ‘pledges to set up consultative bodies at both country and inter-African levels to promote the exchange of experience obtained, among such bodies’.


44. More recently, the VIIth Iberian-American Summit of Heads of State and Government (at Isla Margarita, Venezuela, 7-9 November 1997) supported the creation of national ethics committees, depending on the context and needs of each country and in co-ordination with UNESCO.
V. Information Communicated by Member States Relative to the Implementation of the Universal Declaration on the Human Genome and Human Rights

45. By circular letter CL/3478 of 13 March 1998, the Director-General transmitted to the Member States of the Organization the text of the Universal Declaration on the Human Genome and Human Rights, together with Resolution 29 C/17 adopted for the implementation of the Declaration. Furthermore, the Director-General drew the attention of Member States in particular to paragraph 1(a) of this Resolution in which the General Conference urges them to take appropriate steps including where necessary the introduction of legislation or regulations, to promote the principles set forth in the Declaration, and to promote their implementation. In his letter, the Director-General invited Member States to inform him, no later than 30 June 1998, of the texts of any legislation or regulations already adopted, or in preparation in the fields of bioethics, in particular genetics and biotechnology.

46. By 15 October 1998, the Secretariat had received contributions from the following 23 Member States:

Austria, Benin, Colombia, Dominican Republic, Egypt, Ecuador, Estonia, Germany, Indonesia, Ireland, Iceland, Italy, Japan, Luxembourg, Mexico, Namibia, New Zealand, Niger, Norway, Poland, Portugal, Slovakia and the United Kingdom.

47. A letter was therefore sent, on 3 November 1998, to States which had not replied to the Director-General’s letter, to remind them that it was important that pertinent information be transmitted to the Secretariat. In fact, the Director-General’s Report to the General Conference will reflect all the information that he will have received.

48. A document, including elements of information communicated by Member States as well as other information already at hand in the Secretariat, is available.

VI. Conclusion

49. To give effect to the above orientations, in addition to an eventual action at the normative level, the Universal Declaration on the Human Genome and Human Rights underlines the importance of actions for education, training and information. These should help to strengthen individual awareness of the fact that life sciences do not in themselves guarantee social and human progress even if their vocation is to contribute to it.
50. The success of any strategy for the follow-up of the Declaration will depend mainly on the firm commitment by States to implement it and their ability to mobilize the resources needed. With this in view, the International Bioethics Committee of UNESCO, through the intermediary of its members, has a role of paramount importance to play to promote the principles laid out in the Declaration and to assure the pertinence and the effectiveness of any action undertaken to this effect. For example, the members of the IBC could be the relay for action taken by UNESCO in the States of which they are a national, and, if needed, counsel their national authorities on the steps likely to be taken in the framework of the implementation of the Declaration, in particular by way of legislative or regulatory measures taken in the field of bioethics.
Chapter 3

Speeches at the Fifth Session of the IBC

• **Mr Federico Mayor**,  
  Director-General of UNESCO

• **Mr Stephen M. Schwebel**,  
  President of the International Court of Justice, The Hague

• **H. Ex. Mrs Vigdís Finnbogadóttir**,  
  Former President of the Republic of Iceland  
  Chairperson of the World Commission on the Ethics of  
  Scientific Knowledge and Technology of UNESCO

• **Dr (Mrs) Els Borts-Eilers**,  
  Vice Prime Minister  
  Minister of Health, Welfare and Sport of the Netherlands

• **Presentation by Mr Ryuichi Ida**,  
  Chairperson of the IBC

• **H. Ex. Mr Héctor Gros Espiell**,  
  Former Ambassador of Uruguay in France  
  and to UNESCO

• **Closing Speech of Mr Ryuichi Ida**,  
  Chairperson of the IBC
I. Mr Federico Mayor,
Director-General of UNESCO

Your Majesty,
Madam Vice-Prime Minister,
Madam Chairperson of UNESCO’s World Commission on the Ethics of Scientific Knowledge and Technology of UNESCO,
Mr President of the International Court of Justice,
Mr Chairperson and Members of the International Bioethics Committee of UNESCO,
Excellencies,
Ladies and Gentlemen,

I wish, first and foremost, to thank the Government of the Kingdom of the Netherlands for their kind offer to hold this Fifth Session of the International Bioethics Committee of UNESCO here in Noordwijk. I would also like to express my gratitude to the newly elected Chairperson and the members of the IBC for having accepted the wide-ranging responsibilities that are theirs. Last but not least, I would like to express my appreciation to the experts and specialists attending this meeting in impressive numbers. Most have followed the work of UNESCO in the field of bioethics for several years now and that close involvement helps make bioethics a truly participatory process.

Just over a year ago, a landmark in the history of the Organization was made when the 186 Member States of UNESCO adopted, unanimously and by acclamation, the Universal Declaration on the Human Genome and Human Rights. It was historic because this text is the first instrument in its field within the United Nations system and represents a moral commitment of all Member States to adhere to a coherent set of ethical principles concerning genetics. It was historic because, for the first time, the international community fully recognised its responsibilities generated by the spectacular advances in the life sciences and their
applications. In an ethical stand that transcended religious, cultural and political differences, the human genome was proclaimed heritage of humanity. At the initiative of France, the Declaration on the Human Genome has been endorsed - also unanimously - by the UN General Assembly.

I believe that the Declaration on the Human Genome is one of the most significant contributions of UNESCO to the celebration of the 50th anniversary of the Universal Declaration of Human Rights. Indeed, it is firmly rooted in that great text, proclaimed by the United Nations on 10 December 1948. Its entire architecture rests on the concept of human dignity, a concept that blends the uniqueness of each individual with the fundamental unity of the human species. The authors of the Universal Declaration of Human Rights could scarcely have imagined, fifty years ago, today’s extraordinary unveiling of the secrets of the genes and their DNA. But they would have fully grasped the notion of the fundamental unity of all members of the human family beyond their genetic diversity. They would have rejected all genetic reductionism that attempts to define individuals by their genetic material.

In the spirit of the Universal Declaration of Human Rights, the Declaration on the human genome aims to protect all individuals or groups of people from any form of discrimination based on their genetic characteristics. This is of crucial importance in the face of a possible threat to individuals’ access to employment, or health and life insurance, or for that matter to education, on the basis of their genetic make-up.

The Declaration also sets limits to patents on human genetic material in its natural state. Both as a biochemist and as Director-General of UNESCO, this question has been one of my main concerns in the field of genetics for the last decade. How can anyone patent the mere description of genetic sequences or of DNA molecules? How can one patent the library of life or the words of the language of life? We have reached the point where we have to chose: either scientific knowledge becomes a commodity and will no longer be shared by all, or it remains part of our universal intellectual heritage for the benefit of all humanity.

UNESCO, I can assure you, will continue to promote the free exchange of knowledge, as its Constitution requires. In the same spirit, we will continue to promote international scientific co-operation between the countries of the North and of the South. Bridging the gap between those who are rich in research infrastructures and those who are not is a matter of utmost priority. This priority is highlighted in the Declaration.
There is today more than ever, a need to emphasise solidarity as an ethical imperative: solidarity between members of a nation, a community or a family; between those who are healthy and those who are affected by a disease or a disability. The text on the human genome makes this point clear. It also strikes an important balance between the protection of human rights and fundamental freedoms and the need to guarantee freedom of scientific research. It clearly states that practices which are contrary to human dignity, such as reproductive cloning of human beings, shall not be permitted. To pre-determine the characteristics of a distinct human being goes against the essence of each person and the endless diversity in every moment of each unique, evolving life, both in biological and socio-cultural terms.

If I have gone into the content and aims of the Declaration in such detail, it is not only because it is important to recall and publicise this landmark text. It is also because you - ladies and gentlemen of the IBC - have taken up the challenge of bringing the bioethical process forward to yet another stage. From the starting point of this Declaration and the high standard set by the five years of admirable work which went into its elaboration, you will aim for fresh goals. You will now broaden your reflections even further, pushing back the borders of the bioethical review process and working with an intergovernmental committee to ensure recommendations are followed by implementation.

The follow-up to the recommendations is what matters now. At this point, I wish to express my deep gratitude to all those who have contributed to the elaboration, drafting, approval and dissemination of the Declaration, at all levels, starting with Madam Noëlle Lenoir who chaired the IBC remarkably and is at present my advisor on bioethical issues.

The Executive Board of the Organization, in May of this year, adopted the Statutes of the IBC, since it had until then functioned on an ad hoc basis. The Statutes establish two bodies: the IBC, composed of thirty-six members designated by myself, who sit in their personal capacity, and an Intergovernmental Committee of thirty-six Member States, elected by the General Conference. As an interim measure, the Executive Board, in October last, proceeded with this election. The Intergovernmental Committee will examine the advice and recommendations of the IBC, including those concerned with the follow-up of the Universal Declaration, and inform the IBC of its opinions. Joint sessions of these two bodies will foster dialogue on matters of mutual concern. I intend to convene the Intergovernmental Committee in 1999, after the sixth session of the IBC, to be followed by a Joint Session of both bodies.
Your Majesty,
Ladies and Gentlemen,

This innovative mechanism is unprecedented. I am convinced that it will open a new and fruitful chapter in the bioethical review process. Indeed, successful models in this field may provide the international community with a formula that can be used to tackle many other issues. It was Martin Luther King who said we live in an age of ‘guided missiles and misguided men’. Too often, nations meet only in the aftermath of conflict or to attempt to resolve the consequences of other misguided actions. The international community struggles, for example, to agree on measures to reverse the trend of global warming and climate change, or ocean pollution and deforestation. But here, a small start is being made to a new process. One where people meet and nations meet to anticipate problems and to decide on the principles which should guide our actions from the outset.

It is the potentially life-changing powers of the science of genetics which first triggered this process. I believe that instead of the prospect of run-away, unchannelled genetic engineering, we are now beginning to see a new pattern emerge: a pattern of responsibility and accountability, where the power of science is harnessed by the power of ethics for the benefit of all, not just the few; for the benefit of future generations, not just for the short-term; for the benefit of all life on our planet, not just for humankind.

The International Bioethics Committee, with its renewed membership, is entering a new stage of its existence and faces new challenges. But as ever, its role of inspiration and guidance to Member States, and the international community as a whole, depends on the scientific rigor, the constant reference to the ethical dimension of the issues raised and the serenity of its debates. This is no easy task. The ethical issues raised by genetic engineering and other biomedical techniques are likely to become more acute as more and more potential applications are envisaged. But the quality and diversity of the Committee’s membership is a promise of its efficiency and its success.

The programme of this Session is an exciting one. New and important topics will be examined. ‘Bioethics and Women’s Rights’ places centre stage a set of issues which are raised by many of today’s scientific advances. Indeed, the new technologies stemming from the most recent advances in biology, genetics and embryology directly concern women, their health and their rights within the family and within society. I welcome
the report on Bioethics and Women’s Health, prepared by a distinguished international team of experts as a highly important contribution. It meets a commitment made by the Fourth World Conference on Women, held in Beijing in 1995: a commitment which has now been fulfilled by UNESCO. It places a special focus of the applications of biomedicine on the health and status of women.

Your debate on ‘Ethics and Preventive Medicine’ is also highly topical. Beyond any doubt, molecular biology and imaging technologies have opened up new avenues in the field of preventive medicine. At present, prevention is mainly limited to reproductive choices, often so difficult and painful to make that ‘choice’ is hardly the right word. But we are seeing the first encouraging examples of preventive medicine.

Friday’s Round-Table on the ‘Ethics and Uses of Genetic Engineering in Industry’ takes us to the heart of another area which arouses both promise and concern today. It is clear that the development of biotechnology and biomedical products cannot be driven solely by market forces or checked solely by consumer backlashes! The companies participating in this round-table will discuss the ethical criteria they use to guide them. They will also tackle the important issue of clinical trials, which pose technical and ethical questions, especially in developing countries, especially for developed ones. Another issue here is the cost of medication in countries that can hardly afford basic health care. The world is one or none. Lack of solidarity could result in the emergence or re-emergence of diseases which could have an unforeseeable effect. There is also great concern about the likely risks and benefits of genetically engineered crops.

The public at large is, quite legitimately, keenly interested in all these issues: after all, they pertain to people’s health and reproduction, to their food and environment. The public expects the scientific community and international organizations to respond to their concerns. The Universal Declaration on the Human Genome and Human Rights is a step in that direction, but it is by no means an end in itself. Rather, the Declaration is the beginning of a dynamic process that can only take place with the full involvement of the intellectual community and with the commitment of governments.

UNESCO expects its Member States to translate the principles which they have adopted into their national legislation and regulations. This is already under way in a number of countries, in particular in Eastern Europe, in Latin America and in Africa. It is an encouraging start. UNESCO has also been instrumental in encouraging Member States to
establish national ethics committees. We have to weave ethical structures into the fabric of the local, national and international communities. It is a matter of good governance.

The highest priority is being given in UNESCO’s Programme to its ethical mandate. As we prepare to enter a new century and new millennium, it is clear that the most important challenges ahead have a vital ethical dimension. Whether we look at issues of peace or poverty, the environment or scientific and technological progress, we see that we have to be guided by ethics and that requires innovative mechanisms and procedures. It also requires the dedication and vision of people like yourselves. A great deal is expected of you. For that reason, I thank you again for shouldering these responsibilities.

I wish to take this opportunity to thank Mrs Vigdis Finnbogadóttir once more for agreeing to chair the World Commission on the Ethics of Scientific Knowledge and Technology. This is another undertaking in which - I am sure - groundbreaking work will also be done and in which the equally high expectations of the international community and the public will also be met.

Your Majesty,
Ladies and Gentlemen,

In too many areas, present trends are not good. We need new departures in the economic, social, environmental, cultural and ethical spheres, to reduce the gap between the haves and the have-nots, to include the excluded, to reach the yet unreached, to prevent conflict at its very roots of poverty, isolation, ignorance. We need urgently to share better. We must dare to share! It is a matter of political will, of ethical resolve of a culture of peace. We cannot be guided by ‘market laws’. Democratic ideals, values and principles must guide us. Our common ethical horizon is particularly evident now, as we celebrate the Universal Declaration of Human Rights. UNESCO’s Constitution, fifty years ago, opened the windows of a brighter future: the intellectual and moral solidarity of humankind. The Committee that today is honoured with Your Majesty’s presence is one of the best expressions of this intellectual and moral solidarity, essential to accomplish our mission ‘to build peace in the minds of men’.
II. Mr Stephen M. Schwebel,  
President of the International Court of Justice, The Hague

Your Majesty,  
Mr Mayor,  
Dr Borst-Eilers,  
Mrs Finnbogadóttir,  
Ladies and Gentlemen,

On behalf of the International Court of Justice, permit me to join in welcoming the International Bioethics Committee of UNESCO to a country so long distinguished for its observance of human rights, a country in which the Court has had the good fortune to sit since its foundation. The Court follows with high interest the work of the International Bioethics Committee of UNESCO. That work bears significantly on the core of human rights, rights that are so profoundly linked to the ethics and nature of man.

Let me take this opportunity to speak briefly about salient contributions of the Court to the development of human rights.

The International Court of Justice is not a human rights court in the contemporary sense of that term. Under the Statute of the Court, only States may bring contentious cases before the Court. Intergovernmental organizations, non-governmental organizations, corporations and, most importantly, individuals may not be parties to contentious cases before the Court. This sharply limited access to the Court conforms to the traditional - one might say, outdated - concept that international law creates rights and obligations only among States. This was the generally accepted doctrine when, in 1920, the Statute of the Permanent Court of International Justice was drafted.

And yet it was the Court itself that broke with that doctrine, in a then revolutionary holding, in 1928. The Court’s predecessor, the Permanent Court of International Justice, found that treaties may create rights and obligations for individuals which are enforceable under international law. In other words, it acknowledged that individuals could also be subjects of international law.
The Court thus opened the gateway to the development of modern human rights law, at whose centre stands the individual. Modern human rights law found its first expression in the Universal Declaration of Human Rights, adopted fifty years ago. A series of human rights treaties followed which gave individuals the right of direct access to tribunals and other international fora.

While individuals still do not have direct access to the International Court of Justice, important issues of human rights have been brought before it. The Court plays a significant role in inter-State disputes on human rights, the more so when one recalls that only one inter-State case has ever gone to the European Court of Human Rights and none to the United Nations Commission on Human Rights. Even in inter-State cases which do not on their face deal with human rights issues, questions of international human rights law incidentally and significantly arise. Moreover, the Court may be requested by authorized international organs and agencies, among them UNESCO, to render advisory opinions. Several of these opinions have involved issues of human rights.

The Court’s involvement in human rights has a long history. After the redrawing of the frontiers at the end of First World War, the Permanent Court of International Justice was repeatedly asked to interpret the famous minorities treaties, a favoured instrument for the maintenance of human rights in that period. In so doing, the Court showed a profound insight into what was necessary for the protection of minorities. Its findings contained ideas that were to have a lasting importance in human rights law: for example, that the minority was entitled to equality not only in law, but also in fact; and that equality in fact might require different treatment in order to establish an equilibrium between different groups. This opinion was an early and incisive precursor of what today would be called ‘affirmative action’.

After the Second World War, respect for human rights was enshrined in the Charter of the United Nations. It became one of the principal purposes of the United Nations to achieve international co-operation in promoting respect for human rights and for fundamental freedoms for all without distinction as to race, sex, language, or religion.

The International Court of Justice has played a major role in the development of these human rights. For example, the Court found that apartheid was objectively illegal and that ‘to enforce distinctions, exclusions, restrictions and limitations exclusively based on grounds of race, colour, descent or national or ethnic origin [constitutes] a denial of
fundamental human rights [and] is a flagrant violation of the purposes and principles of the Charter’ (*ICJ Reports 1971*, p. 57).

It held that ‘wrongfully to deprive human beings of their freedom and to subject them to physical constraint in conditions of hardship is in itself manifestly incompatible with the principles of the Charter of the United Nations, as well as with the fundamental principles enunciated in the Universal Declaration of Human Rights’ (*ICJ Reports 1980*, p. 42).

The Court has further found that the rules concerning the basic rights of the human person are not matters exclusively subject to domestic jurisdiction, nor are they confined to bilateral relations between States. This finding is important; violation of fundamental human rights of its citizens by a State no longer is only an ‘internal affair’. All States have a legal interest in the protection of those rights and may lawfully protest their violation.

The Court has also contributed to the strengthening of the system of human rights monitoring and reporting by the United Nations. The UN Human Rights Commission appoints special rapporteurs who investigate and report on various human rights issues. The Court has held that such special rapporteurs were entitled to the privileges and immunities of a United Nations expert on mission. Such immunity enables them to exercise their - often delicate - official functions independently. Next week, the Court will hear oral argument in a case that will require it to consider new, further elements relating to such immunities.

Another pending case is perhaps the most significant human rights case ever brought before the Court. In that case, Bosnia and Herzegovina and Yugoslavia both allege that the other has promoted genocide, in breach of the Convention on the Prevention and Punishment of the Crime of Genocide, adopted by the United Nations General Assembly fifty years ago.

Genocide has been a recurrent concern before the Court. In 1951, the Court held that ‘the principles underlying the Convention are principles which are recognized by civilized nations as binding on States, even without any conventional obligation’.

More recently, the question of genocide came before the Court in connection with the request by the General Assembly for an advisory opinion on the legality of nuclear weapons. In its opinion, the Court emphasized that intent was a key element in the definition of genocide.
In the current case between Bosnia and Herzegovina and Yugoslavia, it will be necessary to address the question of genocide more directly and more thoroughly than ever before. It will be the first time that an international court will examine the responsibility of a State for genocide. At the same time, the International Criminal Tribunal for the former Yugoslavia, also situated in The Hague, continues with its determination of the criminal responsibility of individuals in that conflict, as similarly does the Tribunal for Rwanda.

In all, it is fair to say that the influence of the Court on the evolution of the international law of human rights has been considerable and constructive.
I would like to begin by thanking UNESCO for inviting me to say a few words to you at the opening of this learned gathering today. It is a privilege to be here and follow these discussions and deliberations on bioethics, dealing with an area of science which for most people still has a vague air of science fiction about it but which seems likely will become an integral part of our lives as the new century progresses.

I was recently invited to chair UNESCO’s World Commission on the Ethics of Scientific Knowledge and Technology which will address present and potential ethical problems in three areas: energy, fresh water and information technology. All of these are tall tasks for the scientific community and their outcome will have an impact on humankind as a whole. Since science and technology are parts of our society, their results reflect the generic social inequalities of the world we live in, over and above all the problems specific to each branch of science. The ethical issues raised by science will shape our attitudes and behaviour, our very relationship with the world around us.

Ethics can be simply defined as an attempt to evaluate choices from an essential human perspective. For most people today, energy in the form of electricity or petrol has become one of the basic necessities of life, but its use still involves choices or controversial decisions. For example, where is the balance between rights and obligations when an energy resource is utilized? Likewise, energy used in one place can affect the entire world, not just local users - which is the reason underlying the need for new ethics to address issues such as global warming. Even the choice of an energy source can involve complex choices. Fossil fuels pollute the global atmosphere but are relatively cheap; nuclear fuels pose risks on an unpredictable scale, but even pollution-free renewable resources such as hydropower entail sacrifices. In my country, Iceland, a fierce debate is going on today about whether the scarce resource of our pure and natural
highland landscapes should be sacrificed for hydropower development - to build an aluminium factory. Which is more precious and how do we quantify such value?

Fresh water is another problem addressed by the Commission, involving a resource which most of us take more or less for granted. There we face problems such as balancing the right to this prerequisite for life with the right of ownership - how to agree on preventing contamination or selfish exploitation of a shared basic resource. Access to fresh water has been increasingly identified as a major potential threat to world peace in the coming century.

Natural resources such as energy and fresh water are close to what the Greeks believed to be fundamentals of life itself, the archetypal elements of earth, air, fire and water. Their use affects human survival and aspirations towards material advancement and the quality of life, but developments in science and technology make the issues surrounding them more complex by the day. However, we should not allow scientific specialization, which is a product of the quest for knowledge, to leave those of us who are not scientists feeling disqualified to discuss these issues, since as human beings we are all affected by them and have a different set of values to contribute towards their development.

But within the past ten years or so a fifth archetypal element has been added to the human experience. I am referring of course to cyberspace, the new dimension which is omnipresent but also invisible and therefore calls for a different range of ethical responses. These include a new definition of literacy - an approach to the way that computer literacy or illiteracy will probably widen the gap between rich and poor even further. Another complex issue is access, not only to computer technology and the benefits it brings, but also access to computerized information, which calls for both technical and political safeguards against misuse.

The eighteen-man Commission on the Ethics of Scientific Knowledge and Technology has more or less been fully appointed and is scheduled to meet in Oslo on 28-30 April 1999. Working committees have been addressing the issues I have just mentioned, in order to feed the Commission with material for its deliberations. A report on energy has already been produced, another on fresh water is now being worked on and discussions on info-ethics are under way.

I often wonder and am often asked myself, what is the benefit of appointing these commissions and committees to discuss topics which it is often not popular to criticize. What does our work actually produce? Nothing immediately tangible, perhaps, since we cannot give orders
around the world and would not want to. But the important point is that we are talking about these subjects, making issues of them, striving to establish perspectives on them instead of blindly accepting or rejecting them for better or for worse. By trying to reflect on what is ethical in the decisions made by the powers-that-be, our discussions are an example of ethical behaviour. That is why I am ready to participate in all discussions - to learn and then convey to others as widely as I am able.

I was pleased to note that the World Commission on the Ethics of Scientific Knowledge and Technology shares offices at UNESCO Headquarters with the International Bioethics Committee because this symbolic cohabitation underlines the fact that we have more points of contact than might appear at first sight. In fact all questions of ethics in any branch of science and technology are environmental considerations, dealing with responses to man-made changes in the environment in the broadest sense of the term, from a variety of perspectives.

Biotechnology and the biological sciences however, clearly deal with something that is different from physical resources, such as fresh water. We are concerned here with the very essence and mechanics of life itself, and as scientists probe deeper towards the innermost secrets, they acquire the power, in effect, to alter the makeup of humankind. A whole new realm of ethical problems emerges which this conference is challenged and privileged to address and to begin presenting for decision-makers and laymen to consider as well.

Biotechnology perhaps imposes a greater responsibility on scientists than ever before. As their work extends into uncharted territory, we have to remind them of the supreme need to take the individual into account. Their subject is increasingly becoming the essence of the individual himself or herself, and they must avoid doing anything which could harm the individual or humankind as a whole.

In our wonder and delight at all that we are now finding out about the human makeup, we should not forget that these discoveries involve nothing more than the mechanism that nature itself has already developed. If anything, our admiration and reverence for nature will increase as biotechnology unravels its complexities.

Ladies and Gentlemen,

Earlier on I associated biotechnology with science fiction, but in another sense we see its principles stretching back to man’s very first attempts to understand his origins. Let us take, as an example, the account of the birth of humankind in old Norse mythology as retold by
Iceland's greatest medieval historian Snorri Sturluson. He describes how two wondrously beautiful trees floated onto a deserted shore where they were found by the gods who made them into man and woman. The gods gave them essentially human qualities, and in equal shares: spirit and life, understanding and power of movement, and form, speech, hearing and sight. Incidentally, we note with interest that the gods were not guilty of gender discrimination. The man was called Askr, meaning 'Ash tree', and the woman Embla, which probably mans 'Elm tree'. What is such a creation myth, I wonder, apart from an attempt to understand nature's own process of 'genetic engineering' which caused *homo sapiens* to evolve and distinguish himself from his environment?

Ancient myths, which seem so fascinating and charming to us today, are essentially attempts to explain, to acquire knowledge. Modern science is guided by precisely the same longing, different as both its methods and its results may be. The thirst for knowledge cannot be stopped or quenched. Knowledge is not evil in itself, only possibly some of the uses to which it can be put.

I mentioned before that we cannot issue orders; but we can put forward guidelines, present reasoned and humanistic arguments, and offer leadership. These contributions can be incorporated into agreements and policies about how to control the use or misuse of knowledge. We can lay down certain basic principles, for example that the search for knowledge must not damage the environment, and we also need to insist on some reliable way for laymen to weigh up the issues at stake in a highly complex field. Furthermore, since new knowledge is by its very nature unpredictable and therefore impossible to control in advance, above all, we need to develop a critical frame of mind and system of values which prepare us to judge each new issue as it evolves. Regulations however, must not, and probably cannot, stop progress from being made; they should simply channel new knowledge into the most beneficial fields for the individual, societies and the global community as a whole.

This then, distinguished ladies and gentlemen, is the enormous challenge that you face in the next few days and at all times in your work. Let us remember the words of the great English poet, John Donne that 'No man is an island entire of itself; every man is a piece of the continent, a part of the main'. There are no islands in bioethics, no isolated cases. The values that you work towards developing should be guided by the principle of universality. Science and technology will shape the future; your work will help to determine how the world can benefit the most from that future. I wish you all success in your deliberations.
IV. Dr (Mrs) Els Borts-Eilers,  
Vice-Prime Minister  
Minister of Health, Welfare and Sports of the Netherlands

Excellencies,  
Ladies and Gentlemen,  

Before the break, in the opening session, we all listened with great interest to Mr Mayor, Mr Schwebel and Mrs Finnbogadóttir. Their words represent a worthy beginning to this session of the International Bioethics Committee of UNESCO (IBC).

Her Majesty the Queen has already underlined the importance of this meeting by her presence. She also took the opportunity to speak to the chairman of the sessions and a number of other distinguished guests.

Ladies and Gentlemen, you are here as independent scientists, invited to be members of the IBC due to your impressive personal expertise. The challenge of the first IBC was to find its way in a sometimes difficult initial period. This IBC now begins a second period with a new composition and new rules, all established after intensive consultation.

Looking at your agenda for the coming days I see subjects which have had a place on the agenda of various international bodies over past years, including the World Health Organization and the Council of Europe, but never in so special a forum as this. This meeting has a unique make-up of participants - people from East and West, North and South, rich and poor countries - will talk on matters connected to universal human values with consequences for living standards everywhere.

The themes to be discussed are based on values valid across the globe, but their application will have to take place with full respect for all individual cultures. This makes your work extremely interesting and important. It also places heavy responsibility for formulating the values and priorities for the public debate firmly and squarely on your collective shoulders. Ladies and gentlemen, I hope you find it easier than it looks from here.
But precisely because you are all independent experts you will be able
to discuss the many subjects freely, you will be able to formulate your
opinions and make recommendations to the Member States without
restraint. And those recommendations will lead to real progress.

The establishment of the Universal Declaration on the Human
Genome and Human Rights showed just how difficult such a task can be.
Formulating the conditions under which research on the human genome
can be carried out was in no way simple. It is unexplored and uncertain
territory. And there must be optimal protection for individuals. I know that it
has all gone hand in hand with much discussion.

When one studies the Declaration one sees how far it seeks to
reconcile essential UNESCO objectives. They include promoting scientific
research, stimulating work to upgrade living conditions, anticipating
developments of the future, improving peoples’ health, but just as
importantly, respecting the rights of the individual.

At the same time, the Declaration also attempts to bring things within
reasonable bounds, to protect people from unbridled attempts to test
everything, and to study everything possible, as it were, to unravel the
past, present and future of man.

This last-mentioned prospect harbours fear for some. We are coming
to the point where everything seems possible, we can study more and
more, but is there a limit and where should it be set? What guarantee is
there to avoid giving the individual the feeling that he is simply a subject
on the table of scientific research, or to put it another way, a toy in the
hands of scientific researchers?

The answer in the Declaration is very clear. It shows the balance
between, on the one hand, revolutionary and promising research into all
that of which we yet know little, and, on the other, the conditions under
which such research should be allowed to proceed, and what rights and
responsibilities are reserved for the individual.

In doing so the Declaration lays a great claim on Member States to
give attention to all of these aspects in a balanced manner on the basis of
responsibility for the inhabitants of all States. No easy assignment, but
certainly one of honourable and weighty character. It is no exaggeration to
say the future of humankind is at stake. A great call will be made on
mutual solidarity and assistance.

The agenda includes the follow-up of the Declaration.
I do not know how you will approach this theme. I do know that much awaits to be done. So I hope that you are able to make good progress on implementation on the basis of sound discussion and joint effort.

But that will not happen in a day. Bearing in mind the state of development of research in the field of the human genome, I suspect this theme will continue to have a place on your agendas for the next few years. Progress will be gradual so that implementation will successfully take root. Herein lies an important task for our Member States. I appeal to them to give it their utmost attention. The Netherlands too will try to make its contribution!

Of the other points on the agenda may I single out the roundtable discussion on Friday morning. It is especially interesting in my eyes. I am very sorry I will be unable to attend as I have a Cabinet meeting at that moment.

I notice some disquiet amongst the public at large on the issue of current developments in genetic engineering and its place in the bio-industry, food preparation and processing and the pharmaceutical industry. I am pleased that this issue will be discussed from the perspective of the ethical aspects involved - how far should we go, what is responsible behaviour, what permission will be necessary, what should be the role of ethics review committees?

I am an advocate of an open debate on all issues which need careful ethical consideration.

Also in the Netherlands we are seeking to stimulate open debate on issues such as gene therapy, cloning, research with embryos, developments in the field of transplants, diagnostics, the theme of termination of human life. There was a recent discussion in our Parliament on some of these themes. It is difficult subject matter, but we must not side-step the debate, we have to continue to talk to each other.

In conclusion, as member of the Dutch Cabinet, I feel it is the task of my country to invest best efforts in promoting scientific research on the one hand, and to pay the utmost attention to the rights of the individual and promoting good health on the other.

And I am naturally delighted that the Netherlands has been able to make a constructive contribution to the establishment of the Declaration, and to the new working methods of the IBC.
Ladies and Gentlemen,

The issues which you will discuss are without exception all of great importance - for the practical challenge of getting along well with each other, for the way we value each other as people in our own individual cultures - and for the incorporation of scientific research in the rights of the individual.

I look forward with great interest to reading of your achievements these coming days.
V. Presentation by Mr Ryuichi Ida,
Chairperson of the IBC

Madam Minister,
Mr President of the International Court of Justice,
Your Excellencies,
Colleagues,
Ladies and Gentlemen,

We were honoured by the presence of the Queen of the Netherlands at the opening ceremony of the Fifth Session of the International Bioethics Committee.

On behalf of all the members of the Committee, I should like to begin by thanking the Government of the Netherlands for having invited the Committee to hold its Fifth Session in Noordwijk, this very pleasant place which offers all the facilities that will enable us to carry out our work successfully.

I should like, first of all, to introduce to all those present the members of the International Bioethics Committee, who have been appointed by the Director-General of UNESCO, Mr Federico Mayor, pursuant to Article 3 of the Statutes of the Committee. (The Chairperson introduces the members in alphabetical order.)

Some of them have sent apologies for absence, owing to circumstances beyond their control.

The International Bioethics Committee was established by Mr Federico Mayor in 1993, and chaired until 1997 by Ms Noëlle Lenoir, a member of the Constitutional Court of France. Having been set up to examine the major ethical issues raised by the achievements in the life and health sciences, particularly in genetics and biotechnology, the Committee is interdisciplinary and multicultural in character. Until the last session, it
comprised 55 members acting in a personal capacity, all of them eminent persons from all regions of the world and a variety of fields, including science, law, history, philosophy, politics and sociology. The Committee is the only body of the United Nations system to be engaged in ethical debate on biological and genetic research and their applications.

The present Committee is composed of 36 members, also appointed in a personal capacity by the Director-General. Its motto is twofold: continuity and innovation.

As is indicated by the title of this meeting, our work, which began five years ago, has a thread of continuity running through it. And continuity is again borne out by the fact that one of the main tasks of the Committee is the implementation of the Universal Declaration on the Human Genome and Human Rights, the first draft of which was produced by the Committee itself, and which the General Conference of UNESCO adopted just a year ago, in November 1997.

Innovation, because the Committee will function henceforward on the basis of Statutes and a composition of mostly new members. This innovative facet is also expressed by the parallel creation of the Intergovernmental Committee. It demonstrates the interest taken by the governments in following the discussions which take place in our Committee. The States are now conscious of and alerted to the bioethical issues which we, and humanity as a whole, have to face.

It is time for us briefly to take stock of the past work of the Committee, now that fresh responsibilities, even heavier than before, have devolved upon us.

Since its establishment, the IBC has been examining different subjects. At its second session, in 1994, it looked at the ethical and legal issues raised by genetic screening and testing, and gene therapy. At its third session, in 1995, the Committee dealt with genetic counselling and examined the problems posed by the neurosciences and research work on population genetics. At the fourth session of the IBC, in 1997, two reports were submitted which dealt with the ethical issues raised by access to experimental treatment, on the one hand, and by plant biotechnology and genetically modified foods, on the other. At each of its sessions, the Committee also took stock of the state of bioethical education worldwide.

At the same time, the Director-General had entrusted the Committee with the task of drafting a universal instrument on the human genome. The Director-General thought it necessary to establish universal guiding
principles, given that research on the human genome and its applications could lead to either happiness or unhappiness for each individual and for humanity as a whole. The development of genetics concerns the dignity and existence of the human person, over and above the life and death of the individual human being.

The Committee approved the first draft of a universal declaration after four years of deliberations carried out, in particular, in its Legal Commission which is chaired by His Excellency Mr Héctor Gros Espiell. The text was finalized by the Committee of Governmental Experts in July 1997. The Universal Declaration on the Human Genome and Human Rights was then adopted unanimously and by acclamation by the General Conference of UNESCO on 11 November 1997. Attention should be drawn to the fact that this year has witnessed the adoption by the United Nations General Assembly at its fifty-third session of a resolution by which the General Assembly ‘endorses’ the Universal Declaration of UNESCO.

The Declaration is based on the concept that human dignity and human rights have a universal and absolute value. Having adopted human dignity as its basis, the Declaration stipulates in its first article that the human genome is the heritage of humanity. Humanity is always at the heart of the action carried out by UNESCO, and is at the heart of reflection on bioethical issues, in particular. Moreover, as Article 2 stipulates, everyone has a right to respect for their dignity. Indeed, genetic diversity implies that each person is an individual in his or her own right.

Human rights are dealt with in the Declaration in three parts. First of all, everyone, with his or her genetic characteristics, is entitled to respect as an individual, and no one should be subjected to discrimination. The fundamental principle of non-discrimination is the cornerstone of the text. The second part concerns freedom of research. Freedom of research, it is true, underpins any human progress. Nonetheless, it is agreed that such freedom should be exercised without infringing on the other human rights. The third part concerns the protection of the persons who are the subject of research and its applications.

The States themselves are responsible, on the one hand, for supporting and fostering research on the human genome and, on the other, for evaluating and solving the ethical, legal and social issues raised by the development of the life sciences. The obvious conclusion to be drawn is that the principle of solidarity plays a crucial role in the protection of vulnerable persons by means of international co-operation.
All these points can be summarized in one phrase: the ideology of humanity. And because it is the ideology of humanity, the Declaration was not restricted to the framework of UNESCO, but was also endorsed by the United Nations General Assembly. The Declaration has thus become ‘universal’ in every sense of the word.

Today, the International Bioethics Committee embarks on a new stage. The scale of our task is even greater than before. Pursuant to Article 2 of the Statutes, our Committee should promote ‘reflection on the ethical and legal issues raised by research in the life sciences and their applications’, encourage ‘the exchange of ideas and information, particularly through education’ and ‘action to heighten awareness among the general public, specialized groups and public and private decision-makers involved in bioethics’. It should also co-operate ‘with the international governmental and non-governmental organizations concerned by the issues raised in the field of bioethics as well as with the national and regional bioethics committees and similar bodies’.

Pursuant to Article 24 of the Declaration and Article 2 of its Statutes, the IBC should contribute ‘to the dissemination of the principles set out in the Declaration and to the further examination of issues raised by their applications and by the evolution of the technologies in question’.

Starting from today, we shall examine a variety of current and future bioethical issues. Several subjects have already been put forward for debate at the ad hoc meeting of the representatives of States which was convened by the Director-General in March 1998: organ transplants in the light of the possibilities held out by genetics (transgenesis, xenotransplantation, etc.); genetic testing in the context of antenatal diagnosis; genetic work on plants and animals; the identification of practices that could be contrary to human dignity, such as germ-line interventions; genetic data-banks and the principle of confidentiality; and genetic applications in the pharmaceutical industry (the cost of medicines derived from genetic engineering, particularly in the developing countries).

The recent attempts to carry out clinical tests in the field of xenotransplantation - interspecific transplants of organs and grafting of tissues - have led the scientific community to envisage this technique as a possible solution to the shortage of organs. But this use which could be made of animal organs and tissues raises both technical and ethical questions.
The confidentiality of medical data is at the very heart of the doctor-patient relationship, and is also an imperative in the field of biomedical research. The advances made in computer science and knowledge of the human genome, and the specific character of genetic data, are leading to a rethinking of the boundaries of this confidentiality in respect of the individual, the family and society as a whole.

Discoveries made in the field of cellular biology, since March 1998, open up new vistas of both research and treatment, and raise novel ethical issues.

For instance, at the beginning of October, a team of American researchers at the University of New York announced that they had succeeded in transferring the nucleus from one ovocyte into another which had had its nucleus removed, prior to carrying out an *in vitro* fertilization. The development of this technique constitutes a new and important phase in the treatment of female infertility. Moreover, the new technique may not only alleviate certain cases of female infertility, but also prevent the communication of mitochondrial diseases. This new technique produces an ovocyte containing both the genetic heritage from the nucleus of the ovocyte of one woman and the mitochondrial genetic material from another.

In November 1998, a team of American researchers from the University of Wisconsin succeeded in isolating and carrying out the cell culture of undifferentiated embryonic human ‘stem cells’, which could produce the various tissues of which the human body is composed. Such a technique enables virtually unlimited cell division. Its possible therapeutic applications are far from negligible, especially in the area of cellular therapy.

More recently, another team of American researchers, from the Advanced Cell Technology Company of Massachusetts, successfully implanted the nucleus of an adult human cell into a cow ovum which had had its nucleus removed. The resulting cells are, in effect, hybrid bovine/human cells. Such undifferentiated cells can provide unlimited amounts of cells which can be cultivated *in vitro* to replace different types of human tissue.

This, in broad outline, is the framework for our reflections and discussions.

To conclude this talk, I should like to put forward an Eastern idea as the benchmark for our reflections. It is the idea of Harmony. Already, some 1,400 years ago in Japan, the first Japanese Constitution
proclaimed that harmony was to be accorded the greatest respect, and since that time harmony has formed the basis of world peace for Japan, as well as for humanity as a whole. In fact, we live in a society which is characterized by confrontation: confrontation between the light and the shadow of progress. Time and again, humanity has had to face situations in which progress scorned the concepts of human value and dignity because the idea of harmony had been forgotten. That is why the 1970 Universal Exhibition in Osaka revolved around ‘human progress based on harmony’. The best solution can be found, thanks to the idea of harmony. Bioethical issues should be examined and discussed in this context of harmony. In this way, our future and our happiness both depend entirely on these two ‘Hs’, namely, Humanity and Harmony.
Mr Chairperson of the International Bioethics Committee,

Ladies and Gentlemen,

I should like to begin by saying how much I appreciate the honour of being allowed to chair this meeting on the follow-up of the implementation of the Universal Declaration on the Human Genome and Human Rights.

To quote Mr Federico Mayor: 'The moral commitment entered into by States in adopting the Universal Declaration on the Human Genome and Human Rights is a starting point, the beginning of international awareness of the need for ethical issues to be addressed in science and technology. It is now up to States, through the measures they decide to adopt, to put the Declaration into practice and thus ensure its continued existence'.

I should like, first of all, to go back in time so as to remind those of us who are participating for the first time in a session of the IBC that, throughout the drafting of the Declaration, the Committee has always been careful to ensure that its work is fully accountable. Accordingly, numerous consultations took place on the nine drafts of the text which preceded the drawing up of the draft Declaration proper by the Member States of UNESCO. The various versions were enriched by the opinions and suggestions emanating from international governmental and non-governmental organizations, science and medical academies, law faculties, national ethics committees, the representatives of associations of patients and of relatives and friends of people suffering from genetic diseases, as well as from a variety of prominent individuals. The States were regularly informed of the results of these consultations, and they, in their turn, were asked to make comments.
I should also like to recall that, as the IBC had chosen such an interactive method, the Declaration was drawn up on the basis of an up-to-date evaluation of genetic research work and the applications of its results. As stated by the Chairperson of our Committee, at its annual sessions between 1993 and 1997, the IBC took stock of the ethical and legal aspects of the issues raised by genetic screening and testing, genetic counselling, gene therapy, population genetics, the neurosciences, access to experimental treatments and the development of plant biotechnology.

Those of us who were present in the International Bioethics Committee, during the work of drawing up the text, during the 29th session of the General Conference of UNESCO, and during the debates which took place before the Declaration was adopted unanimously and by acclamation, will remember the emphasis placed on the importance of the follow-up to the Declaration. That importance was officially endorsed by the General Conference’s adoption of Resolution 29 C/17, which is entitled ‘Implementation of the Universal Declaration on the Human Genome and Human Rights’ and which establishes the basis for follow-up action on the Declaration.

Ladies and Gentlemen,

As mentioned in Part II of the document prepared for this meeting, it can usefully be pointed out that to date, no declaration adopted by the Member States of UNESCO has resulted in the establishment of a follow-up mechanism, apart from the special case of the Declaration on Race and Racial Prejudice, adopted by the General Conference of UNESCO on 27 November 1978. So the Universal Declaration on the Human Genome and Human Rights is breaking new ground by entrusting the IBC with a role in the follow-up of the implementation of the Declaration.

It should be noted further that the Declaration is also the first declarative text in international law which provides for a follow-up and application mechanism. This particularity has great consequences, not only for the work of the IBC, but also for the development of international law. We must remember that the UNESCO Universal Declaration on the Human Genome and Human Rights, now endorsed by the United Nations General Assembly - which is itself an innovation with far-reaching consequences in international law - lays down in its Chapter G, under the heading ‘Implementation of the Declaration’, standards concerning the duties of States (Articles 22 and 23), contains a very complex provision on the work that the International Bioethics Committee of UNESCO should
carry out to implement the Declaration (Article 24), and includes a final Article 25 - which draws direct inspiration from the Universal Declaration of Human Rights - on the interpretation of the Declaration on the Human Genome. Article 25 has major consequences for the implementation and application of the Declaration.

Part III of our working document concerns the procedures of the follow-up of the implementation of the Declaration. Part III recalls, on the basis of Article 24 of the Declaration, that the IBC should contribute to the dissemination of the principles set out in the Declaration, and to the further examination of issues raised by their applications and by the evolution of the technologies in question. It should organize appropriate consultations with parties concerned, such as vulnerable groups, and should make recommendations, in accordance with UNESCO's statutory procedures, addressed to the General Conference, and give advice concerning the follow-up of the Declaration. In order to enable the IBC to carry out these objectives, its functions have been clearly established in Article 2 of its Statutes, adopted on 7 May 1998 by the Executive Board at its 154th session.

I should like to emphasize the fact that the new situation caused by the adoption of the Declaration has led to the widely-shared opinion that it is important that the results of the IBC's work be communicated to the States, especially when issues are at stake which may have legal, social, economic and political consequences at the national level. It will be the responsibility of the States, in addition to other obligations, to take the required steps in order to integrate bioethics in their national legislation and promote the principles set out in the Declaration. These considerations led the Executive Board to endorse the proposals of the ad hoc Working Group, comprising State representatives, which was convened by the Director-General under 29 C/Resolution 17, the text of which has been made available to you.

Thus, Article 11 of the Statutes of the IBC establishes the Intergovernmental Committee, a body in which the States shall be represented. According to paragraph 2 of Article 11: 'The Intergovernmental Committee shall examine the advice and recommendations of the IBC, including those concerned with the follow-up of the Universal Declaration. The Intergovernmental Committee shall inform the IBC of its opinions. It shall submit its opinions to the Director-General for transmission, together with the advice and recommendations of the IBC, to the Member States, the Executive Board and the General Conference. It may transmit any proposals for the follow-up of the advice and recommendations of the IBC'.
As paragraph 7 of Article 11 stipulates, where the Director-General of UNESCO or the Intergovernmental Committee so decides, the IBC and the Intergovernmental Committee shall be convened to hold Joint Sessions in order to foster dialogue between the IBC and the Intergovernmental Committee on matters of mutual concern, including consideration of any proposals to: ‘(a) amend the Universal Declaration on the Human Genome and Human Rights’ or ‘(b) adopt any further declaration or any other international instrument within the field of competence of the IBC’. I should like to draw attention to the importance of this paragraph 7(b) for the future development of international law in areas concerning the human genome.

Parts IV and V of the document made available to you deal with the actions undertaken by UNESCO within the framework of the tasks entrusted to it under paragraph (b) of Article 19 of the Declaration and paragraph 2 of Resolution 29 C/17. UNESCO has been active in several areas: the dissemination of the Declaration, the promotion of the principles set out in it through education, training and information, the setting up of the national ethics committees and, lastly, the gathering of information on the steps taken by the Member States of the Organization with a view to implementing the principles set out in the Declaration. The result of this latter action is reflected in the annex to the document which refers to the replies of the States to a correspondence addressed to them by the Director-General.

Mr Chairperson,
Ladies and Gentlemen,

To conclude, I think I speak for all of you when I say that the implementation of the Declaration should, like its preparation, be conducive to the development of international law and the pursuit of democratic dialogue on the progress of genetics, among us and with all the participants involved, so that society can exercise its responsibilities to the full. One cannot overemphasize the fact that the Universal Declaration on the Human Genome and Human Rights is not an end in itself, but the starting-point of international legal awareness of the need for ethical issues to be addressed in science and technology.
Your Excellencies,
Colleagues,
Ladies and Gentlemen,

The Fifth Session of the International Bioethics Committee is drawing to a close.

Over the past three days, we have held an intense and extremely stimulating debate on a variety of bioethical subjects.

At the opening ceremony, we were honoured by the presence of Her Majesty, the Queen of the Netherlands. The presence of Her Majesty and the interviews which she granted to us deeply convinced us of her interest and concern for various bioethical issues.

As I said in my introductory remarks, today's society is one of adversarial debate, and this basic characteristic was clearly apparent at each of our meetings.

Before the official opening of the session, the exchanges of views between the members of the new International Bioethics Committee, meeting as a select committee, revealed the scope and complexity of our task.

At the beginning of the opening ceremony, the Deputy Prime Minister and Minister of Health, Welfare and Sport, Dr Els Borst-Eilers, emphasized the fundamental importance of bioethics in the life of present and future humanity. The addresses given by the Director-General of UNESCO, Mr Federico Mayor, and the President of the International Court of Justice, Mr Stephen Schwebel, and in particular, those of Her Excellency
President Vigdís Finnbogadóttir and Mrs Borst-Eilers, gave us renewed and heightened understanding of our duty and responsibility to promote scientific progress, particularly with respect to the further development of genetics, with a balance being maintained between the latter and human dignity and the absolute value of the rights of the human person.

The meeting chaired by Mrs Michèle Jean, former Deputy Minister of Health of Canada and a new member of the Committee, showed us the extent to which the status of women should be improved and even, if I may say so, ‘normalized’. The report submitted by Dr Attiya Inayatullah and Mrs Lorraine Dennerstein touched us deeply and reminded us of the scale of the problem. We must warmly commend the efforts of all the members of the working group on ‘Women’s Health, Bioethics and Human Rights’, who began work on the subject in October 1996. The report mentions, although in an indirect way, the rights of children at birth or even those who died before birth. I must say that the report and the efforts of the working group encourage us, men and women, to fight for the dignity of women, or else forfeit the right to pronounce the words ‘human dignity’. The comprehensive and concrete report was largely devoted to the comparative study of the different issues involved, and it includes the concept of diversity, one of the fundamental aspects of our broad subject of deliberation, namely, bioethics.

The meeting on ethics and preventive medicine, chaired by Professor Michel Revel, revealed the light and shade of preventive medicine to us. Professor Bompiani, Mrs Cohen-Haguenauer, Professor Cruz-Coke, Professor Fox, Professor Galjaard, Professor Reich and Professor Yang — each of these seven rapporteurs emphasized that it was incumbent on us to investigate the usefulness and efficacy of advanced biotechnology and genetic engineering, and to devote more thought to the doctor-patient relationship and to numerous other aspects of bioethics in the context of human rights. In particular, to the question of the confidentiality of genetic data and that of the right to know or not to know, which constitute fundamental aspects of the Universal Declaration on the Human Genome and Human Rights.

His Excellency Mr Héctor Gros Espiell gave us a clear outline of the principal issues involved in the follow-up of the Universal Declaration; he is, if I may say so, ‘the originator’ of our Declaration. The adoption of the Declaration by the General Conference of UNESCO is not an end in itself, but the point of departure for our debate on the behaviour of the researchers, patients and other persons concerned - in short, on the behaviour of each of us. As a result, the discussion of the follow-up is a
crucial and urgent issue for the future of humanity. The opinions expressed both by members of the Committee and the audience should be taken into consideration so that they can be included in our work programme.

The round table dealt with the delicate issue of ethics in the context of the use of genetic engineering in industry. Different opinions were expressed by the representatives of different pharmaceutical and food businesses. I should like to thank Mrs Penelope Manasco, Mrs Elizabeth McGregor, Mr Yves Champey, Mr Robin Fears, Mr Ewald Wermut and Mr Gerard van Beynum for their particularly interesting papers describing the present situation at the cutting edge. References were also made, on several occasions, to the ethical dilemmas encountered. The round table, which was chaired by Mr van Hoogstraten, gave us another perspective on the applications of the results of biotechnological progress. It is extremely difficult to resolve such dilemmas, which sometimes start to look like a confrontation between bioethics and human rights, on the one hand, and the rationale of the market economy, on the other. These dilemmas bring into play a whole series of ethical, legal and social issues. There are no ‘easy answers’ in this area. From this point of view, the remarks made by two speakers about what is called ‘ELSI issues’ raised, each in their own way, the problems involved, and proposed ways of solving them.

The points of view of the developing countries were put forward by our colleagues, Professor Kilama and Professor Tadjudin. We should not forget this aspect of the issues at stake. The principle of international solidarity has been established as one of the main guidelines of the Universal Declaration on the Human Genome and Human Rights.

As we come to the end of this fifth session of the International Bioethics Committee of UNESCO, I should like to emphasize that all the opinions, suggestions and proposals, including all the criticisms, expressed during our discussions have been noted and will be duly taken into account in our work.

Let me tell you now about our programme of work. We are going to set up two working groups. One of them will concentrate on the subject of the follow-up of the Universal Declaration on the Human Genome and Human Rights. The task of the other working group will be defined as soon as possible. I have requested all the members of the Committee to put forward suggestions on issues that we should analyse more closely.
A major concern, which is indeed justified, has been expressed by several members of the Committee concerning the method of work to be used at the next session. All the meetings were open to the public, owing to the transition from the old Committee to the new one. It goes without saying that the opinions expressed by non-members of the Committee are of great value and indispensable to our action, which concerns humanity as a whole. Nonetheless, the task entrusted to the International Bioethics Committee and its members is to reflect on and discuss bioethical issues within the circle of the Committee. We therefore decided, during a select committee meeting, that the sixth session of the IBC will be held in two parts. As far as is possible, we shall reserve two meetings for the members of the Committee; two other meetings will be open to the public. In this way, we shall be sure of a more concentrated discussion within the Committee itself. Again, it goes without saying that all governments, and the general public, will be informed of the outcome of the discussions by every possible means.

I must make another remark concerning the question of cooperation with other bodies in charge of bioethical issues. National bioethics committees exist in many countries. Tokyo recently played host to the International Summit of National Consultative Bioethics Commissions, during which it was agreed that a system should be set up to coordinate the committees. Unfortunately, the International Bioethics Committee of UNESCO was only partially represented, and no particular attention was paid to its role in this new system. Our Committee is the only body of the United Nations system to bear the name of International Bioethics Committee, and we are therefore examining the possibility of taking the initiative to form the nucleus of this new coordinating mechanism. The question of our relations with regional bodies will also be examined in the near future.

To conclude, I would say how grateful I am to the Director-General of UNESCO, to all the members of the Committee and to all the participants in this session for their relevant and useful contributions. My thanks also go to Mrs Noëlle Lenoir, the former Chairperson, who has guided our work from the earliest days of the International Bioethics Committee in 1993.

I should also like to thank all the staff members of the Secretariat, and more particularly Mr Georges Kutukdjian, for their tireless efforts which have enabled these valuable results to be achieved. We should not have been able to complete our work without their assistance.
My thanks, too, to the *Expo & Hoc* team for their faultless organization, and to our valued interpreters, without whom an international meeting of this kind could not be a success.

Lastly, allow me to thank the Government of the Netherlands. A warm welcome and efficient organization have enabled us to bring the fifth session to a successful conclusion. All the members of the Committee, all the participants in this session and the staff members of the Secretariat will long remember the gracious kindness of Her Majesty the Queen of the Netherlands, and the generosity and friendship that have been extended to us during the past three days in this wonderful 'House on the Dune'.

When we first began our discussions, the skies were grey. Today, they are blue and sunny as if the heavens were expressing appreciation for our proceedings. May our work in Noordwijk usher in a sunny future!

In my introductory address to this session, I spoke about the importance of the two ‘Hs’, namely Harmony and Humanity. But after these three days which, thanks to your Government, have been fruitful and pleasant in equal measure, I have discovered another letter ‘H’. It is the cornerstone of our future and our happiness, and it stands for Holland.
Chapter 4

• Statutes of the IBC
• Composition of the IBC for 1998-1999
• Bureau of the IBC
Article 1
A permanent Committee, named the International Bioethics Committee of UNESCO (IBC), hereafter referred to as ‘the IBC’, is hereby established within the United Nations Educational, Scientific and Cultural Organization (UNESCO).

Article 2 - Functions
1. The Committee shall have the following functions:
   (a) it shall promote reflection on the ethical and legal issues raised by research in the life sciences and their applications, as well as encourage the exchange of ideas and information, particularly through education;
   (b) it shall encourage action to heighten awareness among the general public, specialized groups and public and private decision-makers involved in bioethics;
   (c) it shall co-operate with the international governmental and non-governmental organizations concerned by the issues raised in the field of bioethics as well as with the national and regional bioethics committees and similar bodies;
   (d) in accordance with Article 24 of the Universal Declaration on the Human Genome and Human Rights, hereafter referred to as ‘the Declaration’:
      (i) it shall contribute to the dissemination of the principles set out in the Declaration and to the further examination of issues raised by their applications and by the evolution of the technologies in question;

1. Adopted by the Executive Board at its 154th Session, on 7 May 1998.
(ii) it shall organize appropriate consultations with parties concerned, such as vulnerable groups;

(iii) it shall make recommendations, in accordance with UNESCO’s statutory procedures, addressed to the General Conference and give advice concerning the follow-up of the Declaration, and it shall identify practices that could be contrary to human dignity.

2. The IBC shall determine its programme of work which shall be made public. The IBC shall include in that programme any item so requested by the Director-General or the Executive Board. It shall take into account the views of the Intergovernmental Committee, hereafter provided under Article 11, concerning its programme.

Article 3 - Membership

1. The IBC shall be composed of 36 members appointed by the Director-General. The members shall be independent and shall act in their personal capacity. When making his choice, the Director-General shall take into account cultural diversity, balanced geographical representation and the need to ensure appropriate rotation. He shall also take into account the nominations for membership of the IBC received from the Member States of UNESCO, Associate Members and non-Member States which have set up a permanent observer mission to UNESCO.

2. When proposing their candidates for the IBC, states shall endeavour to include eminent persons who are specialists in the life sciences and in the social and human sciences, including law, human rights, philosophy, education and communication, with the necessary competence and authority to perform the IBC’s duties.

3. The Director-General shall not appoint simultaneously more than one national of the same state.

Article 4 - Observers

1. Member States and Associate Members of UNESCO may take part as observers in the meetings of the IBC.

2. Non-Member States which have set up a permanent observer mission to UNESCO may take part as observers in the meetings of the IBC on the invitation of the Director-General.
3. The United Nations and the other organizations of the United Nations system with which UNESCO has concluded an agreement providing for reciprocal representation may take part as observers in the meetings of the IBC.

4. International governmental or non-governmental organizations with similar objectives to those of the IBC may be invited to take part as observers in the meetings of the IBC.

5. Specialists or other relevant persons or groups may be consulted on matters within the competence of the IBC.

**Article 5 - Sessions**

The Director-General shall convene the IBC at least once a year.

**Article 6 - Terms of Office**

1. The term of office for members of the IBC shall be four years.
2. Half the IBC’s members shall be replaced every two years.
3. The Director-General shall not appoint the same person for more than two consecutive terms of office.

**Interim provision**

Notwithstanding Article 6.1, the term of office of half the members appointed by the Director-General shall expire at the end of the 30th session of the General Conference. Each outgoing member shall be replaced by a national of a state belonging to the same regional group.

**Article 7 - Advice and Recommendations**

The advice and recommendations of the IBC shall be taken by consensus, promptly made public and widely disseminated. Any member of the IBC shall have the right to record a dissenting opinion.

**Article 8 - Rules of Procedure**

The IBC shall adopt its Rules of Procedure.

**Article 9 - Secretariat**

1. The Director-General of UNESCO shall provide the staff and other means required for the operation of the secretariat of the IBC.
2. The Director-General shall appoint a member of the Secretariat of UNESCO as Secretary-General of the IBC.
Article 10 - Expenses
1. The servicing expenses of the sessions of the IBC shall be financed by the appropriations allocated for this purpose by the General Conference.

2. Member States of UNESCO, Associate Members and non-Member States which have set up a permanent observer mission to UNESCO shall bear the expenses of the participation of their observers at the sessions of the IBC and of their participation in the Intergovernmental Committee.

3. UNESCO shall bear the expenses of the participation of specialists in connection with hearings requested by the IBC.

Article 11 - Intergovernmental Committee
1. An Intergovernmental Committee, hereafter referred to as ‘the Intergovernmental Committee’, is hereby established within the United Nations Educational, Scientific and Cultural Organization (UNESCO).

2. The Intergovernmental Committee shall examine the advice and recommendations of the IBC, including those concerned with the follow-up of the Universal Declaration. The Intergovernmental Committee shall inform the IBC of its opinions. It shall submit its opinions to the Director-General for transmission, together with the advice and recommendations of the IBC, to the Member States, the Executive Board and the General Conference. It may transmit any proposals for the follow-up of the advice and recommendations of the IBC.

3. The Intergovernmental Committee shall be composed of 36 representatives of the Member States elected by the General Conference. Associate Members of UNESCO shall be invited to participate. When electing the members of the Intergovernmental Committee, the General Conference shall take into account cultural diversity, balanced geographical representation and the need to ensure appropriate rotation.

4. The term of office of members of the Intergovernmental Committee shall extend from the end of the ordinary session of the General Conference during which they are elected until the end of its second subsequent ordinary session.

Interim provision
The Executive Board, at its 155th session, as an interim measure, shall elect the first members of the Intergovernmental Committee to hold
office until the next succeeding General Conference. When electing these members, the Executive Board shall take into account cultural diversity, balanced geographical representation and the need to ensure appropriate rotation.

5. Member States of UNESCO, Associate Members and non-Member States which have set up a permanent observer mission to UNESCO may take part in the meetings of the Intergovernmental Committee. The provisions of Article 4 relating to the IBC shall apply mutatis mutandis to the Intergovernmental Committee.

6. The sessions of the Intergovernmental Committee shall be convened by the Director-General at least once every two years.

7. Where the Intergovernmental Committee or the Director-General so decides, a Joint Session of the IBC and the Intergovernmental Committee, hereafter referred to as ‘the Joint Session’, shall be convened. The Joint Session shall foster dialogue between the IBC and the Intergovernmental Committee on matters of mutual concern. Without limiting the generality of such matters, they may include consideration of any proposals to:

   (a) amend the Universal Declaration on the Human Genome and Human Rights; or
   (b) adopt any further declaration or any other international instrument within the field of competence of the IBC.

The Joint Session shall:

   (a) be chaired by the chairpersons of the IBC and of the Intergovernmental Committee as joint presiding officers;
   (b) be open to observers mutatis mutandis in accordance with Article 4; and
   (c) present a report on the meeting to the Director-General, who shall provide it to the Member States for such action as they may decide before it is presented to the General Conference.

**Article 12 - Revision**

These Statutes may be revised by the UNESCO Executive Board.
## Composition of the IBC for 1998-1999

<table>
<thead>
<tr>
<th>Name</th>
<th>Term of Office</th>
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<tbody>
<tr>
<td>Dr. (Mr) Roberto Luis <strong>Andorno</strong> (Argentina)</td>
<td>1998-2001</td>
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<tr>
<td>Professor of Civil Law</td>
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<tr>
<td><strong>Mr Mohammed Bedjaoui</strong> (Algeria)</td>
<td>1998-2001</td>
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<tr>
<td>Judge to the International Court of Justice, The Hague</td>
<td></td>
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<tr>
<td>Former Minister of Justice (Algeria)</td>
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<tr>
<td>Former Ambassador of Algeria in France, to UNESCO and to the United Nations</td>
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<tr>
<td>Former President of the International Court of Justice</td>
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<tr>
<td><strong>Prof. (Mr) Adriano Bompiani</strong> (Italy)</td>
<td>1998-1999</td>
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<tr>
<td>Professor of Gynaecology</td>
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<tr>
<td>Former Senator</td>
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<td>Former Minister for Social Affairs</td>
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<td>Former President of the Italian National Bioethics Committee</td>
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<tr>
<td><strong>Prof. (Mr) Antonio A. Cançado Trindade</strong> (Brazil)</td>
<td>1998-2001</td>
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<tr>
<td>Professor of International Law</td>
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<tr>
<td>Vice-President of the Inter-American Court of Human Rights</td>
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<tr>
<td><strong>Prof. (Mr) Ricardo Cruz-Coke</strong> (Chile)</td>
<td>1998-1999</td>
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<tr>
<td>Professor of Medicine and Clinical Genetics</td>
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<tr>
<td>Former President of the Latin American Programme on the Human Genome</td>
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<td>Former Director of the Genetic Unit, J.J. Aguirre Hospital, University of Chile</td>
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<tr>
<td>Prof. (Mr) Edmundo Estévez (Ecuador)</td>
<td>1998-1999</td>
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</tbody>
</table>
| Professor of Biochemistry and Molecular Biology and Neuroscience  
Director of Biomedical Centre and Medical School, Central University of Ecuador | |
| Prof. (Mr) Ismail Fates (Libyan Arab Jamahiriya) | 1998-1999 |
| Professor of Cell Biology  
Chairperson of the Department of Anatomy and Histology, Al-Arab Medical University | |
| Prof. (Mr) Maurice Fox (United States of America) | 1998-1999 |
| Lester Wolfe Professor of Molecular Biology | |
| Prof. (Mr) Hans Galjaard (The Netherlands) | 1998-2001 |
| Professor of Human Genetics  
Head of the Department of Clinical Genetics, University Hospital Rotterdam | |
| Prof. (Mr) Héctor Gros Espiell (Uruguay) | 1998-2001 |
| Professor of International Law  
Former Ambassador of Uruguay in France and to UNESCO  
Former Minister of Foreign Affairs of Uruguay  
Former President of the Inter-American Court of Human Rights | |
| Dr (Mr) Mohammad Hamdan (Jordan) | 1998-2001 |
| Secretary General of the Higher Council for Science and Technology  
Vice-Chairperson of the Jordanian National Bioethics Committee  
Former President of the Hashemite University  
Former Minister of Education and Higher Education | |
| Prof. (Mr) Ryuichi Ida (Japan) | 1998-1999 |
| Professor of International Law  
Rapporteur of the Committee of Regional Economic Development Law of the International Law Association | |
<table>
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<tr>
<th>NAME</th>
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<tr>
<td><strong>Mrs Michèle Jean</strong> (Canada)</td>
<td>1998-2001</td>
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<tr>
<td>Special Adviser to the Minister of Foreign Affairs of Canada at the European Commission</td>
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<td>Former Vice-Minister of Health</td>
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<td><strong>Prof. (Mr) W. Kilama</strong> (United Republic of Tanzania)</td>
<td>1998-1999</td>
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<tr>
<td>Chairperson and Co-ordinator of the African Malaria Vaccine Testing Network</td>
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<tr>
<td>Former Director-General of the National Institute for Medical Research</td>
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<td><strong>Justice (Mr) Michael Kirby</strong> (Australia)</td>
<td>1998-2001</td>
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<td>Justice of the High Court of Australia</td>
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<td>Former President of the Courts of Appeal of New South Wales and Solomon Islands</td>
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<td>Former President of the International Commission of Jurists</td>
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<td>Chairperson of the Ethics Committee of the Human Genome Organization (HUGO)</td>
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<td><strong>Prof. (Mr) Alexander McCall Smith</strong> (United Kingdom)</td>
<td>1998-2001</td>
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<td>Professor of Private Law</td>
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<td><strong>Prof. (Mr) D. César Nombela</strong> (Spain)</td>
<td>1998-1999</td>
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<tr>
<td>President of the <em>Consejo Superior de Investigaciones Científicas</em></td>
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<tr>
<td>Former President of the Federation of European Microbiology Societies</td>
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<td><strong>Prof. (Mr) Mehmet Öztürk</strong> (Turkey)</td>
<td>1998-2001</td>
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<tr>
<td>Chairperson, Department of Molecular Biology and Genetics, Bilkent University</td>
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<tr>
<td><strong>Prof. (Mrs) Un Jung Pak</strong> (Republic of Korea)</td>
<td>1998-1999</td>
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<tr>
<td>Professor of Law</td>
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<td>President of the Korean Association of Legal Philosophy</td>
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<tr>
<td>Vice-President, Korean Bioethics Association</td>
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<tr>
<td><strong>Prof. (Mrs) Leena Peltonen</strong> (Finland)</td>
<td>1998-1999</td>
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<tr>
<td>Professor and Chair of the Department of Human Genetics, University of California</td>
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<tr>
<td>Chairperson of the European Medical Research Council</td>
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<td><strong>Academician (Mr) Rem V. Petrov</strong> (Russian Federation)</td>
<td>1998-2001</td>
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<tr>
<td>Vice-President of the Academy of Sciences</td>
<td></td>
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<tr>
<td>Member of the Russian Academy of Medical Sciences</td>
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<tr>
<td>Co-Chairman of the National Bioethics Committee</td>
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<td><strong>Mrs Elisabeth Pognon</strong> (Benin)</td>
<td>1998-2001</td>
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<tr>
<td>Magistrate</td>
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<tr>
<td>Former President of the Constitutional Court of Benin</td>
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<td><strong>Mrs Nicole Questiaux</strong> (France)</td>
<td>1998-1999</td>
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<tr>
<td>Honorary Chairperson of Section of the State Council</td>
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<tr>
<td>Vice-President of the National Consultative Ethics Committee for Health and Life Sciences</td>
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<td>Chairperson of the Permanent European Conference of National Ethics Committees</td>
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<tr>
<td>Former Minister of Social Affairs</td>
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<td><strong>Prof. (Mr) Jens Reich</strong> (Germany)</td>
<td>1998-2001</td>
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<tr>
<td>Professor of Genetics</td>
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<tr>
<td>Former co-editor of the <em>European Journal of Biochemistry</em></td>
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<td><strong>Prof. (Mr) Michel Revel</strong> (Israel)</td>
<td>1998-2001</td>
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<tr>
<td>Professor of Molecular Genetics</td>
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<td>Chief Scientist, <em>Interpharm</em></td>
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<td>President of the National Committee for Biotechnology</td>
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<tr>
<td>Mr Patrick Robinson (Jamaica)</td>
<td>1998-2001</td>
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<tr>
<td>Judge to the International Criminal Tribunal for the former Yugoslavia</td>
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<tr>
<td>Member of the United Nations International Law Commission</td>
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<td>Former Deputy Solicitor-General</td>
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<td>Former Chairperson of the Inter-American Commission on Human Rights</td>
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<td>Prof. (Mr) Emmanuel Roucounas (Greece)</td>
<td>1998-1999</td>
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<td>Professor of International Law</td>
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<tr>
<td>Member of the Academy of Athens</td>
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<td>Member of the Institute of International Law, Geneva</td>
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<tr>
<td>Chairman, National Commission of Patients’ Rights</td>
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<td>Former member of the United Nations International Law Commission</td>
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<tr>
<td>Prof. (Mr) Hamed Roushy El-Kady (Egypt)</td>
<td>1998-1999</td>
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<tr>
<td>Emeritus Professor on Radiation Biology</td>
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<tr>
<td>Secretary of the Egyptian National Committee for Bioethics</td>
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<td>Prof. (Mrs) Sylvia Rumball (New Zealand)</td>
<td>1998-1999</td>
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<tr>
<td>Professor of Chemistry</td>
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<tr>
<td>Director, Science Education and Policy Unit, Massey University</td>
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<td>Justice (Mr) Albie Sachs (South Africa)</td>
<td>1998-1999</td>
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<tr>
<td>Judge of the Constitutional Court of South Africa</td>
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<tr>
<td>Honorary Professor of the Faculty of Law, University of Cape Town</td>
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<td>Dr (Mr) Monkombu Sambasivan Swaminathan (India)</td>
<td>1998-1999</td>
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<tr>
<td>President of the Swaminathan Research Foundation</td>
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<tr>
<td>UNESCO-Cousteau Professor of Ecotechnology for Asia</td>
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<tr>
<td>Prof. (Mr) Muhammad Kamil Tadjudin (Indonesia)</td>
<td>1998-2001</td>
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<tr>
<td>Professor of Biology</td>
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<tr>
<td>Former Rector of the University of Indonesia</td>
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<td>Name</td>
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</table>
| **Prof. (Mrs) Yolande Evelyne TANO BOUAH** (Côte d'Ivoire) | 1998-2001      | Professor of Law  
Vice Chairperson of the University of Abobo-Adjamé                   |
| **Prof. (Mr) Arvo TIKK** (Estonia)        | 1998-1999      | Professor of Neurosurgery  
Chairperson of the Estonian Council of Bioethics                         |
| **Prof. (Mr) Huanming YANG** (China)      | 1998-2001      | Professor of Genetics  
Director of the Human Genome Center, Chinese Academy of Medical Sciences |
| **Prof. (Mr) Jacek Stanislaw ZAREMBA** (Poland) | 1998-1999    | Professor, Head of Department of Genetics, Institute of Psychiatry and Neurology |
BUREAU OF THE IBC

CHAIRPERSON
Prof. Ryuichi IDA (Japan)

VICE-CHAIRPERSONS
(in alphabetical order)
H. Ex. Mr Héctor GROS ESPIELL (Uruguay)
Dr Mohammed HAMDAN (Jordan)
Mrs Michèle JEAN (Canada)
Prof. Jacek ZAREMBA (Poland)

RAPPORTEUR
Prof. (Mrs) Yolande TANO BOUAH (Côte d’Ivoire)

2. Elected on 2 December 1999 at the Fifth Session of the IBC.
Roberto Luis ANDORNO (Argentina)
Born in Santa Fé in 1961, Ph.D. of Law from the National University of Buenos Aires and the University of Paris XII (France), he is Assistant Professor of Civil Law at the National University of Buenos Aires and the Austral University (Buenos Aires). Author of *La distinction juridique entre les personnes et les choses à l’épreuve des procréations artificielles* (1996) and *La bioéthique et la dignité de la personne* (1997) as well as a number of articles on medically-assisted procreation.

Mohammed BEDJAOUI (Algeria)
Born in 1929, political figure, diplomat, jurist, Doctor of Law (1955), graduate in Political Sciences (1952). Since 1982, member of the International Court of Justice (ICJ) The Hague, of which he was President from 1994 to 1997. Mr Bedjaoui was formerly Secretary General of the Algerian Government, Dean of the Faculty of Law and Economical Sciences at the University of Alger, Minister of Justice (1964-70); Ambassador of Algeria in France (1970-1979) and to UNESCO (1971-1979) then to the United Nations (1979-1982) where he was also President of the Group of 77 (1981-1982). He was Head of the Algerian Delegation to the United Nations Conference on the Law of the Sea (1975-1980). Member of various international commissions and international juries, of which the Jury for the UNESCO Felix Houphouët Boigny Peace Prize, he is the author of more than 200 publications and articles, including a manual of international law published by UNESCO. Doctor honoris causa of a number of universities, he is the recipient of several national and foreign awards.
Adriano BOMPIANI (Italy)

Born in Rome in 1923, he began his career as a surgeon and gynaecologist. He is President of the Administrative Council of the Bambino Gesù Paediatric Hospital (Rome) since 1993, and a member of the National Bioethics Committee of which he was President from 1990 to 1992. From 1960 to 1966, he taught obstetric physiopathology and gynaecology at the Faculty of Medicine and Surgery and Gynaecology of Milan. From 1996, he lead the Institute of Clinical Obstetrics at the A. Gemelli Polyclinic in Rome. Elected Senator in 1976, he was re-elected several times. In June 1992, he was appointed Minister of Social Affairs until May 1993. Author of numerous scientific works and of more than 50 publications on bioethics, in particular Bioetica in Italia : lineamenti e tendenze [Bioethics in Italy : Major Lines and Tendencies] (1994), Bioetica in medicina [Bioethics in Medicine] (1996), Bioetica per i deboi [Bioethics for the Weakest] (1997) and Bioetica ed etica medica nell'Europa occidentale [Development of Bioethics and Medical Ethics in Western Europe] (1997).

Antonio A. CANÇADO TRINIDADE (Brazil)

Doctor from the University of Cambridge, he is the Vice-President of the Inter-American Court of Human Rights and Professor of International Law at the University of Brasilia. He is the author of numerous publications in the field of human rights, in particular The Interdependence of all Human Rights - Obstacles and Challenges to their Implementation and Treaties on the International Law of Human Rights ( in Portuguese).

Ricardo CRUZ-COKE (Chile)

Born in 1925, Doctor of Medicine, he is Professor of Medicine and Clinical Genetics at the University of Chile. In 1965, he founded the Department of Medical Genetics at the J.J. Aguirre Hospital of the University of Chile. He was appointed Assistant Dean of the Faculty of Medicine in 1988 and Director of the Genetics Unit from 1980 to 1995. Mr Cruz-Coke was President of the Genetics Society of Chile in 1973 and President of the Latin American Programme on the Human Genome from 1990 to 1992. Member of numerous organizations - in particular the Permanent Committee of the International Congresses of Human Genetics (1971-1981), the Human Genome Organization (HUGO) (1991) and the Academy of Sciences of Latin America (1993) - he is the author of numerous publications and works concerning anthropology, medicine, epidemiology, education, ethics and genetics.
Edmundo ESTEVEZ (Ecuador)
Born in Atuntaqui (Imbabura) in 1956, Doctor of Medicine, specialist in sciences (MSc., Biochemistry), Professor of Biochemistry, Molecular Biology and Neurosciences, he is the Director of the Biomedical Centre at the Central University of Ecuador (Quito) and Director of the Medical School of this University. Member of several organizations, including the International Society of Hematology, the Société française d’étude et recherche sur les éléments traces essentiels (SFERET), the National Academy of Sciences, the Equatorian Society of the History of Medicine, the National Bioethics Committee and the Latin-American Association of Bioethics, he is the author of several scientific articles, particularly in the fields of the history of medicine, biochemistry, nutrition, and bioethics.

Ismail Ayad FATES (Libyan Arab Jamahiriya)
Born in Zuara 1950, Doctor of Cell Biology from Florida State University (United States of America) (1983), he is Professor of Cell Biology and Electron Microscopy, Chairman of the Anatomy and Histology Department of the Faculty of Medicine at the Medical University of El-Arab (Benghazi) and Assistant Dean for Preclinical Departments. His field of research deals with neurogenesis and turnover rate of olfactory sensory cells and the effects of drugs on the histological picture of the liver and kidney.

Maurice S. FOX (United States of America)
Born in New York in 1924, Doctor of Chemistry from the University of Chicago, he is Professor in the Department of Biology of the Massachusetts Institute of Technology (MIT). From 1979 to 1996 he was Lester Wolfe Professor of Molecular Biology at MIT. Member of the National Academy of Science, Institute of Medicine and the American Academy of Arts and Sciences, he is the author of numerous articles and scientific publications. Doctor honoris causa in 1994 from the Paul Sabatier University in Toulouse (France), his research deals with the diagnosis of cancer and the molecular mechanism of genetic recombination.

Hans GALJAARD (The Netherlands)
Born in 1935, Ph.D. and Medical Doctor at the Institute of Rheumatology Research, State University of Leiden, Professor of Cell Biology and Genetics at the Erasmus University Rotterdam in 1966, he is Chairman of the Department of Clinical Genetics at the University Hospital of Rotterdam, since 1980. Member of numerous national and international organizations and Consultant of WHO and UNFPA, he has been award
numerous *honoris causa* doctorates and honorary distinctions in some ten
countries. Mr Galjaard has contributed to a number of radio and television
programs. He is also the author of ca. 500 articles and contributions to
many books on technical, social and ethical aspects of genetic research
and clinical applications in (prenatal) diagnosis and genetic counselling,
and writer of both scientific (*Genetic Metabolic Disease*) and more popular
books (*Life of the Dutchman* and *All people are unequal*).

**Héctor GROS ESPIELL** (Uruguay)

Born in 1926, jurist, specialist in international relations, Mr Gros Espiell
was Ambassador of Uruguay in France and Permanent Delegate of
Uruguay to UNESCO from 1993 to 1997. Formerly Minister of Exterior
Relations of Uruguay, he was President of the Ministerial Commission for
Commercial Negotiations, the GATT *Uruguay Round*. He was also
Assistant Secretary General of the United Nations, the Secretary
General’s special representative for questions concerning the Western
Sahara, Secretary General for the proscription of nuclear arms in Latin
America, Director of the Inter-American Institute for Human Rights and
President of the Inter-American Court of Human Rights. Mr Gros Espiell
was also a member of the United Nations Human Rights Commission
(1968-1871) and President of the International Labour Organization
Administrative Council (1969-1970). He is the author of many articles and
reference books.

**Mohammad A. HAMDAN** (Jordan)

Ph.D. in Mathematical Statistics from Sydney University (Australia), he is
Secretary General of the Higher Council for Science and Technology and
Vice-Chairperson of the Jordanian National Bioethics Committee. Former
President of Yarmouk University (1986-1989) and former President of the
Hashemite University (1992-1998), he was Minister of Education and
Higher Education in (1998-1991 and 1998). He has held several academic
positions and is a member of a number of scientific associations. He is
the author of numerous articles in the field of mathematical statistics.

**Ryuichi IDA** (Japan)

Born in 1948, he is Professor of International Law at the Faculty of Law of
the University of Kyoto. Member of the International Law Association, the
French Society for International Law and the American Society of
International Law. He was Director of Studies at the International Law
Academy of The Hague (1992). Since 1992, he is the Rapporteur of the

**Michèle JEAN** (Canada)

Born in Quebec (Canada), historian, Mrs Jean is Special Adviser to the Minister of Foreign Affairs of Canada at the European Union. Formerly, Under-Secretary of States, she was appointed Vice-Minister of Health in 1993, a position she held until July 1998. She has also held positions as Special Adviser to the International Institute of Educational Planning in Paris, Vice-Minister of Employment and Immigration as well as Vice-President of the Employment and Immigration Commission of Canada. Author of a number of articles and publications, such as *L'histoire des femmes au Québec, de la Nouvelle-France à nos jours et Apprendre: une action volontaire et responsable*, the Quebec Report of the Commission on the Study Group on Training which she chaired.

**W. L. KILAMA** (Republic of Tanzania)

Born in Bukoba (Tanzania) in 1940, Professor at the University of Dar es Salaam since 1977, he is the Chairman and Co-ordinator of the African Malaria Vaccine Testing Network. He was formerly the Director-General of the National Institute for Medical Research (1980-1997). Member of several organizations and committees, he is the president of a number of non-governmental organizations, in particular the World Federation of Public Health Associations. Mr Kilama is the author of over 70 publications, particularly in the field on malaria and parasitic illnesses.

**Michael KIRBY** (Australia)

Judge at the High Court of Australia. He previously served as Judge of the Federal Court of Australia and President of the Courts of Appeal of New South Wales and the Solomon Islands. He is a member of the International Commission of Jurists of which he was President from 1995 to 1998, and a member of the Ethics Committee of the Human Genome Organisation (HUGO). He has held several international positions as member of the Global Commission on AIDS of the World Health Organization (WHO), the Fact-Finding and Conciliation Committee on Freedom of Association of the International Labour Organization (ILO), and Special Representative of the Secretary-General for Human Rights in
Cambodia. He was awarded the Australian Human Rights Medal in 1991 and in 1998 he was the recipient of the UNESCO Prize for the Teaching of Human Rights.

Alexander McCALL SMITH (United Kingdom)
Born in 1948, Professor of Law at the University of Edinburgh, where he attained his doctorate in 1979, Mr McCall Smith has held posts in universities throughout Europe, the United States of America and Africa, where he was Head of the Department of Law at the University of Botswana in 1981. He is the former Chairman of the Legal Rights and Protection Committee, Scottish Action on Dementia, and is a member of several Editorial Boards, including the Medical Law Review and the International Journal of Law and Biosciences. Author of numerous publications in the field of law and medical ethics, he is also the author of various novels and more than thirty books for children.

César NOMBELA CANO (Spain)
Born in 1917 in Toledo (Spain), Doctor in Microbiology from the University of Salamanca, he is President of the Consejo Superior de Investigaciones Científicas (CSIC) since 1996. Professor and Head of Department at the Faculty of Pharmacy of the Complutense University from 1979 to 1996, he is the founder of the Centre for DNA Sequencing of this University and was its Director from 1993 to 1996. Former President of the Federation of European Microbiology Societies (1995-1998), he has been awarded a number of scientific distinctions and is a member of several scientific committees of the European Union. He is also head of a research group dealing with Molecular Microbiology and Biotechnology and author of about 100 publications refereed journals.

Mehmet ÖZTÜRK (Turkey)
Born in 1952 in Mudurnu, Doctor in Biochemistry from the University of Paris XI (France), since 1995 he is Professor and Chairman of the Department of Molecular Biology and Genetics at the Bilkent University of Ankara. He has held several academic and research positions in the United States of America and, from 1992 to 1996, was Director of Research at INSERM in France. Author of numerous scientific publications, he is a member of the European Molecular Biology Organization (since 1994), the Academy of Sciences of Turkey (since 1995) and the Third World Academy of Sciences (since 1997).
Un Jung PAK (Republic of Korea)

Born in Kyung Buk Andong in 1952, Doctor of Law from the University of Freiburg (Germany), she is Professor of Law at the Ewha Women’s University in Seoul. She was formerly Research Professor for the United Nations’ DP Project in Korea (1994-1997), member of the ad hoc Committee for Legal Education under the Educational Reform Department of the Ministry of Education (1994-1996), member of the Educational Reform Advisory Committee of the Ministry of Education (1997-1998). Mrs Pak is President of the Korean Association of Legal Philosophy, Vice-President of the Korean Bioethics Association and member of the Korean National Commission for UNESCO. Author of articles and publications, in particular Thought of Natural Law and Contemporary Social Problems and Legal Philosophy.

Leena PELTONEN-PALOTIE (Finland)

Born in Helsinki in 1952, Doctor of Medicine and Biochemistry from the University of Oulu, she is Professor of Medical Genetics at the University of Helsinki and Professor and Chair of the Department of Human Genetics at the University of California Los Angeles (UCLA). Member of several national and international organizations, Mrs Peltonen is, in particular, member of the European Molecular Biology Organization, of the Council of the Human Genome Organization (HUGO) and was Chairperson of the European Medical Research Council (1996-1998). Member of the editorial board of a number of scientific journals, she was Editor-in-Chief of Annals of Medicine (1990-1994). Author of many publications on gene defects in human diseases and recipient of numerous international scientific awards.

Rem V. PETROV (Russian Federation)

Born in 1930, specialist in immunology, he is a member of the Russian Academy of Medical Sciences since 1978. Doctor honoris causa of the Barilan University (Israel) and Madrid Polytechnic University (Spain), he was elected member of the Russian Academy of Sciences in 1984. Since 1971, he is the Head of the First Chair of Immunology at the Moscow Medical University and Director of the Moscow Institute of Immunology from 1983 to 1988. Vice-President of the Russian Academy of Sciences in 1988, he is Co-chair of the National Bioethics Committee and Vice-President of the Molecular Cell Biology Network of UNESCO. He has been actively involved in numerous activities of the Organization in relation to his specialized field. He is the author of numerous scientific publications concerning immunology and immunogenetics.
Elisabeth K. POGNON (Benin)
Born in 1937, jurist, she is a graduate of the Faculty of Law and Economical Sciences and of the Centre national d'études judiciaires de Paris. She entered the Beninois Magistrates Corps in 1965. She carried out her duties in both judiciary and administrative domains. From the Tribunal de première instance of Cotonou of which she was President, she pursued her career as Counselor at the Appeals Court, at the Supreme Court and the Cour populaire centrale. Nominated to the Constitutional Court in 1992, she was President from 1993 to 1998.

Nicole QUESTIAUX (France)
Born in 1930 in Nantes, graduate from the Institut d'études politiques of Paris, she was Commissaire du gouvernement près l’assemblée du contentieux du Conseil d'Etat (1963-1974) and President of an inter-group for the study of problems concerning the elderly (1969). In 1980, she was also appointed State Counsel. Elected Member of Parliament in 1981, Mrs Questiaux was Minister for National Solidarity from 1981 to 1982. Reinstaed to the Conseil d'Etat in 1982, she was President of a Sub-section of the Section of the Dispute Resolution of the State Council from 1983 to 1988 and President of the Section for Public Works from 1988 to 1995. Honorary Chairperson of Section of the State Council, Mrs Questiaux is Vice Chairperson of the French National Consultative Ethics Committee for Health and Life Sciences and Chairperson of the Permanent European Conference of National Ethics Committees. She is the author of several publication, including Le contrôle de l'administration et la protection des citoyens and Traité du social. Situations, luttes politiques, institutions.

Jens REICH (Germany)
Doctor of Medicine from the Humboldt University of East Berlin, he works in the Division of genomic informatics of the Max Delbrück Center in Berlin-Buch (Germany). He previously worked at the Institute for Molecular Biology at the Academy of Sciences of the German Democratic Republic in the field of computer modelling and biomathematics. Co-author of the monograph Energy Metabolism of the Cell, he was co-editor of the European Journal of Biochemistry for a period of 8 years. Mr Reich co-ordinates several research projects in the framework of the German Human Genome Project and the Biomed Programme of the European Union. He is also a member of the Committee on Bioethics of the German Physicians’ Association.
Michel REVEL (Israel)

Born in 1938, Doctor of Medicine and Biochemistry, he is Professor of Molecular Genetics at the Weizmann Institute of Sciences in Rehovot (Israel). He is also Scientific Director of InterPharm Laboratoires (Ares-Serono Group), a biotechnological company founded in 1979. He was formerly a researcher at the National Scientific Research Centre (CNRS) of France, in the Department directed by Mr François Gros (1966-1968). He is a member of the European Molecular Biology Organization (EMBO) since 1973 and member of the Human Genome Organization (HUGO) since 1990. He is President of the National Committee of Biotechnology which co-ordinates basic and industrial research in this field. Author of several scientific works and of two books on the clinical aspects of interferons and interleukine-6, he brings medical biogenetics research into the context of Jewish tradition with regard to bioethics and the relationship between science and religion.

Patrick L. ROBINSON (Jamaica)

Born in 1944, former Deputy Solicitor-General at the Attorney General’s Department (Jamaica), he is Judge at the International Criminal Tribunal for the former Yugoslavia. Since 1982, he is accredited Delegate to the annual sessions of the General Assembly of the United Nations. He was formerly Crown Counsel for the Director of Public Prosecutions (1968-1971), Legal Advisor to the Ministry of Foreign Affairs (1972-1973) and Assistant Attorney-General (1975-1977). In 1982, Mr Robinson was Accredited Ambassador to the Third United Nations Conference on the Law of the Sea and, in 1991, Chairman of the Inter-American Commission on Human Rights. He is a member of the British Institute of International and Comparative Law and the American Society of International Law.

Emmanuel ROUCOUNAS (Greece)

Born in 1933, Professor of International Law at the University of Athens, he is a member of the Academy of Athens and the Institute of International Law (Geneva). In 1995, he was appointed Independent Jurist for Western Sahara by the Secretary-General of the United Nations. A former member of the United Nations International Law Commission and of the Committee on the Elimination of Racial Discrimination (CERD), he is also President of the National Commission of Patients’ Rights. He is the author of several works on international public law, human rights and history of international relations.
H. M. ROUSHDY EL-KADY (Egypt)

Born in 1930 in Cairo, Doctor in Biological Sciences, he is Professor emeritus on Radiation Biology at the National Centre for Radiation Research and Technology of the Egyptian Atomic Energy Authority, of which he was President from 1986 to 1990. He is a member of the National Committee on Genetic Engineering and Biotechnology, Presidency of the Republic, and Secretary of the Egyptian National Bioethics Committee. Author of more than 300 scientific publications, he is the Editor-in-Chief of the Journal of Radiation Sciences and Application.

Sylvia V. S. RUMBALL (New Zealand)

Born in Leeston (Canterbury), Ph.D in Chemistry (specialising in X-ray Crystallography) from the University of Auckland, Professor of Chemistry, she is Assistant to the Vice-Chancellor (Equity) of Massey University, Director of the Science Education and Policy Unit and Chairperson of the University Research Committee. Member of a number of national and international scientific associations and the recipient of numerous awards, she was the first woman Executive Dean of Science in New Zealand. Author of many scientific papers, particularly concerning the properties of human milk, structure and function of lactoferrin.

Albie SACHS (Republic of South Africa)

Born in 1935, he is a Judge at the Constitutional Court of South Africa since 1994. He began his career as an advocate at the Cape Town Bar in 1957 and worked actively in the civil rights sphere. After completing a doctorate at the University of Sussex, he taught at the Law Faculty of the University of Southampton, United Kingdom (1970-1977). In 1977, he took up a position as Professor of Law at the Eduardo Mondlane University of Maputo (Mozambique) and, from 1983 to 1988, he served as Director of Research in the Ministry of Justice. In 1989, he was Professor at the Law School and in the Department of International Affairs at Columbia University, New York (United States of America). He was the founding Director of the South African Constitution Studies Centre based at the Institute of Commonwealth Studies at the University of London (United Kingdom). Honorary Professor at the Law Faculty of the University of Cape Town, Mr Sachs took an active part in the negotiations for a new Constitution as member of the Constitutional Committee of the ANC and of the National Executive of that organization. Honorary Doctor of the University of Southampton, the University of York, Toronto (Canada), he is the author of numerous works in the field of human rights and law.
Monkombu Sambasivan SWAMINATHAN (India)
Born in 1925 in Tamil Nadu, Doctor of Genetics from the School of Agriculture of the University of Cambridge (United Kingdom), he holds the UNESCO-Cousteau Chair in Ecotechnology for Asia and President of the Swaminathan Research Foundation. Former Director-General of the Indian Council of Agricultural Research (1972-1979) and the International Rice Research Institute (1982-1988), he was Principal Secretary to the Government of India, Ministry of Agriculture and Irrigation from 1979 to 1980. Former President of the National Academy of Sciences (1988 to 1990) and the National Academy of Agricultural Sciences (1991 to 1996), Mr Swaminathan was also Chairman of the United Nations Advisory Committee on Science and Technology for Development from 1980 to 1983. He served as Independent Chairman of the FAO Council during 1981 to 1985 and as President of the International Union for the Conservation of Nature and Natural Resources from 1984 to 1990. Member of a number of national and international scientific institutions and academies of science, including the National Academy of Sciences of the United States of America and the Royal Society (London), he is a founding member of the Third World Academy of Sciences. Doctor honoris causa from various universities, he has been awarded many national and foreign awards. He is the author of over 250 scientific works and publications, including Building a National Food Security System and Science and Integrated Rural Development.

Muhammad Kamil TADJUDIN (Indonesia)
Born in Jakarta in 1937, he is Professor of Biology, Genetics and Research Methodology at the University of Indonesia. He was Rector of this University from 1994 to 1998. Since January 1999 he has also been appointed as the Chairman of the National Accreditation Board of Higher Education. He is member of several national and international scientific institutions, including the South East Asian Ministers of Education Council Center for Tropical Medicine and Public Health (SEAMEO-TROPMED), and is a founding member of the Indonesian Societies for Andrology, the Study of Fertility and Human Genetics.

Yolande TANO BOAH (Côte d'Ivoire)
Born in Grand-Bassam (Côte d'Ivoire) in 1953, Doctor of Private Law from the Faculty of Legal Sciences of Montpellier (France) in 1982, she is agrégée in Private Law since November 1985. Dean of the Faculty of Law of Abidjan in 1995, she is since 1996 Vice-President of the University of
Abobo-Adjamé specialized in natural and environmental sciences, environmental management, food science and technology, and fundamental and applied sciences. She was formerly President of the Bar Examinations Board from 1986 to 1995 and Associate in a law firm (S.C.P.A. Kanga & Partners). Technical Advisor to the Ministry for Relations with Institutions since 1994, Ms Tano was also a member of several Ph.D and agrégation examining boards. She is the author of several publications, including *Le Mineur en droit ivoirien*, *L'inaptitude juridique de l'analphabète*, *La Responsabilité médicale dans les établissements privés* and *La précarité du titre foncier en matière de propriété*.

**Arvo TIKK** (Estonia)

Born in 1929, Doctor of Medical Sciences, he is Professor emeritus at the Department of Neurology and Neurosurgery of the University of Tartu (Estonia). He is member of a number of national institutions, including the Council of Estonian Science Foundation and the Commission on Bioethics of the University of Tartu, of which he was President from 1990 to 1995. He is also a member of the World Federation of Neurology, the European Federation of Neurological Societies, the European Association of Neurological Surgeons and the International Association of Study of Pain. He is member of the Steering Committee on Bioethics of the Council of Europe and Chairperson of the Estonian Council on Bioethics.

**Huanming YANG** (China)

Born in 1952 in Zhejiang, Ph.D., he is Professor of Genetics and Director of the Human Genome Centre, Institute of Genetics, Chinese Academy of Sciences (Beijing). Member of a number of organizations, including the Human Genome Organization (HUGO), the American Society of Human Genetics, the European Society of Human Genetics, the Chinese Genetics Society, the Chinese Society of Medical Genetics and the Chinese Society of Biochemistry. Secretary-General of the Chinese Human Genome Project, he is also Secretary-General of its Ethical, Legal and Social Issues (ELSI) Committee and Human Genome Diversity Committee. He is the author of many publications on ethical, legal and social issues related to human genetics and genomics.

**Jacek S. ZAREMBA** (Poland)

Born in 1936 in Warsaw, he is Professor and Head of the Department of Genetics at the Institute of Psychiatry and Neurology in Pruszkóz
Warsaw. Former member of the Ethical Commission of the Scientific Council of the Ministry of Health and Social Welfare (1996-1998), he is Vice Chairman of the Polish Society of Human Genetics and Chairman of the Commission of Neurogenetics, Polish Academy of Sciences. He is the author of many articles in the field of ethics, reproduction and confidentiality of stored genetic material.
Chapter 6

LIST OF PARTICIPANTS OF 
THE FIFTH SESSION OF THE IBC

I. Members of the Committee

Dr (Mr) Roberto Luis ANDORNO
Mr Mohammed BEDJAOUI
Prof. (Mr) Adriano BOMPIANI
Prof. (Mr) Ricardo CRUZ-COKE
Prof. (Mr) Edmundo ESTEVEZ
Prof. (Mr) Maurice FOX
Prof. (Mr) Hans GALJAARD
Prof. (Mr) Héctor GROS ESPIELL
Dr (Mr) Mohammad HAMDAN
Prof. (Mr) Ryuichi Ida
Mrs Michèle JEAN
Prof. (Mr) W. KILAMA
Prof. (Mr) Alexander McCALL SMITH
Prof. (Mr) D. César NOMBELA
Prof. (Mr) Mehmet ÖZTÜRK
Prof. (Mrs) Un-jung PAK
Academician (Mr) Rem V. PETROV
Mrs Elisabeth POGNON
Mrs Nicole QUESTIAUX
Prof. (Mr) Jens REICH
Prof. (Mr) Michel REVEL
Prof. (Mr) Emmanuel ROUCOUNAS
Prof. (Mr) Hamed ROUSHDY EL-KADY
Prof. (Mr) Muhammad Kamil TADJUDIN
Prof. (Mrs) Yolande Evelyne TANO BOUAH
Prof. (Mr) Arvo TIKK
Prof. (Mr) Huanming YANG
Prof. (Mr) Jacek Stanislaw ZAREMBA

II. Special Guests

Mr Yves CHAMPEY
President
Rhône-Poulenc Rorer Foundation
France

Mrs Odile COHEN HAGUENAUER
Co-ordinator
Regulation of Gene Therapy in Europe (EUREGENETHY)
France

Mrs Lorraine DENNERSTEIN
Director
Key Centre for Women’s Health in Society
Australia

Mr Robin FEAR
Director, Science Policy Analysis
Smithkline Beecham Pharmaceuticals
United Kingdom

Ms Vigdís FINNBOGADOTTIR
President, World Commission on the Ethics of Scientific Knowledge and Technology of UNESCO (COMEST)

Dr (Mrs) Attiya INAYATULLAH
President, International Planned Parenthood Federation (IPPF)
Pakistan
III. Representatives of the United Nations Organization and Organizations of the United Nations System

OFFICE OF THE UNITED NATIONS HIGH COMMISSIONER FOR HUMAN RIGHTS
Mr. Alexandre Ovsiovuk
Geneva, Switzerland

UNITED NATIONS FUND FOR POPULATION ACTIVITIES
Mr. Alphonse Macdonald
Geneva, Switzerland

WORLD HEALTH ORGANIZATION
Mrs. Geneviève Pinet
Chief of Health Legislation
Geneva, Switzerland
IV.Observers from International Intergovernmental and
Non-Governmental Organizations

B’NAI B’RITH INTERNATIONAL
Mrs Norma ANAV

COMMONWEALTH SECRETARIAT
Mrs Judith JOHNSON
Deputy Director, Science and Technology Division
Commonwealth Science Council

COUNCIL OF EUROPE
Mr Claudio ZANGHI
Direction of Human Rights
Strasbourg, France

INTERNATIONAL COUNCIL FOR SCIENCE
Mr Mathias KAISER
Chairman of SCRES

INTERNATIONAL COUNCIL OF JEWISH WOMEN
Dr Gabrielle VOIGNAC

INTERNATIONAL FEDERATION OF CATHOLIC UNIVERSITIES
Prof. Marc CAUDRON

INTERNATIONAL FEDERATION OF UNIVERSITY WOMEN
Mrs Ati Chris BLOM
Vice-President

INTERNATIONAL HUMANIST AND ETHICAL UNION
Mr Georges LIENARD

INTERNATIONAL SOCIAL SCIENCE COUNCIL
Lord Wayland KENNET

INTERNATIONAL UNION OF BIOLOGICAL SCIENCES
Mr Darryl MACER

LA VOIX DE L’ENFANT
Mrs Claire HONIGMAN
V. Observers from Member States, Permanent Missions of Observation and National Commissions for UNESCO

ARGENTINA
Mr Ruben VALLEJO
Argentine Embassy
The Netherlands

AUSTRALIA
Ms Carolyn IRVING
Australian Embassy
France

AUSTRIA
Mr Ulrich KÖRTNER
Institute for Systematic Theology
University of Vienna

BELGIUM
Mrs Sylviane FRIART
Legal Counsellor
Ministry of Justice

CAMEROON
Mr Charles ASSAMBA ONGODO
Second Secretary
Permanent Delegation of Cameroon to UNESCO
UNESCO House

CANADA
Dr Elizabeth McGREGOR
Coordinator
Minister’s National Biotechnology Advisory Committee
Industry Canada
CHILE
H. Ex. Mr Jaime LAVADOS
Ambassador, Permanent Delegate of Chile to UNESCO
UNESCO House

DOMINICAN REPUBLIC
Mrs Laura CALVENTI
First Secretary
Permanent Delegation of the Dominican Republic to UNESCO
UNESCO House

ECUADOR
Mr Javier ALIAGA SANCHO
Second Secretary
Embassy of Ecuador, The Netherlands

FINLAND
Mr Arto KOSONEN
Director, Legal Department
Ministry for Foreign Affairs

FRANCE
Mr Jean-Christophe PAGES
Researcher at Genethon II

GERMANY
Mrs Christianne DEUSSEN
Deputy Secretary-General
German Commission for UNESCO
Mr A. DRECHSLER
Federal Ministry for Education and Research
Mr Otfried GARBE
Head of Division
Ministry of Foreign Affairs

HOLY SEE
Mgr Jean-Marie MPENDAWATU
Conseil pontifical pastoral, Services de santé

LUXEMBOURG
Mr Edmond WAGNER
President
National Ethics Commission of the Grand-Duché of Luxembourg
MOROCCO
Mr Farid HAKKOU
Professor at the Faculty of Law and Pharmacy
Hassan II University

PAKISTAN
Mr Saeed M. KHAN
Ambassador
Embassy of Pakistan
The Netherlands
Mr Tariq JAVED
Second Secretary
Embassy of Pakistan
The Netherlands

PORTUGAL
Mr Daniel SERRAO
Professor of Pathology and Bioethics

QATAR
Mr Khalid A. AL ALI
Vice Dean, Faculty of Science
University of Qatar

SPAIN
Mrs María-Dolores VILA-CORO
Sociedad Española de Estudios Biojuridicos y Bioéticos
Mr Francisco FERRANDIZ
Asesor de la Oficina de Ciencia y Tecnologia de Presidencia de Gobierno
Representative of the National Commission of Spain to UNESCO

TURKEY
Mr Cengiz SANAY
Head of Cultural Department for UNESCO Affairs
Ministry of Foreign Affairs

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