INFORMATION REGARDING
THE IMPLEMENTATION OF 33 C/RESOLUTION 22
"SICKLE-CELL ANAEMIA, A PUBLIC HEALTH PRIORITY"

OUTLINE

Source: 33 C/Resolution 22.

Background: The UNESCO General Conference at its 33rd session requested the Director-General to support the carrying out of a feasibility study, in cooperation with the competent United Nations agencies, with a view to:

(a) drawing up an international preventive education programme on sickle-cell anaemia;

(b) setting up a fund composed of extrabudgetary resources to support such a programme; and

(c) proclaiming 19 June of each year as international day to combat sickle-cell anaemia. The General Conference also invited the Director-General to submit to it at its 34th session a report on the implementation of this resolution, including efforts made at the national, regional and international levels to combat sickle-cell anaemia and its consequences worldwide.

Purpose: In conformity with 33 C/Resolution 22, the Director-General submits this report which presents an overview of the issues related to the feasibility study, the results of consultations held, and recommendations for future action.
Background

1. The World Health Organization report on sickle-cell anaemia (also known as sickle-cell disorder or sickle-cell disease) describes it as a “common genetic condition due to a haemoglobin disorder – inheritance of mutant haemoglobin genes from both parents […] that is particularly common among people whose ancestors come from sub-Saharan Africa, India, Saudi Arabia and Mediterranean countries”. It is one of the most common genetic disorders in the world, affecting up to 1% of newborns in certain parts of Africa. Techniques for diagnosis and treatment of the disorder are well known. Still, the disorder is largely neglected in many parts of the world: statistics are rare and scattered, knowledge about the disorder is inadequate even among health personnel in most countries, and it is not a public health priority in many regions where it is widespread.

2. Outside of the industrialized world, it is estimated that one in two children born with sickle-cell anaemia dies before the age of five. Health consequences for survivors include reduced life expectancy, anaemia, attacks of pain and susceptibility to infection. Many sufferers have severe bouts of incapacitation. Blood tests and prenatal counselling can decrease the number of births of affected children. Early diagnosis and treatment of newborns can reduce complications and increase life expectancy. Techniques exist to manage the condition and increase sufferers’ quality of life. Effective care for young sufferers and support to adults with the condition require that all involved – individuals with the condition, care givers, health workers and education personnel – be informed of the causes and nature of sickle-cell anaemia as well as how to manage it.

3. In countries where sickle-cell is the most widespread, health systems are generally strained and the needs of sickle-cell sufferers require both additional resources and widespread understanding of the disorder. Lack of diagnosis and a poor health care infrastructure can increase the severity of the condition and drastically shorten life. Ignorance about sickle-cell anaemia can result in stigmatization and isolation of parents. Children who are not educated about the nature of their disorder may suffer added psychological strain and will not be able to take the steps necessary to minimize the effects of periodic crises. As children with the disorder can be smaller than normal and perform less well in school, it is very important that education personnel understand their needs.

Public information needs and situation

4. There is relatively little education about sickle-cell anaemia. However, good information for medical and non-medical personnel is available and relatively easy to find on the Internet. Screening of all newborns or of newborns most at risk by their region of origin is widespread in developed countries.

5. Centres for information, screening and treatment are virtually non-existent in the regions where most people with sickle-cell trait live. However, there are many opportunities for existing information materials to be locally reproduced at relatively low cost. These can help provide:
   - counselling for people with sickle-cell trait. This would include encouragement to be tested, and counselling for couples at risk;
   - information and counselling for children and adults with sickle-cell disorder and their families. This includes information about management of the disorder, psychosocial counselling and ensuring that sufferers and their families have access to inclusive education and benefit from all their human rights;

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1 Sickle-cell anaemia: Report by the Secretariat. EB117/34, 22 December 2005. World Health Organization. 5 pages. The information about sickle-cell anaemia given in this document is drawn from or consistent with the WHO report.
• training for health care and education personnel. As testing is not universally available and health care personnel do not always recognize the symptoms of sickle-cell disorder. Opportunities to manage the onset of the disorder and therefore minimize the impact over a lifetime are also wasted, and the stigmatization and misunderstanding of sufferers and their families are increased;

• information for employers and prison personnel. People with the disorder can work, but require the understanding of employers to face crises; and

• public information, notably to encourage screening and ensure rights of people with the disorder. This includes making information available in clinics and through health providers, including traditional healers.

6. These categories of intervention require a level of infrastructure that is generally not available in most developing countries. Some Caribbean countries, notably Jamaica and Cuba, form an exception, with sickle-cell disorder being recognized as an important public health issue and enjoying a fairly high level of research and public information. In the rest of the developing world, much remains to be done.

7. The Sickle-Cell Disease International Organization (SCDIO) is one of the leading civil society entities in raising awareness on issues related to this disease. The Organization holds international conferences and effectively lobbies for more attention to be paid to sickle-cell anaemia. Its efforts are encouraging, and all those contacted by UNESCO agreed that civil society initiatives such as this can go far in increasing awareness of the disorder.

Division of labour within the United Nations

8. Health-related issues, including training, support to and upgrading of health personnel, fall under the mandate of the World Health Organization (WHO). UNESCO has been in regular contact with the WHO Secretariat which had already prepared a report on Sickle-cell Anaemia for consideration by the World Health Assembly (WHA) at its fifty-ninth session in 2006. The report provides an authoritative summary of the issues and potential actions around sickle-cell anaemia prevention, diagnosis and treatment. The resolution adopted by the WHA (Annex) clearly states actions to be undertaken by WHO, including community-level primary health care, with the related training of staff, production of guidelines and materials, and support for civil society organizations of patients and parents.

9. UNESCO and WHO, as co-sponsors of UNAIDS, have ongoing collaboration on matters relating to school health and HIV and AIDS education. Under the agreed UNAIDS division of labour, which all members apply mutatis mutandis to other health-related matters, UNESCO is the lead organization in HIV prevention education with young people in educational institutions, in partnership with ILO, UNFPA, UNICEF, WHO and WFP. Matters related to health care settings and personnel, data collection and public information programmes are primarily the responsibility of WHO.

Results of consultation

10. UNESCO has two main ongoing activities related to the health of school-aged children: Focusing Resources on Effective School Health (FRESH) – a joint programme of UNESCO, UNICEF, WHO, the World Bank, Education International, the Education Development Center and the Partnership for Child Development to promote comprehensive school health; and the Global Initiative on Education and HIV and AIDS (EDUCAIDS) – a programme to support implementation of comprehensive national education sector responses to the HIV and AIDS epidemic within the framework of the agreed UNAIDS division of labour.
11. In response to the General Conference resolution, UNESCO reached out to all its FRESH partners, requesting them to report on any activities related to sickle-cell anaemia and reflect on possible actions. The Organization also questioned a number of organizations working in the field and addressed a brief questionnaire to selected National Commissions for UNESCO (in Africa, the Caribbean and Asia) to assess needs and identify common grounds for cooperation. This report takes into account the consultations in the analysis and conclusions. While the fact that only WHO and SCDIO reported international initiatives related to the disorder may seem disappointing, this is consistent with the mandates of the various organizations and inevitable difficult choices that must be made by national and international organizations, foundations and donors in the field of public health.

12. The consultation confirms that sickle-cell anaemia is indeed a disorder lacking attention. There was also strong consensus that the priorities related to sickle-cell disorder are in the field of public health. Public awareness could be stimulated through national campaigns. General awareness of genetic disorders can and should be part of a science curriculum. However, in the countries in which the sickle-cell anaemia disorder is endemic, the proportion of young people enrolled in schools is too low for such initiatives to significantly improve conditions for sufferers.

13. There was no strong opinion among those surveyed for this study on the question of establishing an international day. Nevertheless, it would seem more appropriate for an organization specializing in health rather than education to take the lead in this endeavour. The reason for this is due to the rather specialized nature of the subject, which requires expertise in public health to establish, manage and promote priorities. As the only possible prevention of the disorder is widespread screening and subsequent counselling for those with sickle cell trait, preventive education is probably not a realistic nor effective option, even in resource-rich settings. Anecdotal evidence from consultations reveals that counselling does not have any significant impact on the occurrence of the disorder, although it helps greatly with management of it.

14. The main categories of necessary actions emerging from the consultations are:

   - the need for simple and standard guidelines for diagnosis and control;
   - improved community education and better use of existing materials in resource-poor settings; and
   - exploration of the possibilities of creating regional expert groups to define priorities, problems, approaches and possible sources of funding for activities.

Conclusions

15. The three operational conclusions requested from the feasibility study are:

   (a) **Setting up of an international prevention education programme.** Following its internal and external consultations, UNESCO considers that sickle-cell anaemia is primarily a public health issue that requires raising awareness among adults about the disorder. The school-related issues (adequate response on the part of teachers and other education personnel to children with sickle-cell disorder) could be addressed more substantially through the FRESH partnership and by encouraging the inclusion of information materials about sickle-cell disorder in teacher-training programmes and science curricula. UNESCO, with its FRESH partners, will increase its attention to this issue. The desirability and impetus of an international programme to expand knowledge should be determined either by WHO or by other international or national partners. UNESCO is prepared to collaborate should WHO or any other competent partner initiate such a programme.

   (b) **Setting up of an international fund with extrabudgetary resources.** UNESCO is not in a position, either by mandate or by competence, to be the lead organization in an initiative of
this kind. The appropriate international organization to lead the discussion and programmatic responses would necessarily be the World Health Organization, where an initiative has been launched and an international network of experts created.

(c) Proclaiming 19 June as International day to combat sickle-cell anaemia. An international day to combat a genetic disorder could not be viewed as falling within the mandate of UNESCO. It would not be appropriate for UNESCO to take an official position on the feasibility or suitability of such a day or to make recommendations on the subject.

16. In conclusion, the Director-General feels that UNESCO’s most appropriate role and contribution will be to continue to work with its key partners in school health, inclusive education and teaching of science to encourage the inclusion of information about genetic diseases (notably sickle-cell anaemia) in science teaching, in teacher training and in school health programmes through its FRESH programme. The Director-General stands ready to support any initiatives taken by WHO or other partners requiring input on the school environment or training of education personnel. By its questionnaire (sent out to some 40 key organizations), UNESCO has called attention to the resolution and issues therein. It is willing to do so again when undertaking activities related to science education, human rights and health issues for schoolchildren.
ANNEX

FIFTY-NINTH WORLD HEALTH ORGANIZATION ASSEMBLY WHA59.20
Agenda item 11.4, 27 May 2006

Sickle-cell anaemia

Having examined the report on sickle-cell anaemia;¹

Recalling resolution WHA57.13 on genomics and world health, and the discussion of the Executive Board at its 116th session on control of genetic diseases, which recognized the role of genetic services in improving health globally and in reducing the global health divide;²

Recalling decision Assembly/AU/Dec.81 (V) of the Assembly of the African Union at its Fifth Ordinary Session;

Noting the conclusions of the 4th International African American Symposium on sickle-cell anaemia (Accra, 26-28 July 2000), and the results of the first and second international congresses of the International Organization to Combat Sickle-Cell Anaemia (respectively, Paris, 25-26 January 2002 and Cotonou, 20-23 January 2003);

Concerned at the impact of genetic diseases, and of sickle-cell anaemia in particular, on global mortality and morbidity, especially in developing countries, and by the suffering of patients and families affected by the disease;

Recognizing that the prevalence of sickle-cell anaemia varies between communities, and that insufficiency of relevant epidemiological data may present a challenge to effective and equitable management;

Deeply concerned at the absence of official recognition of sickle-cell anaemia as a priority in public health;

Recognizing the current inequality of access to safe and appropriate genetic services throughout the world;

Recognizing that effective programmes for sickle-cell anaemia must be sensitive to cultural practices, and appropriate for the given social context;

Recognizing that the pre-natal screening of sickle-cell anaemia raises specific ethical, legal and social issues that require appropriate consideration;

1. URGES Member States having sickle-cell anaemia as a public health problem:

(1) to develop, implement and reinforce in a systematic, equitable and effective manner, comprehensive national, integrated programmes for the prevention and management of sickle-cell anaemia, including surveillance, dissemination of information, awareness-raising, counselling and screening, such programmes being tailored to specific socio-economic, health systems and cultural contexts and aimed at reducing the incidence, morbidity and mortality associated with this genetic disease;

¹ Document A59/9.
² See document EB116/2005/REC/1, Summary record of the first meeting, section 4.
(2) to work to ensure that adequate, appropriate and accessible emergency care is available to persons living with sickle-cell anaemia;

(3) to develop their capacity to evaluate the situation regarding sickle-cell anaemia and the impact of national programmes;

(4) to intensify the training of all health professionals and community volunteers in high-prevalence areas;

(5) to develop and strengthen systematic medical genetics services and holistic care, within existing primary health care systems, in partnership with national and local government agencies, and non-governmental organizations, including parent/patient organizations;

(6) to promote community education, including health counselling, and associated ethical, legal and social issues;

(7) to promote effective international cooperation in combating sickle-cell anaemia;

(8) in collaboration with international organizations, to support basic and applied research on sickle-cell anaemia;

2. REQUESTS the Director-General:

(1) to increase awareness of the international community of the global burden of sickle-cell anaemia, and to promote equitable access to health services for prevention and management of the disease;

(2) to provide technical support and advice to national programmes of Member States through the framing of policies and strategies for prevention and management of sickle-cell anaemia;

(3) to promote and support:

   (a) intercountry collaboration to develop training and expertise of personnel and to support the further transfer of advanced technologies and expertise to developing countries;

   (b) the construction and equipment of referral centres for care, training and research;

(4) to continue WHO’s normative functions in drafting guidelines, including good practices and practical models, on prevention and management of sickle-cell anaemia with a view to elaborating regional plans and fostering the establishment of regional groups of experts;

(5) to promote, support and coordinate the research needed on sickle-cell disorders in order to improve the duration and quality of life of those affected by such disorders.

Ninth plenary meeting, 27 May 2006
A59/VR/9