Implementation of the Universal Declaration on the Human Genome and Human Rights *

Recalling the Universal Declaration on the Human Genome and Human Rights,

Bearing in mind 29 C/Resolution 17 entitled "Implementation of the Universal Declaration on the Human Genome and Human Rights",

Noting resolution 1999/63 entitled "Human Rights and Bioethics", adopted by the United Nations Commission on Human Rights at its fifty-fifth session,

Also noting the Director-General's report on the implementation of the Declaration (30 C/26 and Add.),

1. Endorses the Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights annexed to this resolution;

2. Invites the Director-General to transmit them to the Secretary-General of the United Nations, with a view to the fifty-fourth session of the General Assembly of the United Nations and to the work of the relevant bodies, in particular the United Nations Commission on Human Rights;

3. Further invites the Director-General to transmit them to the United Nations Specialized Agencies and to other relevant international governmental and non-governmental organizations and to disseminate them as widely as possible;

4. Invites Member States, international governmental and non-governmental organizations and all identified partners to take all the necessary steps to implement the Guidelines.

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*Resolution adopted on the report of Commission III at the 25th plenary meeting, on 16 November 1999

Annex: Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights

1. Why guidelines?

The Universal Declaration on the Human Genome and Human Rights sets forth the basic principles bearing on research in genetics and biology and the application of its results. In order to guarantee the application of these principles, the Declaration recommends that they be made known, disseminated and given shape as measures, especially in the form of legislation or regulations. The Declaration also specifies the measures that Member States should take for its application.

The implementation of the Declaration is all the more urgent since scientific progress in genetics and biology is accelerating and both giving humankind hope and creating ethical dilemmas.

These Guidelines seek to identify not only the tasks devolving on the different actors in the implementation of the Declaration but also modalities of action for their achievement.

2. What to do?	3. How?	4. For whom are these guidelines intended?
2.1 The dissemination of the principles set forth in the Universal Declaration on the Human Genome and Human Rights is a priority and a preliminary condition for their effective application. Thus, this dissemination must be as wide as possible and especially oriented towards scientific and intellectual circles, people involved in education and training, especially in universities, and decision-making bodies such as parliaments.	3.1.1 The translation of the Declaration into the largest possible number of national languages. 3.1.2 The organization of seminars, symposia and conferences at the international, regional, subregional and national levels (in Benin, Croatia, Monaco, United Republic of Tanzania, Uruguay, etc.).	Experience shows that to implement an international instrument, synergy needs to be created between all actors at the different levels. Today, international action is characterized by partnership in which each actor, while retaining his identity and specific nature, complements the role played by the others.

2.2 Consciousness-raising, education, and training regarding the principles contained in the Declaration are especially important goals if each and every member of society is to grasp the ethical issues at stake in genetics and biology.	3.2.1 The drafting of the simplest and most explicit possible commentary on each of the articles of the Declaration. 3.2.2 The publishing of books on the subject, designed both for a non-specialist public and for the various professional groups concerned (for example scientists, philosophers, jurists, judges and journalists). 3.2.3 The preparation of programmes of education and training in bioethics designed for the secondary and university levels. 3.2.4 The preparation of training programmes in bioethics designed for teachers and trainers. 3.2.5 The preparation of information kits on specific subjects and their dissemination among public and private decision-makers and the media. 3.2.6 The production of audiovisual materials on bioethics for the general public. 3.2.7 Multimedia exhibitions designed especially for young people.	These guidelines are intended for: ● States and National Commissions for UNESCO; ● UNESCO (Headquarters and field offices); ● the International Bioethics Committee (IBC); ● the Intergovernmental Bioethics Committee (IGBC); ● bodies and specialized institutions of the United Nations system; ● competent governmental and non-governmental organizations at the international, regional and national levels; ● public and private decision-makers, especially in science policy; ● lawmakers; ● ethics committees and similar bodies; ● scientists and research workers; ● individuals, families and populations with genetic mutations that may lead to illnesses or disabilities.

2.3 Exchanges of studies and analyses pertaining to questions of bioethics, and programmes of information on this subject must be organized at the international and regional levels, especially in order to identify practices that could be contrary to human dignity.	3.3.1 The creation of bodies such as independent, pluralist and multidisciplinary ethics committees which would be special partners for decision-makers, the scientific community and civil society. 3.3.2 The networking of these institutions so as to facilitate communication and exchanges of experience among them, especially for carrying out joint activities.	
2.4 The establishment of a dynamic relationship between the different actors is desirable in order to promote dialogue among industrialists, members of civil society, vulnerable groups, scientists and political leaders.	3.4.1 The involvement of the economic actors, especially from industry, and of social organizations such as associations of vulnerable persons and their families and friends. 3.4.2 The organization of public debates on issues covered by the Declaration and the exploration of various approaches (conferences for consensus-building, public consultation, etc.).	

2.5 Freedom of research, especially in genetics and biology, should be respected and scientific and cultural cooperation encouraged and broadened, especially between the countries of the North and the South.	3.5.1 In-depth analysis of the conditions which encourage freedom of research and those which hamper it. 3.5.2 The periodic examination by the IBC of cooperation between the countries of the North and the South and an examination of any obstacles, in order to overcome them.	
2.6 Examples of legislation and regulations that embody the principles set out in the Declaration should be prepared as a source of inspiration for States.	3.6.1 The organization by the IBC of international and/or regional workshops aimed at providing a standard framework of legislation and regulations in the field of bioethics. 3.6.2 The collection and processing of information on the international and regional instruments pertaining to bioethics as well as on national legislation and/or regulations.	

2.7 As most of the issues covered by the Declaration are at the interface of the fields which fall within the assigned tasks of the various organizations, it is through effective cooperation that they will be able to deal with issues in a concerted manner.*	3.7.1 The setting up of an inter-agency committee within the United Nations system open to other interested inter-governmental organizations and responsible for the coordination of activities related to bioethics.	
* See paragraph 3 of resolution 1999/63 entitled "Human Rights and Bioethics" adopted by the United Nations Commission on Human Rights at its fifty-fifth session.		

5. Evaluation

Five years after the adoption of the Declaration, in 2002, UNESCO should evaluate both the results obtained through the guidelines defined above and the impact of the Universal Declaration on the Human Genome and Human Rights worldwide (States, intellectual communities, institutions of the United Nations system, intergovernmental organizations - international and regional - competent non-governmental organizations, etc.).

The evaluation, which should be carried out in accordance with the procedures established by the Executive Board and the General Conference, in particular because of its budgetary implications, will be examined at a joint session of IBC and IGBC and will be submitted by the Director-General in 2003 to the statutory bodies of the Organization along with any relevant recommendations.