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Report of the IBC on Solidarity and International Co-operation between Developed and Developing Countries concerning the Human Genome

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I. INTRODUCTION

1. By virtue of the mandate assigned by its Constitution, UNESCO has the vocation to develop intellectual co-operation in all its forms. The Preamble of the Constitution of UNESCO affirms that *"the wide diffusion of culture, and the education of humanity for justice and liberty and peace are indispensable to the dignity of man and constitute a sacred duty which all the nations must fulfil in a spirit of mutual assistance and concern"*. In the following paragraph it is stated that *"peace must therefore be founded, ... upon the intellectual and moral solidarity of mankind"*.

2. Article 1 of the Constitution, entitled "Purpose and functions", deals more directly with the question of co-operation. Paragraph 2(c) assigns the Organization the fundamental task of helping *"maintain, increase and diffuse knowledge ... by encouraging co-operation among the nations in all branches of intellectual activity, including the international exchange of persons active in the fields of education, science and culture..."*.

3. Article 15 of the United Nations International Covenant on Economic, Social and Cultural Rights of 16 December 1966 recognizes that everyone has the right *"to enjoy the benefits of scientific progress and its applications"*. It also states that *"States Parties to the present Covenant recognize the benefits to be derived from the encouragement and development of international contacts and co-operation in the scientific and cultural fields"*.

4. Furthermore, the UNESCO Recommendation on the Status of Scientific Researchers of 20 November 1974 deals with the question of scientific co-operation, in Section IV in particular. This section is devoted to the vocation of the scientific researcher, firstly as regards the civic and ethical aspects of research and, secondly, as regards its international aspects. In particular, Article 16, recognizing that *"scientific workers encounter, with increasing frequency, situations in which the scientific research and experimental development on which they are engaged has an international dimension"*, stipulates that States should endeavour to assist scientific researchers *"to exploit such situations in the furtherance of international peace, co-operation and understanding, and the common welfare of mankind"*.

5. The Declaration on Science and the Use of Scientific Knowledge, adopted by the World Conference on Science (Budapest, Hungary) on 1 July 1999, mainly refers, particularly in paragraph 3 ("Science for Development"), to international co-operation and to the sharing of scientific knowledge.

Human Genome Research

6. One of the areas where solidarity and international co-operation will become a crucial issue is undoubtedly that of genetic research, especially in the light of recent progress made in human genome sequencing.

7. The notion of 'developed' and 'developing countries' must itself be redefined in the context of biotechnology. Some countries, traditionally classified as developing, are playing an active part in research on the human genome, while others are not.

8. These recent developments have implications for both the developing and the developed countries. They give rise – sometimes simultaneously – to hopes and fears and must be placed in a suitable framework to enable all countries to derive substantial benefits.

9. Research on the human genome and its applications, which are the subject of this report, cannot be isolated from other fields of biotechnology. In the debate on genetically modified organisms (GMOs), for instance, issues concerning solidarity and international co-operation cannot be ignored. It goes without saying that the issues raised by human genome sequencing do not exhaust the subject of solidarity and international co-operation in the life sciences. A number of other issues are raised, particularly in terms of access to health care, access to new therapeutic treatment stemming from genetic engineering (especially gene therapy and new drugs and vaccines), use of new biotechnology, in food and agriculture for example, transfer of knowledge and technology or, further still, with regard to tissue and organ transplants or in terms of protection of biodiversity. The appearance in the debate of new participants, such as non-governmental organizations (NGOs) or private enterprise, has a direct influence on the implications of research and on the ethical debate over new technologies and the human genome.

10. Within the framework of its reflection, the International Bioethics Committee (IBC) has already dealt with, *albeit* indirectly, the question of international co-operation in different fields – see the Report on Human Gene Therapy[1], the Report on Bioethics and Human Population Genetics Research[2], the Report on Food, Plant Biotechnology and Ethics[3], the Report entitled "Ethical Considerations regarding Access to Experimental Treatment and Experimentation on Human Subjects"[4] and the Report of the Fifth Session of the IBC[5].

The Universal Declaration on the Human Genome and Human Rights

11. The first universal instrument concerning the human genome, the **Universal Declaration on the Human Genome and Human Rights** – adopted by the General Conference of UNESCO in 1997 and endorsed by the United Nations General Assembly in 1998 – by the ethical foundations set out therein is an instrument that should serve as a basis for present and future policies of solidarity and international co-operation.

12. Section E of the Declaration (articles 17, 18, 19) is devoted specifically to solidarity and international co-operation. Article 17 describes the measures that States should take to ensure respect for and promotion of active solidarity towards individuals, families and population groups who are particularly vulnerable to or affected by disease or disabilities of a genetic nature. Such solidarity should take two forms. First, it should allow those concerned to exercise their rights freely and with dignity. Secondly, states should encourage research on identification, prevention and treatment of genetically-based and genetically-influenced diseases, in particular rare

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1. See *Proceedings of the Second Session of the IBC*, Vol. I 1995.
2. See *Proceedings of the Third Session of the IBC*, Vol. I 1995.
3. See *Proceedings of the Fourth Session of the IBC*, Vol. I 1996.
4. Idem.
5. See *Proceedings of the Fifth Session of the IBC*, Vol. I 1998.

diseases, as well as endemic diseases affecting large numbers of the world's population.

13. Article 18 stipulates that States should *"make every effort ... to continue fostering the international dissemination of scientific knowledge"* in three specific areas: first, the human genome as an element of general culture; secondly human diversity; and finally, in genetic research. This Article also stresses the need for scientific and cultural co-operation with respect to human genome research, in particular between the industrialized and the developing countries.

14. Article 19, paragraph (a), lists what should be the main objectives of international co-operation with developing countries. The aim is to assess *"the risks and benefits pertaining to research on the human genome to be carried out and abuse to be prevented"*, in particular with respect to research which is liable be carried out in those countries. Similarly, this Article provides for the development and strengthening of the capacity of developing countries to carry out research in biology and genetics. A further clause stipulates that the results and benefits of research, which is carried out primarily in the industrialized countries, should serve to promote economic and social progress for all. Finally, paragraph (a) stresses the importance of the free exchange of knowledge and information in the fields of biology, genetics and medicine. Paragraph (b) emphasizes the role to be played by the relevant international governmental and non-governmental organizations in such co-operation.

15. Within the framework of this report other articles of the Declaration should be recalled, viz. Articles 1[(6)], 4[(7)] and 12[(8)].

16. It should also be recalled that the Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights, endorsed by the General Conference at its 30th session (30 C/Res.23), make two specific references to North-South co-operation. Point 2.5 of the Section entitled "What to do?" states that *"scientific and cultural co-operation should be encouraged and broadened, especially between the countries of the North and the South"*. Within the framework of the modalities of action, point 3.5.2 provides for the *"periodic examination by the IBC of co-operation between the countries of the North and the South and an examination of any obstacles, in order to overcome them"*.

II. GENERAL FRAMEWORK OF SOLIDARITY AND INTERNATIONAL CO-OPERATION

17. The new forms of co-operation between developed and developing countries and the appearance of regional or "South-South" forms of co-operation cause the general framework of solidarity and international co-operation to evolve. This is particularly true in the field of genetic engineering where the appearance of private

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6. "*The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity."*

7. *"The human genome in its natural state shall not give rise to financial gains."*

8. *"a) Benefits from advances in biology, genetics and medicine, concerning the human genome, shall be made available to all, with due regard for the dignity and human rights of each individual.*

b) Freedom of research, which is necessary for the progress of knowledge, is part of freedom of thought. The applications of research, including applications in biology, genetics and medicine, concerning the human genome, shall seek to offer relief from suffering and improve the health of individuals and humankind as a whole."

players such as pharmaceutical companies accentuates the complexity of relations between the different partners.

1. Solidarity in relation to individuals, families and populations in respect of the human genome

18. With its applications, human genome research is of central interest to the populations of the developing countries. It is a source of hope in many fields (for example, research into diseases such as malaria or AIDS); but it may also create risks (abusive use of genetic resources, genetic discrimination). As the developing countries often lack the financial or technical capacities – and at time professionals having received the required training - needed to carry out this type of research, mechanisms of solidarity need to be foreseen. Their purpose is firstly to encourage the dissemination of knowledge and to strengthen protection of the population, families and individuals and secondly to better distribute the benefits arising from exploitation of the human genome.

19. Solidarity has been expressed through various legal instruments seeking to protect the populations against abuse in connection with genetic research and testing. The indigenous populations, which live in certain developing countries, have certain specific genetic features, which may be of particular interest to research. Protection of these populations is essential to safeguard respect for human rights, just as it is necessary for respect of the individual identity.

20. The **Human Genome Diversity Project (HGDP)** is an international project, whose aim is to understand the diversity and unity of the human species by studying the genetic characteristics of populations throughout the world. Only consenting populations can undergo genetic testing. The functional part of this project is divided into regional groups; at present, only South-East Asia and China have collected DNA samples. According to the project leaders, the results obtained will be used for medical research beneficial to the populations concerned and should not be exploited for commercial purposes.

21. The **GDB (Genome Database)** was created in 1990 in order to make available to researchers the results of work on the sequencing of the human genome. It is directly related to the Human Genome Project (see below). The GDB is financed by private funds; everyone can access its data without charge and without distinction on grounds of nationality through a number of mirror sites on the Internet. The GDB has set up such sites in China and will be doing so shortly in India and South Africa.

22. Many initiatives have been taken by international governmental organizations and a number of non-governmental organizations in the context of solidarity with a view to protection of deprived persons or development of scientific projects. For example, the **World Health Organization (WHO)** is particularly active in the financing of research into rare genetic diseases and endemic diseases in developing countries. **UNESCO** has set up chairs of biotechnology in the universities of the developing countries, together with centres of excellence, and is contributing to the training of researchers, aid to research and dissemination of bioethics.

2. Co-operation

23. Co-operation between developed and developing countries takes many different forms today. Other more complex forms of co-operation involving the intervention of other actors have been added to traditional bilateral co-operation between two States.

a) Bilateral

24. Bilateral co-operation, which remains the privileged instrument of the development aid policies pursued by the developed countries, has highly specific features in the field of the human genome. While collaboration exists with countries such as Argentina, Brazil, China, India, Mexico, the Republic of Korea, or South Africa, which are all countries with structures for genetic research, such co-operation is practically non-existent with countries that are less advanced technologically. Only accords concerning certain consequences of human genome research (e.g. in the areas of biodiversity and endemic diseases) have been signed with the latter. However, such accords are more in the nature of solidarity than of effective international scientific co-operation. Here are a few examples of bilateral international co-operation.

25. **France** and **India** have drawn up a co-operation programme following a letter of intent signed in 1998 by Mr Claude Allègre (Minister of National Education, Research and Technology in France) and Mr Y.K. Alagh (Minister of Energy, Research and Technology of India). Co-operation as such has been implemented by the National Centre for Scientific Research (CNRS – France) and the Department of Biotechnology (India). Its scope concerns such matters as co-operation on research into the human X chromosome and a project dealing with the genetic origins of epilepsy.

26. **Germany** and **China** organized a "Sino-German Conference on Genes, Evolution and Diseases" in Beijing from 19 to 22 April 1999. They have also arranged an exchange of researchers.

27. The **United States of America** and **South Africa** are at the origin of the STACK Project (Sequence Tag Alignment and Consense Knowledgebase), set up by the National Center for Genome Resources (NCGR – United States) and by the South African National Bioinformatics Institute with a view to creating a public database on human genome sequences discovered and on biotechnology research tools.

28. "South-South" co-operation has been undertaken between **Argentina** and **Brazil.** In 1986, the two countries created a Brazil-Argentina Centre for Biotechnology. Since 1987, this has been giving courses on bioethics. This is an example of bilateral co-operation between two developing countries, which are active in the field of life technology.

29. Another example of co-operation between two developing countries is provided by the **Republic of Korea** and **China** (again two countries that have reached an advanced stage in human genome research). They have set up two centres: in 1997, the Korea-China and Biotechnology Corporation Centre in the Republic of Korea and, in 1998, the China-Korea Bioscience and Biotechnology Co-operation Centre in Shanghai, China.

30. Many examples of bilateral co-operation exist between universities and research institutes worldwide. These are often local agreements on precise projects. Many exchange of researchers have also been organized.

b) Multilateral

31. A number of projects have been born from multilateral accords. They have often given rise to the creation of new international structures. The number of countries involved in such projects is frequently dependent on the technological capacity of these countries.

32. The **HGP (Human Genome Project)** is a programme for international co-operation seeking to complete the sequencing of the human genome. Created initially by the United States of America (Department of Energy - DoE and National Institutes of Health - NIH), it was then laid open to other countries. Today, over twenty institutions are working on the project in Australia, China, France, Germany, Greece, Japan, Spain, the United Kingdom and the United States of America. The contribution of other developing countries remains marginal because of the research costs.

33. **HUGO (the Human Genome Organization)** was set up in 1988. HUGO is an international organization of scientists involved in the Human Genome Project. It has a thousand or so members, drawn from nearly sixty countries. HUGO also has three regional offices (HUGO Europe, HUGO Americas and HUGO Pacific). The organization meets once a year to discuss the implications of work on human genome sequencing. The aim of the organization is to co-ordinate scientific research to facilitate exchanges of data and technologies and encourage information and public debate on the ethical aspects of the Human Genome Project.

34. **ICGEB (the International Centre for Genetic Engineering and Biotechnology)** is an international research centre specially oriented towards the needs of the developing countries, which seeks to apply the principles of human rights in genetic research. Its two offices in Trieste (Italy) and New Delhi (India) involve around three hundred scientists and are associated with sixty or so countries. The research carried out in Trieste and New Delhi covers diverse fields of human genetics, for example genetic research concerning malaria.

35. A number of international co-operation projects have been set up for specific purposes. For example, **GSEC (International Collaborative Study on Genetic Susceptibility to Environmental Carcinogens)** is an international programme concerning the interactions between polymorphic genes and cancer. One aim of the project is to encourage co-operation between all researchers working on this subject. A certain number of them carry out their activities in developing countries and in Central and Eastern Europe.

c) Regional

36. Regional research in the developing countries was initially set up in the agricultural area. It was because of food supply problems that developing countries conducted priority studies in this field. However, most of this research is associated with human genome research and the question of tropical or endemic diseases should encourage the developing countries to set up human genetic projects. Latin America is particularly active in this field. Herebelow some examples of regional co-operation.

37. **RELAB (Latin-American Biological Sciences Network**) appeared in 1975 following an initiative of the United Nations Development Programme (UNDP) and UNESCO. It is the first regional biology network to have been created and has served as an example for future networks in Africa, Asia and the Arab countries. RELAB seeks to expedite scientific and technological development of the participant countries, to develop biological research into problems directly associated with development and to stimulate exchanges between these countries. In 1982, it created the **Latin-American Programme on Biotechnologies** and in 1988 the **Latin-American Programme on the Human Genome (PLAGH).** PLAGH is an original regional instrument, which enables Latin American countries to participate in human genome research and its applications.

38. **CYTED (Ibero-American Programme on Sciences and Technologies for Development)** is an international programme in which nineteen Latin American countries, Portugal and Spain take part. One division of this programme relates specifically to biotechnology. In this division, three international co-operation projects concerning the human genome have been put in hand. The Central American Network for Co-operation on Tropical Diseases (REDCEN), a pluridisciplinary network dealing with the effects of biotechnological development and an Ibero-American network of molecular genetics applied to legal medicine. A fourth project is likely to be put in hand on biotechnology applied to the development and methods for the diagnosis of infectious diseases.

39. **RICYT** (Ibero-American Network of Science and Technology Indicators), **INFOCyT** (Information Network on Science and Technology), **SYMBIOSIS** (Multinational System of Information specialized in biotechnology and food technology for Latin America and the Caribbean) and **MERCOCyT** (Common Market for Scientific and Technological Knowledge) are also regional actors which facilitate the exchange of information between researchers and between the institutes of the Latin American countries. All these organizations work in co-operation with the **Organization of American States (OAS)**, whose Science and Technology Office is responsible for biotechnology.

40. The **Inter-American Development Bank (BID)** is also active in financing technological programmes and has created the IDU (Information Technology for Development). However, it has no projects specifically linked to the human genome.

41. Finally, the Human Genome Organization (HUGO) is also present in South America through one of its three regional bodies: HUGO Americas.

42. In Asia, regional co-operation has developed through the impetus of countries such as China, India and Japan, together with the member countries of the Association of South-East Asian Nations (ASEAN), such as the Philippines, the Republic of Korea or Thailand which are all active in biotechnology. ASEAN itself, as an association, has undertaken many regional programmes and a working group on biotechnology was set up as long ago as in 1983.

43. In Africa, regional programmes are limited and generally deal with scientific research and technology. Co-operation involving partnership between the French-

speaking countries does exist through the **Network for Genetic Teaching of the Virtual Francophone University (GENET)**. This network currently groups together seven universities and an institute throughout five countries (Benin, Burkina Faso, France, Switzerland and Togo). Via the Internet, a common teaching programme can be followed and a system of "answers to questions" has been created, together with the possibility for exchanges between users (students and teachers).

d) Transnational (between private sectors and States and between private sectors in different countries)

44. The private sector is playing an essential role in biotechnology today. Increasingly, co-operation efforts must involve these new participants, notably to enable the developing countries to benefit from the applications of research into human genetics.

45. The example of the fight against AIDS gives us an idea of the need for, and difficulty of, such co-operation between the public and private sectors. In this field, five companies (Boehringer Ingelheim, Bristol-Myers Squibb, F. Hoffmann-La Roche, Glaxo Wellcome and Merck & Co., Inc.) and five institutions and specialized agencies of the United Nations system (WHO, World Bank, UNICEF, UNFPA and UNAIDS) have launched a process of negotiation with a view to giving the population of the developing countries the benefit of new therapies. (Similar agreements must be adopted for applications of human genome research.)

46. Many commercial companies play an active part in human genome research, even if potential profit sources still seem remote. In 1993, SmithKline concluded agreements to have access to data on the human genome. The new Glaxo SmithKline company (created by the merger of Glaxo Wellcome and SmithKline Beecham) is now working on the identification of genes, for example those involved in asthma (*BusinessWeek Online*, 12 June 2000).

47. Foundations and NGOs are also playing an active part in solidarity and international co-operation. The case of the **Wellcome Trust** is exemplary. This non-profit British institution disseminates and conducts medical research. It has taken part in the work of human genome sequencing by financing the Sanger Centre, one of the main sequencing centres of the Human Genome Project. It has also invested in many international programmes relating, in particular, to research into tropical diseases, foremost among them being malaria (*Le Monde*, 21 June 2000).

3. International Organizations

International organizations of a universal nature

48. The **United Nations Organization (UNO)** plays an active part in the field of the human genome through its various institutions and specialized agencies. The politicization of bioethical questions and matters of biosecurity will no doubt make the UNO an important actor in the future. The fact that the United Nations General Assembly, in 1998, endorsed the Universal Declaration on the Human Genome and Human Rights, thus confirming with force the legitimacy of the principles set out therein, bears particular importance for developing countries.

49. The **United Nations Development Programme (UNDP)** has no specific programme dealing with the human genome and the developing countries. Nevertheless with its Technical Co-operation among Developing Countries (TCDC), it takes part in "South-South" co-operation programmes in the field of science and technology. The **United Nations Conference on Trade and Development (UNCTAD)** does not have any programme in this field either, but it remains an important forum for exchanges between the developing and developed countries.

50. **UNESCO** has been involved for a long time in biology. It is active in many fields relating directly to human genome research. Firstly it has been at the origin of five South-North Human Genome Conferences in Brazil (1992), China (1994), India (1995), Mexico (1997) and Namibia (1999). The organization also plays a central role in exchanges of researchers and in the training of scientists in the developing countries, notably through centres of excellence and in universities where several chairs of biotechnology have been set up. Finally, it originated several regional programmes such as PLAGH (see above) and co-operates with several other organizations on specific human genome programmes.

51. The **World Health Organization (WHO)** plays a particularly active role in this domain through its human genetics programme. It has pursued a policy of prevention and knowledge of diseases linked to the human genome. It has also endeavoured to develop a network of worldwide co-operation through its various programmes (co-operation with over 80 countries). It contributes actively to the training of doctors and has organized many courses (e.g. on methods of genetic diagnosis). More specifically, it has created training courses for specialists from the developing countries and is co-operating with its regional offices in Africa, America, Europe, the Eastern Mediterranean, South-East Asia and the Western Pacific in the fight against the spreading of genetic diseases. It also has an internal WHO Committee of evaluation of research protocols involving human beings (SCRIHS).

52. The **United Nations Organization for Industrial Development (UNIDO)** contributes to the dissemination of technological innovations. However, it does not at present have any project directly linked to human genome research. A new agency, created within UNIDO, the **Asia-Africa Investment and Technology Promotion Centre (AAITPC)**, seeks to promote "South-South" international co-operation in Asia and Africa.

53. The **International Vaccine Institute (IVI)** was created by UNDP and is active in research and distribution of vaccines in the developing countries. In 1996, it held a symposium on biotechnology and world health. With its headquarters in Seoul, Republic of Korea, one aim of this Institute is to promote the role of biotechnology in vaccine research.

54. The **World Bank** does not at present have any projects dealing directly with the human genome, but remains a vital player in solidarity and international co-operation and can be called upon to fund specific programmes.

Other intergovernmental and non-governmental organizations

55. The **Organization for Economic Co-operation and Development (OECD)** showed an early interest in genetic technology. In the 80s, a group of OECD experts drew up recommendations concerning security in the use of biotechnology. In the 90s, the Organization set up several working groups on human genetics. For example, the OECD organized a workshop on xenotransplants, which met in New York in 1998, following which it was decided, in co-operation with WHO, to develop monitoring standards. An Internet site on xenotransplants gives public access to scientific information and details of the social and ethical implications of these new technologies. In February this year, a workshop on genetic testing was held in Vienna at which ethical and technical guidelines for the new millennium were discussed.

56. The **International Council for Science (ICSU)** is directly involved in human genome programmes. It has set up a Steering Committee on Genetics and Biotechnology (SCGB), which is an interface between genetics, genomics and biotechnology and studies the impacts of the new technologies on commercial activities and on society. Another committee, the Committee on Responsibility and Ethics in Science (SCRES) was set up in 1996 to deal with the ethical problems raised by science. A third committee is directly linked to the relations between the developed and developing countries. This is the Committee on Science and Technology in Developing Countries (COSTED). In 1993, this Committee took over the International Biosciences Network (which had been founded in 1979 by ICSU and UNESCO). The task of this committee is to integrate scientists from the developing countries into international programmes; it also contributes to the enhancement of the technological capabilities of these countries. Finally, a programme of study grants has been drawn up in co-operation with UNESCO and the Third World Academy of Science (TWAS).

57. The **Third World Academy of Sciences (TWAS)** is an autonomous international organization founded in Trieste, Italy, in 1983. It was officially put in place by the Secretary General of the United Nations in 1985. In co-operation with UNESCO and ICSU, as indicated previously, a programme of study grants has been created for research and exchanges on the human genome. This is designed to enable those researchers from countries lacking the necessary technical capability to carry out such research to do so elsewhere. In 1988, an initiative was taken to create the **Third World Network of Scientific Organizations (TWNSO)** in order to encourage exchanges between developing countries.

58. It should be further noted that a network now links together various international organizations on matters of biotechnology safety: the **Inter-Organizational Network on Biotechnological Safety (INBS)**. This network groups together eleven organizations active mainly in the fields of agriculture, development and health.

III. SOLIDARITY AND INTERNATIONAL COOPERATION WITHIN THE SPECIFIC FRAMEWORK OF THE HUMAN GENOME

59. It seems clear that co-operation is necessary in the context of research concerning the human genome and its applications. It promotes the pooling of knowledge and technologies while avoiding the duplication of effort. This beneficial co-operation can, however, be contrary to the interests of some countries or companies, which hope to monopolize information or techniques.

60. The IBC considers that solidarity and international co-operation in this field should develop at several levels. It should encourage, support and promote:

- Free access to knowledge and scientific information

61. Information on the human genome in its natural state must be accessible to all humankind without restriction. It is important for the universities, research institutes and companies to have raw information to be able to undertake in-depth research.

62. The adoption by UNESCO of the Universal Declaration on the Human Genome and Human Rights, its endorsement by the United Nations General Assembly and the recent stands taken by a number of leaders (in particular the final communiqué of the Okinawa Summit) give reason to hope that the results of human genome sequencing will be freely available.

63. It is important to recall that already in 1992, Professor Charles Auffray (France) presented UNESCO with the conclusions of work carried out by his research team *Génexpress*. This data, which included a compilation of 2,236 DNA sequences, has been made public in international electronic data banks and is thus accessible to all interested parties.

64. A number of international organizations are active in the dissemination of scientific knowledge. UNESCO is involved in this task, as are WHO and the United Nations Organization. The specific purpose of HUGO is the exchange of knowledge and the principle of the Human Genome Project is the sharing of research results.

65. A majority of States is also favourably disposed to the dissemination of knowledge about the human genome in its natural state. Programmes for co-operation between universities and research institutes are involved in this effort.

66. The developing countries are largely dependent on the goodwill of the developed countries and companies for access to scientific information. The awareness of the importance of human genome research does, however, allow them to influence decisions, notably those taken by international organizations and NGOs. It is also by developing their own research capabilities that these countries will influence the world debate on knowledge of the human genome. Some developing countries have understood this.

67. Finally, the fast progress of new information technology, closely linked to the progress of knowledge on the human genome, can provide an opportunity to facilitate access by all countries to scientific information. The creation of the Genome Data Bank (GDB) was thus made possible through the development of the Internet.

- Access to scientific knowledge and information through training of researchers and experts in the field of human genetics

68. The training of researchers and specialists is the concern of a number of international organizations, such as UNESCO. Through centres of excellence and chairs of biotechnology in the university faculties of the developing countries, UNESCO is helping to train researchers. Study grant programmes have also been created with other international organizations allowing students from the developing

countries to go to the countries in which human genome technology exist. However, the risk of a "brain drain" is not negligible.

69. Programmes for the exchange of researchers have also been undertaken by States and universities. The development of distance teaching can be a solution to restrict training costs.

- Research in human genetics

70. Research in human genetics is possible only in countries where the necessary infrastructures exist. In years to come, research costs will, however, fall and new technologies are certain to appear. Both international organizations and States can therefore participate and encourage the creation of research tools in the developing countries **as well as the transfer of technology on reasonable terms**. UNIDO, for instance, is encouraging the creation of technology projects, which can be useful for the application of biotechnology to medicine.

71. Genetic research presupposes a willingness on the part of the actors concerned to contribute financially. Research does not generally lead directly to commercial applications. The authorities concerned are therefore reluctant to allocate funds. International organizations and the developed countries should assist the developing countries in the field of human genetics without expecting financial profit. Similarly, credit agencies such as the World Bank or regional development banks should be able to finance projects of this type. The creation of an international mechanism or a fund financed from a proportion of the profits earned, would enable a part of the research conducted in the developing countries to be financed.

- Implementation of research and educational structures

72. Over and above the infrastructures already advocated, international organizations and the developed countries should participate in the setting up of research and education structures enabling the developing countries to conduct human genome research. UNESCO must be involved in this task for education, as must the UNDP and the International Education Office (IEO).

73. The creation of research structures, that are often cumbersome, expensive and difficult for a single country to manage, can be put in place through "South-South" co-operation or regional programmes.

- Evaluation of risks and benefits of human genome research

74. New technologies concerning the human genome often bring both risks and benefits for the developed countries and developing countries alike. An effort of co-operation must enable the various actors concerned to take stock of the benefits and drawbacks. International institutions must be called upon for this purpose, in a desire for objectivity so as to avoid the appearance of new forms of discrimination towards the developing countries.

IV. RECOMMENDATIONS

75. At the outcome of its reflections, the IBC recommends a two-folded approach in order to stimulate international solidarity and co-operation between developed and developing countries concerning the human genome.

A. Bilateral, multilateral and transnational co-operation

76. The IBC recommends that States be invited to promote bilateral, multilateral and transnational co-operation concerning the human genome. Such co-operation should seek to support existing centres of excellence in developing countries or creating them when they do not exist. It should give priority to promoting scientific research in those countries and to the transfer of technology implied by genetic research and its applications.

B. Creation of a mechanism or an international fund

77. The IBC recommends to the Director-General to call for the creation of a mechanism or an international fund, financed from a proportion of the profits of private and public companies earned from human genome data as well as from other sources. Such a mechanism or fund would permit, in accordance with Articles 14, 17, 18, 19, 20 and 21 of the Declaration, the financing of:

- education and training (exchange of scientists and researchers, fellowships and travel grants, in-service refresher courses, etc.);
- dissemination and information (access to available information generated by the human genome mapping, publication facilities, etc.);
- scientific research (joint projects between developed and developing countries or between developing countries);
- transfer of technology (infrastructure, logistics and maintenance);
- ethical research, education and information (national or regional projects of ethical analysis of issues raised by genetic research or their applications as well as ethical educational and information programmes);
- support to vulnerable groups.

78. Once the principle of the creation of such a mechanism or international fund has been established, UNESCO should undertake a feasibility study. Such a feasibility study should involve all actors concerned, governmental and non-governmental, private and public, in order to outline the functioning of the mechanism or international fund, the criteria of contributions as well as the attributions of the funds, etc. The feasibility study should also review mechanisms or international funds, within and outside the United Nations system, which can serve *mutatis mutandis* as examples.

V. CONCLUSION

79. No doubt it is too soon, three years after the adoption of the Universal Declaration on the Human Genome and Human Rights, to take stock of the application of this Declaration in the spheres of solidarity and international co-operation. The international community has become aware of the importance of the issues at stake.

The need for the existence of ethical rules is accepted. However, research and its applications must now be backed by legislative instruments and policies, which take account of the new actors involved in technological advances. Thus new forms of co-operation and also new forms of monitoring must include industries, private and public institutions and NGOs, in addition to States and international organizations. States rapidly recognized the implications of the new scientific advances, but they have not always been so prompt in undertaking projects of solidarity and international co-operation as set out in the Universal Declaration on the Human Genome and Human Rights.

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ANNEX

Distribution: limited

COMPOSITION OF THE WORKING GROUP OF THE IBC ON SOLIDARITY AND INTERNATIONAL CO-OPERATION BETWEEN DEVELOPED AND DEVELOPING COUNTRIES CONCERNING THE HUMAN GENOME

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Former President of the Hashemite University
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