REPORT OF THE

SECOND SESSION OF THE

INTERGOVERNMENTAL BIOETHICS COMMITTEE (IGBC)

UNESCO House, Paris 14-16 May 2001

Table of Contents

I. INTRODUCTION

1. The Second Session of the Intergovernmental Bioethics Committee (IGBC) was held at UNESCO House in Paris (France) from 14 to 16 May 2001. The following Member States of the IGBC were represented: Algeria, Azerbaijan, Bahrain, Benin, Canada, Chile, Colombia, Croatia, Cuba, Egypt, Finland, France, Germany, Hungary, Iran (Islamic Republic of), Italy, Japan, Kenya, Lithuania, Madagascar, Malaysia, Mexico, Morocco, Netherlands, Pakistan, Peru, Republic of Korea, Uganda, United Kingdom, United Republic of Tanzania and Venezuela. Thirty-five other Member States sent observers: Argentina, Austria, Bangladesh, Belgium, Brazil, Cambodia, Chad, Costa Rica, Czech Republic, Democratic People’s Republic of Korea, El Salvador, Haiti, Iceland, Indonesia, Iraq, Jamaica, Lebanon, Libyan Arab Jamahiriya, Malawi, Malta, Nicaragua, Panama, Papua New Guinea, Poland, Portugal, Romania, Saint Vincent and the Grenadines, Senegal, Slovenia, Syrian Arab Republic, Tunisia, Turkey, Ukraine, Uzbekistan, and a representative of the Holy See. The Chaiperson, three Vice-Chaipersons and two members of the IBC took part in the discussions. Finally, two observers from non-governmental international organizations and representatives of various press bodies took part.

2. In his opening address, the Director-General called attention to the extraordinarily rapid progress of research in biology, culminating in the complete sequencing of the human genome in 2000. He also emphasized the unique international role, which UNESCO must play in bioethics. The Director-General reminded the meeting that the Executive Board had approved his proposal to consider the ethics of science and technology, including bioethics, as one of the five main priorities of the Organization’s programme and budget. In this context, he felt it appropriate for UNESCO to embark upon a wide-ranging study, which should ideally lead up to the drafting of an international instrument on bioethics. The role of UNESCO is that of *“pronouncing equity”* but only the legislation of the different Member States could make the principles set out in the Universal Declaration on the Human Genome and Human Rights a living reality. The States must take on board the ideas put forward by UNESCO and the principles defined by it. The IGBC would therefore enable UNESCO to discharge the catalytic and multiplier role that falls to it.

3. On a proposal from the electoral groups, H. Exc. Mr Najib Zerouali Ouariti, Minister of Higher Education, Executive Training and Scientific Research of Morocco, was re-elected Chairman of the IGBC. Benin, Chile and Hungary were elected Vice-Chaipersons and Canada Rapporteur.

4. After thanking the IGBC Members for the confidence placed in him by renewing his term of office, the Chairman pointed out that the IGBC must act as an essential relay between the IBC and all the Member States on the one hand and between the IBC and civil societies on the other. He also referred to the scale of the biotechnological revolution now under way. New hazards were the other side of the coin of biomedical discoveries. Care must be taken to ensure that the progress of biology and medicine is not allowed to prejudice human dignity. The political will to encompass ethical questions is therefore essential. Researchers and industrialists must be mobilized, information circulated and public debate encouraged.

5. The Chaiperson asked the meeting to adopt the provisional agenda. The representatives of France and the Netherlands proposed amendments. On the amendment proposed by the representative of the Netherlands, the Chairman stated that the future programme of the IBC could be examined when the outcome of the 7th Session of the IBC was discussed. The proposal made by France was included as a new Item 8 on the agenda. With these amendments, the agenda was adopted. The rules of procedure adopted by the IGBC at its 1st Session (Rabat, Morocco, 11-12 October 1999) were also approved.

II. INITIATIVES TAKEN BY MEMBER STATES FOR THE IMPLEMENTATION OF THE UNIVERSAL DECLARATION ON THE HUMAN GENOME AND HUMAN RIGHTS

6. Introducing the discussion on this point, the Chairman invited the Secretary General of the IBC to present the broad outline of the document entitled *"Transposing into domestic law the principles set out in the Universal Declaration on the Human Genome and Human Rights: an international overview"* (1) (document SHS-201/01/4 dated 14 March 2001).

7. The Members of the IGBC called attention to the many legislative initiatives which had been taken. Legislation had been adopted or was currently being drafted in the areas covered by the Declaration. Some States had also adopted or were envisaging guiding principles applicable to research. One speaker referred to the creation of a Ministerial Division with the express task of applying bioethical laws in his country. Some States preferred to adopt regulatory provisions rather than legislation. Finally, some countries had imposed a system of penalties under criminal law on all experiments in cloning for human reproductive purposes and in cases where any discrimination based on genetic characteristics was proven. For instance, no employer should be allowed to impose predictive tests.

8. The importance of organizing international and/or regional workshops designed to provide model legislative or regulatory provisions in the field of bioethics pursuant to Section 3.4.2 of the *"Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights"* was also mentioned.

9. Some countries reported problems experienced by them in implementing the Universal Declaration on the Human Genome and Human Rights. One major obstacle resided in the difficulty of defining notions such as human dignity or reaching agreement on the time at which the existence of a human individual began. Others pointed out that the lack of training, both of decision makers and of the general public, could also be an obstacle.

10. In this regard, the initiatives reported by the different Member States reflected a shared desire to promote education and training in bioethics. Several faculties of medicine now offered courses in bioethics and this subject was also beginning to make its appearance in faculties of law and philosophy. The introduction of bioethics in secondary schools, which is proving increasingly necessary, could be based on an agreement between a national Bioethics Committee and the Ministry of Education. The creation of national teaching centres may be an appropriate formula for teacher training purposes. Public days could be organized to create awareness and train the general public.

11. Education in bioethics is necessary not just for specialists but also for the public at large. The aim must be to set up a global strategy for training and information in bioethical matters. In this regard, most countries have taken steps to improve the circulation of information. The media have been mobilized: the press, with the publication of the Universal Declaration on the Human Genome and Human Rights in prestigious scientific journals or even the appearance of reviews dealing specifically with bioethical matters; prime time TV broadcasts have also been made on the ethical aspects of genetics. The use of studies on the perception of bioethical questions by public opinion was also mentioned. However, some members felt that greater efforts should be made to provide the general public with dependable information to avoid creating the impression that some experimental treatments, for example in gene therapy, were already available.

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1. This document is available in French and English from the Division of Human Sciences, Philosophy and Ethics of Science and Technology.

12. The Chairperson of the IGBC summarized the discussion by laying emphasis on the following points: a) the introduction of bioethics not only in universities but also in secondary schools; b) the need to organize a public debate on bioethics, based on enlightened information with a view to participation of all the citizens; c) the imposition of sanctions for infringing statutory or regulatory provisions on bioethics; d) the need for equal respect of the principles and rights set out in the Universal Declaration on the Human Genome and Human Rights, without creating any hierarchy between them.

III. WORK OF THE 7TH SESSION OF THE IBC

13. The Chairperson of the IBC, Mr Ryuichi Ida, began by reminding the meeting that the Director-General of UNESCO had renewed half the members of the IBC for another four-year term and that at its 7th Session (Quito, Ecuador, 7-9 November 2000), the IBC had re-elected its Bureau, as follows: Chaiperson, Mr Ryuichi Ida (Japan); four Vice-Chaipersons, H. Exc. Mr Héctor Gros Espiell (Uruguay), Mr Mohammed Hamdan (Jordan), Mrs Michèle Jean (Canada) and Mr Jacek Zaremba (Poland); Rapporteur, Mrs Yolande Tano Bouah (Cote d'Ivoire).

14. He went on to present a summary of the outcomes of the 7th Session of the IBC. This session had included three working meetings, a round table on education in bioethics, a meeting for consultation with associations of patients and the state-of-the-art on three topics. These latter covered research on ageing, research in the neurosciences and the prospects held out by mapping of the human genome. Two working meetings were devoted to examination of the draft report by the IBC Working Group on Ethical Aspects of Research into Embryonic Stem Cells, economic aspects of research on the human genome and examination of the draft report by the IBC Working Group on Solidarity and International Cooperation between the Developed and Developing Countries on the Human Genome.

15. Mr Ida outlined the IBC's work programme for 2001. He announced the formation of two working groups which would meet in Paris in June 2001. One would be asked to formulate proposals for follow-up action to the International Symposium on *"Ethics, Intellectual Property and Genomics"* (Paris, 30 January – 1 February 2001), while the other would prepare an overall report on matters involved in the gathering, processing, storage and use of genetic data. The 8th Session of the IBC would be held in Paris from 12 to 14 September 2001. In addition to the examination of the two draft reports, and with a view to clarifying the work of the IBC on genetic data, a hearing of national commissioners responsible for personal data protection would be organized. Two specific topics would also be reviewed: *"Brain research: cerebral imaging, grafts and implants"* and *"Research in proteonomics"*. A round table on *"Education in Bioethics and Youth"* was also scheduled.

16. Following this presentation, some delegates expressed a wish for better coordination between the IBC and the IGBC. They hoped that the IBC work programme and the report for its meetings would be available before the IGBC sessions to enable them to be the subject of consideration and possible proposals, without in any way encroaching on the independence of the IBC. They also expressed the hope that the dates of the IGBC sessions would be suitably scheduled to enable the Director-General of UNESCO to take account of the conclusions of the IGBC in his programme and budget proposals to the Executive Board and General Conference. Finally, some Member States suggested that pre-implantation genetic diagnosis and interventions on germ-line cells should be examined by the IBC in its future detailed work programme.

17. The IGBC Chairman reminded the meeting of the respective roles of the IBC and IGBC. While the IBC comprised 36 prominent figures, personally nominated by the Director-General, the IGBC was made up of 36 Member States elected by the General Conference. The role of the IGBC was therefore to examine the recommendations of the IBC, which must be set out in a national or

international framework and, if appropriate, to make suggestions to the IBC for its work programme and call its attention to matters felt by the IGBC to be of topical interest.

IV. RECOMMENDATIONS OF THE IBC ON *"CONFIDENTIALITY AND GENETIC DATA"*

18. Mrs Michèle Jean, Chairperson of the IBC Working Group on *"Confidentiality and genetic data"* presented her report and reminded the meeting that at the 6th Session of the IBC and the 1st Session of the IGBC, both of which were held in Rabat (Morocco), the two Committees had already examined the draft report; the observations made on that occasion had been incorporated into the final version of the report.(2) The IGBC welcomed this fact. However, some IGBC Members made observations designed to dispel ambiguity, especially over the disclosure of genetic data to third parties.

19. The members of the IGBC concerned wanted to see an explanation of this aspect of the report, with particular reference to consent for disclosure and the notion of *"imperious reasons"* which figured in the report and enable the need for consent to be waived.

20. The authorization to disclose genetic information to insurance companies or employers in the few specific instances mentioned in the report was the subject of several comments. The body within the health insurance companies which could be allowed access to such information must be better defined. A clear stipulation must be made to the effect that, within the health insurance companies, this authority must be delegated to a medical practitioner who was alone bound by medical secrecy. Some speakers felt that no exceptions whatsoever should be made since the report rightly stated that *"employers and insurers who deny employment and insurance on the ground of an individual's genotype are at variance with Article 6 of the Declaration"*. The precise nature of the information which the insurer would be entitled to request must therefore be defined. In this regard, it would no doubt be appropriate to make a distinction between different types of insurance policy (health insurance, life insurance, etc.) for the purpose of disclosure of genetic information.

21. Some Members of the IGBC also hoped that the IBC would define more precise distinctions between the different types of genetic data. As to the use of this data, they felt it appropriate to distinguish between data obtained for a predictive use and data acquired for diagnostic purposes. They also felt that the distinction made in the report between nominal data, i.e. information pertaining to an identifiable person, and anonymous data which could not be associated with an identifiable person was insufficient. Computer programmes could in fact be written to permit identification of an individual from data, which had been rendered anonymous under certain non-randomized conditions. Questions associated with the collection of genetic data and the formation of databases and their future use, especially in the case of a particular group or population, were also raised.

22. Several members pointed out that children were a vulnerable group. Hence, children were involved, they must reach their majority before personal genetic information was disclosed to them.

23. The importance of broad circulation of the report was emphasized. The Secretary General of the IBC stated that the report was available at the Internet site <www.unesco.org/ibc> and that printed copies had been sent to all the permanent delegations and national committees, to the National Ethics Committees and the Institutions concerned worldwide and also to a network of some 2,000 specialists. Incidentally, two members of the IGBC expressed the hope that the IBC and IGBC documents would be more directly accessible from the general Internet site of UNESCO.

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2. Report available in English and French at Internet site <www.unesco.org/ibc> and published in the **Proceedings** of the 6th Session of the IBC (1999), available from the Division of Human Sciences, Philosophy and Ethics of Science and Technology.

24. The IBC Chairman said that some of the matters dealt with during the discussion would be examined in June 2001 by the IBC Working Group on Genetic Data. For his part, the Secretary General of IBC reported on the proposals by the Director-General set out in the Draft Programme and Budget for 2002-2003 (31C/5) concerning the possible drafting of an international instrument on genetic data, with particular reference to the gathering, processing, storage, availability and use (in time and space) of such data, especially in healthcare systems. Several IGBC Members welcomed this proposal by the Director-General.

V. RECOMMENDATIONS OF THE IBC ON "*THE USE OF EMBRYONIC STEM CELLS IN THERAPEUTIC RESEARCH*"

25. Mr Alexander McCall Smith, co-rapporteur with Michel Revel for the Working Group of the IBC on ethical aspects of research into embryonic stem cells, presented the report entitled "*The Use of Embryonic Stem Cells in Therapeutic Research*".(3) The IGBC acknowledged the excellent quality of this report and welcomed its pluralist and balanced character.

26. Several Members of the IGBC referred to cultural and religious differences over the status of the embryo. While some felt that agreement on the use of embryonic stem cells might be hard to reach because of these differences, others maintained that a broad consensus should be feasible because of the importance of research in this field. For the former, the question was whether each State should or should not be left with the task of legislating in this area, in the light of its own cultural and religious traditions; the latter on the other hand hoped that a body like UNESCO would draw up supranational regulatory provisions. Be that as it may, the IGBC felt that the State should adopt national statutory or regulatory provisions on the import and export of embryonic stem cells from or to countries in which embryonic research is prohibited.

27. Finally, some participants referred to other new technologies, especially those which made use of adult stem cells, and invited the IBC to examine this aspect in more detail.

VI. RECOMMENDATIONS OF THE IBC ON "*SOLIDARITY AND INTERNATIONAL COOPERATION BETWEEN DEVELOPED AND DEVELOPING COUNTRIES CONCERNING THE HUMAN GENOME*"

28. The Rapporteur, Mr Mehmet Öztürk, presented the IBC report on "*Solidarity and International Cooperation between Developed and Developing Countries concerning the Human Genome*"(4). The IGBC stressed the high quality of this report.

29. During the discussion, the Members of the IGBC congratulated the IBC on having dealt with this question and reaffirm the need to promote solidarity and international cooperation in the area of the human genome.

30. The proposal for the creation of a mechanism or an international fund, with resources derived from a percentage of the profits made by private and public companies earned from genomic research and by money from other sources, proved somewhat controversial. Some speakers felt that a fund of this kind might duplicate other financing mechanisms, which already

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3. Report available in English and French at the Internet site <www.unesco.org/ibc> and published in the **Proceedings** of the 7th IBC Session (2000) available from the Division of Human Sciences, Philosophy and the Ethics of Science and Technology.

4. Report available in English and French at the Internet site <www.unesco.org/ibc> and published in the **Proceedings** of the 7th IBC Session (2000) available from the Division of Human Sciences, Philosophy and the Ethics of Science and Technology.

exist within the United Nations system and the many bilateral agreements already in force. While expressing their agreement to the principle of financing of this fund, some members of the IGBC felt this proposal to be premature.

31. The Chairperson of the IBC and the Rapporteur pointed out that Section E of the Universal Declaration on the Human Genome and Human Rights entitled *"Solidarity and International Cooperation"* and the provisions set out in Art. 17 to 19 must be implemented. The IBC therefore felt it appropriate to envisage suitable mechanisms.

32. At the end of the discussion, and on a proposal from the Chairperson of the IGBC, the Secretariat was requested to carry out a study mechanisms for the promotion and strengthening of solidarity and international cooperation in this field in order to determine the most appropriate measures to achieve the goals set in the IBC report.

VII. IMPLEMENTATION OF 30C/ RESOLUTION 24 ON *"BIOETHICS AND THE RIGHTS OF THE CHILD"*

33. The Secretary General of the IBC outlined the work done by the International Symposium on "Bioethics and the Rights of the Child" organized jointly by the World Association of the Friends of Children (AMADE) and UNESCO, which was held in Monaco on 28 to 30 April 2000, pursuant to Resolution 30 C/24 adopted by the General Conference at its 30th Session. He pointed out that this matter also figured on the agenda of the 31st Session of the General Conference and that the Director-General wished to present the final document drafted at the end of the symposium to the IGBC. This document was entitled *"Monaco Statement: Considerations on Bioethics and the Rights of the Child"*.[5] He said that the title of this text must certainly not be construed as implying a declaration which was binding on the Member States. Moreover in English, the text was called a "Statement " and not a declaration.

34. The Members of the CIGB thanked the Secretary General of the IBC for this clarification. They welcomed the interest taken by UNESCO in matters of bioethics and the rights of children and took note of the document entitled *"Monaco Statement: Considerations on Bioethics and the Rights of the Child"*.

VIII. DRAFT RECOMMENDATION TABLED BY FRANCE

35. Drawing on a resolution adopted by the Human Rights Commission of the United Nations at its 57th Session, April 2001, a draft recommendation designed to ensure better coordination of bioethical matters within the United Nations system was tabled by France.

36. The Secretary General of the IBC reminded the meeting that the Director-General had already taken initiatives in this direction. Moreover, he pointed out that the group of independent experts whose creation was advocated in the draft recommendation by France, would duplicate the IGBC and/or the IBC which was itself composed of independent experts. However, the Director-General was aware of the need for better coordination of the actions undertaken by the different member organizations of the United Nations system on bioethics and had accordingly proposed to the Secretary General of the United Nations and the executive heads of various specialized institutions and bodies of the United Nations, such as the FAO, the High Commission for Human

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[5] A concise report on the International Symposium and the text of the *"Monaco Statement: Considerations on Bioethics and the Rights of the Child"* are available in English and French on the Internet site <www.unesco.org/ibc>. The **Proceedings** of the Symposium have been published and are available from the Division of Human Sciences, Philosophy, Ethics of Science and Technology.

Rights, WHO, WIPO and UNICEF, the creation of an Inter-agency Committee responsible for such coordination.

37. The draft proposed by France was felt to be redundant by the IGBC, which welcomed the initiative by the Director-General of UNESCO and decided to refer to it in its recommendations. It also called upon the Director-General to give more details to the Executive Board at its 161st Session.

IX. ADOPTION OF THE RECOMMENDATIONS OF THE IGBC

38. At its Second Session, the Intergovernmental Bioethics Committee (IGBC):

1. *Congratulates* the International Bioethics Committee (IBC) and the Secretariat on the quality of the reports and documents presented.
2. *Reaffirms* that human reproductive cloning is a practice contrary to human dignity, as provided by Article 11 of the Universal Declaration on the Human Genome and Human Rights, and *encourages* Member States to take appropriate measures, including legislative or regulatory, in order to prohibit effectively human reproductive cloning.
3. *Requests* the Secretariat to update the information on the activities undertaken by Member States in order to implement the Universal Declaration on the Human Genome and Human Rights.
4. So as to enable the Secretariat to undertake this updating, *calls upon* Member States who have not yet done so to communicate to the Secretariat all relevant information concerning initiatives taken at the national level in relation to the fields covered by the Universal Declaration on the Human Genome and Human Rights.
5. *Encourages* the IBC to organise international and/or regional workshops aimed at providing a model framework of legislation and regulations in the field of bioethics, in accordance with the *"Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights"*, endorsed by the General Conference of UNESCO at its 30th session (paragraph 3.6.1).
6. *Invites* the IBC when outlining its detailed two year work programme, to consider at its earliest convenience the inclusion of the following topics:
    (i) Pre-implantation genetic diagnosis,
    (ii) Interventions on germ-line cells.
7. Recognizing the importance of its role in reflecting on the work programme of the IBC, *requests* that reports both on the work programme of the IBC and of the IBC meetings are made available prior to the meetings of the IGBC and *further requests* that the timing of the IGBC sessions are such as to enable the Director-General to take the IGBC's conclusions into consideration in his proposals to the Executive Board and to the General Conference.
8. *Appreciates* the participation of several IBC members in the IGBC Session, in particular of the Chairperson of the IBC, and *invites* the Director-General to examine ways and means that can foster ongoing dialogue between the IBC and the IGBC, for instance through joint meetings of the Bureaux of both bodies.
9. *Deems appropriate* that a summary of its comments on IBC reports be made available with these reports, in particular on the UNESCO web site.

- In relation to the **IBC Report on Confidentiality and Genetic Data**,

10. *Suggests* that the IBC, when examining the whole range of issues related to genetic data, further distinguish between the different types of data and continue to examine

the issue of disclosure of genetic information to third parties and the issue of disclosure where children are concerned.

- Following the conclusions of the **IBC Report on the Use of Embryonic Stem Cells in Therapeutic Research**,

11. *Encourages* Member States, according to the relevant provisions of the Universal Declaration on the Human Genome and Human Rights, to hold debates on the ethical issues raised by the use of embryonic stem cells in therapeutic research, involving all actors concerned, so as to adopt national regulations or legislation, for example, on the question of the import and export of embryonic cells from or to countries where embryo research is forbidden.
12. *Also encourages* the IBC to keep this issue under consideration taking into account possible alternative new technologies, in particular concerning adult stem cells.

- In relation to the **IBC Report on Solidarity and International Cooperation between Developed and Developing Countries concerning the Human Genome**,

13. *Recognizes* the efforts made and difficulties encountered by some developing countries in the implementation of the Universal Declaration on the Human Genome and Human Rights.
14. *Recognizes* the necessity to promote solidarity and international cooperation in this field and *considers* that efforts should be made at national, regional and international levels to achieve the objectives identified by the IBC in the recommendations of its report.
15. *Invites* the Secretariat to undertake a study, based on a state of the art, aimed at highlighting mechanisms for the promotion and reinforcement of solidarity and international co-operation in this field, both bilateral and multilateral, within and outside the United Nations system.

- In relation to the **International Symposium on Bioethics and the Rights of the Child**, organized jointly by AMADE and UNESCO (Monaco, 28 – 30 April 2000),

16. *Takes note* of its conclusions entitled *“Monaco Statement: Considerations on Bioethics and the Rights of the Child”*.

- Further to the Draft Recommendation presented by France,

17. Acknowledging the Director-General’s initiative of proposing the creation of an inter-agency committee with the task of improving coordination of the activities of these different organizations with regard to bioethics, and of considering bioethical issues which should give rise to increased cooperation, *supports* this initiative and *invites* him to act on it as soon as possible.

X. Conclusions

39. Winding up this 2nd IGBC Session, its Chairperson, H. Exc. Mr Najib Zerouali Ouariti, welcomed the valuable work done during these three days and the recommendations adopted. He paid tribute to the cooperation, frankness and mutual respect shown by the participants and welcomed the diversity of the constructive critical contributions, without which no improvement would be possible. He reminded the meeting how difficult it was to adopt a clear-cut position on such sensitive matters as the confidentiality of genetic data, the use of embryonic stem cells, solidarity and international cooperation in the field of the human genome and welcomed the progress made during this meeting.

40. Summarizing the proceedings, he called attention to what in his view were the key matters: the consensus reached on the drafting of an international instrument on genetic data as proposed by the UNESCO Director-General; agreement on the feasibility study of a mechanism to impart greater dynamism and promote solidarity and international cooperation; the importance accorded to education in bioethics and the means of effectively providing such education; clarification of the task of the IGBC; and, awareness that solidarity was an essential aspect of bioethics.

41. He thanked all the members of the IGBC, the members of the IBC and its Chairman, in particular, for the quality of the reports drafted by them. He also thanked the IGBC Rapporteur for the work done, together with the Director-General of UNESCO and the Secretary General of the IBC. In conclusion, he called attention to the need to take all possible action to permit scientific progress while making sure that it always remained in the service of mankind.