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**Annual Report of the Bioethics Commission
to the Federal Chancellor
October 2007 – September 2008**

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Table of Contents

| | |
|--|----------|
| 1. Introduction | 3 |
| 2. Issues Examined by the Bioethics Commission | 5 |
| 2.1. Research on Persons who are Incapable of Giving Consent | 5 |
| 2.2. Ratification of the Convention on Human Rights and Biomedicine..... | 5 |
| 2.3. Stem Cell Research | 6 |
| 2.4. Research on Ageing..... | 6 |
| 2.5. Research Ethics Commission / Gender Issues | 6 |
| 3. Rulings, Reports and Recommendations | 7 |
| 4. Events..... | 7 |
| 5. Publications | 8 |
| 6. Outlook, Projects in 2008..... | 8 |
| 6.1. Long Night of Research, 8 November 2008 | 8 |
| 6.2. Bioethics at Schools, Further Training for Teachers 21/22 October 2008 | 8 |
| 6.3. Austrian-Slovak Bioethics Symposium, 23 October 2008 | 9 |
| 7. Secretariat of the Bioethics Commission..... | 9 |
| 8. Contacts and Cooperation..... | 9 |

Appendix

| | |
|---|-----------|
| I Order of the Federal Chancellery Regarding the Establishment of a Bioethics Commission Federal Law Gazette II No. 226/2001 | 10 |
| II Members of the Austrian Bioethics Commission, October 2007-2009 | 13 |

1. Introduction

The Bioethics Commission was established at the Federal Chancellery in June 2001. It is tasked with advising the Federal Chancellor from an ethical point of view on all social, scientific and legal issues arising from scientific advances in the field of human medicine and biology (Federal Law Gazette 226/2001, Federal Law Gazette II 517/2003, Federal Law Gazette II 362/2005).

In October 2007 the members of the Bioethics Commission were reappointed as scheduled. Following the resignation of the Chairman UnivProf. DDr. Johannes C. Huber, the Chancellor appointed Dr. Christiane Druml as the new Chair of the Bioethics Commission. UnivProf. Dr. Pöltner and UnivProf. Dr. Mannhalter were confirmed in their positions as Deputy Chairpersons.

The appointments made for the Commission's fourth term of office satisfied the requirement formulated in the Order Federal Law Gazette II 2001/226 for a mixed Commission which made explicit reference to the fields from which the experts should be drawn. Thirteen of the 19 members who had served on the Commission during its third term of office were reappointed. Furthermore, the size of the Commission was increased to 25 members and thus almost one-half of the members were appointed for the first time.¹

When selecting new members care was taken to ensure that:

- the percentage of women on the Commission was increased,
- all the fields referred to in the Federal Chancellor's Order concerning the appointment of a Bioethics Commission were represented on the Commission
- links to other institutions engaged in this area were both preserved and expanded.

This action was taken in response to criticism that had been publicly raised ever since the Bioethics Commission was established.²

The reappointment of the Bioethics Commission opened up the possibility of refocusing its work, a demand that had also been made by individual members of the Commission during previous terms of office.

Public Dialogue: In the past the Bioethics Commission had only emerged from its "academic ivory tower" to a limited extent. Public events were therefore used to initiate a dialogue with the public (sponsoring organisations / scientific community). In each case, this dialogue picks up on one of the main areas of the Bioethics Commission's work with the aim of broadening the overly academic discourse of the Commission's members by raising issues that arise in practice.

International Focus: So far, the Bioethics Commission has engaged in international activities within the framework of the Forum of National Ethics Committees in other

¹ A complete list of the current members can be found in the Appendix.

² Compare Huber/Gmeiner, "Zwischenbilanz der Bioethikkommission beim Bundeskanzleramt", in: Kohl/Ofner/Burkert-Dottolo/Karner (eds.), Österreichisches Jahrbuch für Politik 2003, Verlag für Geschichte und Politik, Wien, Oldenbourg-Verlag, München, Wien-München, 2004, p. 497 ff; Ulrich Körtner, Neue Regierung: Wo bleibt die Biopolitik?, in: <http://science.orf.at/science/koertner/146885>.

EU member states (Forum NEC) and the Conference of National Ethics Committees of the Council of Europe. The Commission is also represented by a member with observer status at the International Bioethics Committee of UNESCO. The stronger international orientation of the Bioethics Commission is reflected in this wide-ranging involvement.

2. Issues Examined by the Bioethics Commission

At the first meeting of the Bioethics Commission in its fourth term of office on 15 October 2007 it was agreed that priority would be given to the following topics:

- Research on persons who are incapable of giving consent,
- Ratification of the Convention on Human Rights and Biomedicine,
- Stem cell research,
- Preimplantation genetic diagnostics,
- The allocation of resources (in medicine and research),
- Research on ageing,
- Actively including the gender aspect in all topics.

The work schedule of the Bioethics Commission for 2008 covered the key thematic areas: ratification of the Convention on Human Rights and Biomedicine, stem cell research, research on ageing and research on persons who are incapable of giving consent. It will probably no longer be possible to deal with the issues of preimplantation genetic diagnostics and the allocation of resources (in medicine and research) in 2008.

2.1. Research on Persons who are Incapable of Giving Consent

The question of research on persons who are incapable of giving consent was already dealt with in the Commission's third term of office, but was not brought to a conclusion. At the meeting held on 15 October 2007 it was agreed that this issue would be taken up again.

At the meeting on 4 February a document was accepted that summarised the questions to be dealt with within the scope of the analysis of this topic.

2.2. Ratification of the Convention on Human Rights and Biomedicine

The Biomedicine Convention has been open for signature since 1997. Austria has not yet started the ratification process. Ratification was included in the Government Programme for the previous legislative period, but the process could not be started as organisations representing the disabled objected to Article 17 (2) (research for non-therapeutic purposes on persons without the capacity to consent). The amendment of the Guardianship Act (Sachwalterrechts-Änderungsgesetz 2006, Federal Law Gazette I, 92/2006) has allowed a solution to be reached that accommodates the organisations representing the interests of the disabled, making it possible to restart the ratification process.

Contact was made with officials of both the Ministry of Justice (BMJ) and the Ministry of Health, the Family and Youth (BMGFJ) to clarify which ministry could carry out the necessary preparatory work, with the BMGFJ expressing an interest in doing so.

If ratification is to be expedited then a commitment is required at the political level. Furthermore, politicians must seek discussions with the spokespersons for disability

related issues from the parliamentary parties / organisations representing the disabled.

As soon as these activities have been initiated and their positive conclusion is in sight, the Bioethics Commission will take up work to renew its resolution of 11 February 2002 with regard to the ratification of the Biomedicine Convention.

2.3. Stem Cell Research

To date the Bioethics Commission has only dealt with the question of stem cell research / embryo protection within the framework of the EU's Sixth Framework Programme for Research. The Bioethics Commission now plans to deal with the topic more broadly following the adoption of a resolution at its meeting on 15 October 2007.

At the meeting on 13 December 2007 a paper was accepted that summarised the questions to be dealt with within the framework of this analysis. At a meeting on 10 March a discussion was held together with Dr. Griessler (Institute for Advanced Studies, IHS) regarding the methods of dealing with the questions that were accepted. A broad debate on the content of the topic took place on 14 July. The document is to be adopted at the closed conference to take place on 14/15 November.

2.4. Research on Ageing

The working group that has been set up on ageing research presented a document at the meeting on 4 February identifying the possible focus of the Bioethics Commission's further work on this topic (assistive technologies, prevention research, health care research). On the basis of a paper by Univ.Prof. Dr. Wagner, the Bioethics Commission at its meeting on 7 April agreed that it wished to draw up a report on the subject of assistive technologies. It is planned to complete the topic before November.

2.5. Research Ethics Commission / Gender Issues

The intense discussion on research ethics commissions and the related gender aspects at the Bioethics and Women event on 2 June 2008 again revealed the urgent need for a set of guidelines for research ethics commissions drawn up by the Bioethics Commission. A draft will therefore be presented at the meeting on 6 October. It is planned to complete the document before the end of the year.

3. Rulings, Reports and Recommendations

During the reporting period the Bioethics Commission issued the following document

- Report of the Bioethics Commission Regarding Umbilical Cord Blood Banks of the Bioethics Commission at the Federal Chancellery of 19 May 2008.

The document can be viewed on the Bioethics Commission website at <http://www.bka.gv.at/DesktopDefault.aspx?TabID=3575&Alias=english> .

4. Events

The Bioethics Commission organised or was instrumental in organising the following events:

- *Conference on Ageing Research, 5 October 2007*
Opening event at the start of the Bioethics Commission's fourth term of office. The conference featured and was attended by 100 participants.
- *Stem Cell Research – Ethical and Legal Aspects, 17/18 January 2008*
Public event on stem cell research held in cooperation with the Institute for Ethics and Law in Medicine. The conference featured international speakers and was attended by 135 participants.
- *Ethics in Research, 26 May 2008*
As part of the Research Dialogue a public event on ethics in research was held with the support of the Bioethics Commission and in cooperation with Joanneum Research. This event featured international speakers and was attended by 90 people.
- *Women and Bioethics Commissions, 2 June 2008*
The purpose of the event was to examine specific women's issues in the area of bioethics. Due to the large number of speakers and participants from abroad the event was held in English. Number of participants: 90.

During the reporting period members of the Bioethics Commission and representatives of the Secretariat took part in a variety of events, only a small number of which are mentioned here:

- *10th European Forum of National Ethics Committees, Lisbon 11/12 October 2007* (participation by the Chairperson of the Bioethics Commission and the head of the Secretariat).
- *Meeting of the Steering Committee on Bioethics of the Council of Europe (CDBI), Strasbourg, 5 December 2007* (participation by the head of the Secretariat).
- *11th European Forum of National Ethics Committees, Ljubljana 28/29 February 2008*, Presentation by the Chairperson on the Austrian Report "Nano-Technology,

Catalogue of Ethical Problems and Recommendations” of 13 June 2007. At this meeting an international working party on DNA databases was set up under the auspices of Portugal and the United Kingdom. UnivProf. Dr. Mannhalter was nominated to represent the Bioethics Commission in this working group.

- *Nuffield Council, Annual Forward Look Seminar*, London 7/8 May 2008, which was attended by the Chairperson of the Bioethics Commission. The seminar covered the following topics:
 - Nanotechnology, presentation by the Chairperson on the Austrian Report of 13 June 2007;
 - Volunteering, donation and payment in clinical practice and research;
 - Establishment and use of cord blood and other cell banks.
- *Governance and Ethics of Nanotechnology, European Commission Conference, 8 May*, presentation by the Deputy Chairperson on the Austrian Report of 13 June 2007.
- *Meeting of the Steering Committee on Bioethics of the Council of Europe (CDBI)*, Strasbourg 4-6 June 2008 (participation by the head of the Secretariat).
- *Alpbach Technology Forum*, 21/22 August 2008, presentation by the Chairperson at the plenary session of the Technology Forum and leadership of a workshop.
- *Global Summit, National Consultative Ethics Committees*, Paris, 1-2 September 2008, presentation by the Chairperson on transplantation medicine.

5. Publications

- Conference Volume, Conference on Ageing Research, 5 October 2007
- Ruling on Cord Blood Banking, 19 May 2008;

6. Outlook, Projects in 2008

6.1. Long Night of Research, 8 November 2008

As part of the Long Night of Research two meetings of the Bioethics Commission on the topic of ageing will be re-enacted for the public in cooperation with “dialogue<>gentechnik”. The issue will be discussed in public and an attempt made to reach a joint decision. Three or four members of the Bioethics Commission and visitors will take part in the discussion rounds.

6.2. Bioethics at Schools, Further Training for Teachers 21/22 October 2008

The Bioethics Commission has actively taken the issue of bioethics to schools. It has been agreed with the responsible departments of the Ministry of Education (BMUKK) that European Council teaching aids on the topics of organ donation, medically assisted reproduction, genetic testing and cloning should be translated into German. A further training programme for teachers will also be developed covering the area of public health as well as those issues dealt with by the European Council. It was also

agreed to set up a “Bioethics at School” portal. The teacher training seminar will be held on 21/22 October.

6.3. Austrian-Slovak Bioethics Symposium, 23 October 2008

The Austrian-Slovak Symposium that is organised jointly by the two national Bioethics Commissions has already been held twice at the Austrian Embassy in Bratislava. Topics in recent years were: *Innovative Austria* and *Human Naturality as a Touchstone for Ethics*. The theme of the event in 2008 will be the Advanced Care Directive Act.

7. Secretariat of the Bioethics Commission

The Secretariat of the Bioethics Commission was established at the Federal Chancellery. The Secretariat supports the Commission, the Chairperson and the working groups in the performance of their duties. In particular it handles the day-to-day business of the Commission, prepares its meetings and where necessary those of the working groups, keeps written records, obtains necessary information, documents working material and implements rulings. The Secretariat is headed by Mag. Dr. Doris Wolfslehner.

8. Contacts and Cooperation

Depending on the task at hand, the Bioethics Commission collaborates with the relevant government departments (e.g. Ministry of Science and Research, Ministry of Health, Family and Youth, the Ministry of Justice, the Ministry of Social Affairs and Consumer Protection, the Ministry of Transport, Innovation and Technology). Contact has also been made and deepened with relevant organisations (including organisations representing the disabled and self-help organisations, the Austrian Advisory Board on Gene Technology).

Besides bilateral contacts with comparable national ethics committees (e.g. Germany, Slovakia) the Bioethics Commission actively participates in international networks, in particular the National Ethics Committees of the EU and the European Conference of National Ethics Committees (COMETH) within the framework of the Council of Europe. At the end of 2007 the members of the UNESCO/International Bioethics Committee (IBC) were reappointed. The Chairperson of the Bioethics Commission, Dr. Druml, was chosen as a new member of this Committee.

I Order of the Federal Chancellor Regarding the Establishment of a Bioethics Commission Federal Law Gazette II No. 226/2001

Amendment

As amended

Federal Law Gazette II No. 517/2003

Federal Law Gazette II No. 362/2005

Preamble/Promulgatory Clause

Pursuant to § 8 para. 1 and 2 of the Federal Ministries Act 1986 Federal Law Gazette No. 76, most recently amended by Federal Law Gazette I No. 141/2000 it is ordered:

- **Text**

Establishment of the Bioethics Commission

§ 1. A Bioethics Commission (Commission) shall be established at the Federal Chancellery.

- **Tasks**

§ 2. (1) The task of the Bioethics Commission is to advise the Federal Chancellor from an ethical point of view on all social, scientific and legal issues arising from scientific advances in the field of human medicine and biology. In particular, this includes:

1. Providing information and promoting discussion within society on key findings in the fields of human medicine and biology and the related ethical issues,
2. Submitting recommendations for practical use,
3. Submitting suggestions concerning necessary legal measures,
4. Preparing expert reports on particular issues.

(2) The tasks referred to in para. 1 shall be carried out with reference to those general affairs of government policy that fall within the competence of the Federal Chancellery, including the coordination of the entire federal administration and efforts to achieve consistent cooperation between local authorities.

- **Composition of the Bioethics Commission**

§ 3. (1) The Commission has 15 members. If necessary additional members may be appointed, but only up to a maximum number of 25.

(2) The Commission shall include in particular experts from the following fields:

1. Medicine (in particular reproductive medicine, gynaecology, psychiatry, oncology, pathology)
2. Molecular biology and genetics
3. Law
4. Sociology
5. Philosophy
6. Theology

• **Appointment of Members**

§ 4. (1) The members of the Commission shall be appointed by the Federal Chancellor for a period of two years. They may be reappointed.

(2) The Federal Chancellor shall appoint the Chairperson of the Commission and two Deputy Chairpersons for a period of two years.

(3) Membership of the Commission is an honorary unpaid position. However, members shall be entitled to the reimbursement of travel expenses.

• **Convocation of Meetings**

§ 5. (1) Meetings of the Commission shall be convened by the Federal Chancellor or the Chairperson. Meetings shall be convened as necessary, but at least every three months.

(2) The invitation to the meeting should if possible be delivered to members no later than three weeks before the date of the meeting and should include the provisional agenda.

(3) For the purposes of an expert discussion of an item of the agenda the Commission may invite to its meetings experts or other persons who are able to provide information.

• **Working Groups**

§ 6. The Commission may set up working groups for the preliminary discussion of issues.

- **Presiding Officer and Procedures**

§ 7. (1) The Chairperson shall open and preside over the meeting. If the Federal Chancellor has convened the meeting it shall be incumbent upon him to chair the meeting if he attends it. The final agenda must be set at the start of the meeting.

(2) The presence of at least one third of the members shall be necessary for the Commission to have a quorum. The Commission must strive to achieve the greatest possible degree of consensus when adopting resolutions. Resolutions shall be adopted by a majority of the votes cast; abstentions are not permissible.

(3) The Commission may decide that its deliberations and the documents upon which they are based must be held in confidence.

- **Public**

§ 8. The meetings of the Commission shall not be open to the public.

- **Minutes, Documents, Reports**

§ 9. (1) Written records must be kept of the Commission's deliberations. This record must also record dissenting opinions.

(2) It shall be incumbent upon the Federal Chancellery to keep these minutes and document the Commission's working material.

(3) Each year the Commission shall submit an annual report to the Federal Chancellor.

- **Rules of Internal Procedure**

§ 10. The Commission may lay down more detailed rules concerning the conduct of its business. These must be approved by the Federal Chancellor.

Top

II Members of the Austrian Bioethics Commission, October 2007-2009**Christiane Druml (Dr.), Chairperson**

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