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CENTER
FOR ETHICS
AND LAW
IN BIOMEDICINE

ANNUAL REPORT

2005-2006



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Executive editor: Enikő Demény

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1. FOREWORD

Biotechnology is a field with one of the most promising applications of scientific discoveries. It is not surprising, then, that the uses and effects of biomedical and biotechnological advances are the subject of intense debates in society. Yet, the legal and policy impacts of life sciences have remained so far understudied or at least not adequately elaborated, even though legal issues such as privacy, data protection, new forms of discrimination, intellectual property, benefit sharing, and the protection of vulnerable groups would provide a broad scope of study in this area. Moreover, the most recently developed technologies, such as genetic testing, tissue engineering, biobanks, or stem cell research, constantly pose new questions about the frontiers of life, the boundaries and autonomy of the body and the difference between therapy and eugenic selection.

Although biotechnology, as an application of the most recent scientific discoveries and innovations in the field of biomedicine, is mainly the technology of the future, it already has an impact on various fields of life: medicine and pharmacology, agriculture and environmental management – but to a certain extent also on law enforcement, insurance and intellectual property law.

These interdisciplinary issues of ethics and law of science and technology create a unique intersection of research fields. It has already been observed at Central European University that more and more students choose topics in bioethical and scientific ethical issues for their MA or PhD theses at the Departments of Legal Studies, Political Science, Sociology, Anthropology and Gender Studies. Their interest in this interdisciplinary domain is indicative of the growing importance of this field of study.

Having recognized these challenges, Central European University established the Center for Ethics and Law in Biomedicine (CELAB) on September 15, 2005. We, at the Center, think this step was an essential element to developing a research think tank, to providing an intellectual and institutional basis for ethical and legal research, and to promoting teaching and policy activities in the field of life sciences, including the broad scope of biomedicine.

This document is the first Annual Report, highlighting the major activities of CELAB during the 2005–2006 academic year.

Among the research activities of the Center, one of the most influential achievements was to set up an internet-based bio-law database. This database is regularly updated, thus it provides a basic research tool for lawyers and social scientists. The database contains legal norms categorized thematically, and in addition, sources and countries can also be used for search criteria.

“Of course, common sense, being full of illusions about the world, needs to be informed, without any reservation, by the sciences. The scientific theories, which intrude upon the lifeworld, however do not essentially touch on the framework of our everyday knowledge, which is linked to the self-understanding of speakers and actors. Learning something new about the world, and about ourselves as beings in the world, changes the content of our selfunderstanding.”

(Jürgen Habermas: The Future of Human Nature)

Over the past academic year, the fellows of CELAB (under CEU auspices) have completed two research projects funded by the European Union: *Public Understanding of Genetics: A Cross-Cultural and Ethnographic Study of the ‘New Genetics’ and Social Identity* (Acronym: PUG) and *Privacy in Research Ethics and Law* (Acronym: PRIVIREAL).

In addition, the Center (already as an autonomous institution) finished the preparation for two new European research projects: *Privacy though Law and Ethics in Genetic Data* (Acronym: PRIVILEGED, duration: 2006–2009) and *Genetic Bio- and Data-Banking: Confidentiality and Protection of Data* (Acronym: GeneBanc, duration: 2006–2009).

Researchers of the Center have also been involved in translating and disseminating the Universal Declaration on Bioethics and Human Rights, adopted by UNESCO in 2005.

During the spring semester of the 2005–2006 academic year, several workshops were organized by CELAB with the participation of Scandinavian, Asian and European ethical, legal, and health experts, as well as social scientists and economists. Pressing social issues of stem cell research, biobanks and reproductive cloning were covered, as well as challenges for public health as the avian flu.

In relation to the research topics covered by the Center, CELAB fellows have also analyzed and evaluated policy and regulative applications; participated in various lawmaking projects and consultations, as well as disseminated their research results through publications and the media.

CELAB has started to establish academic partnerships with other universities. Over the past academic year, the Center has taken part in developing biotechnology and law courses at the University of Siena and in the bioethics summer university program of the Masaryk University in Brno.

On behalf of CELAB, I wish you a very exciting journey in the domain of our Center. Please do not hesitate to contact us via email to suggest future cooperation in the field of our activities.

In addition to this Annual Report, you may follow the ongoing activities, debates, workshops and teaching curricula on our regularly updated website at <http://www.ceu.hu/celab>

Judit Sándor
Director of Center for Ethics and Law in Biomedicine
Central European University

2. OUR MAIN GOALS AND PARTNERS

The major goal of the Center is to enhance research by establishing multidisciplinary research teams in the fields of bioethics, biomedical law and biotechnology; to analyze current ethical dilemmas in the field of science and technology; to work out policy papers; and to organize workshops with the invitation of outstanding international experts.

In order to achieve these goals, in the first year of its existence CELAB started to build up partnerships and collaboration with academic institutions, centers, international organizations engaged or interested in CELAB's main topics. Our web-page has played an important role in this effort, which has been accessed from over 50 countries in five continents.

Through its networking activities, CELAB has established research contacts with various CEU Departments, Centers and Programs; with other Universities and Centers in Hungary and abroad, with numerous international organizations, such as UNESCO, WHO and with EU Directorates. These contacts have resulted in various types of partnerships and cooperation.

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 Advocacy Center, Budapest
 Ants NOMPER, Estonia
 Imre SZEBIK, SOTE, Budapest

VISITING FELLOWS

As a result of collaboration between CELAB and the CEU/SPO Fellowships Program in the Academic Year 2006/2007 Violeta Besirevic, the winner of the CEU/SPO Visiting Research Fellowship Grants will carry out a research at CELAB on legal aspects of euthanasia, entitled: *Medical Global Challenges: Should International Law Enforce Euthanasia?*

ACADEMIC PARTNERS:**Hungarian Universities**

Semmelweis University, Faculty of Medicine,
Institute of Behavioural Sciences
University of Debrecen, Faculty of Public Health,
Institute of Behavioural Sciences

Other Universities

Katholieke Universiteit Leuven
University of Vienna
University of Oslo
University of Leeds
University of Maastricht

PARTNERSHIP WITH OTHER CENTERS AND ASSOCIATIONS:

European Association of Centres of Medical Ethics (EACME)

<http://www.eacmeweb.com/>

World Association for Medical Law

<http://waml.haifa.ac.il/>

<http://www.waml.ws/pages/concilpre.asp>

Cardiff Centre for Ethics Law & Society

<http://www.ccels.cardiff.ac.uk/>

International Center for Health, Law and Ethics
UNESCO Chair in Bioethics
University of Haifa

<http://research.haifa.ac.il/~medlaw/eindex.htm>

Centre for Law and Biotechnology
University of Sienna

<http://www.biolaw.it/Centre/index.htm>

CESAGEN – Centre for Economic and Social
Aspects of Genomics

Lancaster University

Cardiff University

<http://www.cesagen.lancs.ac.uk/index.htm>

Lithuanian Bioethics Committee

<http://bioetika.sam.lt/indexeng.htm>

CO-OPERATION WITH INTERNATIONAL ORGANIZATIONS:

UNESCO, Division on Ethics of Science
and Technology

Social and Human Sciences Sector

[http://portal.unesco.org/shs/es/ev.php-URL_ID=](http://portal.unesco.org/shs/es/ev.php-URL_ID=1373&URL_DO=DO_TOPIC&URL_SECTION=201.html)

[1373&URL_DO=DO_TOPIC&URL_SECTION=201.html](http://portal.unesco.org/shs/es/ev.php-URL_ID=1373&URL_DO=DO_TOPIC&URL_SECTION=201.html)

WHO

Ethics, Trade, Human Rights and Health Law

<http://www.who.int/eth/en/>

Council of Europe

Bioethics Department Secretary of the Steering
Committee on Bioethics (CDBI)

[http://www.coe.int/T/E/Legal_Affairs/Legal_co-operation/
Bioethics/CDBI/](http://www.coe.int/T/E/Legal_Affairs/Legal_co-operation/Bioethics/CDBI/)

European Commission DG Research,
Directorate C - Science and Society
Unit 3: Ethics and science

[http://europa.eu.int/comm/dgs/research/
organisation.cfm?lang=en#C](http://europa.eu.int/comm/dgs/research/organisation.cfm?lang=en#C)

3. ACTIVITIES

3.1. RESEARCH

CELAB main research topics are:

- ▶ Biobanks
- ▶ Biomedical research
- ▶ Biotechnology
- ▶ Euthanasia
- ▶ Cloning
- ▶ Genetic testing, screening
- ▶ Health data
- ▶ Human genetics
- ▶ Medically assisted reproduction
- ▶ Stem cell research

3.1.1. CELAB in EU Research Projects

During the Academic Year of 2005/2006 CELAB prepared for its participation in two EU projects, both starting in the Academic Year of 2006/2007.

3.1.1.1. EU Fifth Framework Projects: CELAB's 'pre-history'

Public Understanding of Genetics (PUG)

<http://les1.man.ac.uk/sa/pug/>

The project Public Understanding of Genetics (PUG) aimed to investigate the way in which different publics across Europe identify the social implications of new genetic technologies. It focuses on a range of sites in which the public understanding of genetics is produced and mobilized: for example, the media, the clinic, community settings, parliamentary and legal debates, and within campaigning and 'self-help' groups. A series of case studies in seven European countries (Britain, Spain,

Italy, France, Lithuania, Norway and Hungary) provided new empirical data on the way in which a variety of 'publics' mobilize, or not, genetics. Findings from the case studies informed an investigation of the relationship between genetics and kinship, genetics and race, and genetics and governance.

The Hungarian team of the project (Judit Sándor, principal investigator and Enikő Demény, research assistant) has been involved mainly in the work-package 3 of the project, entitled *Governance and Normative Understanding of Genetics in Europe*.

The research has been designed to meet the following objectives:

- ▶ to identify and explore the European specificity by mapping the contours of the legislative debate surrounding genetics in a number of European countries;
- ▶ to analyze the conceptual issues involved in the legal construction of ethical responses to new biomedical technologies;
- ▶ to compare the predominant conceptual views in various European biomedical laws.

During the project, the research team has monitored biomedical norms (ethical and legal) in the territory of the European Union and Council of Europe in the field of genetics (including genetic testing, screening, stem cell research, gene banks, gene therapy and patenting). Furthermore, based on the systematic review of the relevant legal sources and literature, it has identified ethical and legal principles in the field of study within the European Union and within the Council of Europe, and compared and analyzed laws, legislative proposals, reports and cases decided by the European Court of Human Rights (ECHR) and European Court of Justice (ECJ).

The aim of the sub-workpackage 3.1., entitled *PUG and Legislation in Europe* was to collect and analyze data

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from the European partners on legislation, ethics and genetics. It has produced a short pamphlet designed for a non-specialist audience, which is being disseminated through a variety of non-specialist networks and user-groups. This collection of data formed the base of CELAB's Biolaw Database (see more about this in the next section).

Privacy in Research Ethics & Law (PRIVREAL)

<http://www.privireal.org>

Privreal was a European Commission framework 5 funded project that examined the implementation of the Data Protection Directive 95/46/EC in relation to medical research and the role of ethics committees. The Directive, in general, aims to remove obstacles to the flow of personal data by requiring a high level of protection of fundamental rights (in particular, privacy) in the Member States. Each State has implemented the Directive differently and it is unclear how medical research, specifically, will be affected. This project was created to gather information regarding the implementation of this Directive across Europe.

The PRIVIREAL project finished at the end of June 2005. The final meeting to discuss the results of the PRIVIREAL project and to allow the issues to be promoted by relevant policy and decision makers, was held at the Finnish Permanent Representation, Brussels on 14 June 2005. The recommendations were presented initially relating to the adequacy of domestic implementation of the provisions of Directive 95/46/EC, focusing particularly on medical research. Attention was then given to the role of Research Ethics Committee (REC) review in relation to the protection of rights granted to research participants by this Directive, advising on the remit that needs to be given to RECs to ensure that such review fully protects those rights.

CELAB's actual involvement in *Privacy in Law, Ethics and Genetic Data (PRIVILEGED)* project is the direct outcome of this project.

3.1.1.2. EU Sixth Framework Projects: the Present

Privacy in Law, Ethics and Genetic Data (PRIVILEGED)

The project aims to make recommendations for research practice and public policy-making, including regulatory options at the national and European

level, to promote optimal relations between research using genetic data and bio-banks and ethical interests in privacy. PRIVILEGED will identify, analyze and compare plural ethical, cultural, and social concepts of legitimate privacy interest engaged by research using genetic databases and bio-banks. It will articulate the relation between such concepts and the current regulation of research using genetic data and bio-banks. Describing areas of common understanding while also showing points of difference throughout the EU, EEA, NAS, Israel, Japan and Taiwan (the research area), PRIVILEGED will provide a comprehensive and systematic study of the inter-relationship between privacy interests and advances in genetic science and information technology within a diverse cultural and regulatory context.

Assessment will be made of both the coherence and adequacy of existing regulation, in particular data protection, for the protection and promotion of both individual and group interests in privacy. PRIVILEGED will bring together experts in medicine, public health, philosophy, ethics, science and law from across the whole research area. A series of workshops, web-resources, national and comparative papers will be coordinated through three centers (Lithuania, Portugal and the UK) to address points of both potential conflict and synergy within and between the interests of science and privacy, individuals and groups, and diverse cultures and fundamental ethical principles.

Duration: 2006–2009

The Role of CELAB in the Project

Beside the contribution to all the 12 work-packages of the project, Professor Judit Sándor, Director of CELAB is a member of the project's Steering Committee. The Steering Group has the two distinct functions of being: 1) a project management group; and, 2) a scientific advisory group. The Steering Committee will fulfill these functions by meeting seven times during the project, as indicated in B5. The membership of the Steering Group is chosen to reflect experience in the management of projects, especially in relation to budgets and staffing, and to reflect the interests of the broader membership of the Consortium, the interdisciplinary and geographical balance of the project, and experience in scientific projects of this nature.

Genetic Bio- and Data-Banking: Confidentiality and the Protection of Data (GeneBanC)

www.genebanc.eu

The last few years have witnessed an important expansion of collection and processing of human biological samples and of the related information data. This activity has strategic importance for genetic research, clinical care and future treatments. Biobanks are huge repositories of human biological specimens. They are often the key links between abstract genomic data and concrete patient medical records, between genotype and phenotype. This research project aims to investigate the ethical, legal and social issues of three types of biobanks: classical banking, population banking and forensic DNA databases.

The first objective of the research project is to study the issue of privacy and confidentiality. In the context of modern biobanking, the duty of confidentiality and the right to privacy have been seen mainly as basic features of ethical biobanking, and the required confidentiality has rarely been problematized. There is, however, reason to believe that an unquestioned transfer of the traditional concept of confidentiality to the three types of biobanking described may be problematic, and that the concept needs to be reanalyzed in these new contexts. The second objective is to investigate the existing regulatory framework of biobanks across the EU and to focus on the collection and analysis of legislation and regulation regarding the establishment, management and functioning of classical, population and forensic biobanks.

The analysis of existing legislation will also provide some suggestions for “best rules.” The third objective is to investigate the ethical and policy issues related to forensic databases. Until now ethical and legal research has been mainly focused on population-based genetic databases. Moreover in a post-9/11 era, forensic genetic databases (crime, terrorism) generate many questions that have received no attention so far on a European level. The fourth objective is to investigate governance aspects of biobanks. The objective is to study the social, ethical, scientific-technological, and political-regulatory embedding of biobanks, to help the understanding of the ethical, socio-economic, scientific-technological and political implications of biobank development on the local and the national level, and in the transnational field and, thereby, to

contribute to a better understanding of biobank governance.

The results obtained within the different objectives described above will be of great use for the development of policy-oriented recommendations concerning the organization and management of small-scale biobanks, population databanks and forensic DNA databases. We aim also to make proposals in order to reach, where appropriate, a harmonized regulatory framework across the European Union. This will be done in broad consultation with experts not involved in the project.

Duration: 2006–2009

The Role of CELAB in the Project

CELAB (partner 4 in the project), in cooperation with Maastricht University, is responsible for the work package 4 of this project (WP4) entitled “*Comparative research regarding the regulatory framework of biobanks in the EU Member States.*”

This workpackage aims to investigate the existing regulatory framework of biobanks across the EU and will focus on the following objectives (1) Collecting and analyzing legislation and regulations regarding the establishment, management and functioning of classical, population and forensic biobanks across Europe; (2) Describing the similarities and differences in such legislation and regulations; (3) Looking for the “best rules” by comparing these similarities and differences; (4) Making proposals in order to reach, where appropriate, a harmonized regulatory framework across the EU.

3.1.1.3. EU Seventh Framework Projects: the Future

CELAB has been invited to become a consortium member of the EU-FP7 Marie Curie Human Mobility RTN proposal: a European bioethical postgraduate and postdoctoral research training network (EU BIO-CAMPUS). The preparatory work will start in fall 2006. The participation in this project will contribute to the development of a Bioethics Teaching Network in the CEE region.

3.1.2. Research Conducted within CELAB

3.1.2.1. Comparative and interdisciplinary approaches on reproductive cloning and stem cell research (results to be discussed in a workshop/conference in Spring 2007)

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Research objectives:

- ▶ to analyze the dominant ethical arguments and principles governing the regulation of stem cell research
- ▶ to compare European and US approaches on stem cell research
- ▶ to compare the interconnections between regulation of reproductive cloning and stem cell research
- ▶ to analyze public debates on reproductive cloning and stem cell in a number of EU member states: this monitoring is based on a continuous analysis of relevant laws and decisions on this topic; these documents are reviewed permanently for the bio-law database of CELAB. The laws and regulations in this field of study are changing very rapidly so no legal and ethical research on this topic can be conducted without having a clear view of the continuously changing legislative landscape
- ▶ to investigate the arguments of different stakeholders of stem cell research

Description of the research methodology:

- ▶ monitoring biomedical norms (ethical and legal) in the territory of the European Union and the Council of Europe in the field of reproductive cloning and stem cell research
- ▶ analysis of ethical and legal principles in the field of the study within the European Union and within the Council of Europe
- ▶ comparative analysis of laws, legislative proposals, reports and cases decided by European courts

Innovative or original character of the research:

The research is highly innovative as regards its topic and its interdisciplinary approach (legal, ethical, social and public policy aspects are taken into consideration).

A character apart is being conferred to this initiative by the fact that its results are planned to be debated by leading specialists in this field, who can offer immediate feedback concerning the relevance of the research results on a global scale.

3.1.2.2. From Therapy to Selection: Legal and Ethical Debates on the New Methods of Assisted Reproduction

The aim of the research is to analyze the problems of regulating assisted procreation from two angles: first,

the current status of the regulation of assisted procreation, second, the application of reproductive technologies in the Hungarian law. In addition, the research goes beyond the 1997-demarcation line of the Hungarian health legislation and examines the ethical and legal impacts of new technologies. In this domain of biomedicine, new technologies almost always require reconsideration of existing regulation. While in the beginning, reproductive medicine served therapeutic purposes, today new technologies, such as pre-implantation genetic testing, sex-selection, various forms of gamete donation often pose the question where the line is between therapy and selection, and what constitutes eugenic purposes in selection.

3.1.2.3. Legal aspects of euthanasia: Medical Global Challenges: Should International Law Enforce Euthanasia?

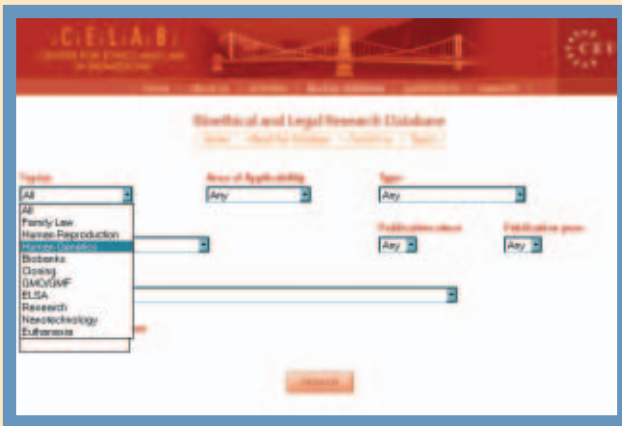
In the 2006/2007 Academic Year Violeta Besirevic, the winner of the CEU/SPO Visiting Research Fellowship Grants will carry out a research at CELAB on legal aspects of euthanasia. Besirevic started her research at CELAB on September 1, 2006. The purpose of her research is to examine the controversy of euthanasia in the context of international law and establish whether legalization is an inevitable accompaniment to globalization. Besirevic will associate euthanasia with an action or omission with the intent of bringing about a patient's death in order to end her suffering.

3.2. Bio-Ethical and Legal Database

www.biolaw-database.com

The Bioethical and Legal Research Database has started as a joint initiative of the Central European University (CEU) and the Public Understanding of Genetics in Europe (PUG) research project, financed by the European Commission Fifth framework Programme: Quality of Life and Management of Living Resources. (Contract number: QLG7-CT-2001-01668)

The European Union project was launched to investigate the ways in which the wider public across Europe identifies the social, ethical and legal implications of new genetic technologies. One of the



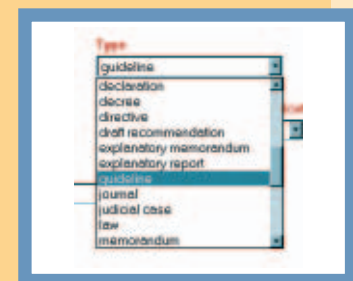
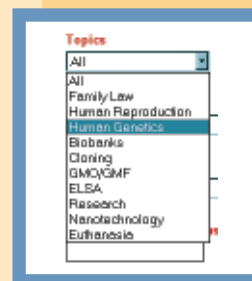
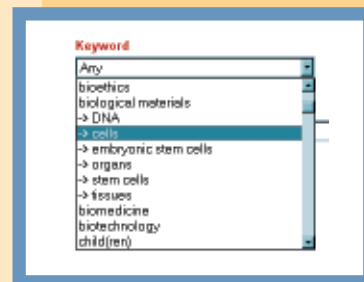
research areas within this EU project was an exploration of the legislative debates on genetics and genetic technologies in the participating European countries (France, Hungary, Italy, Lithuania, Norway, Spain, and the United Kingdom). The Hungarian team of the PUG project (Professor Judit Sándor, principal investigator and Enikő Demény, research assistant) initiated the creation of this Bioethical and Legal Research database to bring about a searchable archive of legal and normative documents. Central European University offered financial support for the creation of the database.

The main purpose of this project was to identify key documents on the ethical, legal and social aspects of human genetics in biomedical treatment and research and to create from them a Bioethical and Legal Research Database that is accessible through the Internet. This database intends to provide an indispensable resource for researchers, university professors and graduate students to promote academic and policy research in the domain of biomedical law and ethics.

For this purpose, a wide range of laws, legal cases and expert opinions have been screened for inclusion in the database. The possible entries have been reviewed, indexed by keywords and systematically organized into seven main topic areas in order to make them available for further research and education. The seven topics are the following: social and biological bonds; human reproduction; human genetics; biobanks; cloning; genetically modified organisms and food; and general ethical, legal and social aspects. Under these seven topics a number of keywords can be selected, with the help of which the database can be searched.

The seven main topics were identified on the basis of the classification used in the Public Understanding of Genetics EU project, which served as a starting point for the present database. Therefore, besides screening the topics, explicitly addressing the issues of genetics and biomedicine (human reproduction, human genetics, biobanks, cloning and genetically modified organisms), we have also collected and analyzed documents on social and biological family bonds. We started out with an interest in finding out how the regulation of family issues, marriage, adoption or abortion is connected with the regulation of new genetic advances.

The web-page was designed by a hired consultant, who also offered support in the maintenance of the database, and in the procurement of a domain name for it. The database allows searching based on the following categories: keyword; type of the document (for example law, regulation, policy document, report, etc.); issuing agency or institution (for exam-



3. ACTIVITIES

ple European Union, WHO, French government, HEFA, and so on); exact publication year; and publication after a certain year. It also allows for a simple search by any word or phrase. The web page contains documents in English, French, Italian, Spanish, Norwegian, Hungarian and German. For each document



a country flag indicates the language of the document. The database contains laws, professional guidelines, ethical codes, recommendations, directives, and legislative reports. These documents are produced and issued by legislatures, governmental organizations, and various non-governmental organizations, such as professional associations and consumer groups. Depending on the range of applicabil-

ity, the documents are further divided into the categories of national, regional and international.

The database website had been launched on December 15, 2004, when Enikő Demény presented it to the public forum “Genetics and Society”, organized in Barcelona, by the PUG project. On this occasion the support offered by Central European University for the creation of a searchable bioethical and legal research database was acknowledged in front of a large audience. The database was highly appreciated by project members and this acknowledgement has been reported to the European Union as well.

The database has been indexed under the main search engines, therefore it can be reached by all those who are searching the internet on the topics of bio-law, biomedicine.

During the Academic Year of 2005/2006 the Biolaw Database was updated regularly and expanded with more than 100 new entries. The Database aims to include as much regional material as possible. New topics have been added to the database, such as euthanasia or nanotechnology.

The database is expanding week by week to include laws, legal cases, professional guidelines and expert opinions published not only in the seven original European countries but also by international organizations, national governments, legislative bodies and NGOs throughout the world.

The database has been accessed up to now from 34 countries of the five continents.

3.3. WORKSHOPS

3.3.1. CELAB “Bioethics Around the World” Series

The main goal of this series is to present the prevailing ethical views of different parts of the world and the specific regulations of biomedical issues existing throughout the world as well as to engage in a constructive dialogue with these different positions.

3.3.1.1. *Bioethics in Scandinavia*

The workshop took place on February 17, 2006, in the Senate room of Central European University. The workshop was opened by Judit Sándor, director of Center for Ethics and Law in Biomedicine. The opening speech was followed by the presentations of three



invited guests from three Scandinavian countries: Denmark, Norway and Sweden. Each presentation was followed by discussions.

Twenty participants were present at the workshop. Among the participants, there were CELAB research fellows from the Semmelweis University, the University of Debrecen and CEU; students of CEU and ELTE; Hungarian MDs, lawyers, professors; and the representatives of the Hungarian Institute for Data Protection and the UNESCO's COMEST committee.



In her opening presentation, Judit Sándor briefly introduced Central European University to the participants and informed them about the recently opened CEU research center, the Center for Ethics and Law in Biomedicine. She pointed out that it is a big challenge to address in the framework of one center the issue of law and ethics, as these two fields of inquiry are kept separate even in our days. The question worth addressing in this context is therefore how law and ethics shall relate to each other in the issues raised in the field of biomedicine. This question proved to be a very provocative and interesting one, since all the invited guests reflected on it, and the discussions also dealt with it.

Professor Sándor pointed out that although Scandinavia is well ahead in matters of biotechnological applications and the development of bioethics, in our region little is known about Scandinavian bioethics. Therefore, the workshop may represent a first step towards building collaboration between CEU and Scandinavian universities in the field of bioethics.

The first presentation was delivered by Professor Dr. Knut W. Ruyter. His presentation focused, from a Norwegian perspective, on issues concerning the influence of law on research ethics. Professor Ruyter

pointed out that over the past decade Norway has passed several laws with implications for health care and health care research. Some of them implement EU directives, while others are special acts within specific areas. Most important are the acts concerning patients' rights, health personnel, biobanks, the medical use of biotechnology, and health registry. These acts do not focus primarily on research, but have, in the process, been made applicable to research. The latest inquiry into the topic concluded that the acts regulating research are fragmented and unclear. There is a proposal in Norway for a separate new act regulating health care research. According to the presenter, the main problem with this proposal is that it gives very detailed regulations on the basis of the acts already passed. This has two important consequences: it puts unnecessary limitations on certain types of research, and it redefines the task of the research ethics committees. The limitations concern mainly research in which valid consent cannot or should not be obtained. The committee's review changes the foundation for discernment: from professional guidelines and common moralities to acts that are in need of legal interpretation. The second case study, selected for illustrating the above mentioned statement, the establishment of research biobanks, introduced to the audience the main topic of the next two presentations, that of biobanks.

Within the field of biomedical research there is a growing demand for the establishment of national or other institutional biobanks. Biobanks, whether used solely to store biological samples, genetic data, to process such data, or to operate as a tissue bank, require special regulation.

Biobanks are repositories for genetic information derived either directly from patients or indirectly from stored tissue sources. In recent years, in many countries governments and the private sector have invested in biobanks for a number of reasons. Population biobanks have been established to explore the relationship between genetic variation and disease in human populations. Biobanks have also been established to support criminal investigation and for military purposes.

The ethical and legal implications of the operation of biological material banks arise in connection with, for instance, the possible reuse of collected body material for other purposes. This raises the question of how far patients and donors or, as the case may be,

3. ACTIVITIES

their families should be informed of this possibility in order for them to give their consent.

Biobanks enable research that cannot be wholly anticipated at the time the bank is created. Any defense of the benefits of biobanks must, therefore, be based in large part on a belief in the value of subsequent research. While there are highly visible and optimistic accounts of the products of the yet-to-be-completed research, actual benefits are likely to be distant in time and difficult to articulate in detail. Primary critiques of biobanks typically focus on social risks and lost opportunity costs that cannot be assessed or managed through individual informed consent or privacy protection.

The establishment and use of biobanks raise a number of ethical dilemmas and are creating a need for adequate regulatory framework. Shall we use the same ethical and legal standards for all kinds of tissue collection? What constitutes a biobank? Which specific features require additional ethical and legal guarantees: The fact that samples are taken from vulnerable groups, such as minors? Or what matters more is the frequency of the collection, the size of the biobank, or the type of the actual biologic material that is collected? Do DNA-banks require special attention? These



were some of the issues addressed in their presentation by Mette Hartlev and Teresa Kulawik.

The presentation of Mette Hartlev, entitled *Balancing of values and interests in biobank regulation* focused on biobank regulation from a Danish and Nordic perspective. Hartlev pointed out that for many decades it has been a practice to collect tissue samples from patients and research subjects for diagnostic or research purposes. In Denmark many of



these samples have been kept at hospitals and research institutions, in so-called biobanks. In spite of this, for many years there was no public knowledge and, thus, no public concern in Denmark with regard to biobanks. It was in the mid-1990s when the public's attention was brought to the storage of blood samples from all newborns in the national PKU-biobank. As a response to public concern, initiatives were taken to issue legal regulation in the area. However, it took a number of years until Parliament, in year 2004, was ready to set up a legal framework for biobanks. In the meantime other countries, including two other Scandinavian countries (Norway and Sweden) had issued rules and regulations in the area.

Hartlev pointed out that there are a number of different interests and values involved in biobanking. Most tissue samples have been collected in connection with diagnostics and treatment, and there could be weighty diagnostic arguments for keeping the samples in a biobank – at least for a period of time. However, the main purpose of storing the samples is for research. Consequently, there is a very strong *research interest* both in the storing of tissue samples in biobanks, and in the possibility of using the samples for research purposes. Seen from the perspective of *society* and *public health*, biobanking could also be useful as it provides a source for valuable research. *Private companies* could also have an economic interest in establishing and using biobanks. However, these interests must be balanced against the *interests of the tissue donor*. The donor will normally have a strong *privacy* interest as tissue samples contain very sensible information about the donor. Furthermore, donors might also have an

interest in *controlling* or influencing the use of tissue samples for various purposes. Some tissue donors might e.g. not want to contribute to specific kinds of research. The interest of the donor could be in conflict with the interests of research, society and private business. However, creating trust in biomedicine is of immense importance both from the perspective of research, society and industry; and respect for donors' privacy and autonomy rights is a way to create trust. Accordingly, it is important not to overestimate the conflict between the interests of the donor and other stakeholders. Hartlev in her presentation took a closer look into how these interests and values are addressed and balanced in Danish law and she also made a comparison with the Norwegian and Swedish biobank legislation.

In the third presentation, offered by Teresa Kulawik, entitled *The politics of stem cells in Sweden. Explaining liberal regulations in the social democratic state* the speaker pointed out that Sweden stands out in its biomedical policy through remarkably liberal, lenient regulations, which, in European comparison, are closest to those of Great Britain. Sweden's legislation, for example, allows for the use of so-called "spare" human embryos, resulting from IVF procedures, for research purposes, pre-implantation genetic diagnosis, and egg donation. In 2005 the creation of human embryos for research purposes and so-called therapeutic cloning were legalized. Kulawik pointed out that this policy-making process provoked only a moderate deal of controversy. Parliamentary resolutions concerning the issue were backed by a broad consensus among all parties in Parliament. To say the least, the politicization of biomedical issues has been quite limited. This corresponds well to the virtual lack of noticeable mobilization of extra-parliamentary groups. This may come as a surprise for at least two reasons. Sweden generated one of the largest environmentalist movements in the 1970s. From a comparative perspective, Sweden has been classified as having high political potential regarding "new politics." Kulawik argued that the Swedish model is based on a productivist paradigm, the institutional and discursive parameters of which have not been decisively extended through its "new politics." In this way, elitist policy-making structures within environmental and technology policies have remained intact. Sweden's heritage of utilitarian ethics and

pragmatic legal tradition and its assertions make it even more difficult for leftists or feminists to formulate a critical stance.

At the end of the discussions Judit Sándor concluded that the workshop was very interesting and she expressed in the name of CELAB thanks to Oslo University, which made possible the participation of Knut Reyter at the workshop and to the Humanities Center, that covered the costs of Mrs. Kulawik and Mrs. Hartlev. The last part of the workshop was devoted to discussing further ways of cooperation between CELAB and the invited guests. The idea of a common, small-scale research project was discussed. As a follow up of this workshop, Judit Sándor took part in a workshop "Bioethics and Human Rights", organized in Oslo in May, 2006.

3.3.1.2. Bioethics in Asia



On June 21, 2006 the CEU Center for Ethics and Law in Biomedicine (CELAB), in the framework of its *Bioethics Around the World Series* organized the workshop "Bioethics in Asia." The workshop illustrated some elements of the Asian ethical and legal attitudes towards science. After the introduction by Judit Sándor, two distinguished guest speakers provided an overview of the most recent developments in the field of law and bioethics in Asia.

Darryl Macer, Ph.D., UNESCO's Regional Advisor in Human and Social Sciences for Asia and Pacific, Bangkok gave a lecture on "*Bioethics and Communities: Reflections on Bioethics and Social Responsibility.*"

The discussion of the ethical, social and legal aspects of human relationships with life has a long history of discussion in Asia. While the general principles to resolve

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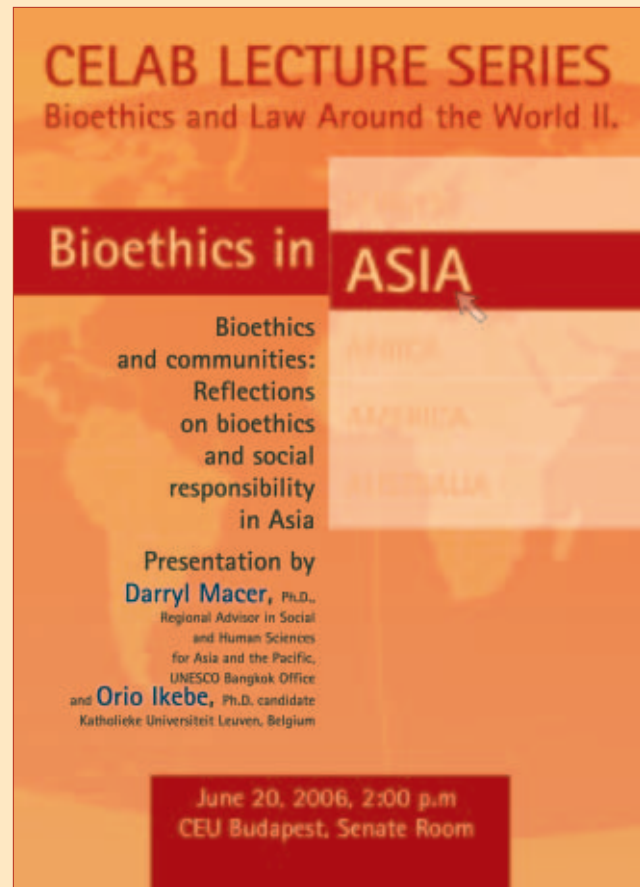
bioethics dilemmas in Asia may be similar to global ones, there have been some different emphases, especially in policy making for environmental and medical ethics. Fundamental to the discussion of the topic of bioethics in Asia is the definition of bioethics. There are two ways to think of the term bioethics, one is descriptive bioethics – the way people view life and their moral interactions and responsibilities with living organisms in life. The other is prescriptive bioethics – to tell others what is good or bad, what principles are most important; or to say something/someone has rights and therefore others have duties to them. Both these concepts have old roots, which we can trace in religions and cultural patterns that may share some universal ideals.

Macer gave his own definition, according to which bioethics is the study of ethical issues arising from human involvement with life, and he called it the “love of life.” Macer distinguished four main principles of his ethics: being self-love (autonomy), love of others (justice), loving life (non-maleficence) and loving good (beneficence). These cover all the ideas and concepts of bioethics, and are found in ancient writings around the world – both as descriptions of behavior and as prescriptions that others have made on the desirable standards of society.

Macer pointed out that the future of bioethics and universality are major issues in bioethics in Asia today. Bioethics networks play a role in our understanding of other people and groups. Studies of descriptive bioethics suggest there is much in common among cul-



tures, which can be called “universal bioethics.” This includes international law, the ideals that all human beings have equal rights, and that love is good; and do



no harm. We should also respect others solely because they have life. Universal cross-cultural ethics should be developed to allow diverse views to be maintained even within a single community, as well as throughout the world in the global community.

According to Macer, the call for international approaches is also based on the shared biological heritage and destiny of human beings in all “nations,” and the precedents for international law to protect common interests of humanity. However, the strongest call is based on another fact: people everywhere live in groups of societies called nations, and these are shown to be microcosms of diversity. The range of the genetic, social and spiritual diversity inside each is as broad as the total of all nations. This is universal bioethics. This descriptive reality of bioethics challenges the prescriptive side – policy and guidelines – to be international.

One of the efforts of universal prescriptive bioethics is the work of the UNESCO International Bioethics Committee to develop guidelines and a UN Declaration on the Protection of the Human Genome which at-

tempts to protect humanity from future abuses of human genetics. The draft UNESCO Declaration on Protection of the Human Genome includes 20 articles, and its formal title is “A Declaration on the human genome and its protection in relation to human dignity and human rights.” It had to be general to obtain the broad support of the United Nations General Assembly. It encourages national governments to enact laws to protect people against misuse of genetics.

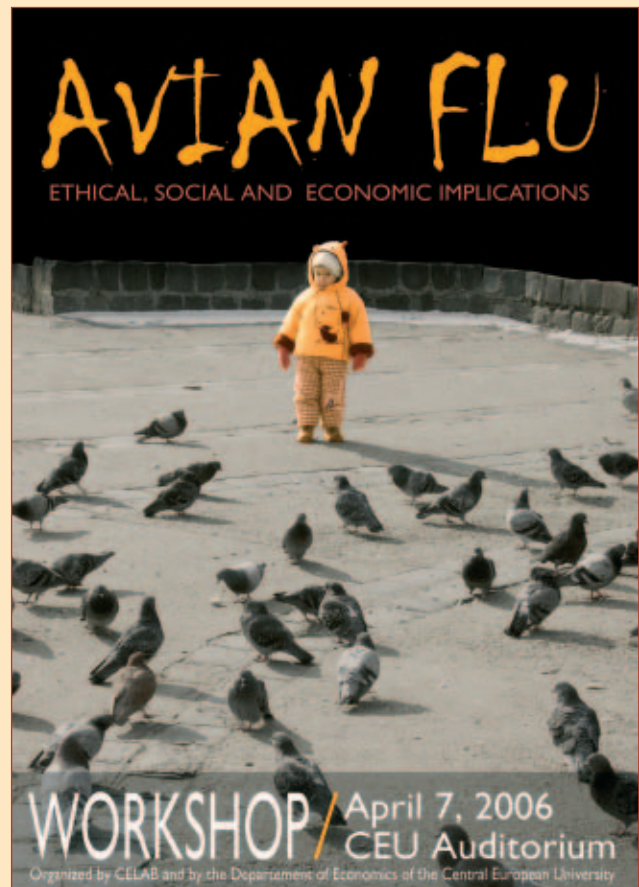
At the end of his presentation, Macer highlighted the importance of teaching bioethics at all levels of education.

Orio Ikebe, Ph.D. candidate, from Catholic University, Leuven presented a lecture on *The regulations of human cloning research in Japan and other Asian Countries*. The different views about the moral status of the human embryo, together with various religious teachings and socio-cultural values have influenced the development of different regulation of human cloning research in the world. Ikebe pointed out that the cultural attitudes towards the human fetus and embryo in Asia provide a kind of continuity in the life cycle of the fetus. It follows from this special cultural meaning of the human embryo that it is less likely to hinder the research on human cloning in Asia than in other parts of the world. Furthermore, Asian countries have a more permissive attitude towards therapeutic cloning too. At the end of her lecture, Ikebe concluded that in addition to controversial moral issues, safety and potential applications of stem cell research should be taken into account in formulating national laws in this field.

In the last part of the workshop, participants discussed possible ways of cooperation between CELAB and bioethicists from Asia.

3.3.2. Workshops Organized in Collaboration with other CEU Departments or Centers

The aim of these workshops organized by CELAB in cooperation with other CEU Centers and Departments is to contribute to the promotion of interdisciplinary research at CEU. Through organizing workshops, conferences in relevant biomedical topics, CELAB would like to create a high profile for research connected with life science and biotechnology. In the 2005-2006 academic year the topic of the workshop was the avian influenza pandemic.



Avian Flu Workshop

On April 7, 2006 – the World Health Day – Central European University’s Center for Ethics and Law in Biomedicine and the Department of Economic organized a workshop on the topic “*Avian Flu: Ethical, Social and Economic Implications*.” The spread of avian influenza from South East Asia to countries of Central and Eastern Europe, and the global concern at the possible emergence of a new pandemic-causing virus made the avian flue a hot topic for public health authorities. In addition, avian influenza raises important ethical, social and economic questions, such as allocation of scarce resources, human-animal relations, animal rights, priority setting, limiting personal freedom, etc. Speakers coming from different disciplines contributed to the understanding of the complex issues related to a possible avian influenza pandemic, ranging from panic reaction, risk perception and risk communication to the glob-

3. ACTIVITIES

al macroeconomic consequences, public health and environmental issues or global governance implications.

The keynote speaker of the workshop was Professor Elemér Hankiss, from the Institute of Political Science of the Hungarian Academy of Sciences. According to Hankiss, the spread of the avian flu causes a panic that might have both negative and positive implications. The positive aspect would be that those concerned would start to work hard to solve the problem, but at the same time the panic would materialize in profits for some others (for example pharmaceutical companies or media). He also pointed out that the fight against avian flu raises certain ethical and moral questions, namely whether people have the right to interfere in the laws of nature. Another question might be whether human beings are really superior and have the right to destroy animals?

The European Commission was represented by Octavi Quintana Trías, Director of the Health Directorate, Directorate-General for Research. Quintana Trías pointed out that in general there are 2 or 3 pandemics in each century. The three pandemics of the 20th century – the 1918-1919 Spanish flu, the 1957-1958 Asian flu, and the 1968-1969



Hong-Kong flu – caused the death of millions of people. Quintana-Trías highlighted that the pandemic caused by the H5N1 virus is not yet a human pandemic, it is only an avian pandemic, which affects millions of birds but has caused the death of human



beings on very rare occasions. Nevertheless, the risk of a human pandemic remains high. According to Quintana Trías, the main instruments in the fight against avian flu are early prevention systems (namely the veterinary surveillance networks), vaccines and virus killing drugs.

The history of pandemics in Europe was presented by Dr. Benedek Varga, Deputy Director General, Semmelweis Museum, Library and Archives of Medical History, in his presentation entitled *Pandemics in Europe since the 1346/48 Pest Pandemic*.

The first panel, Avian Flu: Challenges to Public Health and Economy, was chaired by Dr. Ferenc Oberfrank. It included three lectures: *Human flu pandemics in the past and the predicted future developments and perspectives*, presented by Professor Dr. György Berencsi, Head of Virology Department, Béla Johan National Center for Epidemiology; *Economic and political implications of the avian flu*, presented by Professor Dr. Péter Mihályi, Department of Economics, Central European University, and *Avian flu and its public health significance*, presented by Professor Dr. János Varga, Department of Microbiology and Infectious Diseases, Faculty of Veterinary Sciences, Szent István University.

The second panel, Avian Flu: Ethical, Legal and Media Aspects, chaired by Professor Judit Sándor, Department of Gender, Law and Political Science, Central European University included three lectures: A new war against animals: The Animal Liberation movement under the threat of avian flu epidemic, presented by László Nemes, Ph.D. candidate, research

assistant, Institute of Behavioural Sciences, Medical and Health Sciences Center, University of Debrecen; *Ethics, Law and the Social Construction of Risk: Emerging ethical guidelines for an avian flu pandemic*, presented by Péter Kakuk, Ph.D. candidate, research assistant, Institute of Behavioural Sciences, Medical and Health

Sciences Centre, University of Debrecen/CELAB research associate; and “*Silent spring*” revisited: *birds, humans, and the media representation of risks related to the avian flu epidemic*, presented by Miklós Sükösd, Associate Professor of Political Science, Department of Political Science, Central European University.

3.4. TEACHING

CELAB's staff and fellows are involved in teaching activity both at CEU and in other Universities in Hungary and in other countries in the region. They offer courses that are in close connection with CELAB's main fields of inquiry. One of CELAB's goals is to develop a **teaching network** for Bioethics and Biolaw in the region.

3.4.1. Teaching at CEU

3.4.1.1. *Reproduction, Self, and State*

Professor Judit Sándor
Gender Studies Department
2005/2006 Fall Semester

3.4.1.2. *Contemporary Interpretations of Privacy*

Professor Judit Sándor
Gender Studies Department
2005/2006 Winter Semester

3.4.1.3. *Human Rights and Bioethics: A New Generation of Rights?*

Professor Judit Sándor
Legal Studies Department
2005/2006 Winter Semester

3.4.1.4. *Privacy and Data Protection*

Professor Judit Sándor
Legal Studies Department
2005/2006 Winter Semester

3.4.1.5. *Human Rights in the 21st Century*

Professor Judit Sándor
Political Science Department
2005/2006 Winter Semester

3.4.1.5. *Mental Disability Law and Advocacy*

Oliver Lewis, Visiting Lecturer
Legal Department,
Human Rights MA Program
Fifth Module, 2006

3.4.2. Teaching in Other Institutions

3.4.2.1. *European Course on Biotechnology Ethics*

Professor Judit Sándor:
Privacy and Genetic Information
June 29 to July 6, 2006, Brno

3.4.2.2. *Law of Assisted Reproduction*

Professor Judit Sándor, at ELTE,
Postgraduate Institute of Law
Faculty of Law, Budapest, 25 May 2006

3.4.2.3. *Family and Identity in the Age of Genetics*

Enikő Demény, Visiting Lecturer
Babes-Bolyai University,
Faculty of European Studies, Cluj, Romania
Spring Semester, 2006

3.4.2.4. *Legal Aspects of Euthanasia*

Violeta Besirevic, Visiting Lecturer
Union University School of Law, Belgrade, Serbia
April, 2006

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3.5. PARTICIPATION AT CONFERENCES

During the Academic Year of 2005/2006, CELAB staff and fellows took part in the following academic and scientific events:

3.5.1. EuroSOCAP

Brussels, September 8, 2005
European Standard on Confidentiality and Privacy in Healthcare among Vulnerable Patient Population.
Comments by Judit Sándor.

3.5.2. The Ethical Aspects of Profit Oriented Research

Budapest, October 5, 2005
Lecture presented by József Kovács at the Hungarian Bioethics Society

3.5.3. Depression and the Ethical Aspects of Drug Treatment

Tihany, October 6, 2005
Roundtable discussion with the participation of József Kovács at the 8th Congress of Neuro-Psychopharmacology

3.5.4. EURECA Project: Biobank Case Study

Tenerife, October 6–9, 2005
Biobanks: law of the stored (t)issues,
lecture by Judit Sándor

3.5.5. Ethical and Legal Questions of Biotechnology

Conference organized by the Hungarian Academy of Sciences and the Department of Research on Law and Governance of the Faculty of Law at the Károli Gáspár University,
Budapest, October 13, 2005
Biobanks: ethical and legal dilemmas,
lecture by Judit Sándor

3.5.6. UNESCO/COMEST session

Hungarian COMEST Session at the Hungarian Academy of Sciences
Budapest, October 21, 2005
The Universal Declaration on Bioethics and Human Rights,
lecture by Judit Sándor

3.5.7. Human Rights and Bioethics in the 21st Century

Budapest, October 26, 2005

Meeting with the Swiss-Hungarian Students' Association
Invited guest: Judit Sándor

3.5.8. Immortality of the Human Body

Talks at the Hauer Pastry-shop, organized by the Club of Scientific Journalists
Budapest, November 3, 2005
Immortality of the human body: the future of bioethics in the 21st century, lecture by Judit Sándor

3.5.9. Access to Assisted Reproduction

Single and single infertile women's access to assisted reproduction. Public debate
Budapest, November 5, 2005
Invited expert: Judit Sándor
CELAB Participant: Enikő Demény

3.5.10. Embedding Ethics

Organized at the Hungarian Academy of Sciences:
Budapest, November 6–9, 2005
Embedding Ethics in Scientific Practice,
Expert Meeting
UN Declaration on Human Cloning, lecture by Judit Sándor
The international world of bioethics and human rights,
lecture by Judit Sándor

3.5.11. World Science Forum

Organized by the Hungarian Academy of Sciences, following the recommendations of the first World Science Forum - Budapest, in partnership with UNESCO and ICSU, and with the support of the Hungarian Government.
Budapest, November 10–12, 2005
The Forum focused on Knowledge, Ethics and Responsibility.
Participant: Judit Sándor

3.5.12. Contemporary Perspectives on Kinship in Europe

Workshop organized by French-Norwegian Center for Cooperation in the Field of Social Science and Humanities
Paris, November 24–25, 2005
Natural parenthood in the age of new reproductive technologies and genetics,
lecture by Enikő Demény

3.5.13. Law, Ethics and Regulation of Assisted Procreation

Budapest, November 26, 2005

Changing society - changing family: assisted reproduction and the law, lecture by Judit Sándor

3.5.14. European Commission Science and Society Seminar

Science in Society Seminar organized by the European Commission Research Directorate-General
Budapest, January 23, 2006

Participant: Judit Sándor as keynote speaker

3.5.15. Social Attitudes toward Psychiatric Diseases - Symposium

Organized by the Nádasdy Foundation and the Hungarian Society of Cognitive Neurology
Budapest, February 11, 2006

The stigmatization of psychiatric diseases from the point of view of bioethics, lecture presented by József Kovács

3.5.16. Stealth Seeds: Bioproperty, Biosafety, Biopolitics

Public lecture offered by Ronald Herring, Professor of Political Science, Cornell University, USA
Budapest, February 16, 2006

Discussants: Judit Sándor, Director of the CELAB and Richard Scher, Professor of Political Science at University of Florida, USA, and Visiting Professor at the Political Science Department, CEU.

3.5.17. Regional Meeting of the UNESCO National Commissions

Budapest, March 24, 2006

From international to national: implementation of the Universal Declaration of Bioethics and Human Rights, lecture by Judit Sándor

3.5.18. Death and Dying: Legal Aspects

Workshop organized at the Hungarian Academy of Science

Budapest, March 28, 2006

Death and dying: legal aspects, lecture by Judit Sándor

3.5.19. Council for European Studies Fifteenth International Conference

Chicago, March 29–April 2, 2006

Panel *Regulating the politics of life – perspectives from East and West*

Participant: Judit Sándor

3.5.20. Medical Practice and Biomedical Research

Who owns medicine? Conflict of interests in medical practice and biomedical research.

Public lecture offered by Prof. Kathleen C. Glass
Budapest, May 3, 2006

Participant: Judit Sándor

3.5.21. Person and Property in Biotechnology

Budapest, May 9, 2006

Lecture series organized by the Hungarian Patent Office
Person and property in biotechnology, lecture by Judit Sándor

3.5.22. Philosophical Questions of Psychiatric Disease

Workshop organized by University of Debrecen
Debrecen, May 10, 2006

Philosophical Questions of Psychiatric Disease, lecture by József Kovács

3.5.23. Bioethics and Human Rights Workshop

Oslo, Norway, May 12–13, 2006

Follow-up to the CELAB Scandinavian Workshop
Participant: Judit Sándor

3.5.24. Genetic Research and Insurance

Workshop organized by the Hungarian Law Association and the Hungarian Bar Association
Budapest, May 17, 2006

Round table discussion: *Genetic research and insurance*
Participant: Judit Sándor

3.5.25. Conference on Rare Diseases and Congenital Anomalies

First Conference of the Hungarian Association of People with Rare Diseases and Congenital Anomalies (RIROSZ)

Budapest, May 29, 2006

Participant: Judit Sándor

3.5.26. Debate on Sterilization

Organized by the Committee for Human Rights, Minority, Civic and Religious Issues of the Hungarian Parliament.
Budapest, July 20, 2006

The bioethical aspects of sterilization, lecture presented by József Kovács

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3.5.27. 16th World Congress on Medical Law

Toulouse, August 7–11, 2006
Election of Judit Sándor as Chair of the Council of Presidents of the World Association of Medical Law (WAML)

Bodies that matter: legal dilemmas in the realm of biotechnology, lecture by Judit Sándor

3.5.28. Science and Democracy

Science and Democracy: A New Frontier between Eastern and Western Europe?
Stockholm, 4-6 September, 2006

Regulated reproduction in Hungary: science, law and the lessons for new democracies, lecture by Judit Sándor

3.5.29. New Pathways for European Bioethics Congress

The Center for Biomedical Ethics and Law at the

Catholic University of Leuven, Belgium, and the European Association of Centers of Medical Ethics (EACME)'s annual conference on the occasion of their 20th anniversary.

Leuven, September 28–30, 2006

Commentator of the session on bioethics, politics and law: Judit Sándor

First steps in the development of an international bio-law-or something else? New dimensions of bioethics. Response to Roberto Andorno, lecture by Judit Sándor

Critiques of Genethics: The role of epistemology in bioethical reflection, lecture by Péter, Kakuk.

3.5.30. “We Don’t Need Pity, but Participation”

Open day at the Municipal Community Center
Budapest, September 30, 2006

The rights of disabled persons in the EU,
lecture by Petra Bárd

3.6 MEDIA EVENTS

CELAB’s Director and Fellows took part in many media events in which they contributed to the awareness-raising about current ethical dilemmas in the field of biomedicine and had the opportunity to make CELAB more widely known in the media.

Patients’ Rights and Access to Health Care

Interview by Béla Pál with József Kovács
Kossuth Radio, „Rádióélet”, September 23, 2005

On Bioethics

Interview with József Kovács, reporter: Béla Pál
Kossuth Radio, „Kopogtató”, September 24, 2005

No for Surrogate Motherhood

Interview by Natália Zirkovics with József Kovács
Magyar Nemzet, October 20, 2005

Science, Ethics and the Media

Interview with Judit Sándor,
interviewer: Tamás Torma
Mediamix, October, 2005

Debate on Euthanasia

Participants: Judit Sándor, Andrea Békési; Moderator
György Baló

M1 (Channel 1 of the Hungarian Public Television),
Dokuzone, November, 2005

Ethics of Health Care in Hungary

Interview with Judit Sándor, interviewer: Eszter Rádai.

Title: Exhausted and Dependent. Ethics of Health Care in Hungary.

Élet és irodalom, 2005

The Ethical Aspects of Facial Plastic Surgery

Interview with József Kovács, interviewer Anna Danó
Népszabadság, December 3, 2005

Our Life into our Hands!

Forum column by József Kovács,
Népszabadság 53, 2005

Human Rights, Genetics, Gen(e)thics

Interview with Judit Sándor,
interviewer: László Sándor
Népszava, January 7, 2006

The Ethical, Legal and Social Aspects of Egg Donation

Participants: Judit Sándor, János Urbancsek;

Moderator: Robert Kárász
ECHO Hungaria TV, February, 2006

The Social Stigma of Psychiatric Diseases

Viktória Kun J. article based
on József Kovács's lecture
Népszabadság, February 13, 2006

On the Advertisement of Health Care Services

Interview with József Kovács,
interviewer Viktória Kun J.
Népszabadság, February 21, 2006

What Can Genetics Offer Us Today and What is Its Promise for the Future?

Lecture by György Kosztolányi
Discussant: Judit Sándor
Duna TV, Mindentudás Egyeteme, March, 2006

Televised Public Lecture on Genetically Modified Organisms

GMO: facts, hopes and fictions,
presentation by Ervin Balázs;
Discussant: Judit Sándor
Duna TV, Mindentudás Egyeteme, April, 2006

Televised Public Lecture on the Promise of Genetics

Moderator: Galamb
Invited Guests: Dr. István Raskó, Dr. Judit Sándor,
Márton Karinthy MTV1, Kultúrház Extra, May 12, 2006

Genetic Screening for Embryos in the UK

Scientific news: The UK extends gene screening
for embryos.
Moderator: Júlia Gimes. Commentaries by Judit
Sándor.
Kossuth Rádió, "Szonda" Science Magazine, May, 2006

Space-Time: The World of Researchers. A portrait of Judit Sándor

Moderator: Júlia Gimes, Interviewee: Judit Sándor
Kossuth Rádió, July 2006

On the new Regulation of Artificial Sterilization

Article by Viktória Kun J,
based on a lecture of József Kovács
Népszabadság, July 21, 2006

3.7. Selected Publications by CELAB Fellows and Researchers

- Petra Bárd (2006) Az egyenlő bánásmód elvének érvényesítése és az alkotmányos alapjogok korlátozhatósága [The Enforceability of the Equal Treatment Principle and the Limitation of Fundamental Rights]. In *Fundamentum* [in print].
- Petra Bárd (2006) The German Anti-Discrimination Legislation with a Special Focus on Disability. In *Acta Juridica Hungarica* [47, No. 3, 273-301].
- Petra Bárd (2006) The Regulation of the Rights of Persons with Disabilities in the European Union, Fifth Workshop for Young Scholars WISH, Les Travaux du CERIC, Brussels: Bruylant [in print].
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3. ACTIVITIES

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Translations

UNESCO: Universal Declaration on Bioethics and Human Rights [UNESCO: A bioetika és az emberi jogok egyetemes nyilatkozata] Hungarian translation by Enikő Demény. In *Acta Humana* 17(1), pp.97-105.

4. BUDGET

Approved Budget: 26,614 Euro

4.1. DETAILED BUDGET

Budget category	Amount in Euro
Personnel cost	25,894,00
Web-page design	269,00
Workshop costs	279,00
Other costs	57,00
TOTAL spending	26,499,00

4.1.1. Web-page design

Web-page design: 269 Euro

4.1.2. Workshop costs

4.1.2.1. *Bioethics in Asia workshop*

Cost category	Description	Amount in Euro
Accommodation	Guest lecturer's	146
Travel	Taxi	8
Catering	Buffet lunch + 1 coffee break	102
Other	poster, office supplies	23
Total		279

4.1.3. Other Costs

Cost category	Description	Amount in Euro
Office supplies	Toner for the printer	35
Mailing	DHL	22
Total		57



