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CENTER
FOR ETHICS AND LAW
IN BIOMEDICINE

ANNUAL REPORT

2007-2008



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1. FOREWORD

Ethics and law of biotechnology have obtained increasingly global dimensions. Responding to emerging data protection and intellectual property issues in biomedical law and working towards a better international coordination of regulatory policies in these fields have been probably the two most important issues that the CEU Center for Ethics and Law in Biomedicine (CELAB) has focused on in its activities. The Third Annual Report of CELAB that the reader holds in her hands is a summary of our main achievements during the 2007–2008 academic year.

Our first year of operation (2005–2006) was dedicated to setting priorities, developing networks and creating a biomedical-legal database. In the second year we submitted numerous applications to various research grants, and within a short time we started two new research projects. During our third year of research activities, the network of CELAB partners, associates and collaborators have become truly international, which is accentuated by our participation in five European research projects. Our small research team has been consequently expanded, and together with our new colleagues and research associates, we are working on a wide range of academic and administrative tasks. Regardless of this necessary institutional expansion, our staff has been able to preserve its original enthusiasm to work in the exciting cross-disciplinary domain of biomedical law and ethics.

In 2005 the idea behind establishing this Center was related to the recognition of a new and increasingly developing interdisciplinary field: the ethical, legal, and social implications of biotechnological advances. Life sciences, especially biomedicine, traditionally focused on the restoration of health and ‘normality’. Entering the age of the human genome project, biobanks, stem cell research, and nanotechnology the role of biomedical science has shifted toward the purposeful transformation of various human capacities. For instance, while the new reproductive technologies could overcome some problems of infertility, they also pose new questions of what sexuality, gender, and kinship mean in our contemporary societies. We also have to realize that the technologies of genetic testing and preimplantation diagnosis allow for enhancement. And all these changes force the various social sciences and the practice of governance to rethink decision-making in science policy, the way resources are allocated, and the ethical and legal concerns related to the various uses of genetic data. Our Center has focused on these issues in the framework of different European research projects funded by the European Union and UNESCO.

CELAB works on the national, regional, and international levels. In European research consortia knowledge about the Hungarian and Central European legal system is often required while it is also essential to be familiar with other European legal and ethical approaches. Nevertheless, as international research projects have become increasingly global in their scope, we have also developed a wider comparative perspective in our work that includes studies of North American and East Asian legal and ethical discourses.

1. FOREWORD

In the context of biotechnology, globalization adds further complexity to policy-making in an area that is already clouded by moral ambiguity, regulatory uncertainty, and rapid scientific advance. Globalization forces, such as the rapid dissemination of scientific knowledge and the international nature of the biotechnology industry, suggest that the world community should, as much as possible, coordinate regulatory policy. Without such coordination, there is likely to be a degree of corporate forum-shopping and we will be unable to respond rapidly to emerging intellectual property issues or broader ethical, social, and legal concerns.

Timothy Caulfield

Moreover, we seek to integrate the results of these research projects into our academic teaching curricula. Therefore, we have organized workshops and seminars, film screenings and policy debates that are open to the CEU community and beyond. We also participate in legal policy development activities and provide research tools for the international scientific community. For instance, in 2007 we launched the new version of the Biolaw Database that makes it possible for researchers and students to study legal instruments and ethical norms in the field of biomedicine and biotechnology more systematically, or just to learn about the possible directions of future comparative research. In addition, we update our CELAB website on a daily basis.

At the beginning of 2008 we received a UNESCO grant. Within less than a year we completed a very ambitious project: the promotion of implementing the three bioethics-related Declarations of UNESCO in five countries – Croatia, the Czech Republic, Italy, Hungary, and Serbia. This project required legal policy work but it also gave us an opportunity to develop and reaffirm further professional contacts in the region with similar centers and scholars. As a result, CELAB published a series of booklets in five languages and organized a workshop with lectures and panels to discuss the possible methods to implement these instruments in teaching and to influence national legislation in the field of bioethics and related human rights. Although the working language of CELAB is English, this UNESCO funded project gave us the opportunity to learn about different cultural approaches to working in the field of bioethics and human rights.

Since 2007 we have also participated in the Francophone network of biomedical lawyers. The first workshop in Rennes, organized by Professor Brigitte Feuillet-Liger, was a big success and the first publication of the network on Assisted Reproduction and Anonymity (in French: *Medicalement assistée et anonymat*) has been submitted to the publisher. The first book is expected to come out in January 2009. The next workshop of the network will be held in Kyoto in 2009.

Two members of our staff participated in a project financed by the European Science Foundation chaired by Roberto Andorno and organized by the Institute of Biomedical Ethics at the University of Zürich. The aim of this project was to explore and compare different legal regimes that govern advance directives, the scope of legal recognition of end of life decisions. The results have already been compiled in an edited volume available on the internet. Based on the success of this project further collaboration between our Centers will be developed.

Besides these relatively more limited-scope research activities, the main task of our Center was to prepare and participate in five extensive projects funded by the European Commission. At the moment, perhaps our strongest research field is the one that analyzes the ethical, social and legal implications of biobanks. This is reflected by our involvement in three projects that deal with privacy and genetic data.

The EU project that is perhaps in the most advanced stage is called PRIVILEGED (Privacy in Law, Ethics and Genetic Data). The aims of this project are to make recommendations for research practice and public policy-making, including regulatory options at the national, regional, and European levels. PRIVILEGED has sought to identify, analyze and compare plural ethical, cultural, and social concepts of legitimate privacy interest engaged by research using genetic databases and biobanks. It articulates the relation between such concepts and the current regulation of research using genetic data and biobanks. PRIVILEGED focuses on the various privacy interests, particularly grounded within intimate and familial relationships in various research areas, especially in the so-called biobanking applications. This is a mega-project in which representatives of no less than thirty-two universities participate, among them not only European experts but also lawyers from Japan, Taiwan, and Israel. As part of the project, two major reports have already been submitted. A workshop in Bawtry, United Kingdom examined the divergent concepts of privacy in various European countries, the different dimensions of privacy rights and their applicability in the field of creating and maintaining biobanks.

The second project focuses on the governance of genebanks and the European legal and ethical framework to regulate their activities (Acronym: GeneBanC). Our team focuses mainly on the cases of countries that joined the European Union in 2004, most of which have not adopted legislation or guidelines in the field of classical biobanks, or have done so relatively recently without extensive experience. As far as forensic databases are concerned, we have an easier task since this field is governed not only by domestic laws, but also numerous international initiatives and measures provoked legislation in criminal law. The recommendation of the Council of Europe, the resolution of the Council of the European Union, the cooperation within Interpol, and more recently the incorporation of the Prüm Treaty into EU law have also underlined the importance of some legal harmonization in this field. After having shared our experience at the Paris workshop of this project, we presented and discussed position papers in Vienna and now we prepare for the upcoming stakeholder meeting and a conference to be held in Leuven in 2009. The project envisions the publication of our findings in booklets and journal articles.

In 2008 we started our third research project in this field, Tiss.EU, mobilizing the resources of ten universities in Europe. The major aim of this project is to carry out a high-quality interdisciplinary comparative analysis of European health policies in order to assess the impact of EU legislation and to explore the relevant ethical and legal situation across the European Union. The first Tiss.EU project meeting was held in Göttingen, Germany and focused on the ethical and legal challenges to conduct research on human tissues. Our Center will organize the next workshop in Budapest in 2009.

Another EU funded project, NANOPLAT (Framing the Deliberative Process on the Responsible Development of Nanosciences and Nanotechnologies) also started in 2008, is focusing on ‘deliberative processes’ in nanotechnology because these may be seen as useful, although possibly highly problematic regulatory forms supplementing democratic mechanisms. On the other hand, the conceptual shift from ‘government’ to ‘governance’ might allow for more participatory forms of shaping public policy. So far two workshops have been held: one in Bergen and another in Manchester.

The fifth EU funded research project we participate in is REMEDiE (Regenerative Medicine in Europe: Emerging Needs and Challenges in a Global Context). This project focuses on the present and future role of regenerative medicine in the health care industry, especially on the relevant intellectual property rights and patent issues. Therefore, the contributors to this project will explore and analyze international and regional policies regarding the patentability of living organisms, human genes and stem cells, as these are highly critical areas of research where market interests and ethical concerns frequently collide.

As in the previous years of our activities, our Center’s research staff has continued to develop new methods of teaching human rights and bioethics. For example, the CELAB Bioethics Film Session, co-organized with the Human Rights Students’ Initiative of CEU, included several film screenings, which were followed by lively debates each time. Topics included organ trafficking, assisted suicide, abortion, and research on the terminally ill. The seminar and film session was a big success and it has become clear that more and more scholars within the CEU community and outside it have expressed their interests in the ethics of science and technology. Therefore, in the near future, we also envision the development of specific teaching curricula in this field, once we have the necessary resources available.

Finally, we should also mention that over the course of the past academic year, CELAB fellows have regularly participated in different media events and, for the first time, in July 2008 an entire radio program was dedicated to the activities of CELAB.

For more information about CELAB, please consult: www.ceu.hu/celab

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

2. CELAB MEMBERS

2.1. DIRECTOR



JUDIT SÁNDOR

Founding director of CELAB, Judit Sándor is a Professor at the Faculty of Political Science, Legal Studies and Gender Studies of the Central European University (CEU), Budapest. In 1996 she received her Ph.D. in Law and Political Science. She was one of the

founders of the first Patients' Rights Organization (*Szószó*) in Hungary. She is a member of the Hungarian Science and Research Ethics Council and the Hungarian UNESCO Commission. She participated in different national and international standard-setting activities in the field of biomedical law. In 2004–2005 she worked as the Chief of the Bioethics Section at the UNESCO. She has published six books in the field of human rights and biomedical law. Since September 2005 she has been the Director of the Center for Ethics and Law in Biomedicine (CELAB) at the Central European University. She participates in the UNESCO project, in the PRIVILEGED, GeneBanC, Tiss.EU, NANOPLAT and REMEDIÉ Projects funded by the European Union.

2.2. RESEARCHERS



PETRA BÁRD

Petra Bárd is a Researcher at the CEU Center for Ethics and Law in Biomedicine (CELAB) where she participates in EU FP6 and FP7 projects investigat-

ing the legal framework of biobanks. She is the Vice-Chairperson of the Hungarian Europe Society, lectures at the Central European University and the Ecole supérieure des sciences commerciale d'Angers (ESSCA). In her writings she primarily addresses European constitutionalism, human rights in the European Union, the rights of persons living with disabilities and judicial and police cooperation in criminal matters. Petra Bárd is a CEU alumna; she received her LLM in international business law in 2001, and was awarded her SJD in the field of comparative constitutional law in 2008. She participates in the UNESCO, in the GeneBanC and the Tiss.EU projects.

2. CELAB MEMBERS

VIOLETA
BEŠIREVIĆ



Violeta Beširević holds an LLM and an SJD in Comparative Constitutional Law from the Central European University. She is an Associate Professor, Vice Dean and Head of the Postgraduate Studies of the Union University Law School Belgrade. She teaches Medical Law, International Criminal Law, Comparative Constitutional Law and European Court of Human Rights Jurisprudence. She is also a member of the Board of Directors of the European Public Law Organization (Athens), a member of the Pardon Committee appointed by the President of the Republic of Serbia and a Research Associate at the CEU Center for Ethics and Law in Biomedicine, Budapest. Her previous posts include Research Coordinator at the CEU Center for Human Rights, Head of the Consular Department at the Embassy of Serbia in Hungary, Staff Attorney at the Constitutional and Legal Policy Institute, Budapest and Senior Legal Adviser at the Ministry of Justice of the former Yugoslavia. Her research work and fields of interest include topics of medical law, human rights law, international criminal law and constitutional law. She participated in the UNESCO Project conducted by the Center for Ethics and Law in Biomedicine (CELAB), as well as the ESF Project on advanced directives.

ENIKŐ DEMÉNY



Enikő Demény is a Researcher at the CEU Center for Ethics and Law in Biomedicine (CELAB) and Visiting Lecturer at the Babes-Bolyai University, Cluj, Romania. She received her Ph.D. in Philosophy in 2006 at the Babes-Bolyai University. She has MA degrees in Anthropology and in Gender Studies, BA in Sociology and BSc in Civil Engineering. Her research interests include the impact of new technologies on identity and the family; ELSA aspects of biotechnology and nanotechnology, social sciences and bioethics. She participates in the UNESCO and the NANOPLAT Projects.

PÉTER KAKUK



Péter Kakuk is a Research Assistant at the University of Debrecen, Medical and Health Sciences Centre since 2000, where he teaches Medical Ethics and Bioethics at the Department of Behavioral Sciences. In 2005 he joined the Centre for Ethics and Law in Biomedicine (CELAB) at the Central European University as a Research Associate. He holds an MA in Philosophy (Department of Philosophy at the University of Debrecen, 1999) and an MA in Health Care Ethics and Law (Faculty of Humanities, School of Law, University of Manchester, 2005). His teaching activity focuses on the ethical aspects of health care related fields, and his research interests cover a broad area of science-society relationship, and more particularly the

ELSI of genetics. He has published several papers on the ELSI of genetics, on informed consent, on the drug policy debate, and on research ethics. He is a member of the International Association of Bioethics (IAB) and of the European Society for Philosophy of Medicine and Health Care (ESMPH). Currently, he participates in the NANOPLAT project on deliberative processes in developing policies on nanotechnology as a part-time Researcher of CELAB.



JÓZSEF KOVÁCS

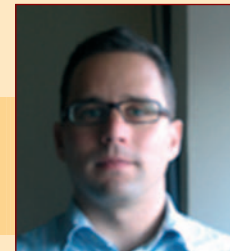
József Kovács is an Associate Professor, Deputy Director, Head of the Department of Bioethics (Semmelweis University, Institute of Behavioural Sciences) and Research Associate at the Center for Ethics and Law in Biomedicine (CELAB). He is a physician and a philosopher. He is a licensed physician in community medicine (1985) and in psychotherapy (2002). He received his Ph.D. in medicine (1995). He has studied bioethics in various academic centers outside Hungary: at the Hastings Center, Briarcliff Manor, New York, USA (1990); the Centre for the Study of Philosophy and Health Care, Swansea, United Kingdom (1990–91); the King's Fund College, London (1993, 1994); the Hogeschool van Amsterdam, Netherlands (1995); and Boston, Massachusetts, USA (1999). He has been teaching undergraduate and postgraduate courses in medical ethics and bioethics since 1982. His publications include three books, ten book chapters, and thirty-one journal articles. He participates in national and international scientific conferences and is a member of various national and international scientific organizations in bioethics.

GYÖRGY
KOVÁCS



György Kovács works as an attorney at law at Faludi Wolf Theiss, dealing with corporate M&A, IP/IT, Energy and Real Estate related matters. He regularly lectures at the Deák Ferenc Post-Graduate Institute of the Pázmány Péter Catholic University, in the field of EU IP law and EU law. He was a Fulbright Scholar in the Boston University School of Law during the academic year 2005–2006, where he was taking courses and was conducting research in the fields of general business law and patent law. Besides these activities, he also carried out additional research and participated in conferences in the Harvard European Law Research Center. He is also a member of the seven-member board of the Hungarian Fulbright Alumni Association. He joined CELAB as a Researcher in the REMEDiE project.

MÁRTON VARJU



Márton Varju is a law graduate employed currently as a Lecturer at the University of Debrecen. He holds a Ph.D. in Law from the University of Hull, United Kingdom. His research interest lies in European Union constitutional law, European Union governance and regulation, European (EU and ECHR) human rights law and policy. He is a part-time Researcher in the REMEDiE project.

3. ACTIVITIES

3.1. RESEARCH

CELAB's main research topics in the 2007–2008 academic year were the ethical, social and legal implications of

- ▶ biobanks;
- ▶ biomedical research;
- ▶ biotechnology;
- ▶ nanotechnology;
- ▶ organ donation;
- ▶ stem cell research; and
- ▶ regenerative medicine.

3.1.1. GeneBanC: Genetic Bio- and Data-Banking: Confidentiality and the Protection of Data



Partners:

University of Oslo, Norway

University of Leeds, United Kingdom

Catholic University of Leuven, Belgium

CEU, CELAB, Hungary

University of Vienna, Austria

Website: <http://www.genebanc.eu>

In the GeneBanC project, a Specific Targeted Research Project (STREP) funded by the European Commission in the Sixth Framework Programme, we aim to investigate the existing regulatory framework of biobanks across the EU and focus on the collection and analysis of legislation and regulation regarding the establishment, management and functioning of classical, population and forensic biobanks across Europe. An important objective is to look at the similarities and differences in such legislation and regulations, in

order to formulate recommendations towards a harmonization of European laws and practices.

The European jurisdiction is divided up into two parts: our team focuses on Cyprus, the Czech Republic, Estonia, Greece, Hungary, Italy, Latvia, Lithuania, Malta, Poland, Romania, the Slovak Republic, and Slovenia, whereas the Leuven team will address the laws of the remaining fourteen Member States. The general starting point of the project is that there is no harmony in the laws that regulate biobanks across Europe. Regulations differs in each of the Member States. For that reason, it is very difficult for biomedical researchers to cooperate. Nevertheless, it is crucial that they should work together in this very important but expensive branch of research, which needs to be done on a large scale. In addition, at international and European levels, as well as in most Member States, there is no specific biobank law. Hence, even at the national level, there is a large amount of diverse legislation that is only partly relevant. On top of that, even in our days certain topics are still unregulated in a number of countries. Consequently, it is very difficult for practitioners to know which rules need to be followed and there are a lot of interests that are not properly protected, like the privacy of research subjects, the right to informed consent, etc.

Many countries do not have any laws regulating biobanks, but in the first stage of scrutinizing national legislation, project partners attempted to collect the few countries where there is. In the rest of the Member States one has to rely on laws of diverse nature that serve as background pieces of legislation applicable to biobanks. Since in the majority of the Member States there is no specific law with a matching title, it is often a problem for biologists, doctors or even ethicists to identify the appropriate documents. Even if the laws are identified, the relevant parts have to be found for translation. In order to enhance data collec-

tion, CELAB has prepared two questionnaires together with the Leuven team: one for classical and population biobanks, and another for forensic biobanks. We have identified the contact persons, and sent out the questionnaires. Whenever necessary, researchers have visited biobanks and made interviews.

CELAB researchers have prepared the national reports concerning classical, population and forensic biobanks. The white spots on the map are now mainly covered. Several additional colleagues from problematic countries, where the reply rate was rather low, have been contacted. CELAB researchers also had to clarify internal contradictions, as some experts replied to our questionnaires entirely from a data protection point of view without actually discussing ethical issues covered by different pieces of legislation. Discrepancies have now been settled in most of the countries.

Our next objective for the upcoming academic year is to publish the country reports, to develop a set of best practices based on our findings and identify the points in the national pieces of legislation which need to be harmonized at the European level.

3.1.2. PRIVILEGED: Privacy in Law, Ethics and Genetic Data



Main Partners:

University of Sheffield, United Kingdom
Biomedical Law Center, University of Coimbra, Portugal
University of Vilnius, Lithuania
CELAB, Central European University, Budapest, Hungary
Webpage: <http://www.privileged.group.shef.ac.uk/>

The full title of the PRIVILEGED Project is “Determining the Ethical and Legal Interests in Privacy and Data Protection for Research Involving the Use of Genetic Databases and Biobanks.” The aim of the project is to make recommendations for research practice and public policy, including regulatory options at the national and European level and to promote the optimal relationship between research using genetic data and bio-banks and ethical interests in privacy. Ethical interests in privacy are being explicated through surveys, descriptions and comparisons of the alternative conceptions of privacy currently operating throughout Europe, Israel, Japan, and Taiwan, paying particular attention to the relative interests accorded an individual as a member of a group.

The strategic objectives of the project are: (1) to identify, analyze and compare different ethical, cultural, and social concepts of privacy as engaged by research using genetic data and biobanks; describing areas of common understanding and recognizing significant points of difference within both the conceptions themselves and their relationship with research; (2) to describe and compare Member State regulation of research using genetic data and biobanks, with particular reference to data protection, and to evaluate the relationship between regulation (including associated strategies of compliance) and the ethical needs of privacy; (3) to establish in what ways, and to what extent, data protection regulations may be either consistent or inconsistent with, or insufficient for, the protection of identified ethical interests in privacy; and (4) to make recommendations for research practice and policy at national and European level for the promotion of a harmonious relationship between research using genetic data and biobanks and data protection and privacy interests as articulated at both the national and European levels.

The Project started in 2007 and lasts for 36 months. It is one of the largest research networks in which CELAB participates, including 49 Research Partners in various European countries and in Israel, Taiwan, and Japan.

3.1.3. NANOPLAT: Development of a Platform for Deliberate Processes on Nanotechnology in the European Consumer Market



Partners:

National Institute for Consumer Research, SIFO, Oslo, Norway
CRIC, University of Manchester, Manchester, United Kingdom
Institut für Ökologische Wirtschaftsforschung-IÖW, Berlin, Germany
TUSIAD, Sabanci University Competitiveness ForumCF, Istanbul, Turkey
University of Bergen, UoB, Bergen, Norway
Strategic Design Scenarios, SDS, Brussels, Belgium
CELAB, Central European University, Budapest, Hungary
Webpage: www.nanoplat.org

The objectives of this project are to evaluate selected deliberative processes in Europe, at both EU and

3. ACTIVITIES

national levels, and to develop a deliberate and science-based platform for a stakeholder dialogue in Europe and beyond in the field of nanotechnology.

The kick-off meeting of the project took place on March 3, 2008 in Bergen, Norway. The Hungarian team started its work by mapping the field of nanotechnology in Hungary. The Hungarian project members also contributed to the elaboration of the theoretical work package of the project. The second meeting of the project took place in Manchester, on September 11–12, 2008, where the project partners clarified theoretical issues and prepared the final schedule for empirical research activities. Right before the meeting a conference closely connected to the NANOPLAT project took place: the Manchester 2008 International Workshop on Nanotechnology, Society and Policy, organized by the Manchester Institute for Innovation Research of Manchester Business School, Manchester University. At this meeting the CELAB team presented some aspects of the nanotechnology discourse in Hungary, focusing mainly on the media representation of nanotechnology-related issues.

As part of the second project activity, the Hungarian team has reviewed three deliberative processes on nanotechnology organized at the EU level and will carry out interviews with selected stakeholders and consumer groups. The next project meeting will take place in Istanbul, Turkey on March 25–29, 2008. As part of the project dissemination activity Enikő Demény and Péter Kakuk presented the NANOPLAT project at the conference on “Environmental Ethics: Development and Environmental Responsibility”, organized by the Philosophy Department at the University of Szeged, in September 2008. The title of their presentation was: “Some Issues Related to Nanotechnology and Participatory Governance – The Hungarian Aspects of the NANOPLAT Project.”

NANOPLAT project meeting, September 2008,
Manchester, United Kingdom



3.1.4. REMEDiE: Regenerative Medicine in Europe: Emerging Needs and Challenges in a Global Context



Partners:

SATSU, University of York, United Kingdom
 University of the Basque Country, Spain
 University of Hanover, Germany
 Life Science Governance Institute, Austria
 CELAB, Central European University, Budapest, Hungary
 University of East Anglia, United Kingdom

Webpage: <http://www.york.ac.uk/res/remedie/>

The acronym REMEDiE stands for “Regenerative Medicine in Europe: Emerging Needs and Challenges in a Global Context.” This European Commission funded project started with the kick-off meeting in York, England, in May 2008 and it will last for 36 months. The aim of the collaborative project is to examine the socio-economic, political and bioethical implications for Europe and future global developments in the field of regenerative medicine. Our intention is to apply an interdisciplinary approach, bringing together researchers from the social sciences and humanities, to understand the emerging needs, expectations and challenges that Europe faces. The project is conceptually and methodologically innovative, empirically robust, and policy relevant.

Social and legal policy on the use of regenerative medicine is a key element where competition for the scientific and industrial future of human embryonic stem cells takes place at the national, regional and international levels. That competition is driven by global political forces which transcend national boundaries as they seek to influence the future shape of regulatory policy. The aim of the project is pursued through the analysis of the global aspect of regenerative medicine, mapping various ethical and legal attitudes to commercial and scientific aspects of this new and increasingly important domain of science and health care. Furthermore, we intend to explore and to identify their impact on various regulatory regimes.

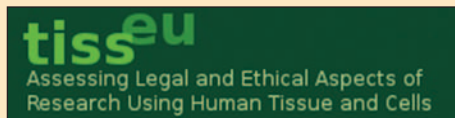
Our first task was to build a viable project team and to identify ethical and legal sources. Firstly, building



REMEDIE project meeting, May 2008, York, United Kingdom

on the existing work of the project team, the legislative, organizational and ethical components of the regulatory models currently in use will be mapped in detail and an initial understanding established of the global dynamic of the intellectual property regimes of regenerative medicine. The Principal Investigator of the project is Judit Sándor. The Researchers involved in the project are Enikő Demény, György Kovács, and Márton Varjú.

3.1.5. Tiss.EU: Evaluation of Legislation and Related Guidelines on the Procurement, Storage and Transfer of Human Tissues and Cells in the European Union – an Evidence-Based Impact Analysis



Partners:

Department for Ethics and History of Medicine, University of Göttingen, Germany – Coordinator
 Medical Law and Bioethics Group, Institute for German and European Private and Commercial Law, University of Hanover, Germany
 Center for the Study of Global Ethics, University of Birmingham, United Kingdom
 Stockholm Bioethics Center, Stockholm University, Sweden
 Fondazione Lanza, Padova, Italy
 Forensic & Legal Medicine, School of Medicine and Medical Science, National University of Ireland, Dublin
 Center de Recherche Droit, Sciences et Techniques, Université Paris 1, France

Institute of Bio-Law „Legal Pathways”, Aerdenhout, Netherlands

Department of Medical History and Ethics, Vilnius University, Lithuania

CELAB, Central European University, Budapest, Hungary

Webpage: <http://www.tisseu.uni-hannover.de/>

The acronym Tiss.EU stands for „Evaluation of Legislation and Related Guidelines on the Procurement, Storage and Transfer of Human Tissues and Cells in the European Union - an Evidence-Based Impact Analysis.” The project, funded by the European Commission as part of the 7th Framework Programme, runs from March 2008 to early 2011 and addresses questions of ethical and legal regulation in relation to research using human tissue. Tiss.EU is made up of four parts, the ethical and legal aspects of which are going to be looked at by the project partners: first, procurement, storage and transfer of tissue and cells for research; second, rights and entitlements to tissue and cells; third, anonymization and pseudonymization to protect privacy rights; and, finally, research using biobanks.

CELAB focuses on anonymization and pseudonymization for privacy protection in the following countries: Bulgaria, Czech Republic, Hungary, Slovakia, and Romania. We will organize a related conference in the spring of 2009 and report on the impact of EU legislation and documents in this country group. This smoothly fits into the overall project aims, which is to assess the impact made by European Union’s regulatory activities to date on research in the Member States and Switzerland. As a culmination of the project, recommendations are to be drafted for possible ethical and legal guidelines in the interests of European-wide convergence and harmonization.

3.1.6. Bio-Ethical and Legal Database



To improve the management of CELAB’s bioethical and legal database, the CELAB team has decided to develop it based on the projects carried out in the research center. Each team working on a certain topic

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is responsible for updating the database with legal and policy materials in the respective field. In this way Petra Bárd, Enikő Demény and Judit Sándor contribute to the biobanks section of the bio-law database; Enikő Demény, Péter Kakuk and Judit Sándor to the nanotechnology section; Violeta Beširević to the euthanasia section; Enikő Demény, György Kovács, Judit Sándor and Márton Varju to the stem cell research and intellectual property regimes sections. Enikő Demény is responsible for the overall management of the database.

Since in many CELAB projects a bulk of the work is to collect and then analyze various legal instruments in the field of biomedicine, the biolaw-database is a practical resource to store the data collected during research. We hope that the database proves to be a good research tool not only for CELAB researchers but also for all those colleagues who are conducting research on these topics. Statistical data shows that the database is searched from a variety of countries, and the number of returning visitors is increasing year by year.

3.2. POLICY ACTIVITY IN CELAB

3.2.1. Developing Models of Implementation of UNESCO Bioethical Instruments

In November 2007 CELAB received a UNESCO grant for developing models for implementation of UNESCO Bioethical Instruments (Grant No: 375423 08 HUN).

From among the specialized agencies of the United Nations, the United Nations Educational, Scientific and Cultural Organisation (UNESCO) has been dealing with ethics of science already since 1970. In 1993 UNESCO called together the International Bioethics Committee, which has worked as a body of experts operating independently from governments. Consequently, within the structure of the United Nations, UNESCO has become the primary actor in the field of bioethics. This was further acknowledged when bioethics-related activities were concentrated in UNESCO and a budget was allocated to UNESCO in this field. Furthermore this priority also means the possibility to conduct standard setting.

So far three international declarations of crucial importance, albeit without binding force, have been adopted. The ambitious stance of UNESCO in the field was reflected already when the first bioethics-related Declaration, the 1997 Universal Declaration on the Human Genome and Human Rights bore a title paralleling the title the Universal Declaration of Human Rights, a basic human rights document of the United Nations.



The UNESCO declarations on bioethics translated by CELAB in five regional languages

The second text, the International Declaration on Human Genetic Data was adopted in 2003 and is also a widely cited document. In 2005, at the 33rd session the General Conference of UNESCO, the Member States unanimously voted for the adoption of the third declaration, the Universal Declaration on Bioethics and Human Rights. Using the phrase “universal declaration” again, UNESCO aimed to

generate wide international legal recognition to the general norms of bioethics. The document is an attempt to determine the subject matter of bioethics and to formulate comprehensive bioethical principles.

Researchers and research associates of CELAB participated in the project and prepared the different language versions. Their work was facilitated and assisted by colleagues from partner institutions in Belgrade, Brno, Rijeka, Siena, and Zagreb. The lessons, experiences, and results of this collaboration were discussed in the framework of a joint workshop on the importance of international bioethical norms and on the specific concerns in the lawmaking processes of the individual countries.

In our work we have sought to contribute to the increasing international awareness of the existence of these UNESCO declarations. We believe that reflections and interpretations of these documents

should be an integral part of ethics education, policy-making, national legislation and international research. Translating the documents into the official languages of the Member States is one of the best ways to spread the idea of bioethical thinking and disseminate the results of policy-making at UNESCO.

Our aim, therefore, was to arrange authoritative, but also accessible, translations of the declarations, produced by legal experts in the field of medical law in their respective countries. The booklets published in five languages will hopefully serve as practical tools to promote the implementation of these key UNESCO instruments on bioethics.

A welcome ‘side effect’ of this collaboration was the development of a research and policy partnership between academic institutions, universities, research centers and governments in the five participating countries: Croatia, Czech Republic, Hungary, Italy, and Serbia.

3.3. TEACHING

CELAB’s staff and fellows are involved in teaching both at the 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.

3.3.1. Teaching at CEU

Judit Sándor

Department of Legal Studies
Privacy and Data Protection
Patients’ Rights in the Twenty First Century

Department of Political Science
Biotechnology and Social Policy
Contemporary Challenges to Human Rights
Reproduction and Gender (cross-listed with
Department of Gender Studies)

Body in Bank: From Private to Public?
Lecture at the Legal Studies Doctoral Seminar,
CEU (April 9, 2008)

Petra Bárd

Department of Legal Studies
Introduction to Law

*Mediation and Other Methods to Foster Democratic
Dialogue* – Summer Course

Total Law: Special Session on the Lisbon Treaty – Guest
Lecture

3.3.2. CELAB Film Session Series at CEU: “Ethical Issues on Film”

Documentary films, in the same way as fiction, can be very important supplementary tools in teaching. Research proves that students who encounter legal cases or ethical dilemmas in artistic representations, including films, will be more likely engaged in class discussions of academic literature and in exploring the moral dilemmas emerging in judicial cases.

During the 2007–2008 academic year three different courses delivered at three different Depart-

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ments (Political Science, Gender and Legal Studies) were accompanied by non-mandatory film sessions and discussions co-organized by the Center for Ethics and Law in Biomedicine (CELAB).

In the 2007–2008 academic year CELAB Film Sessions addressed the issues of organ trade [*Dirty Pretty Things* (2003), directed by Stephen Frears]; the dilemma of whether and how to help with assisted suicide and the problems of legislation in this matter [*The Sea Inside* (2004), directed by Alejandro Amenábar]; the issues of research ethics in case of a dying patient [*Wit* (2001) directed by Mike Nichols]; and the problems of access to abortion in a totalitarian regime [*4 Months, 3 Weeks, 2 Days* (2007), directed by Cristian Mungiu].

3.3.3. Teaching and Lecturing at Other Institutions

Enikő Demény

Family and Identity in the Age of Genetics

Course at the Faculty of Political, Administrative and Communication Sciences, Babes-Bolyai University, Cluj, Romania

Petra Bárd

European Business Law

Course at ESSCA, Budapest, Hungary

Evolution of the Third Pillar,

Public lecture at IE, Instituto de Empresa, School of Law, Madrid, Spain (October 14, 2008)

Violeta Beširević

Medical Law

Course at Union University Law School, Belgrade, Serbia

Péter Kakuk

Bioethics Seminars

General Medical Program, Medical and Health Science Center, University of Debrecen

Bioethics

Medical Diagnostics and Laboratory Analyst, Medical and Health Science Center, University of Debrecen

Dental Ethics

Faculty of Dentistry, Medical and Health Science Center, University of Debrecen

Pharmacy Ethics

Faculty of Pharmacy, Medical and Health Science Center, University of Debrecen

Health Care Ethics

Health Care Management, Medical and Health Science Center, University of Debrecen

József Kovács

Bioethics

Course at Semmelweis University

Ethical Issues in Psychotherapy

Lecture at Semmelweis University (October 16, 2007)

The Ethical Aspects of Health Insurance

Lecture at Semmelweis University (November 15, 2007)

The Stigmatizing Effect of Psychiatric Diagnosis

Roundtable discussion, organized by Sotéria Foundation (April 16, 2008)

3.4. PARTICIPATION IN KEY INTERNATIONAL EVENTS AND NETWORKS IN THE FIELD OF BIOETHICS AND BIOLAW

3.4.1. Establishment of the Inter-University Network in Biomedical Law and Ethics

Professor Brigitte Feuillet-Liger at the Faculty of Law and Political Science of the University of Rennes launched an initiative in 2006 with the aim to create a network of French speaking lawyers in the area of biomedical law. This network seeks to conduct comparative legal research and produce publications in the field of biomedical law and ethics. After a preparatory meeting in Paris, a core group was created in early 2007 with the participation of Françoise Furkel (Germany), Dominique Manai (Switzerland), Thérèse Callus (United Kingdom), Veronica San Julian (Spain), Ryuichi Ida (Japan), Judit Sándor (Hungary), Pénélope Agallopoulou (Greece) Maria-Claudia Crespo Brauner (Brazil), Kristina Orfali (United States), Stéphane Bauzon (Italy) and with Brigitte Feuillet-Liger (France) as chairperson. The first thematic workshop was held at the University of Rennes in December 2007, under the title “Concepts and



Inter-University Network in Biomedical Law and Ethics meeting, December 2007, Rennes, France

Limits of Anonymity in the Field of Assisted Reproduction.” The essays based on the presentations of the network members were submitted during the summer of 2008 and will be published as chapters of a book that is expected to come out at the beginning of 2009 in Brussels. The next focus of this collaboration will be “Adolescents and Medical Interventions.” The members of the network will present their papers at the Kyoto workshop in January 2009.

3.4.2. ELPAT: European Platform for Ethical, Legal, and Psychosocial Aspects of Organ Transplantation



Webpage: www.elpat.org

In April 2007 the congress “Organ Transplantation: Ethical, Legal and Psychosocial Aspects. Towards a Common European Policy” was held in Rotterdam, The Netherlands. The meeting was a great success, with many high quality presentations and 267 people from 35 countries participating. CELAB was represented by Prof. Judit Sándor, who was keynote speaker at the Jubilee debate “*Whose organs are they anyway?*” The aim of the congress was to launch the “European Platform on Ethical, Legal, and Psychosocial Aspects of Organ Transplantation” (ELPAT). ELPAT aims to bring continuity and structure into the dialogue on the complex issues of organ transplantation ethics, to be helpful in mapping and bringing together European expertise on the various legal, ethical and psychosocial aspects of organ transplantation and to formulate European guidelines on ethical, legal and psychosocial aspects of organ transplantation. ELPAT is an official body of the European Society for Organ Transplantation (ESOT).

In December 2007 Enikő Demény was invited to join the ELPAT network. She takes part in two working groups: Subpopulations and Organ Tourism. The working group on Subpopulations addresses issues related to inequalities in the rates of organ donation and transplantation that exist between the different ethnic, social, class, gender, or religious groups. The working group also seeks to achieve a better understanding of the reasons for these differences in order to make “organ gifts” and the donation of organs relevant and meaningful in multi-ethnic and multi-religious societies.

The Organ Tourism working group seeks to set up communication channels that could lead to the exchange and sharing of facts, figures and other relevant information about organ trade and organ tourism, leading to a higher expertise on the topic. Organ

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tourism is taking a more prominent place in Europe. Little is known about exact facts and figures. A Europe-wide survey could help us give more insight in these matters. The working group also aims to explore the difference between organ tourism and organ trafficking, and the effects of commercialism, paid donation or a regulated market. The working groups' results will be presented at the next ELPAT congress, which will take place on April 18–21, 2010 in Rotterdam.

3.4.3. ESF Exploratory Workshop: Advance Directives: Towards a Coordinated European Perspective?

The workshop has been funded by the European Science Foundation and Research Priority Program of the Institute of Biomedical Ethics at the University of Zürich Center for Ethics.

CELAB Participants: Judit Sándor, Violeta Beširević

This project was financed by the European Science Foundation. Legal experts from all European countries submitted and discussed their contributions on different legal regimes that govern end-of life decisions, living wills, advance directives. They compared the level of the legal recognition of the refusal of life



ESF workshop, June 2008, Zurich

saving and life sustaining treatment. The chair of this project was Prof. Roberto Andorno. The exploratory workshop was organized by the Institute of Biomedical Ethics at the University of Zürich. The results have already been compiled in an edited volume available on the internet. Based on the success of this project, further collaboration between our Centers will be developed.

Updated Country Reports on advance directives are available at: <http://www.ethik.uzh.ch/ibme/en>

3.5. PARTICIPATION IN CONFERENCES

During the 2007–2008 academic year, CELAB staff and fellows took part in the following academic and scientific events:

CEU Public lecture

Organized by the Department of History and CELAB

Lecture by Ohad Parnes: “On the Shoulders of Generations. Genealogy and Transmission in the History of Heredity”

October 12, 2007, Budapest, Hungary

UNESCO-L'Oréal Award for Women in Science

Three women scientists in the life sciences from

Hungary received UNESCO- L'ORÉAL reward “For Women in Science”.

UNESCO was represented by Judit Sándor
October 18, 2007, Budapest, Hungary

Conference

Organized by the Hungarian Chief Public Prosecutor's Office

Presentation by Petra Bárd on the European Union's Third Pillar: “Two Steps Too Soon: Mutual Recognition and the Principle of Availability”

October 18–19, 2007, Balatonlelle, Hungary

Reproductive Technologies: Uses and Representations
International conference hosted by the Institute of Sociology, University of Porto, Portugal
Presentation by Judit Sándor: “The Rhetoric of Reproduction”
October 25, 2007, Porto, Portugal

Memorial Day Dedicated to József Eötvös
Hosted by the József Eötvös Secondary School, Budapest, Hungary
Presentation by Judit Sándor: “Biotechnology and Society: Ethics of perfection”
October 27, 2007, Budapest, Hungary

The Global Governance of Genomics: Testing Genes, Profiling DNA – Medicine, Forensics, and Ethics
Presentation by Judit Sándor: “Therapy or Enhancement? Ethical and Legal Issues in Reprogenetics” and
Presentation by Péter Kakuk: “The Governance Implications of the Concept of the Gene: The Case of Genetic Testing”
November 1–3, 2007, Brno, Czech Republic

Good Bioethical Practices
Co-organized by the Hungarian Association for Biotechnology, Hungarian Society for Oncology in the framework of the FP 6 Project
Presentation by Judit Sándor: “National and International Aspects of Biobanks”
November 9, 2007, Budapest, Hungary

Nem-önkéntes gyógykezelés: Hogyan tovább? [The Future of Non-Compulsory Medical Treatment]
Conference organized by MDAC (The Mental Disability Advocacy Center)
Presentation by József Kovács: “The Bioethical Aspects of Compulsory Psychiatric Medical Treatment”
December 11, 2007, Budapest, Hungary

CEU Public Lecture
Organized by CELAB
Lecture by Dr. Amita Dhanda (Professor of Law at the National Academy of Legal Studies and Research, Hyderabad, India): “Sameness and Difference: Twin Track Empowerment for Women with Disabilities”
Commentaries by Petra Bárd
December 5, 2007, Budapest, Hungary

Medically Assisted Reproduction and the Concept of Anonymity
Second Meeting of the European Francophone Network of Lawyers in the Field of Biomedicine, Faculté de Droit de Rennes
Presentation by Judit Sándor: “Anonymat Dans Les Procédures de Procréation Médicalement Assistée: Egalité des Sexes et Vision Pronatale Dans La Réglementation Hongroise” [Anonymity in Assisted Reproduction: Equality of the Sexes and Prenatal Attitudes in the Hungarian Law]
December 6–7, 2007, Rennes, France

PRIVILEGED Project Conference
Presentation by Judit Sándor: “A Dynamic Concept of Privacy: Challenges to Harmonization”
January 9–11, 2008, Sheffield, United Kingdom

Guest Lecture Series at the National Institute of Criminology
Presentation by Judit Sándor: “Ethics and Law of Biotechnology”
January 23, 2008, Budapest, Hungary

Stem Cell Conference
Presentation by Judit Sándor: “Ethical and Legal Dilemmas of Stem Cell Research”
February 29, 2008, Szeged, Hungary

NANOPLAT Project Kick-Off Meeting
CELAB participant: Enikő Demény
March 13, 2008, Bergen, Norway

Future Talks
Event organized by the Hungarian Cultural Institute in London
Presentation by Judit Sándor: “Tissue Talk: Ethical and Legal Challenges in Biotechnology”
April 3, 2008, London, United Kingdom

The Foundation Meeting of the Public Health Genomics Hungarian National Task Force
CELAB participant: Judit Sándor
April 22–23, 2008, Budapest, Hungary

Legal Aspects of the Situation of Persons Living With Intellectual Disability and the Draft of the New Civil Code
Organized by Hungarian Academy of Science, Institute of Legal Studies, Károli Gáspár University of the Reformed Church, Faculty of

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Law, Hungarian Lawyers' Association, Civil Law Section, Hungarian Association for Persons with Intellectual Disability on the Rights of Persons with Mental Disabilities

Presentation by Petra Bárd: "Losers of the Social Model of Disability"

April 25, 2008, Budapest, Hungary

GeneBanC Project Workshop

CELAB participants: Judit Sándor and Petra Bárd

Presentation by Judit Sándor: "Genetic Data and Biobanks in Hungary: Legislative Attempts in Hungary"

May 7–8, 2008, Leeds, United Kingdom

RemediE Project Kick-Off Meeting

Presentation by Judit Sándor: "EU and Global Bioethics: Intellectual Property and Cultural Difference"

May 22, 2008, York, United Kingdom

3rd Professional Ethics Conference: Tolerance in Professional Ethics

Presentation by Petra Bárd: "The Rights of Persons Living with Disabilities: Tolerance in the Social Contract"

May 15–16, 2008, Pécs, Hungary

4th Vienna Workshop on International Constitutional Law

Presentation by Petra Bárd: "Freedom, Security and Justice - Where is the Emphasis?"

May 16–17, 2008, Vienna, Austria

Conference on Boundary Works in Science and Public Understanding

Organized jointly by Budapest University of Technology and Economics, Department of Philosophy and History of Science and Eötvös Loránd University, Department of History and Philosophy of Science

Presentation by Péter Kakuk: "The Return of Eugenics. Ethical Boundary Work in the Public Discourse on the New Genetics"

May 29–30, 2008, Budapest, Hungary

European Biobanks

BBMRI (Biobanking and Biomolecular Resources Research Infrastructure) ELSI meeting

Invited expert: Judit Sándor

May 31, 2008, Barcelona, Spain

Stem Cell Conference

CELAB Participant: Judit Sándor

June 5, 2008, Budapest, Hungary

CEU Conference on "Constitutional Axiology, or Is There Anything Behind/Above Constitutions?"

Presentation by Judit Sándor: "Centaur Laws: International Norms between Law and Ethics"

June 7–8, 2008, Budapest, Hungary

Advance Directives:

Towards a Coordinated European Perspective?

Workshop funded by the European Science Foundation and Research Priority Program of the University of Zurich Center for Ethics, Institute of Biomedical Ethics

CELAB Participants: Judit Sándor and Violeta Beširević

Presentation by Violeta Beširević:

"Advance Directives: The State of Art in Serbia"

June 19–21, 2008, Zürich, Switzerland

5th European Course on Biotechnology Ethics

Presentation by József Kovács:

"Ethical Questions of Human Research"

June 22–29, 2008, Budapest, Hungary

Tiss.EU Project Kick-Off Meeting

CELAB Participants: Judit Sándor and Petra Bárd

June 26, 2008, Göttingen, Germany

Ethical & Legal Aspects of Research with Human Tissue in Europe

First International Conference of the Tiss.EU project organized by University Medical Center of the University of Göttingen, Germany

CELAB Participants: Judit Sándor and Petra Bárd

June 26–28, 2008, Göttingen, Germany

NICLAS – New International Constitutional Law Approach

Summer School: NICLAS for Security Workshop on "Counterterrorism Measures and Genetic Data Protection" led by Petra Bárd

July 7–19, 2008, Vienna, Austria

GeneBanC Project workshop

CELAB Participants: Judit Sándor and Petra Bárd

September 2–3, 2008, Vienna, Austria

9th International Congress on Bioethics

Presentation by Péter Kakuk: “Is There a Crisis in the Ethics of Scientific Research?”

Presentation by Violeta Beširević: “Medical Global Challenges: Should International Law Enforce Euthanasia? Or, Does the Universal Rights Talk Help Here?”

September 3–8, 2008, Rijeka, Croatia

International Workshop on Nanotechnology, Society, and Policy

Organized by Manchester Institute of Innovation Research, Manchester Business School

CELAB Participants: Enikő Demény and Péter Kakuk

September 9–12, 2008, Manchester, United Kingdom

NANOPLAT Project Workshop

CELAB Participants: Enikő Demény and Péter Kakuk

September 11–12, 2008, Manchester, United Kingdom

BBMRI Project Meeting

Biobanking and Biomolecular Resources Research Infrastructure (BBMRI)

CELAB Participant: Judit Sándor

September 25, 2008, Paris, France

Environmental Ethics: Development and Environmental Responsibility

Conference organized by Philosophy Department, University of Szeged

Presentation by Enikő Demény and Péter Kakuk: “Some Issues Related to Nanotechnology and Participatory Governance”

September 25–26, 2008, Szeged, Hungary

Researchers’ Night

Open House Event Series

Presentation by Péter Kakuk:

“A genetika mint társadalmi, etikai és jogi probléma: reflexiók az új genetikai törvényről”

[Genetics as a Social, Ethical and Legal Issue: Some Reflections on the New Genetic Law]

September 26, 2008, Debrecen, Hungary

3.6. MEDIA EVENTS

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

Valódi viták kelleneek [We Need real Debates]

Interview with József Kovács by Anikó Köbli Anikó

Medical Tribune,
November 8, 2007, p. 3.

A Right to Dignified Death

News article by Violeta Beširević

Gradjanski list,
December 7, 2007.

A bioetikáról [On Bioethics]

Interview with József Kovács by Gábor Zempléni

Radio Program “Bölcsök köve”,

Civil Rádió,

December 18, 2007.

A Közép-európai Egyetem Jogi és Bioetikai Központja, a CELAB [CELAB: The Bioethical and Legal

Research Center of the Central European University]

Media spot about CELAB

HVG.hu, online magazine,

February 11, 2008.

A terminális állapotú betegek jogairól [The Rights of Terminally Ill Patients]

Interview with József Kovács by Ilona Gál

Radio Program “Magánhangzó”, *MRI*,

February 18, 2008.

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Az eutanázia Európai Unió szabályozásáról
[The Regulation of Euthanasia in the EU]
Interview with József Kovács by Judit Kutasi
Radio Program “Eurozóna”, *Klub Rádió*,
March 26, 2008.

Milyen döntéseket hozhat a szülő a gyermekével kapcsolatban? [What Kinds of Decisions Can Parents Make about Their Children?]
Interview with József Kovács by Gabriella Jakupcsek
Television Program “Mokka”, *TV2*,
April 1, 2008.

A szülői döntés lehetőségének korlátai gyerekek esetén [The Limits of Parental Decision Making]
Interview with József Kovács
Television Program “Napkelte”, *M1*,
April 3, 2008.

Kötelező védőoltás és szülői felelősség [Compulsory Vaccination and Parental Responsibility]
Interview with József Kovács by Emese Nagy
Radio Program “180 perc”, *MRI*,
April 9, 2008.

A kötelező védőoltások etikai kérdéseiről
[The Ethical Issues of Compulsory Vaccination]
Interview with József Kovács by Klaudia Liptay
Television Program “Mokka”, *TV2*,
April 22, 2008.

Az ember-állat hibrid létrehozásának angol engedélyezéséről [On the UK Law on the Creation of Human-Animal Hybrids]
Interview with József Kovács by Balázs Németh
Television Program “Tények”, *TV2*,
May 20, 2008.

A művi abortusz jogi szabályozása Angliában és Magyarországon
[The Regulation of Abortion in the UK and Hungary]
Interview with József Kovács by Júlia Torda
Info Rádió,
May 21, 2008.

Az ember-állat hibrid létrehozásának etikai kérdései
[The Ethical Aspects of Creating Human-Animal Hybrids]
Interview with József Kovács by Krisztina Gótfalvi

Television Program “TV-híradó”, *Duna TV*,
May 22, 2008.

Az emberi szaporodás és a tudomány
[Human Reproduction and Science]
Discussion with Judit Sándor (CEU, CELAB),
János Urbancsek (SOTE) by Júlia Gimes
Radio Program “Tér-Idő: a tudomány világa”, *MRI*,
May 23, 2008.

Átláthatóvá válnak a biobankok
[Biobanks Are Becoming More Transparent]
Interview with Judit Sándor by András Kósa
Hírszerző.hu, online news channel,
May 11, 2008.

Ki jön a házamba? Mesterséges reprodukció és jogi szabályozás
[Artificial Reproduction and Legal Regulation]
Article by Judit Sándor
Magyar Narancs, June 26, 2008
(Vol. XX, No. 26), pp. 26–28.

Őssejt kutatások etikája
[The Ethics of Stem Cell Research]
Interview with Judit Sándor and Balázs Sarkadi by
Júlia Gimes
Radio Program “Tér-Idő: a tudomány világa”, *MRI*,
June 6, 2008.

Petesejtet vegyenek! [Eggs on Sale]
Interview with Judit Sándor by Éva Fejős
Nők Lapja,
July 2, 2008.

Ugrás a sötétbe. Kockázatos gyorsítópályán a gyógyszervizsgálatok kísérleti alanyai
[On the Subjects of Clinical Trials of New Medications]
Interview with József Kovács by Viktória J. Kun
Népszabadság,
July 15, 2008, p. 12.

Esti beszélgetés a CELAB-ról
[Radio program on CELAB]
Interview with Judit Sándor, Petra Bárd, Enikő Demény, and Péter Kakuk by Júlia Gimes
Radio Program “Esti beszélgetés a tudományról”,
MRI,
August 5, 2008.

Ötmillió forint hat életért. A pénzért való szervátültetés etikai kérdései [Five Million for Six Lives. Ethical Issues of Paid Organ Transplantation] Interview with József Kovács by Anna Danó *Népszabadság*, August 8, 2008, p. 4.

Emberi jogok és az emberi test [Human Rights and the Human Body] Interview with Judit Sándor by Ilona Mélykúti Radio Program “Reggeli gyors”, *Klub Rádió*, August 21, 2008.

Manipulálható a transzplantáció? [Can Transplantation Be Manipulated?] Interview with József Kovács by Anita Kazai *Medical Tribune*, August 28, 2008, pp. 4–5.

Meddőség Magyarországon: Szerelem a naptár után [Infertility Treatments in Hungary. Interviews with Judit Sándor, György Kosztolányi, and János Urbancsek by Szilvia Varró *Magyar Narancs*, September 18, 2008 (Vol. XX, No. 38), pp. 27–28.

3.7. PUBLICATIONS

Sándor, Judit (2008) Kutatási alanyból alkotótárs? [From Research Subject to Coauthor?] In *Lege Artis Medicinæ*, 8(4): 338–342.

Sándor, Judit (2008) Human Rights and Bioethics: Competitors or Allies? The Role of International Law in Shaping the Contours of a New Discipline. In *Medicine and Law*, 27: 15–28.

Sándor, Judit (2007) Body Immortal. In Jennifer Gunning and Søren Holm (eds.) *Ethics, Law and Society*. Aldershot: Ashgate, pp. 123–133.

Bárd, Petra (2008) A társadalmpolitikai paradigma vesztesei. Gondolatok az értelmi fogyatékkal élő személyek jogairól [Losers of the Social Policy Model. Thoughts on the Rights of Persons Living with Mental Disabilities]. In *Értelmi Fogyatékossgal Élők és Segítőik Országos Érdekvédelmi Szövetsége: Az értelmi fogyatékossgal élők helyzetének jogi aspektusa és az új Polgári Törvénykönyv tervezete* [Hungarian Association for Persons with Intellectual Disability, Legal Aspects of the Situation of Persons Living With Intellectual Disability and the Draft of the New Civil Code]. Budapest: ÉFOÉSZ, pp. 84–98.

Bárd, Petra (2007) A prümi szerződés: csapdahelyzet [The Prüm Treaty: A Trap]. In *Rendészeti Szemle*, 10: 86–91.

Beširević, Violeta (2008) Eutanasi, retten til ærverdigg død og døende pasienter i Serbia, (in Norwegian).

Omsorg. Nordic Journal of Palliative Medicine, 4/2008. (forthcoming)

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3. ACTIVITIES

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4. BUDGET

4.1 REVENUES IN AY 2007/08

APPROVED BUDGET FROM CEU FOR AY 2007/08 (CODE C-5036):	€ 28,448
EXTERNAL FUNDING IN AY 2007/2008:	€ 76,602
• GENEBA NC PROJECT FOR AY 2007/08 (CODE C-8239):	€ 59,165
• UNESCO PROJECT (CODE C-8324)	€ 15,195
• GENEBA NC PROJECT OVERHEAD (CODE C-8249)	€ 2,242

4.2 SPENDING IN AY 2007/08

C-5036 CELAB MAIN BUDGET CODE

Budget category	Amount in Euro
Personnel cost	27,728
Web-page design	720
Total	28,448

C-8249 CELAB ADMIN

Budget category	Amount in Euro
CELAB Annual Report 2006/2007	1,300
Equipment (laptop)	172
GeneBanC VAT	553
Other office costs	411
Total	2,436

C-8239 GENEBA NC PROJECT

Budget category	Total Amount in Euro
Personnel	32,753
Equipment	1,080
Travel	3,113
Other costs	1,269
Total	38,215

C-8324 UNESCO PROJECT

Budget category	Amount in Euro
Translation	6,448
Dissemination	910
CELAB Workshop	2,405
Design and Printing of booklets	5,352
Other office costs	80
TOTAL	15,195



