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Center For Ethics And Law In Biomedicine

2006–2007

ANNUAL REPORT

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1. FOREWORD

The Center for Ethics and Law in Biomedicine (CELAB), established on September 15, 2005 at the Central European University in Budapest, is an international research think tank that provides an intellectual and institutional basis for ethical and legal research and promotes teaching and policy activities in the field of life sciences, including the broad scope of biomedicine. This document is the second Annual Report of the Center that highlights the major activities of CELAB in the 2006–2007 academic year.

During the second year of its operations, the Center focused on an increasingly important interdisciplinary domain: the ethical, legal and social implications of biotechnology. Life sciences, and especially biomedicine, have traditionally been preoccupied with the restoration of health and 'normality'. More recently, however, in an era symbolized by the Human Genome Project, the interest of life sciences has shifted towards the possibilities of mapping, transforming, and even enhancing various human capacities. For instance, while new reproductive technologies may provide solutions to certain previously untreatable problems of infertility, they also pose new questions of sexuality, gender, and kinship as genetic testing and pre-implantation diagnosis may lead to selection, thus to enhancement. All these developments pose provocative questions to the social and cultural sciences, challenge governance and decision-making in scientific policy, and raise ethical and legal concerns related to the various uses of genetic data. The emerging fields of stem cell research, nanotechnological applications in biomedicine, the protection of genetic data, and the establishment of biobanks signify this process.

Entering the third year of its operation, CELAB has developed an extensive network of international cooperation: the Center participates in numerous European research projects, organizes academic workshops, and offers university courses.

In the field of research activities, one of the most significant developments has been to launch a *legal research project on biobanks and data protection* that involves thirteen countries of Europe. This research is part of *GeneBanC*, a project financed by the European Commission. In order to complete our task, we have recruited a new staff member, Petra Bárd, a promising young legal scholar who is in charge of collecting legal norms and guidelines in this field. In the framework of this project, we work hard on identifying key partners, types of biobanks, and legal instruments, in East Central and South European countries. We have realized that in this new domain, definitions may vary from country to country. According to the British Nuffield Report, the term 'tissue bank' encompasses both institutions that handle fresh tissues primarily and those that maintain collections of preserved tissue. In our research we focus on the *types of biobanks that supply tissues and cells primarily for*

"The things that biotechnology makes and deals in – genes, cells, plants, embryos, drugs, bacteria, DNA sequences, genetic test, transgenic creatures – have often been the focus of controversy at one time or another in the past twenty years, and some still remain so. Yet, many social technologies that were vital to the birth of modern biotechnology have fallen curiously outside the center field of political analysis, for example, venture capital, start-up firms, technology transfer, and intellectual property law…"

Sheila Jasanoff, *Designs on Nature* (Princeton University Press, 2005), p. 203.

research and not for therapy: databases that are developed by and restricted to authorized clinical investigations (e.g. oncology, pathology, etc.) in several academic medical centers. These databases contain genetic and other biomedical information about connecting individual patients derived from their clinically collected tissues, with electronic data sometimes being transmitted to a central database. Another exciting research field within this project is *mapping the legal landscape of forensic biobanks* in Europe. In addition to the methods of using detailed questionnaires we have also conducted on-site interviews. Genebanks require a new interpretation of established legal terms, such as property, ownership, or personality, and they require the development of a new legal approach in this specific field of biomedical research and data protection.

During the past academic year, we have also worked out new research fields and submitted several applications to the European Commission jointly with prestigious research networks. As a result, three entirely new projects will start from the beginning of 2008. One of the promising new research projects, *REMEDiE* (Regenerative Medicine in Europe: Emerging Needs and Challenges in a Global Context) will start in 2008 and last for 36 months. This is a collaborative project that will examine the socio-economic, political and bioethical implications for Europe and future global developments in the field of regenerative medicine. It will adopt 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.

Another new and exciting research area is the ethics of nanotechnology. When in the 1980s Eric Drexler first used the word 'nanotechnology', he was talking about building machines on the scale of molecules, that is, a few nanometers: tiny motors, miniscule robot arms, and nanocomputers. Since then nanotechnology has become an accepted concept and the meaning of the word shifted to encompass the various types of nanometer-scale technology. Starting from the 2007–2008 academic year, CELAB will participate in *NANOPLAT*, another research project financed by the European Commission. The project will concentrate on deliberative processes concerning human and environmental safety, ethical and moral dilemmas, and perception of risks and responsibilities.

One of the most prominent events during the past academic year was *Perfect Copy?* – an international workshop held on March 1–2, 2007 on cloning. During the two-day workshop the invited speakers explored the challenges and analyzed the major ethical dilemmas that have appeared in public debates on reproductive cloning and stem cell research. Presentations and discussions explored the differences between European and U.S. ethical debates and gave an insight into the

lessons drawn from the Korean embryonic stem cell case. Participants in the discussion included ethicists, lawyers, scientists and policy makers. The closing presentation was delivered by *Violeta Besirević*, Associate Professor at the Union University Law School in Belgrade, Serbia, who has been a fellow of our Center in the 2006–2007 academic year.

Another major achievement is the renewed Biolaw database launched by CELAB. Starting from the 2007–2008 academic year students, researchers, and partners can see not only a more user-friendly research tool but also thousands of new items that are regularly uploaded into the database, and last but not least, visitors will enjoy an entirely new design. All this was possible due to team efforts; Enikő Demény has worked on the database since the beginning, she and Ildikó Chikán has worked hard to achieve this new form and structure. Lawyers such as Petra Bárd and myself have examined and structured the legal part of this work, while Zsolt Sándor has helped us with our new design.

CELAB also participated in the summer seminar of the School for Biotech Industrial Innovation Management in Siena. The seminar discussed how to drive the best strategies on patenting or maintaining know-how in order to delay the competitors' knowledge of one's own innovative lines, how to cope with the different conditions of disclosure required by various patent systems, and how to enlarge the scope of protection of a patent without risking the loss of its validity.

Members of CELAB have conducted several courses, as can be seen on our website. From September 2007 a new interdisciplinary course will start with the title *Biotechnology and Social Policy: Genetics, Reproduction, and Enhancement*. This course is accompanied by non-mandatory film sessions and discussions co-organized by CELAB.

Students at the Central European University may benefit from the expanding research fields and activities of CELAB in several ways. First, they can access the Biolaw Database and work with other research tools the Center offers; second, they may participate in various research projects at or through CELAB; and third, they can freely attend the conferences, workshops, and other scholarly events organized by the Center.

CELAB operates with small seed money. In addition to CEU funding, several EU grants and other external financial sources make the daily operation possible. The work is completed by a core staff; and we owe a lot to our associates, especially to Violeta Besirević, Péter Kakuk and József Kovács.

Looking through our records of the past year, I realize that it is almost impossible to list all its achievements. For more detailed information, please consult the Center's website at: www.ceu.hu/celab.

Judit Sándor
Director of the 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 field of bioethics, biomedical law and biotechnology; to analyze current ethical dilemmas in the field of science and technology; to work out policy papers in the field; and to organize workshops, inviting outstanding international experts.

In order to achieve these goals, CELAB builds up partnerships and collaboration with academic institutions, centers, international organizations engaged or interested in CELAB's main topics.

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 and WHO, and with EU Directorates. These contacts have resulted in various types of partnerships and cooperation.

2.1. ACADEMIC PARTNERS

2.1.1 Hungarian Universities

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

2.1.2 Other Universities

Catholic University of Leuven, Centre for Biomedical Ethics and Law
University of Vienna, Department of Political Science
University of Oslo, Section for Medical Ethics
University of Leeds, Institute of Health Sciences and Public Health Research
University of Maastricht
University of Rennes-1, Faculty of Law and Political Science; Centre for Private Law
Babes-Bolyai University, Cluj

2.1.3 Partnership with other Centers and Associations

European Privacy Institute
http://www.privacyinstitute.eu/

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 and 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

University of Siena
Centre for Law and Biotechnology
http://www.biolaw.it/Centre/index.htm

Lancaster University
CESAGEN - Centre for Economic
and Social Aspects of Genomics
http://www.cesagen.lancs.ac.uk/index.htm

Lithuanian Bioethics Committee
http://bioetika.sam.lt/indexeng.htm

2.1.4 Cooperation 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=1373&URL_DO=DO_TOPIC&URL_SECTION=201.html

United Nations Economic and Social Council
Commission on Human Rights
Sub-Commission on the Promotion and Protection of Human Rights
http://www.unhchr.ch/html/menu2/2/sc.htm

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/

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

3. ACTIVITIES

3.1. Research

CELAB's main research topics are the ethical, social and legal implications of

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

3.1.1 CELAB in EU Research Projects

3.1.1.1 EU Sixth Framework Projects

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

Duration: 36 months
Partners:
- University of Oslo, Norway
- University of Leeds, UK
- Catholic University of Leuven, Belgium
- Central European University, Hungary
- University of Vienna, Austria

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 this 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 mainly focused on population-based genetic databases. Moreover in the post-9/11 era, forensic genetic databases (crime, terrorism) generate many questions that have received no attention so far at the 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 embeddings 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 also aim 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.

The Role of CELAB in the Project

CELAB (partner 4 in the project), in cooperation with the Catholic University of Leuven, is responsible for work-package 4 of this project (WP4) entitled „Comparative research regarding the regulatory framework of biobanks in the EU Member States". This work-package 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 legislations and regulations; (3) looking for the "best rules" by comparing these similarities and differences; and (4) making proposals in order to reach, where appropriate, a harmonized regulatory framework across the EU.

On December 1–2, 2006 the kick-off meeting of the project took place in Leuven, Belgium. In the framework of the workshop, a Steering Committee and an Advisory Board meeting were held with all the participants introducing their institutions, professors and researchers; the representative of the DG Research European Commission also being present. The participants explained the general framework of the research and presented the seven work packages.

A second meeting was held on September 4–5, 2007 in Paris with the aim of summarizing the findings of work-packages so far on the one hand, and going into the merits of confidentiality, privacy and control on the other. The workshop addressed the issue of confidentiality in relation to two types of biobanks (small scale and population based), to analyze what the implications of confidentiality are in biobanks with multiple uses, and in biobanks that have changed their function since their establishment. During the first year of the project, Judit Sándor and Petra Bárd have collected the academic literature, and acquired other scholarly materials. The documents have been uploaded to CELAB's website at www.biolaw-database.com. International legal sources have been identified, and a list of legal sources has been compiled. CELAB has drafted the first version of the legal questionnaires which have been modified according to the comments by the Leuven Team. In order to avoid misunderstandings, CELAB offers a definition of biobanks partly on the basis of a a Council of Europe Recommendation, and partly on the basis of the definition of Robert F. Weir and Robert S. Olick. In the questionnaires, questions have been posed as to the laws dealing with biobanks, their establishment, ownership, management, the type of samples collected, the purpose of collection, the pecuniary aspects, whether consent is required, whether withdrawal is possible, whether individuals with limited capabilities can consent, and how data and samples can be accessed, whether cross-linking is allowed, and how storage, property aspects, supervision, compensation and penalties for non-compliance are regulated. As to forensic databanks, the questions are slightly different, but the structure is similar.

In the framework of the GeneBanC research program, several biobanks have been contacted and interviews have been conducted: CELAB Director Judit Sándor and Researcher Petra Bárd visited a Hungarian forensic databank, the National Public Health Institute's Molecular and Genetic Diagnostics Department, the Neuromuscular Laboratory of the University of Ljubljana, the Medical Faculty, Institute of Anatomy, and a Tissue Bank of the University Hospital Brno. Several Italian biobanks have also been contacted by Judit Sándor, and interviews have been conducted by CELAB Researcher Enikő Demény in Lithuanian biobanks. At the present stage of the

research, international legal documents applicable to biobanks are summarized and materials for national country reports are gathered.

Website:
http://www.genebanc.eu

3.1.1.1.2 Determining the Ethical and Legal Interests in Privacy and Data Protection for Research Involving the Use of Genetic Databases and Bio-banks (PRIVILEGED)

Duration: 36 months
Main Partners:
- University of Sheffield, UK
- Biomedical Law Center, University of Coimbra, Portugal
- University of Vilnius, Lithuania
- CELAB, Central European University, Hungary

PRIVILEGED is an EU six framework project. 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.

The Role of CELAB in the Project

Besides contributing to all the twelve work-packages of the project, Professor Judit Sándor, Director of CELAB is a member of the project's Steering Group. The Steering Group has the two distinct functions of being a project management group and a scientific advisory group. The Steering Group will fulfill these functions by meeting seven times during the project, as indicated in work module 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.

3.1.1.2 EU Seventh Framework Projects

During the 2006–2007 academic year, CELAB prepared its participation in four EU FP7 framework projects, out of which the following three have been successfully accepted and will start in the 2007–2008 academic year.

3.1.1.2.1 NANOPLAT – Development of a Platform for Deliberate Processes on Nanotechnology in the European Consumer Market

Duration: 18 months
Partners:
- National Institute for Consumer Research, Oslo, Norway
- CRIC, University of Manchester, UK
- Institut für Ökologische Wirtshaftsforschung, Berlin, Germany
- TUSIAD, Sabanci University Competitiveness Forum, Istambul, Turkey
- University of Bergen, Norway
- Strategic Design Scenarios, Brussels, Belgium
- CELAB, Central European University, Hungary

The objectives of this project are to evaluate selected deliberative processes in Europe, both at the EU and national level. In both levels evaluations will have a general NS&T perspective, but will concentrate on the value chain of consumer goods and services; to identify the needs and interests of relevant stakeholders along this value chain, especially focusing on NGOs and the civil society; to develop a deliberate and science-based platform for a stakeholder dialogue in Europe and beyond in this area, where the main elements for the platform are: content, participants, physical and technical solutions and arenas and lastly the responsibility for the platform and to formulate recommendations for research and political actions.

CELAB's role is to map the ethical and legal framework of nanoscience in Europe.

3.1.1.2.2 REMEDiE – Regenerative Medicine in Europe: Emerging Needs and Challenges in a Global Context

Duration: 36 months
Partners:
- SATSU, University of York, UK
- University of the Basque Country, Spain
- University of Hanover, Germany
- Life Science Governance Institute, Austria
- CELAB, Central European University, Hungary
- University of East Anglia, UK

The objectives of the project are to provide (1) detailed analysis of the competitive position of Europe within the globalization of regenerative medicine, the requirements of successful innovation in this field and the EU policies that need to be developed to support Europe's global advantage in the field; (2) an integrated series of work-packages organized around three inter-related streams of research (economic, political and bioethical) that constitute the platform for this analysis; an integrated quantitative relational database on the geo-economic pattern of activity within regenerative medicine derived from a) ongoing review of secondary data sources and b) primary data derived from partner projects; and (3) continuing engagement with national and international policy makers to test and refine the implications of emergent findings for future European policy and regulation in particular.

CELAB will be responsible for Work Package No. 6 "Global bioethics: intellectual property and cultural difference." The objective of this work is to explore the relevance of bioethical soft laws in different intellectual property regimes. Special attention will be paid to the status of the human body in the field of regenerative medicine, benefit-sharing and morality clauses, especially in cases of transnational research.

3.1.1.2.3 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

Duration: 36 months
Partners:
- Department for Ethics and History of Medicine, University of Goettingen, 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, UK
- Stockholm Bioethics Center, Stockholm University, Sweden
- Fondazione Lanza, Padova, Italy
- Forensic & Legal Medicine, School of Medicine and Medical Science, National University of Ireland, Dublin, Ireland
- Center de Recherche Droit, Sciences et Techniques, Université Paris 1, France
- Institute of Bio-Law "Legal Pathways", Aerdenhout, the Netherlands
- Department of Medical History and Ethics, Vilnius University, Lithuania
- CELAB, Central European University, Hungary

The Tiss.EU project will analyze the impact of current EU legislation and guidelines on biomedical research which are based on the procurement, storage and transfer of human tissues and cells in and across the European Union. The importance of tissue derived from the human body for biomedical research is ever increasing. In the Theme "Translating research for human health" of FP7, the EU actively encourages the networking of human sample biobank initiatives. National differences in the regulation of the handling of these tissues and cells, however, represent a serious

barrier for biomedical research in the Member States and associated countries. EU legislation has dealt with these topics but covers mainly clinical application. An EU biobanking directive is still missing. This is a major handicap for transnational research involving human samples. The project will evaluate the consequences of current EU legislation and related guidelines, as well as the way they are implemented at a national level, on transnational research activities. It will identify regulation deficits and inconsistencies, and create an evidence base for the revision of legislation, if necessary.

CELAB's role will be to organize and to carry out the first workshop on focal theme C (Anonymization and Pseudonymization for Privacy Protection) together with country reports by invited experts from Bulgaria, Czech Republic, Hungary, Slovakia and Romania; to analyze approaches of anonymization and pseudonymization for the protection of patients' privacy in biomedical research with human tissues and cells; and to identify problems to be addressed in future EU legislation and related guidelines; to collect up-to-date information about current national regulations, important case studies and the impact of EU legislation and related guidelines on biomedical research in this country group and to discuss the main similarities and differences between national legislation and ethical guidelines and EU legislation in this country group.

3.1.2 Research Conducted within CELAB

3.1.2.1 Comparative and Interdisciplinary Approaches on Reproductive Cloning and Stem Cell Research

This research started in the 2005–2006 academic year and continued during 2006–2007. In March 2007 CELAB organized a workshop on this topic (see the workshops section of the present Report), and will publish the workshop proceedings in a book.

Research objectives were to analyze the dominant ethical arguments and principles governing the regulation of stem cell research; to compare the 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 ongoing analysis of relevant laws and decisions on this topic, these documents are continuously reviewed for the bio-law database of CELAB. The laws and regulations in this field of study are changing very rapidly, therefore no legal and ethical research on the topic can be conducted without having a clear view of the continuously changing legislative landscape and without investigating the arguments of different stakeholders in stem cell research.

The applied research methodology includes:

- monitoring biomedical norms (ethical and legal) on 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; and
- comparative analysis of laws, legislative proposals, reports and cases decided by European courts.

3.1.2.2 Ethical and Legal Implications of ICT Implants: Research Study in Cooperation with the National Communications Authority

In December 2006 CELAB was contacted by the Hungarian National Communications Authority with the request to write a policy analysis on the ethical and legal implications of the so-called ICT (information and communication technologies) Implants. The Director of CELAB, Judit Sándor, together with Balázs Rátai, wrote the Opinion in Hungarian which was presented to and discussed at the National Communications Authority.

This policy research was inspired by the work of the European Group on Ethics in Science and New Technologies (EGE) on the same issues. In March 2005 EGE adopted an Opinion with the title *Ethical Aspects of ICT Implants in the Human Body* (Opinion No. 20). Medical science has been using various kinds of implants, such as cardiac pacemakers and similar devices, for a long time. However, other types of ICT implants, such as those that may be used to repair certain deficient physical capabilities, may pose new challenges – especially if they are accessible via digital networks. These problems have not yet been tackled in Hungary.

The authors of this study analyzed the issues of privacy and data protection especially with regard to the

traceability of implant users. They also discussed the ethical dimensions of enhancement or the realistic possibility that ICT implants may provide 'better than normal' biological and physiological capabilities to their users. Expectations regarding the slowing down the aging process, extending life expectancy, diminishing suffering and reducing the cases of disability seem to have changed, at the very least, in societies where scientific advances have flirted with the idea of stretching the boundaries and increasing the capacities of the human body. Expanding the human lifespan has become a scientific project as it is transformed from an object of utopian desire to mundane biotechnological bricolage.

After highlighting the most important ethical dilemmas concerning the use of ICT implants, the authors discussed possible future scenarios.

3.1.2.3 Legal Aspects of Euthanasia

In the 2006–2007 academic year Violeta Besirević, the winner of a CEU/SPO Visiting Research Fellowship Grant carried out a research at CELAB on legal aspects of euthanasia. Besirević started her fellowship at CELAB on September 1, 2006. Defining euthanasia as an action or inaction with the intent of bringing about a patient's death in order to end their suffering, the purpose of Besirević's research was to examine the controversy of euthanasia in the context of international law and to establish whether legalization will be an inevitable outcome of global trends.

3.1.2.4 Bioethics and Social Sciences

Many current debates on the social and ethical aspects of biotechnology are framed in the context of bioethics discourse. Why does bioethics have more voice in this field than social sciences in general, and anthropology in particular? What kind of disciplinary or gendered power relations shape the production of knowledge and the practices of legitimization in this field? To which areas can an anthropological approach offer meaningful insights?

This research tries to find new pathways for anthropological engagement in biotechnological fields. One possible solution is offered by the social science and feminist critique of mainstream bioethics discourse, which can open a niche for anthropological expertise on biotechnology related issues. The gender perspective can be employed as a critical tool in anthropological research while addressing, for example, the challenges brought by modern biotechnologies into the world of human relationships. Furthermore, this perspective is useful for revealing hidden power relations in knowledge production and in the creation of expert discourses and normative frameworks. In turn, anthropologists' engagement with biotechnology can contribute to the rethinking of some fundamental concepts of anthropological theory and practice, such as nature, kinship and identity.

Some results of this research have been presented by Enikő Demény at the International Conference "Anthropology, Ethnography and Biotechnology," held in Vilnius, in September 2007.

3.2. BIOETHICAL AND LEGAL RESEARCH DATABASE

The Bioethical and Legal Research Database was 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*, and having Prof. Judit Sándor as principal investigator representing CEU. The database website was launched on December 15, 2004, when Enikő Demény presented it to the public forum "Genetics and Society," organized in Barcelona.

Since then the Biolaw Database has been expanding week by week to include laws, legal cases, professional guidelines and expert opinions published by international organizations, national governments, legislative bodies and NGOs throughout the world.

The database has been indexed under the main search engines, therefore it can be reached by all those who are searching the internet on topics of bioethics, biolaw and biomedicine. Up to now the database has been accessed from forty countries on five continents.

In 2006–2007 CELAB decided to restructure the database in order to, on the one hand, make it more user-friendly and, on the other, to reflect CELAB's research profile in a more accurate way. As a result, the database now covers the following tagged and searchable fields of research: biobanks; biomedical research; cloning; euthanasia; GMO; gender, family, identity; human genetics; human reproduction; intellectual property; nanotechnology.

CELAB plans to launch the redesigned version of the database at the same time as the present Annual Report.

3.3. WORKSHOPS, MEETINGS

3.3.1 CELAB First Annual Meeting and CELAB Fellow's Book Launch

To celebrate its first year of existence and to sum up the results and achievements of its first year of activity, CELAB organized its first Annual Meeting on December 14, 2006. The meeting was attended by CELAB fellows and invited guests. The opening address was offered by Director of CELAB, Prof. Judit Sándor, who expressed her acknowledgements for all the efforts of CELAB's staff and fellows in the first year. The major achievements of CELAB were presented by József Kovács, Petra Bárd and Enikő Demény.

The meeting ended with the launch and distribution of CELAB's Annual Report 2005–2006. The meeting had another important agenda: launching the book of CELAB fellow Violeta Besirević, titled *Euthanasia: Legal Principles and Policy Choices*. This book, first published by a CELAB fellow, was reviewed and praised by Péter Kakuk.

3.3.2 CELAB Workshop: Perfect Copy? Comparative and Interdisciplinary Approaches to Reproductive Cloning and Stem Cell Research

One of the most prominent events organized by CELAB over the last academic year was "Perfect Copy?" – an international workshop on cloning held on March 1–2, 2007. During the two days of the workshop, invited speakers analyzed major ethical dilemmas that have appeared in public debates on reproductive cloning and stem cell research and explored challenges related to these issues.

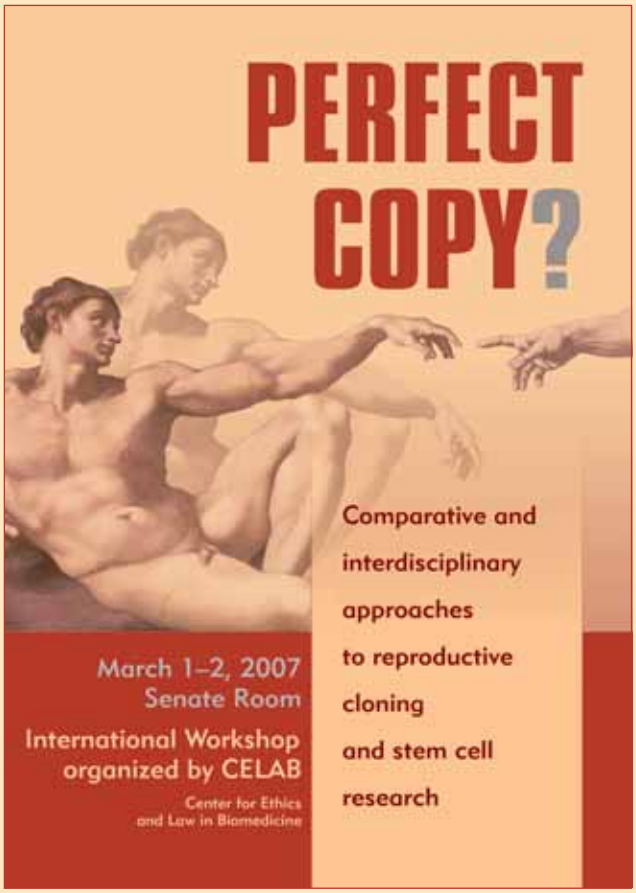
By applying a comparative method, the presentations and discussions highlighted the differences between the European and U.S. ethical debates and gave an insight into the lessons drawn from the Korean embryonic stem cell case. Participants in the discussions included ethicists, lawyers, scientists and policy makers. The workshop was opened by CEU Rector *Yehuda Elkana*. His opening address was followed by the introductory speech by Director of CELAB *Judit Sándor*, who presented the international political and legal landscape of reproductive cloning and stem cell research and demonstrated the semantic and normative problems behind the superficial and categorical ban on different forms of cloning. After the introduction, presentations were given by the experts András Dinnyés, Maurizio Salvi, Guido van Steendan, Knut Ruyter, Péter Kakuk, Hanne-Maaria Rentola and Violeta Besirević.

András Dinnyés, leader of the only nuclear transfer-cloning laboratory in Hungary, gave an insight into the state-of-the-art of human and animal cloning. Having cloned the first animal in Hungary, a mouse named "Klonilla," he concluded that the subject is very topical, as cloned beings are already in existence. Dinnyés explained the current possibilities of cloning and the technical challenges cloning holds for scientists.

After a fruitful discussion, *Maurizio Salvi* from the European Commission, and the European Group on Ethics in Science and New Technologies presented the European Union's approach to human reproductive cloning and stem cell research. He explained the differences in the weight the European Commission attached to ethical considerations in the Sixth and Seventh Framework Programs of the European Union. The presentation on the history of ethics becoming a key element in European Union funded research was followed by a number of questions. The last paper on the first day of the workshop was delivered by *Guido van Steendan*, Director of the International Forum for Biophilosophy and Professor at the Catholic University of Leuven. He addressed the ethical aspects of reprogenetics by relying on the conclusions of the CLEMIT, a European Commission funded research project dealing with the ethics of new medical technologies, with special focus on developing a network in Central Europe. He addressed the question why human cloning was beyond ethical limits, and quoted the three traditional reasons mostly applied in contemporary discourse, namely that we don't have the intelligence, the wisdom and the mandate to clone human beings. In response to these

arguments, he defeated the premises by holding that moral questions related to cloning should be addressed from a different point of view, which he called "contextual ethics."

The second day of the workshop started with *Knut Ruyter*, Director of the National Committee for Medical Research Ethics and Professor in ethics at the Faculty of Theology, University of Oslo. Knut Ruyter gave a critical assessment of the use of rhetoric in ethical arguments on reproductive cloning and stem cell research. He framed the discussion around the binary nature of the Norwegian rhetoric that evolved around human cloning. The buzz words used in parliamentary negotiations and also in the media are "inclusive society" versus a "sorting society." Positive feelings and words are attached to the former, whereas the negative perceptions of human cloning appear in the frame of the latter phrase. The presentation was followed by a lively discussion. *Péter Kakuk*, member of CELAB and a Research Assistant at the Department of Behavioural Sciences at the Medical and Health Sciences Centre of the University of Debrecen, continued with the presentation of the infamous case of Hwang Woo-Suk, the South-Korean national hero and once celebrated pioneer of stem cell research. Briefly discussing the evolution of his publication and research scandal in science, Péter Kakuk sketched the main lines of the reactions that emerged within the scientific and bioethical discourse on the problem of research misconduct in contemporary biosciences. He interpreted the Hwang case and the surrounding discourse as a case study that might shed light on the worst aspects of high-stakes global science, as an event that could open a door on contemporary scientific practices from which a whole group of problems become visible that endanger scientific integrity.



Aside from this particular case, Péter Kakuk also brought some empirical data on scientists behaving unethically. Many participants responded to the thought-provoking presentation.

Hanne-Maaria Rentola from Finland, currently doing her Th.D. studies at the Department of Systematic Theology at the University of Helsinki, compared the ethical argumentation of the European Union Stem Cell Reports with the reports of the United States President's Council on Bioethics, stating that all reports define the problem of embryonic stem cell research as an interest conflict between human embryos, scientific research, and possible patients. As Hanne-Maaria Rentola showed through a number of examples, the EU reports evaluate the conflict in the light of fundamental ethical principles and the existing pluralism within the EU, whereas the US report assesses the interest conflict through the concept of humanity. After the presentation, an interesting debate evolved around the meanings attached to humanity and human dignity in the different disciplines represented.

The closing presentation was delivered by *Violeta Besirević* from Serbia, CELAB fellow and Associate Professor at the Union University Law School in Belgrade. Her presentation entitled "Cloning and the Constitution" addressed the issue of cloning from a legal, mostly constitutional law point of view. Before entering into the legal arguments, Violeta Besirević emphasized that the ongoing debate has been grounded predominately in religious, ethical, and medical concerns for a clone, a donor, and the society as a whole. The legal arguments, less often debated, revolve around a ban on all cloning, including therapeutic cloning. Seldom – and mainly in the United States – are the points about human cloning made in constitutional terms. Coming to the actual constitutional analysis, Violeta Besirević first recapped general remarks on human cloning, the main concerns, the presently-claimed benefits and legal trends. Subsequently, she addressed the issues whether a constitution speaks about human cloning; which interests a state can claim against its constitutional permissibility; and which interests, if any, a clone, donor or society as a whole may claim in favor of human cloning.

The workshop ended with *Judit Sándor's* closing remarks and a reception that also gave participants a chance for an informal continuation of the debate. The presentations given at the conference are going to be published in an edited volume by CELAB at the beginning of 2008.

3.3.3 CELAB Participation at Key International Events

3.3.3.1 First Regional Meeting of National Bioethics Committees in Cairo

Judit Sándor, Director of CELAB participated in the First Regional Meeting on National Bioethics Committees in Cairo, Egypt. The event was held at the WHO Easter Mediterranean Regional Office (EMRO) on May 5–7, 2007, organized jointly by UNESCO's Cairo Office and WHO EMRO. Experts from fifteen countries in the region (Afghanistan, Egypt, Islamic Republic of Iran, Jordan, Lebanon, Libyan Arab Jamahiriya, Morocco, Pakistan, Qatar, Saudi Arabia, Sudan, Syrian Arab Republic, Tunisia

and Yemen) took part, representing Member States from both the UNESCO Arab Region and the WHO Eastern Mediterranean Region. Prof. Judit Sándor gave a presentation with the title "Ethics and Law of Biobanks."

The Report of the event can be accessed at:
http://www.ceu.hu/celab/First Meeting NECsfinal.pdf

3.3.3.2 CELAB's Participation at the European Platform Organ Transplantation: Ethical, Legal and Psychological Aspects Towards a Common European Policy

The Dutch Transplant Foundation, the Dutch Health Council and the Erasmus University Medical Center organized an international congress titled "Organ Transplantation: Ethical, Legal and Psychological Aspects, Towards a Common European Policy" on April 1–4, 2007 in Rotterdam, the Netherlands. The purpose of the conference was to encourage the exchange of information, ideas, and experience and to establish a permanent European Platform on these issues to formulate guidelines and stimulate joint research efforts. The conference took place at the World Trade Center in Rotterdam. Six main topics were addressed: (1) commercialization and trafficking; (2) legal systems for organ donation and allocation; (3) altruism, counseling and psychological aspects of living donation; (4) minorities, religion and gender aspects; (5) expanded post mortem donor criteria including non-heart-beating donation; and (6) the role of patients, media, and the pharmaceutical industry.

Participants reaffirmed that organ transplantation remains a rapidly evolving medical success story. However, while new technologies and transplantation programs emerge, questions about the ethical, legal and psychological implications of the developments have become apparent. In the various European Union countries, these aspects are developing in different ways. As a result, there are opportunities for cooperation between countries, but also problems to solve, e.g. unequal access to care.

One of the key events of the conference was the *Jubilee Debate* organized by the Dutch transplant

Foundation with the title "Whose organs are they anyway?" Participants of the debate were *Judit Sándor*, Director of CELAB from Hungary and *Henri Kreis* from France. The moderator was *Hans W. de Fijter* from the Netherlands.

Henri Kreis argued in favor of a compulsory organ draft system that would give health officials the authority to harvest organs from cadavers upon a declaration of death. The main expectation towards this system is that it would maximize the number of potential donors. Needless to say, this system would allow some exceptions based on religion. Furthermore, Henri Kreis assessed positively that in their grieving, relatives would not be asked to donate organs of their relatives. His opponent in the debate, Judit Sándor challenged his position on conscription and argued for a consent-based model in which people would be invited to make a statement about their intent on later cadaver donation. Besides, she presented the limits of law and advocated for a wider policy-based approach on cadaver organ transplantation that would stimulate solidarity within society but not only through legal means. While aware of the scarcity of available organs, she stressed that we should not discard altruistic donation as such. On the contrary, we should re-affirm rather than abandon it.

3.4 TEACHING

CELAB's staff and fellows are involved in teaching both at CEU and at other universities in Hungary and in other countries of the East-Central and South-Eastern European region. They offer courses closely connected to 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 Courses Taught at CEU

Judit Sándor

Reproduction and Gender (2007–2008)
– Gender Studies and Political Science
Biotechnology and Social Policy (2007–2008)
– Political Science and Gender Studies
Privacy and Data Protection (2006, 2007–2008)
– Legal Studies
Human Rights and Bioethics: A New Generation of Rights? (2006)
– Legal Studies
Reproduction, Self, and State (2006)
– Gender Studies
Human Rights in the Twenty-First Century (2006)
– Political Science
Anti-Discrimination Law and Policy (2005–2006)
– Ph.D. Political Science
Patients' Rights (2005–2006, 2007–2008)
– Legal Studies

Petra Bárd

Introduction to Law (2005–2006, 2006–2007, 2007–2008) – Legal Studies
Total Law™ (2006) – Introductory Course, Legal Studies
Mediation and Other Methods to Foster Democratic Dialogue (2007)
– Summer University Course
Legal Terminology (2007–2008) – Legal Studies

3.4.2 Teaching and Lecturing at Other Institutions

Judit Sándor

Privacy and Genetic Information
European Course on Biotechnology Ethics
Brno, Czech Republic
June 29 to July 6, 2006

Legal and Ethical Implications of Biotechnology
Semmelweis Medical University, Budapest, Hungary
November 2, 2006

Ethical and Legal Aspects of Biotechnology
Postgraduate School for Pharmaceutical Research, Budapest, Hungary
November 9, 2006

Immortal Body: Contemporary Legal Issues of Human Tissues
ELTE Scientific Council of Students on Criminal Law, Eötvös Loránd University, Faculty of Law, Budapest, Hungary
November 22, 2006

Ethical and Legal Aspects of Genomics
Semmelweis Medical University, PhD Program on Pharmacogenomics, Budapest, Hungary
April 12, 2007

Conclusions
School for Biotech Industrial Innovation Management, Centre for Law & Biotechnologies, University of Siena, Department of Public Law and Department of Private Law, Siena, Italy
July 13–15, 2007

Enikő Demény

Family and Identity in the Age of Genetics
Babeş-Bolyai University, Faculty of European Studies, Cluj, Romania
2006–2007

Petra Bárd

EU-CEE Law
ESSCA, Budapest, Hungary
2005–2006, 2006–2007, 2007–2008

Violeta Besirević

Legal Aspects of Euthanasia
Union University School of Law,
Belgrade, Serbia
April, 2006

Medical Law
Union University Law School,
Belgrade, Serbia
Spring Semester, 2006–2007

Euthanasia as a Right to Die: The European Court of Human Rights Approach
Rijeka University Law School,
Rijeka, Croatia
April 12, 2007

Péter Kakuk

Bioethics
GMP English Program, Medical and Health Science Center, University of Debrecen, Hungary
2006–2007

Dental Ethics
Faculty of Dentistry, Medical and Health Science Center, University of Debrecen, Hungary, 2006–2007

Pharmacy Ethics
Faculty of Pharmacy, Medical and Health Science Center, University of Debrecen, Hungary, 2006–2007

Bioethical Cases
Department of Behavioral Sciences,
University of Debrecen, Hungary, 2006–2007

József Kovács

The Ethics of Help I.
Semmelweis Medical University, Institute for Mental Hygiene, Budapest, Hungary
November 17, 2006

The Ethics of Help II.
Semmelweis Medical University, Institute for Mental Hygiene, Budapest, Hungary
January 5, 2007

Topical Questions of Bioethics in Hungary
Semmelweis Medical University, lecture for exchange students from the USA, Budapest, Hungary February 8, 2007

Ethical Aspects of Financing Health Care
Institute of Economics of the Hungarian Academy of Sciences, Budapest, Hungary, May 3, 2007

3.5. PARTICIPATION AT CONFERENCES

During the 2006–2007 academic year, CELAB staff and fellows took part in the following academic and scientific events:

Immunogenomics & Immunomics: International Conference on Biobanks Networking and Informatics
Participant: Judit Sándor, Director of CELAB
Title of lecture: "Tissue Issue: Ethics and Law of Stored Human Tissues"
October 8–12, 2006, Budapest, Hungary

Meeting of European Lawyers Specialized in Biomedicine
Participant: Judit Sándor, Director of CELAB
October 19, 2006, Paris, France

The Price of Evolutionary Success: From Brain Science to Behavioral Science
Conference organized by the Semmelweis Medical University, Institute for Behavioral Sciences and Knowledge Society Foundation
Participant: József Kovács
Roundtable discussion: "The Social Mission of

Behavioral Sciences: When, Why and How Should Scientific Researchers Contribute?"
November 8, 2006, Budapest, Hungary

Health Insurance Reform 2007–2009
Invited participant from CELAB: Judit Sándor
January 25–26, 2007, Budapest, Hungary

The Ethical Aspects of Research on Human Beings
Presentation by József Kovács at the Quintiles Hungary Ltd. Pharmaceutics Company
February 9, 2007, Budapest, Hungary

The Responsibility of Society in the Improvement of Treatment Possibilities and Recovery Expectations
Conference organized by the Hungarian Society for Oncology
Participant: József Kovács
Title of presentation: "The Ethical Aspects of Health Insurance"
March 27, 2007, Budapest, Hungary

Third Meeting of the Review Committee for the GEO-Law Database
Meeting organized by UNESCO SHS/EST
Legal expert: Judit Sándor, Director of CELAB
March 28–30, 2007, Paris, France

Ethical, Legal and Psychological Aspects of Organ Transplantation
Participant: Judit Sándor, Director of CELAB
Title of presentation: "From Donation to Participation"
April 1–4, 2007, Rotterdam, the Netherlands

European Patent Forum
Organized by the European Commission and the European Patent Office
Introductory speech by Chancellor Angela Merkel
Participant: Judit Sándor, Director of CELAB
April 18–19, 2007, Munich, Germany

Regulating Biotechnology: Does International Law Constrain Sovereign States?
Biocampus Network Meeting
Participant: Judit Sándor, Director of CELAB
April 26, 2007, Copenhagen, Denmark

Regional Meeting of National Bioethics and other Ethics Committees
Organized by the regional offices of UNESCO and WHO
Participant: Judit Sándor, Director of CELAB
Title of presentation: "Ethics and Law of Biobanks"
May 5–7, 2007, Cairo, Egypt

Second Conference on Professional Ethics
Participant: Péter Kakuk
Title of presentation: "On Research Misconduct: Contemporary Crises in the Ethics of Research?"
May 11, 2007, Pécs, Hungary

The Future of the European Union: Democratic Constitutionalization of the EU and the Role of States
CEPSA 2007 Conference
Participant: Petra Bárd
Title of presentation: "The Charter of Fundamental Rights"
May 23–25, 2007, Portorož, Slovenia

Internal and External Challenges
Conference organized by the Center for Social Science in cooperation with the Institute for Ethnic and National Minorities Studies of the Hungarian Academy of Sciences
Participant: Judit Sándor, Director of CELAB
Title of presentation: "Genetic Data and Bioethical Challenges"
May 24–25, 2007, Budapest, Hungary

Anthropology, Ethnography and Biotechnology
International conference organized by the Lithuanian Institute of History and the University of Vilnius
Participant: Enikő Demény
Title of presentation: "Gender, Power and Knowledge Production in Addressing Current Issues Related to Biotechnology"
September 12–14, 2007, Vilnius, Lithuania

Bioethics in the Real World
21st Annual Conference of the European Association of Centers of Medical Ethics (EACME)
Participant: József Kovács
Title of presentation: "The Paradox of Bioethical Expertise"
September 13–15, 2007, Zurich, Switzerland

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.

Judit Sándor on Reproductive Rights
Interview by Györgyi Tóth and Erika Kispéter in "Drágám, hol a vacsorám? (Where is my dinner, darling?) – a radio program on women's rights
Tilos Radio, November 15, 2006, 10:00–12:00

The Transformations of the Hippocratic Oath
Interview with József Kovács by Anita Élő
Medical Tribune, vol. 4, no. 25–26 (December 21, 2006), pp. 4–6.

On the Ethical Aspects of Health Reform
Interview with József Kovács by Péter Szűcs in "Aréna" – a radio program on political issues
Info Radio, April 16, 2007, 7.00–8.00 p.m.

The Case of Sellafield Research on Cadaver Human Tissues: Post-Mortem Examination of Occupational Hazards
Interview with Judit Sándor, Director of CELAB
HVG, vol. 29, no. 17 (April 28, 2007), pp. 39–40.

The Ethical Aspects of Therapeutic Cloning and Regenerative Medicine
Interview with József Kovács by Petra Hajdu
TV2, Tények, May 25, 2007, 6.30–7.00 p.m.

Screenings: Compulsorily on a Voluntary Basis
Interview with József Kovács by Viktória Kun J.
Népszabadság, August 13, 2007

"Green Light to the Human–AnimalEmbryo?"
Discussion with Judit Sándor, Director of CELAB and Professor László Solti, Rector of Szent István University
Moderator: József Orosz
Club Radio: Kontra, September 6, 2007, 6.30–7.00 p.m.

The Permissibility of Sex Selection
Interview with Judit Sándor, Director of CELAB
Nők Lapja Egészség, September 2007, p. 8.

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Sándor, Judit (2006) Body that Matters. *Journal de médecine legale, droit medical, victimiologie, dommage corporel*, vol. 49, no. 2–3 (Mars–Mai 2006), p. 59.

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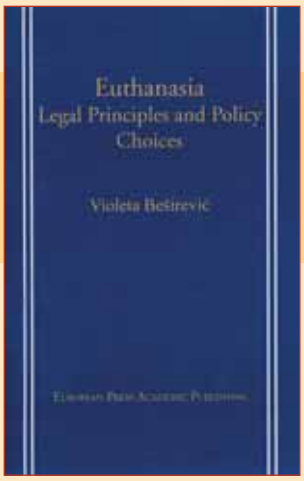

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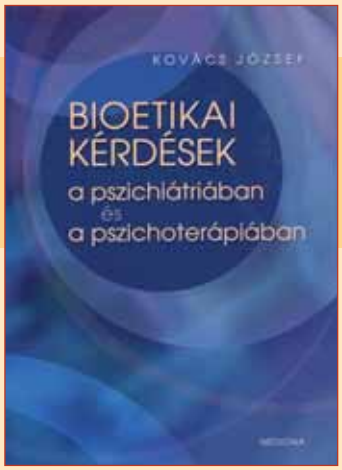

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4. BUDGET

Funding in the 2006–2007 Academic Year

C-5036 – Approved Budget from CEU
Total funding for AY 2006–07: 27,262 Euros
C-8239 – External Funding: GeneBanC Project
Total funding for AY 2006–07: 59,165 Euros
C-8249 – CELAB Admin

Budget category	Amount in Euro
Closing of PUG/EU FP5 budget code	3,018
GeneBanC project overhead	4,293
National Council for Communication and Information	393
Total	7,704

Spending in the 2006–2007 Academic Year

C-5036 – Approved Budget from CEU

Budget category	Amount in Euro
Personnel cost	26,542
Web-page design	720
Total	27,262

C-8239 – GeneBanC Project

Budget category	Total Amount in Euro	Net sum	VAT - from C-8249
Personnel	22,950	22,950	0
Equipment	3,931	3,274	655
Travel	3,272	2,623	655
Other costs	1,571	1,494	76
Total	31,720	30,389	1,385

C-8249 – CELAB Admin

Budget category	Amount in Euro
CELAB Annual Report 2005/2006	676
CELAB Annual Meeting	158
CELAB Workshop	1,340
Equipment (monitor)	216
GeneBanC VAT	1,385
Other office costs	300
Total	4,075