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CENTER
FOR ETHICS AND LAW
IN BIOMEDICINE

ANNUAL REPORT

2010–2011



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Address:
1051 Budapest Nádor u. 9. Hungary
Telephone: +36-1-327-3000/ext.2128
Fax: +36-1-327-3220
E-mail: celab@ceu.hu
Website: <http://www.ceu.hu/celab>

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1. FOREWORD

In the Sixth Annual Report of the Center for Ethics and Law in Biomedicine (CELAB) at the Central European University in Budapest we present a summary of our activities and main achievements during the 2010–2011 academic year and the 2011 calendar year.

The creation of CELAB was based on the recognition of a new and increasingly developing interdisciplinary field that explores and scrutinizes the ethical and legal implications, as well as the social and cultural consequences of biotechnological and biomedical advances. Within this multidisciplinary context, CELAB embraces a wide variety of activities conducted by lawyers, ethicists, philosophers, anthropologists, sociologists, and other social scientists.

CELAB works on the national, regional, and international levels. In European research consortia, knowledge about the Hungarian and Central European legal systems 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 the studies of North American and East Asian legal and ethical discourses.

In our sixth year of operation, we enlarged and reinforced our international network of research and policy partners, and the CELAB associates and fellows participated in numerous project workshops, scientific conferences, and policy meetings. Among other activities, we completed two EU-funded international research projects (*Tiss.EU* and *RemediE*) and continued another one (*EULOD*); participated in the Francophone network of biomedical lawyers; organized the CEU Twentieth Anniversary Bioethics Lecture Series and a week-long workshop for visiting scholars within the framework of the Special and Extension Programs; as well as hosted policy debates and film sessions for the CEU community and beyond.

The year 2011 marked the twentieth anniversary of establishing the Central European University. As our contribution to the celebrations of CEU, we organized an Anniversary Lecture Series on Bioethics, focusing on the new technological frontiers of life and the social responsibilities of life sciences. The lecture series was conceptualized and planned during the spring and summer of 2011, and from a generous funding from CEU we managed to invite three distinguished speakers: *John Harris*, Lord Alliance Professor of Bioethics at the University of Manchester; *Inez de Beaufort*, professor of health care ethics at the Erasmus Medical Centre in Rotterdam; and *Donna Dickenson*, emeritus professor of medical ethics and humanities at the University of London.

All the three Anniversary Lectures on Bioethics focused on the ethical, legal, and social challenges of the new scientific advances in the field of life sciences. Enhancement of the bodily capacities, extension of the life span, and commercialization of the human body are at the core of ethical debates that engage a wide range of disciplines outside of the life sciences: from philosophy to anthropology, from ethics to law, from gender studies to public health, among others.

In the first lecture entitled “What Is Science For? A Magical Mystery Tour,” *Professor Harris* challenged the existing ethical concerns about scientific innovation and the emergence of new

“Any attempt to define the body of science more closely comes up against the fact that the knowledge comprised by science is not known to any single person. Indeed, nobody knows more than a tiny fragment of science well enough to judge its validity and value at first hand.”

Michael Polányi, *Personal Knowledge: Towards a Post-Critical Philosophy*

technologies, especially those brought up against human enhancement. Advances in embryonic stem cell research, gene therapy, synthetic biology, and many other fields of bioscience have generated considerable interest among ethicists and legal scholars, social and cultural scientists, as well as policymakers. This interest emerges primarily because these scientific developments challenge our taken-for-granted understanding of the relationship between the body and mind, between nature and nurture, between human and animal, or between flesh and machine. The practical possibility of the existence of chimeras and cyborgs change our perceptions and conceptions of identities. In his presentation, Professor Harris suggested to look at scientific innovations as “opportunities for good” as opposed to “causes for concern” and ventured to argue for the sustainability, and even desirability, of different forms of human enhancement. The lecture was followed by a lively debate in the CEU Auditorium and also informal discussions with the CELAB associates.

The second presentation in the Anniversary Lecture Series, entitled “Will You Still Love Me When I Am 128?” focused on the ethical and social implications of extending the human life span. In this lecture, *Professor de Beaufort* discussed several ethical and moral dilemmas that we will face if it is technologically possible to prolong human life: Should everyone have access to life prolonging medical treatments? Is there a fair minimum of years to live? How will our ideas about good and worthy life change? She also explored some of the social and cultural implications of introducing medical treatments that slow down the aging process. Will we have two or more careers in our longer life? What kind of rejuvenating enhancements will be considered socially acceptable? How will the still existing discourses of sexism and ageism change? Professor de Beaufort’s lecture generated a multidisciplinary debate and discussion in the CEU Auditorium with the participation of faculty and students from several CEU Departments and the CELAB research fellows.

In the third lecture with the title “Exploitation and Choice in the Global Egg Trade: Emotive Terminology or Necessarily Critique?” *Professor Dickenson* discussed the ethical and legal implications of paying for egg donation. In an elegant exploration of the moral pitfalls of global human egg trade, she scrutinized the utilitarian liberal discourse of talking about individual choice, autonomy, and (reproductive) freedom, all perennial metaphors, even idols of the market economy, and proposed instead a critical reexamination of such political economic terms as exploitation, commodification, and commercialization, overcoming the emotive connotations of these terms. Prof. Dickenson’s presentation was followed by a lively interdisciplinary debate moderated, just as in the case of the previous lectures, by *Judit Sándor*, director of CELAB. Many of the comments centered around the interconnected questions of whether we should rely on altruism instead of commercialization in egg donation, and whether we should keep or modify the ethical and legal framework in Europe, which is based on the prohibition of financial gain. Others proposed that we should make more nuanced legal distinctions in the regulation of egg donation. The success of the Anniversary Bioethics Lecture Series can be measured by the broad interest shown by faculty members and students from across a wide variety of departments within CEU.

Over the course of the 2010–2011 Academic Year we continued to participate in research project funded by the European Union. In 2011 we completed the *Tiss.EU* project. The major aim of this project was to carry out a high-quality interdisciplinary comparative analysis of European health policies in order to assess the impact of EU legislation in the field of tissue banks and to explore the relevant ethical and legal context across the

European Union. The *Tiss.EU* project primarily focused on the ethical and legal challenges to conducting research on human tissues, but it provided perhaps the most comprehensive analysis among the EU projects on the ethical and legal aspects of tissue collections: from the issues of anonymity to data protection, from property law aspects to the commercial use of these biological collections. After a series of workshops in Göttingen, Budapest, Paris, Padova, Leiden, Stockholm, and Vilnius, the final conference in 2011 again took place in Göttingen.

Collaboration within the project resulted in a number of publications. One of the most important achievements was the book titled *Biobanks and Tissue Research: The Public, the Patient and the Regulation*, which was edited by Christian Lenk, Judit Sándor, and Bert Gordijn and published by Springer. Furthermore, participants in the *Tiss.EU* project, Judit Sándor, Petra Bárd, Claudio Tamburrini, and Torbjörn Tännsjö wrote a joint article titled “The Case of Biobank with the Law: Between a Legal and Scientific Fiction” for the *Journal of Medical Ethics*, which has already been published online. Results of this project will be also disseminated in two other, forthcoming books; these will contain the proceedings of the Padova workshop and the policy recommendations of the *Tiss.EU* project participants.

In 2011 we also completed the *RemediE* project which explored and compared different legal regimes on the patenting of biotechnological inventions, especially in the field of regenerative medicine. During the three years of the project CELAB worked on mapping the intellectual property regulations of regenerative medicine both within and outside the European Union and produced a comparative analysis of the legal regimes based on our own *Biola^{aw} Database* (Bioethical and Legal Research Database). The project had workshop meetings in York, London, Madison, Vienna, and Bilbao. Final publications shall be completed in 2012 based on the success of negotiations with publishers.

It has to be noted that as the project unfolded, the field of our research has also significantly changed. The patentability of biotechnological inventions has been interpreted differently in the various landmark legal cases, from the *Myriad* to the *Sherley v. Sebelius* case. Most recently, the October 2011 judgment of the European Court of Justice in the *Brüstle v. Greenpeace e.V.* case shook the status quo when it ruled that a process which involves removal of a stem cell from a human embryo at the blastocyst stage, entailing the destruction of that embryo, cannot be patented. The Court interpreted Article 6(2) of the Biotechnological Inventions Directive in a way to rule that research on embryos that aims to develop biotechnological inventions constitute commercial use, and therefore it cannot be patented. This landmark decision will surely have significant ramifications for stem cell research in Europe and the new legal context will require further analysis by the *RemediE* project partners, including CELAB.

In the framework of *EULOD*, the third European research project in which CELAB has participated over the past academic year, we intend to analyze the patterns of violating laws and legal norms on organ transplantation. In order to achieve this, we launched three different types of questionnaires: the first mapped the anti-trafficking legislations adopted and enforced in the European countries; the second surveyed court cases on organ trafficking; and the third, based on fieldwork findings, aimed to explore those cases that did not reach the courts.

Within this project CELAB researchers participated and gave presentations in the workshop meetings held

1. FOREWORD

in Sofia, Munich, and Berlin. For the final report to this project we will develop, in the first half of 2012, an ‘organ trafficking severity scale’ to measure and compare different patterns of violations from the mildest to the most serious ones. We intend to account for the divergence between national regulations on organ donation and identify administrative irregularities that may infringe the rules on waiting lists. We also look to explain why in several countries, for example, organ trade and organ trafficking constitute severe forms of violations, but the prohibition is not adequately enforced, while organ tourism is still tolerated in several places.

In 2010–2011 we continued to participate in the Francophone network of biomedical lawyers and social scientists (Réseau Universitaire International de Bioéthique, RUIB or International Academic Network on Bioethics, IANB), which is based on a series of workshop meetings that lead to the publication of the contributions presented. The workshop topics each year focus on the intersection of family law, medical law, and bioethics from a cross-cultural perspective: the Rennes workshop in 2008 explored donor anonymity and assisted reproduction; the Kyoto meeting in 2009 investigated adolescent rights in relation to medical treatments; the second Rennes conference in 2010 compared various cultural forms of involving family members and relatives in end-of-life decisions; while the 2011 workshop will be held in Tozeur, Tunisia, with the overall topic of the uses and visions of the woman’s body in biomedicine.

The proceedings of the first two workshops have been already published in French and translated to English. At the moment two books are under preparation: one in English on the adolescents’ decision making in medical care, and one in French on the end-of-life decisions within the family. The structure of these books is based on a comparative legal approach, as each chapter explores and analyzes the research theme of the year from a cross-cultural perspective.

For several years CELAB associates have participated also in the development of the Global Ethics Observatory (GEObs) of UNESCO. GEObs is a worldwide system of interconnected databases that covers bioethics and other areas of applied ethics in science and technology, such as environmental ethics, science ethics, and technology ethics. Especially important is GEObs Database 4, which deals with Ethics Related Legislation and Guidelines. Information for this database is collected and analyzed by legal experts from various member state countries, and subsequently reviewed and validated by an international Review Committee consisting of experts from various regions and legal traditions. Since GEObs was initiated by UNESCO in 2004, *Judit Sándor* has participated in its work in a dual function: as a country expert for Hungary and a member of an international Review Committee representing the European continent. Since 2011 *Violeta Beširević* has also contributed to this global initiative as a country expert for Serbia.

In addition to our main work that is based on participation in research projects and research collaboration we also take part in other professional events: for example, in October 2010 at the Science and Technology Options Assessment (STOA) Workshop on “Making Perfect Life: Bioengineering in the 21st Century” held at the European Parliament in Brussels, or in September

2011 at the Annual Conference of the European Association of Centers of Medical Ethics (EACME) in Istanbul.

The Annual Report provides further details on these research and policy activities. We continue to integrate the results of the 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.

As in the previous years of our activities, the research staff of our Center has continued to develop new methods of teaching human rights and bioethics. For example, the CELAB Bioethics Film Series 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 seminars and film sessions have been a big success and it has become clear that more and more scholars within and outside of the CEU community express 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.

One example of incorporating our expertise and research findings into university curricula was the week-long workshop, titled “From Trash to Gold? Contemporary Ethical Challenges to the Use of Human Tissues and Organs in Biotechnology” that CELAB organized in collaboration with the Curriculum Research Center (CRC). This workshop featured lectures held and seminar discussions coordinated by CELAB associates for Special and Extension Programs (SEP) visiting scholars who intend to develop courses on the ethical, legal and social implications of biobanks, stem cell research, or organ transplantation. The sessions also explored intellectual property issues of stem cell research and the problems of regulating biotechnological advances.

We also collaborate in the CEU 20th Anniversary Postdoctoral Fellowship Program initiated by the Department of Medieval Studies of the Central European University. The title of the project is “To Make Dead Bodies Talk. Bio-Archaeological Heritage: Historical Human Remains and Their Academic, Social and Religious Context.” The project – based on a network of physical anthropologists, bioethics experts, scholars of religious studies, and heritage specialists – aims at collecting academic research findings and legal regulations, ethical guidelines and policy protocols related to the exploration and investigation of medieval and early modern human remains in order to establish a repository that can be a basis for working out best-practice reference materials.

For more information about CELAB, we recommend that you read this Annual Report and consult the CELAB website at www.ceu.hu/celab; the bioethics research pages of the CEU website at www.ceu.hu/bioethics; and the official Facebook page of CELAB at www.facebook.com/pages/CELAB/321473511079

Judit Sándor

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

2. RESEARCH AND POLICY ACTIVITIES.....

2.1. PARTICIPATION AND COLLABORATION IN RESEARCH NETWORKS

2.1.1. Living Organ Donation in Europe (EULOD)



Partners:

Erasmus University Medical Center (*Erasmus Universitair Medisch Centrum, EMC*), Rotterdam, The Netherlands (*Coordinator*)

European Society for Organ Transplantation (*ESOT*), The Netherlands

University of Gothenburg (*Göteborgs Universitet, UGOT*), Sweden

University of Münster (*Westfälische Wilhelms-Universität, WWUM*), Germany

Catholic University of Leuven (*Katholieke Universiteit Leuven, KU*), Belgium

Center for Ethics and Law in Biomedicine, Central European University (*Közép-Európai Egyetem, CEU*), Budapest, Hungary

Bulgarian Center for Bioethics (*Български център по биоетика, BCB*), Sofia, Bulgaria

Kidney Foundation (*Fundația Renală, FR*), Chișinău, Moldova

Tartu University Hospital (*Sihtasutus Tartu Uelikooli Kliinikum, TUH*), Estonia

Academic Society for the Research of Religions and Ideologies (*Societatea Academică de Cercetare a Religiiilor și Ideologiilor, SACRI*), Cluj, Romania

Polish Transplant Coordinating Center (*Centrum Organizacyjno-Koordynacyjne do spraw Transplantacji, Poltransplant*), Warszawa, Poland

Duration of the project: 2010–2012

Webpage: www.eulod.eu

The project on living organ donation in Europe is a coordination action that aims to establish an inventory of living donation practices in Europe; to explore and promote living donation as a way to increase organ availability; and to develop tools that improve the quality and safety of living organ donations throughout Europe. This action aims to achieve broad European coverage with a specific focus on the new EU Member States. It draws upon the support, knowledge and network of the European Platform on Ethical, Legal and Psychosocial Aspects of Organ Transplantation (ELPAT) and the European Society for Organ Transplantation (ESOT).

The project contains two scientific research packages. The first package focuses on living-unrelated donation practices in Europe. The second package focuses on legal restrictions and safeguards for living donations in Europe. The remaining three work packages ensure the coordination of this work, the dissemination of project results, and the organization of meetings. The major goal of the project is to exchange best practice and effective organizational models to promote and safeguard living donation in Europe.

The CELAB team contributes to WP3 part II, which focuses on legal restrictions and safeguards for living donations in Europe, paying attention to issues related to organ trafficking and tourism by analyzing the effectiveness of the existing legal provisions (and their maintenance) against organ trafficking and tourism, as well as the ethical, social and legal contexts of living organ and tissue donation.

The project kickoff meeting took place in April 2010 along with the conference *Ethical, Legal and Psychosocial Aspects of Organ Transplantation: Expanding the European Platform* (ELPAT). CELAB has been repre-



George-Tudor Florea presenting the EULOD project at the EACME Conference held on September 15–18, 2011 in Istanbul, Turkey

sented at this event by the principal investigator Judit Sándor who gave a presentation on Ethical, Legal and Psychosocial Aspects of Organ Transplantation. CELAB researchers started to contribute to the project in May 2010, and they continued their work during the 2010–2011 academic year.

One of the main project events in the 2010–2011 academic year was the 3rd ELPAT conference and project meeting, organized on October 8–10, 2010, in Sofia, Bulgaria. The CELAB team members presented their papers in the “Organ Tourism and Paid Donation” Working Group of ELPAT. Judit Sándor delivered a presentation titled “Body Shopping from Gametes to Organs? The Prohibitionist Legal Strategy and its Challenges in Hungary”; Violeta Beširević presented on “Organ Transplantation and Trade in Serbia: Legal Perspectives”; Enikő Demény on “Case Studies on Organ Trade in Romania”; and George-Tudor Florea on “Organ Trade in Romania: Interviews with Stakeholders”.

After mapping the literature and the regulatory framework of organ trafficking, tourism and paid donation, the CELAB team started to analyze the identified organ trafficking cases in the region, based on the templates developed by the project principal investigator Judit Sándor. Parallel with these activities, Research Assistant George-Tudor Florea continued his fieldwork in Romania and Moldova, where he conducted stakeholder interviews. The next important meeting was the EULOD Project Management Board Meeting, which took place on March 25–26, 2011, in Munich, Germany. CELAB was represented by Prof. Judit Sándor as prin-

cipal investigator. The board members evaluated the progress of the project and agreed on the next step to be done, as well as on the outline of the final reports.

The CELAB team continued their research activity based on the plans agreed at the board meeting in Munich. Accordingly, principal investigator Judit Sándor, assisted by Violeta Beširević, developed a questionnaire for mapping the national laws on organ trafficking, paid donation and organ tourism throughout Europe. The questionnaire has been sent out to various stakeholders identified in the previous phase of the project, and its results are going to be analyzed and evaluated in the next academic year. Enikő Demény and George-Tudor Florea, assisted by Romanian legal experts, completed the questionnaire for Romania and concentrated their attention on the role of the ethics committees in the living organ donation decision making process.

In parallel with the ongoing research activities, the CELAB team has also become involved in the dissemination of the project results. In this context, Judit Sándor gave a lecture on “The Right to Health and the Human Organ: A Right by Consequence?” at the *19th Annual Conference on ‘The Individual vs. the State’* organized by the Department of Legal Studies of CEU. This year the annual conference focused on the topic: “An Enforceable Right to Health?” In her presentation, Prof. Sándor analyzed the relationship between *right to health* and *right to health care* within the field of organ and tissue donation. It has been argued that the cases of organ and tissue transplantation provide useful means for the discussion of the main conceptual challenges to these twin rights. Violeta Beširević presented the EULOD project at the “Organ Donation” Workshop organized at the Union University Law School, Belgrade, Serbia. Finally, Enikő Demény and George-Tudor Florea presented their work on the role of ethics committees in preventing abuses in transplantation practices at the “Ethics and Professions” Conference, organized at the Babes Bolyai University, Cluj, Romania, and the Annual Conference of the European Association of Medical Ethics, Istanbul, Turkey.

CELAB participants in the EULOD project: Judit Sándor (Principal Investigator); Enikő Demény; Violeta Beširević (Researchers); George-Tudor Florea (Research Assistant)

2. RESEARCH AND POLICY ACTIVITIES

2.1.2. Regenerative Medicine in Europe: Emerging Needs and Challenges in a Global Context (REMEDIe)



Partners:

Science and Technology Studies Unit (SATSU),
University of York, United Kingdom (*Coordinator*)

University of the Basque Country (*Universidad del País Vasco, Euskal Herriko Unibertsitatea, EHU*), Bilbao/
Bilbo, Spain

University of Hanover (*Leibniz Universität, Hannover*),
Germany

Life–Science–Governance Institute, Vienna, Austria
Center for Ethics and Law in Biomedicine, Central
European University (*Közép-Európai Egyetem, CEU*),
Budapest, Hungary

University of East Anglia, Norwich, United Kingdom

Duration of the project: 2008–2011

Webpage: www.york.ac.uk/res/remedie/index.htm

This three-year collaborative project aimed to examine the socio-economic, political and bioethical implications for Europe of shorter and longer term global developments in the field of regenerative medicine. *RemediE* adopted an interdisciplinary approach to bring together social science and humanities researchers to understand the emerging needs, expectations, and challenges that Europe faces. The main objective of this project was to provide a detailed analysis of the competitive position of Europe within the globalization of regenerative medicine, the requirements of successful innovation in this domain, and the EU policies that need to be developed to support Europe's global advantage in the field.

For this purpose, *RemediE* set out to organize an integrated series of work packages around three inter-related streams of research that constitute the plat-



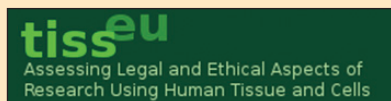
The RemediE project team at the final conference of the project, April 18–19, in Bilbao, Spain

form for this analysis: the socio-economic, the political, and the bioethical. The project also sought to develop a continuing engagement with national and international policy makers and others to test and refine the implications of emergent findings for future European policy and regulation in particular.

During the last year of the *RemediE* project, several members of the research consortium participated at the Science and Technology Options Assessment (STOA) conference with the title *Making Perfect Life: Bioengineering (in) the 21st Century*, held at the European Parliament in Brussels, on November 10–11, 2010. For more information on this conference, which was organized as part of a STOA project, see Section 2.2.2. below. During the final conference organized in Bilbao between April 18–19, 2011, a joint paper was presented by Kathrin Braun, Susanne Schultz, and Judit Sándor with the title “Oöcytes for Research: Between Commercialization and Anti-Payment Provisions: The Case of Spain and the European Framework”. The publication of this paper is forthcoming during the first half of 2012.

CELAB participants in the *RemediE* project: Judit Sándor (Principal Investigator); György Kovács and Márton Varju (Researchers)

2.1.3. 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 (Tiss.EU)



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 (*Leibniz Universität,
Hannover*), Germany
Center for the Study of Global Ethics, University of
Birmingham, United Kingdom
Stockholm Bioethics Center, Stockholm University
(*Stockholms Universitet*), Sweden
Lanza Foundation (*Fondazione Lanza*), Padova, Italy
Forensic & Legal Medicine, School of Medicine and
Medical Science, National University of Ireland,
Dublin, Ireland
Center for Research on Law, Science, and
Technology (*Centre de Recherche 'Droit, Sciences et
Techniques'*), CNRS Université Paris 1, France
Legal Pathways Institute for Health and Bio-Law,
Aerdenhout, Netherlands
Department of Medical History and Ethics, Vilnius
University (*Vilniaus Universitetas*), Lithuania
Center for Ethics and Law in Biomedicine, Central
European University (*Közép-Európai Egyetem, CEU*),
Budapest, Hungary

Duration of the project: 2008–2011

Webpage: 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 Program, ran from March 2008 to 2011 and addressed questions of ethical and legal regulation in relation to research using human tissues. *Tiss.EU* was made up of



Judit Sándor at the Tiss.EU Final Conference, January 19–21, 2011, Göttingen, Germany

four parts – (1) procurement, storage and transfer of tissue and cells for research; (2) rights and entitlements to tissue and cells; (3) anonymization and pseudonymization to protect privacy rights; and (4) research using biobanks – and the project partners looked at the ethical and legal aspects of these four fields.

Within the *Tiss.EU* project, the CELAB team focused on anonymization and pseudonymization for privacy protection in the following countries: Bulgaria, Czech Republic, Hungary, Slovakia and Romania. CELAB organized a conference in the spring of 2009 in Budapest and reported on the impact of EU legislation and documents in this country group.

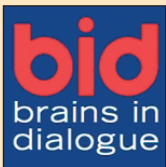
During the second part of the project several workshops were organized in Leiden (2009), Stockholm (2010), Dublin (2010), Birmingham (2010), and Vilnius (2010). The final conference was held in 2011 in Göttingen. One of the major outputs of the work was the collection of chapters from each research partner into a book titled *Biobanks and Tissue Research: The Public, the Patient and the Regulation* and edited by Christian Lenk, Judit Sándor, and Bert Gordijn. A book chapter was written by Judit Sándor and Petra Bárd. The book was published by Springer within the Series of the International Library of Ethics, Law and Technology in 2011. Furthermore, also in 2011, a series of refereed articles were accepted and published online in the *Journal of Medical Ethics*. Future plans include a publication based on the proceedings of the Padova workshop and another

2. RESEARCH AND POLICY ACTIVITIES

book that would consist of policy recommendations made by the members of the consortium. This project proved to be an extremely successful team work and the research cooperation created strong professional ties between the partners.

CELAB participants in the *Tiss.EU* project: Judit Sándor (Principal Investigator) and Petra Bárd (Researcher)

2.1.4. Brains in Dialogue (BID)



Brains in Dialogue (BID) was a three-year project supported by the European Commission under the Seventh Framework Program and coordinated by Interdisciplinary Laboratory of Advanced Studies at SISSA, Trieste, Italy. The *BID* project aimed at fostering dialogue among key stakeholders in neuroscience: scientists, clinicians, patients, sociologists, lawyers, philosophers, science journalists, and lay citizens. It focused on three scientific areas: brain imaging, brain devices, and preventive medicine. The *BID* team organized meetings and videoconferences to discuss the expectations, benefits and risks of new technologies and therapies; to build constructive debates on the ethical, legal and social issues; and to create novel “dialogue products” which integrate lay and scientific technical knowledge or scientific and community purposes.

During the three years of the project, the following workshops were organized: “Brains in Dialogue on Brain Imaging” on March 17–18, 2009, in London; “Brains in Dialogue on Genetic Testing” on January 28–29, 2010, in Trieste; “Brains in Dialogue on Deep Brain Stimulation” on September 20–21, 2010, in Warsaw; a “Neuroscience Communication Workshop” on June 20–22, 2011, in Trieste; and the *BID* final conference “Dialogue to Dialogue” on July 6, 2011, in Brussels.

CELAB was represented by Judit Sándor in two of these meetings. The *BID* Genetic Testing workshop in Trieste focused on the genetic tests that are now easily accessible even to healthy individuals who want to find

out whether or not they will develop a certain disorder. An increasing number of genetic tests are also available for main neurodegenerative diseases, like Alzheimer, Parkinson, and Huntington, which are still incurable. The workshop addressed the following questions: How reliable are these tests and what type of information are they offering? Do they help people to take decisions about their life? And who should be notified of the results? Prof. Sándor gave a paper on the ethical and legal aspects of predictive neurogenetic testing.

The *BID* Final Conference in Brussels offered an opportunity to all previous workshop participants, including Judit Sándor, to discuss key challenges and potential approaches to improve dialogue between neuroscience and society.

For more information, please consult the website of the BID Project: www.neuromedia.eu

2.1.5. International Academic Network on Bioethics (IANB)



Based on the idea of Prof. Brigitte Feuillet-Liger, a Francophone international academic network was created in 2007 to discuss various bioethics-related issues in annual thematic workshops. In the framework of this cooperation lawyers, legal scholars, and social scientists explore the legal and cultural differences in medical discourses and social practices. Therefore, research in this interdisciplinary collaboration combines the perspectives of bioethics, medical law, and family law. Members of the network are: Brigitte Feuillet-Liger, Pénélope Agallopoulou, Amel Aouij-Mrad, Thérèse Callus, Maria-Claudia Crespo-Brauner, Françoise Furkel, Ryuichi Ida, Dominique Manai, Kristina Orfali, Véronica San Julian, Geneviève Schamps, Marco Ventura, and Judit Sándor. Depending on the topic of the annual workshop, new researchers join the network each time. Judit Sándor has been a member of the Advisory Board and the network since the beginnings.

After a preparatory meeting held in Paris, the first workshop was organized on December 5–7, 2007, in Rennes, France and it focused on medically assisted reproduction and anonymization. The second conference took place on January 5–6, 2009, in Kyoto, Japan and it mapped the cultural differences in the medical treatment of adolescents. The third meeting was held on May 27–28, 2010, in Rennes, again, with the topic of dying patients and their relatives. The fourth workshop will convene in Tozeur, Tunisia in December 2011, and focus on the uses and visions of the woman's body in biomedicine.

The major output of this international network is a book series titled *Droit, bioéthique et société (Law, Bioethics and Society)* and published in Belgium by Bruylant. Three edited books have been completed: two in French and one in English. The first book came out in January 2009 with the title *Procréation médicalement assistée et anonymat: Panorama international*, and its English version, *Who is My Genetic Parent? Donor Anonymity and Assisted Reproduction: A Cross-Cultural Perspective* followed at the end of 2010. The third book was published at the beginning of 2011 as a result of the Kyoto workshop, entitled *Adolescent et acte médical, regards croisés*. The English version of this edited volume is forthcoming in early 2012.

For more information please consult:

rui-bioethique.univ-rennes1.fr/themes/LavieduRUIB/

2.1.6. To Make Dead Bodies Talk: Bio-Archaeological Heritage – Historical Human Remains and Their Academic, Social and Religious Context

In the form of historical human remains, bio-archaeological heritage can be considered a repository of knowledge about the ways people interact with both the natural and socially constructed world. Thus, the dead make their presence felt in a variety of ways: in academic, religious, ethical and social contexts – all of which have their own justifications and contradictions. Human bodies and how they were treated during their life and after their death are source material for physical anthropology. Physical anthropological

research and policies toward bio-archaeological heritage of various periods, and especially the Middle-Ages and the Early Modern period, themselves have a variety of social and religious implications. Modern legal and ethical concepts of respect for the dead impact the research practices of scholars and the management of heritage institutions.

Despite this, a critical overview of physical anthropology has never been attempted, especially in light of more recent technological advances in the field (such as DNA and heavy isotope sampling). In this context, *To Make Dead Bodies Talk* is an interdisciplinary research project that wants to confront the policy and heritage issues arising when the search for knowledge sits uncomfortably with what society regards as right and good. The project is based on a network of physical anthropologists, bioethical and legal experts, scholars of religious studies and heritage specialists already established by an ESF project application by Irene Barbiera, an alumna of the CEU Department of Medieval Studies who, as a research fellow, coordinates the project in the form of a CEU 20th Anniversary Postdoctoral Fellowship. The project is aiming to collect academic research results related to medieval and early modern human remains, policy protocols, legal regulations, research protocols and guidelines as a repository for working out best-practice reference materials.

The project is based at the Department of Medieval Studies and involves the cooperation with several CEU programs and research centers: the Department of Medieval Studies (represented by the supervisor of the project, József Laszlovszky, and Gerhard Jaritz); the Center for Law and Ethics in Biomedicine (represented by Judit Sándor); the Religious Studies Program (Matthias Riedl), the Jewish Studies Program (Carsten Wilke); the Department of History (Katalin Szende and Daniel Ziemann); and the Center for Eastern Mediterranean Studies.

For more information on this project, consult the website at medievalstudies.ceu.hu/projects/ceu-20th-anniversary-postdoctoral-fellowship-to-make-dead-bodies-talk

2. RESEARCH AND POLICY ACTIVITIES

2.2. POLICY AND OUTREACH ACTIVITY

2.2.1. Participation in the Global Ethics Observatory (GEObs), Established by UNESCO



The Global Ethics Observatory (GEObs) of UNESCO is a worldwide system of interconnected databases that covers bioethics and other areas of applied ethics in science and technology, such as environmental ethics, science ethics, and technology ethics. The GEObs Database 4 is the most complex set in the system as it focuses on “Ethics Related Legislation and Guidelines” in a global context. Information for this database is collected and analyzed by legal experts from various member state countries, and subsequently reviewed and validated by an international Review Committee (RC) consisting of experts from various regions and legal traditions. The RC members, each representing a group of member states, are: Prof. Herman Nys, Belgium (Coordinator); Dr. Thomas Faunce, Australia; Prof. Monica Serra, Brazil; Prof. Bartha Knoppers, Canada; Dr. Dirk Lanzerath, Germany; Prof. Judit Sándor, Hungary; Prof. Cinzia Caporale, Italy; Prof. Ryuichi Ida, Japan; Prof. Carter Snead, USA; and Mrs Geneviève Pinet, WHO.

So far, legislation and legal cases on the following bioethical themes have been incorporated into the database: medical research on human beings; access to health care and availability of essential medications; genetic counseling; protection of future generations; freedom of scientific research; human cloning (reproductive and therapeutic); organ transplantation; biobanking; non-discrimination in health care; protection of genetic resources; and ethics committees.

As of October 2011 data from Australia, Brazil, the Cook Islands, Egypt, Ethiopia, Fiji, Germany, Hungary, Indonesia, Israel, Japan, Jordan, Kiribati, Nauru, Niue, Panama, Samoa, Solomon Islands, South Africa, Tonga, Tuvalu and Vanuatu are available online. Data from Finland, Greece, Ireland, Kenya, Malawi, Tanzania and Uganda have been collected and are in the process of being reviewed and validated.

Since GEObs was initiated by UNESCO in 2004, Judit Sándor has participated in its work in a dual func-

tion: as a country expert for Hungary and a member of the Review Committee representing the European continent. Since 2011 Violeta Beširević has also contributed to this global initiative as a country expert for Serbia.

The GEObs can be accessed at:

www.unesco.org/new/en/social-and-human-sciences/themes/global-ethics-observatory/access-geobs/

2.2.2. Making Perfect Life: Bio-Engineering in the 21st Century

According to the Science and Technology Policy Options Assessment (STOA) bureau of the European Parliament, scientific and technological progress in the 21st century will strongly depend on the mutual interplay between four key technological fields: nanotechnology, bio-sciences, information technology, and cognitive sciences (NBIC). This combination of engineering fields promises a “new technology wave” challenging traditional boundaries between the biological and the physical sciences.

Making Perfect Life is a two-year long STOA project coordinated by the Rathenau Institute from The Hague, Netherlands that explores the emerging complex interplay between biology and technology in four different fields of bio-engineering: the engineering of the human body and the brain; and the engineering of living and intelligent artifacts. Two major trends demonstrate the interplay between biology and technology in these different fields. “Biology becoming technology” implies a growing power to intervene in living systems, including the body and the brain. “Technology becoming biology” involves an increasing capability to create a variety of artifacts with life-like and intelligent qualities. These two trends are radically broadening the existing bio-debate in today’s European societies.

On November 10, 2010, the monitoring report of this STOA project was debated at the European Parliament in a conference titled *Making Perfect Life: Bio-Engineering (in) the 21st Century*. Judit Sándor,

Director of CELAB participated in the panel on the political and policy implications of bio-engineering, which was chaired by Vittorio Prodi (STOA Member). Bernd Beckert from Fraunhofer Institute for Systems and Innovation Research, Karlsruhe (which cooperates with the Rathenau Institute in carrying out the project) moderated the debate that was followed by a discussion with the Members of European Parliament.

For more on this STOA project, see
www.europarl.europa.eu/stoa/cms/cache/offonce/home/events/workshops/workshop_20111011

2.2.3. European Association of Centers of Medical Ethics (EACME) 25th Annual Conference “Bioethics from a Cross-Cultural Perspective”

The Turkish Bioethics Association and the Acibadem University School of Medicine (Medical Ethics Department) hosted, for the first time in Turkey, the Annual Conference of EACME in Istanbul. The scientific program covered a wide range of topics related to bioethics from a cross-cultural perspective, including bioethics and humanities, universal values and cultural diversity, European Biomedicine Convention, human rights and bioethics, and health care policy making.

Enikő Demény and George-Tudor Florea attended this conference and presented their work on the “Applied Case Studies in Ethics and Medicine in Eastern Europe: The Role of Bioethics in Living Organ Donation Decision Making.”

They started with the observation that there has been an increasing role of bioethics in legislation regulating organ transplantation in Eastern Europe. New legislative measures in public health law have stipulated the presence of bioethicists in the committees supervising the living organ donation process. One of

their roles is to wither suspicions surrounding paid organ exchanges between donors and recipients and wither potential organ trafficking schemes. The relevance of their activity is enhanced in countries permitting unrelated living donations where the potential of abuse is much higher. However, the decision-making practice of such committees is far from being unitary in translating the law into practice through purely objective criteria. There is an inherent risk of the process becoming purely conveyor belt-like: formal instead of following its initial task of evaluating exhaustively each case. Comparatively, certain transplantation units give the green light to such life-saving procedures at a higher percentage rate than in others even within the same country.

Consequently, in light of the suspected subjectivity of decision-making of the members present in such committees, it is interesting to evaluate their decision-making process from certain contextual variables. The researchers hypothesized that such indicators are related to the institutional and cultural environment under which the members of the commissions operate, their heterogeneous professional background, and the longitudinal experience of commission members in evaluating such practices. The question arising out of their analysis was whether best practices of such ethics commissions can be translated from one cultural and legislative context to another. For instance, can Dutch good practices be transposed on the same efficiency level in the Eastern European countries? In their analysis, the CELAB Researchers presented case studies in the regional context by focusing on both the legislation, and the actual practice of these committees. They relied in their analysis on 45 semi-structured interviews conducted with stakeholders of organ transplantation in the region acquired during their research within the EU FP7 framework project, Living Organ Donation in Europe (EULOD).

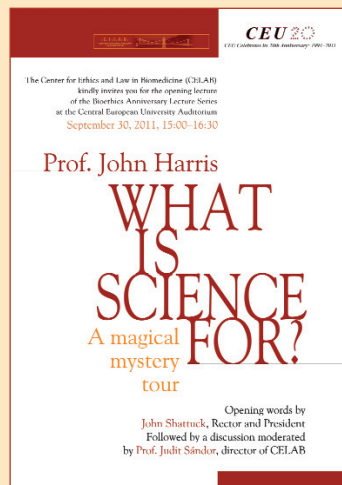
3. ACADEMIC ACTIVITIES

3.1. PUBLIC LECTURES ORGANIZED BY CELAB

Throughout the year 2011, the Central European University celebrated the twentieth anniversary of its establishment with a series of events arranged by the various departments and centers of the university. The Center for Ethics and Law in Biomedicine contributed with the organization of an Anniversary Lecture Series on Bioethics, focusing on the new technological frontiers of life and the social responsibilities of life sciences. The lecture series was conceptualized and planned during the spring and summer of 2011, and a generous funding received from the university allowed CELAB to invite three speakers who have distinguished themselves in the field of European bioethics and medical ethics: *John Harris*, Lord Alliance Professor of Bioethics at the University of Manchester; *Inez de Beaufort*, Professor of Health Care Ethics at the Erasmus Medical Centre in Rotterdam; and *Donna Dickenson*, Emeritus Professor of Medical Ethics and Humanities at the University of London.

The lectures, which took place between September 30 and October 14, 2011 at the Auditorium of the Central European University, focused on the ethical, legal, and social implications of recent scientific advances in the field of life sciences. The three main topics of the lectures – enhancement of the bodily capacities, extension of the life span, and commercialization of the human

body – are all at the core of ethical debates that engage a wide range of disciplines outside of the life sciences: from philosophy to anthropology, from ethics to law, from gender studies to public health, among others. After each lecture, and under the moderation of *Judit Sándor*, Director of CELAB, lively debates and discussions developed between the lecturers and the audience which consisted of faculty and students from various CEU departments, as well as associates and research fellows representing different CEU centers.



The poster for John Harris' lecture



John Harris

3.1.1. "What Is Science For? A Magical Mystery Tour." Public Lecture by Professor John Harris

The Anniversary Bioethics Lecture Series started with a presentation by *John Harris* on September 30, 2011. Following the welcoming words by *John Shattuck*, President and Rector of the Central European University, and a brief introduction by *Judit Sándor*, Professor Harris set out to challenge in his lecture, titled "What Is Science For? A Magical Mystery Tour," the existing ethical concerns about scientific innovation and the emergence of new technologies, especially those brought up against human enhancement.

As Professor Harris argued, recent discussions of innovation in science and technology have been characterized by a general tendency to regard

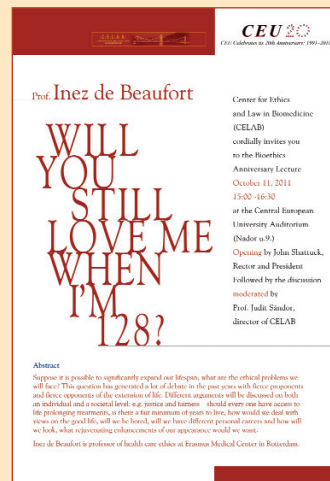
them as ‘causes for concern’ rather than as ‘opportunities for good’. Of course, people, even scientists, do not tend to develop things they think will be a disaster, thus they usually see the opportunities for good – but, obviously, they can be wrong sometimes. The lecturer continued that we need, therefore, to decide more rationally and more readily what we should be worried about and what we should welcome. Of course, we must always be vigilant; vigilance is not only the price of liberty but the price of safety. But a precautionary approach can be self-defeating when it prevents or delays innovation which will save or improve lives. We must remember that we need more and better science and innovation so that the ethical imperative of making the world a better place can be realized.

In his presentation, and during the discussion following the lecture, Professor Harris proposed to look at scientific innovations as “opportunities for good” as opposed to “causes for concern” and ventured to argue for the sustainability, and even desirability, of different forms of human enhancement.

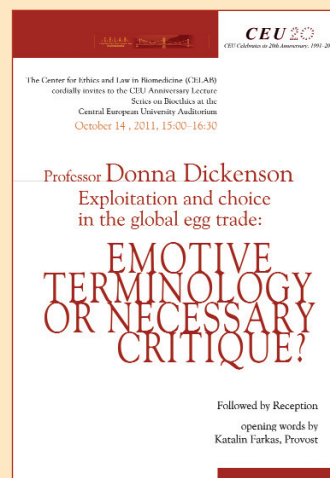
3.1.2. “Will You Still Love Me When I’m 128?” Public Lecture on the Ethical Implications of Extending Human Life by Professor Inez de Beaufort

The second presentation in the Anniversary Lecture Series on October 11, 2011, titled “Will You Still Love Me When I Am 128?” focused on the ethical and social implications of extending the human life span. After the welcoming words of *John Shattuck*, President and Rector of the Central European University, *Judit Sándor* introduced the lecture highlighting the major steps in medical history in extending the human life span and calling attention to the ethical and social implications of such changes in the individual life cycles and in the wider scope of demography.

In her thought-provoking and inspiring lecture, *Inez de Beaufort* discussed several ethical and moral dilemmas that we will face if it is technologically possible to prolong human life: Should everyone have access to life prolonging medical treatments? Is there a fair minimum of years to live? How will our ideas about good and worthy life change? She also explored some of the social and cultural implications of introducing medical treatments that slow down the aging process. Will we have two or more careers in our longer life? What kind of rejuvenating enhancements will be considered socially acceptable? How will the still existing discourses of sexism and ageism change? Professor de Beaufort’s lecture generated a multidisciplinary debate and discussion in the CEU Auditorium.



Inez de Beaufort's lecture poster



Donna Dickenson's Lecture Poster

3.1.3. “Exploitation and Choice in the Global Egg Trade: Emotive Terminology or Necessary Critique?” Public Lecture by Professor Donna Dickenson

The third lecture of the series, titled “Exploitation and Choice in the Global Egg Trade: Emotive Terminology or Necessarily Critique?” discussed the ethical and legal implications of paying for egg donation. *Katalin Farkas*, Provost of the Central European University welcomed the lecturer, *Donna Dickenson*, who proposed to reverse the prevalent understandings of exploitation and choice in the context of the debate on the worldwide human tissue market and argued that a revised concept of exploitation can provide a more sophisticated analysis than the standard neo-liberal rhetoric of choice.

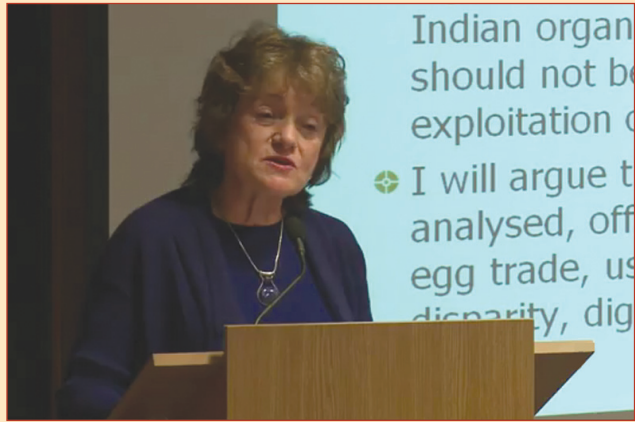
In her elegant exploration of the moral pitfalls of global human egg trade, thus, Prof. Dickenson scrutinized the utilitarian liberal discourse of talking about individual choice, autonomy, and (reproductive) freedom, all perennial metaphors, even idols of the market economy and proposed instead a critical reexamination of such political economic terms as

3. ACADEMIC ACTIVITIES



Inez de Beaufort and Judit Sándor

exploitation, commodification, and commercialization, overcoming the emotive connotations of these terms. While emphasis on respecting individual choice among liberal and utilitarian thinkers was originally intended to extend rights to oppressed groups, particularly women, and while it was put to use by feminist groups in the ongoing debates over abortion, it is now too laden with vagueness and pro-market rhetoric to provide explanatory or prescriptive guidance on concrete issues like the rights and wrongs of the global trade in human tissue, particularly human eggs. By developing a more nuanced concept of exploitation, Prof. Dickenson elaborated a critique of the tissue markets.



Donna Dickenson

The presentation was followed by a lively interdisciplinary debate moderated, just as in the case of the previous lectures, by *Judit Sándor*, director of CELAB. Many of the comments centered around the interconnected questions of whether we should rely on altruism instead of commercialization in egg donation, and whether we should keep or modify the ethical and legal framework in Europe, which is based on the prohibition of financial gain. Others proposed that we should make more nuanced legal distinctions in the regulation of egg donation.

The success of the Anniversary Bioethics Lecture Series can be measured by the broad interest shown by faculty members and students from across a wide variety of departments within CEU.

3.2. 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.

3.2.1. Teaching at CEU

Courses offered in the 2010–2011 Academic Year and in the Autumn 2011 semester

Judit Sándor

Human Rights and Biopolitics

Department of Political Science and Department of Gender Studies

Privacy and Data Protection – Challenges of Biotechnology Patients' Rights in the Twenty-First Century

Department of Legal Studies

Gender and Biotechnology: The Self, the Family and the State in the Post-Genomic Era

Department of Gender Studies

Petra Bárd

EU Constitutional Law

EU Criminal Law

Selected Issues in Forensic Sciences

Department of Legal Studies

3.2.2. From Trash to Gold: Contemporary Ethical Challenges to the Use of Human Tissues and Organs in Biotechnology. Joint CELAB-CRC SESSION

CELAB Participants: Judit Sándor; Enikő Demény; Violeta Beširević; Péter Kakuk; and George-Tudor Florea

At the end of March 2011, CELAB organized a week-long workshop, titled “From Trash to Gold? Contemporary Ethical Challenges to the Use of Human Tissues and Organs in Biotechnology” in collaboration with the Curriculum Research Center (CRC). The workshop featured lectures held and seminar discussions coordinated by CELAB associates for Special and Extension Programs (SEP) visiting scholars who intend to develop courses on the ethical, legal and social implications of biobanks, stem cell research, or organ transplantation. The sessions also explored intellectual property issues of stem cell research and the problems of regulating biotechnological advances.

The four CRC participants of the workshop arrived from four different countries: Researcher Temirkan Kulkhan, from the Health Development Institute of Kazakhstan; Associate Professor Oksana Kashyntseva, from Kyiv University of Law of the National Academy of Sciences of Ukraine; Professor Bratislav Stanković, from the School of Law at the University American College, Skopje, Macedonia; and Ana Andrejić, MA, from the Department of Sociology at the Faculty of Philosophy, University of Niš, Serbia.

During the first day of the workshop, CELAB Director *Judit Sándor* gave an introductory lecture on the “Contemporary Ethical Challenges to the Use of Human Tissues and Organs in Biotechnology”. It was followed by a presentation in which *Violeta*



CRC participants at Péter Kakuk's lecture

Beširević talked about her experiences with teaching bioethics and law, using one of her specific fields of scientific interests, euthanasia, as an example. On the next day, *Judit Sándor*, *Violeta Beširević*, and *Enikő Demény* moderated a workshop discussion on the methodologies of teaching ethics. The workshop participants had the opportunity to explain their own experiences with ethics teaching, to exchange ideas and to learn from each other. The CRC participants presented the course they are developing within the framework of the CRC session and they received advice from the CELAB members on how to improve their courses.

On the third day, *Enikő Demény* spoke about “Presenting Ethical Issues through Films”, with a special focus on the case of organ trafficking, which was one of main themes of the CRC session and also one of CELAB's current research fields. The workshop participants watched the documentary film *Kidney on Ice*, directed by Anja Dalhoff and Alina Radu, which was followed by a discussion about ethical issues related to organ transplantation. In the afternoon of the same day CELAB Research Associate, *Péter Kakuk* offered a lecture on “Teaching Medical Ethics”, focusing on the issue of conflict of interest. The presentation was followed by a discussion with the lecturer, CELAB members and CRC participants.

In the last day of the session CRC participants visited CELAB offices, had informal discussions with CELAB members, and were provided with teaching materials and CELAB publications.

3.2.3. Teaching Ethics through Films



Kidney on Ice Poster

close cooperation with Moldovan journalist Alina Radu, Anja Dalhoff also examines the role played by the criminal network behind this heartless trade and a former policeman is interviewed in prison, where he is now serving 10 years for organ trafficking. The film also describes how unscrupulous surgeons in Turkey perform secret illegal operations on living donors from European countries. The film screening was followed by a discussion with the producers, CELAB team, CEU students and interested faculty members.

Moderator: Prof. Judit Sándor

Kidney on Ice

Documentary film screening, followed by a discussion with Film Directors Anja Dalhoff and Alina Radu, on November 19, 2010, CEU, Budapest

Kidney on Ice looks at organ trafficking from a variety of perspectives, exploring the tragic stories of people selling their organs and those who desperately need a transplant. In

vides customers with a cost effective solution using outsourcing of the surrogacy element to India as way to lower prices. The preferred genetic material is selected by the clients and the rest is left in the hands of the producer: Sperm and eggs are purchased on-line and multiple embryos are produced and frozen. Packed in liquid nitrogen only the embryos that fit the customers preferences are shipped by air to India where they are implanted into the wombs of local surrogates. The customers arrive only at the end of the nine month pregnancy period to pick up their babies.

Moderator: Prof. Judit Sándor

3.2.4. Teaching and Lecturing at Other Institutions

Petra Bárd

Criminal Policy Course

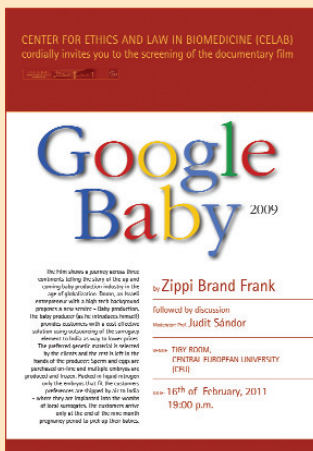
ELTE Law School's Criminology MA program, Budapest, Hungary

EU Accession to the ECHR

Total Law™ summer course, CEU
July 4, 2011, Budapest, Hungary

Human Rights in the EU (workshop leader)

Total Law™ summer course, CEU
July 5–6, 2011, Budapest, Hungary



Google Baby Poster

background proposes a new service: baby production. The baby producer (as he introduces himself pro-

Google Baby

Screening of a documentary film directed by Zippi Brand Frank (2009) on February 16, 2011, CEU, Budapest

The film shows a journey across three continents telling the story of the up and coming baby production industry in the age of globalization. Doron, an Israeli entrepreneur with a high tech

"Double Standards for Visible Minorities"

Lecture given at the NICLAS summer school, European University Institute, Florence
July 14, 2011, Florence, Italy

Roma Migration Workshop (chair)

NICLAS summer school, European University Institute, Florence
July 14, 2011, Florence, Italy

*"The Four Basic Freedoms";**"The Case of Data Protection";**"Minorities and Anti-Discrimination in the EU"*

Lecture series at the ASSEI summer school organized by the Club Albach
September 21–23, 2011, Belgrade, Serbia

Violeta Beširević

Medical Law Courses at Union University Law School, Belgrade, Serbia

Law and Ethics in Biomedicine (Specialized Studies in Medical Law)

Patients' Rights (Specialized Studies in Medical Law)

Péter Kakuk

Bioethics courses at University of Debrecen, Debrecen, Hungary

Biotechnology Ethics (Biotechnology MSc)

Health Care Ethics and Law (Health Policy MSc)

Ethics in Medical Rehabilitation (Medical Rehabilitation MSc)

Bioethics on Films (university credit course)

Ethics of Science: Responsible Conduct of Research (university credit course)

József Kovács

“Ethical Questions of Psychotherapy”

Lecture held as an invited speaker for clinical psychologists in postgraduate training, organized by the Department of Clinical Psychology of the Semmelweis University

October 7, 2010, Budapest, Hungary

“Ethical Foundations of Informed Consent”

Lecture held as an invited speaker at the postgraduate course *Information and Consent in Everyday Health Care – Ethical and Legal Aspects*

February 4, 2011 and September 9, 2011, Budapest, Hungary

“Ethical Questions of Capacity to Consent”

Lecture held at the postgraduate course *Information and Consent in Everyday Health Care – Ethical and Legal Aspects*

February 5, 2011 and September 10, 2011, Budapest, Hungary

“Dental Ethics”

Lecture held at the postgraduate course *Current Issues in Dental Science*

February 11, 2011, Budapest, Hungary

“Ethics of Psychotherapy”

Lecture held at the postgraduate course on Psychotherapy

February 25, 2011, Budapest, Hungary

“Bioethical aspects of the relationship with aggressive patients”

Lecture held as an invited speaker at the CME course *Possibilities of Prevention and Management of Aggression in Clinical Practice*

March 5, 2011, Budapest, Hungary

“Ethical Questions of Research on Human Subjects”

Lecture held at the Institute of Forensic- and Insurance Medicine of Semmelweis University

March 18, 2011, Budapest, Hungary

“Ethical Questions of Psychotherapy”

Lecture held at Institute for Psychology of Eötvös Lóránd University

March 22, 2011, Budapest, Hungary

“The Responsibility of the Medical Profession”

Lecture held at the CME course for Pulmonologists

March 26, 2011, Budapest, Hungary

“Mental Illness, Stigmatization, Society”

Lecture held at the Institute of Behavioral Sciences of the Semmelweis University

April 6, 2011, Budapest, Hungary

4. EVENTS AND ACHIEVEMENTS IN CHRONOLOGICAL ORDER

4.1. PARTICIPATION IN CONFERENCES

During the 2010–2011 academic year, CELAB staff and fellows took part in the following academic and scientific events:

3rd ELPAT Conference and EULOD meeting

Participants: Judit Sándor, Violeta Beširević, Enikő Demény, George-Tudor Florea
October 8–10, 2010, Sofia, Bulgaria

Ethics & Clinical Applications of Synthetic Biology: An Interdisciplinary Dialogue

Presentation by József Kovács on “How Synthetic Biology (Synbio) Techniques May Change the Concepts of Health, Disease, Therapy and Suffering?”
November 2, 2010, Bilbao, Spain

Judit Sándor at the GEObs meeting in Windhoek, Namibia, on December 8–10, 2010



Making Perfect Life: Bioengineering in the 21st Century (STOA Conference)

Participant: Judit Sándor
November 10–11, 2010, Brussels, Belgium

The Bioethical Contexts of Personhood Conference

Presentation by József Kovács on “The Notion of Personhood in Bioethics”
November 22, 2010, Debrecen, Hungary

Consumer Choice in Healthcare Markets – Annual Conference

Participant: Éva Földes
December 2, 2010, Tilburg, Netherlands

Meeting of the International Review Committee for the Global Ethics Observatory (GEObs) Database Four on Ethics Related Legislation and Guidelines

Participant: Judit Sándor
December 8–10, 2010, Windhoek, Namibia

Tiss.Eu Final Status Conference

Presentation by Judit Sándor on “The Terminology Can Be Misleading: Reinterpreting Privacy in the Age of Biobanks.”
January 19–21, 2011, Göttingen, Germany

Ethics and Professions Conference

Organized at the Babes-Bolyai University, Cluj
Presentation by George-Tudor Florea and Enikő Demény on the “The Role of Bioethics in Living Organ Donation Decision Making”
April 14–16, 2011, Cluj, Romania

Assisted Reproduction and Changing European Family Structures: Current and Future Issues

Event financed by the European Science Foundation and organized by the Institute for Social Sciences in the 21st Century
Participants: Enikő Demény
April 18–19, 2011, Cork, Ireland

Final Conference of RemediE Project

Participants: Judit Sándor, Márton Varju, György Kovács
April 18–19, 2011, Bilbao, Spain

Advisory Board Meeting of DRZE

Participant: Judit Sándor
May 9–10, 2011, Bonn, Germany

Structures and Futures of Europe

17th Annual Conference of the Hungarian Political Science Association at the Central European University
Presentation by Petra Bárd on “Challenges of EU Accession to the ECHR”
May 20–21, 2011, Budapest, Hungary

19th Annual Conference on “The Individual vs. the State: An Enforceable Right to Health?”

Presentation by Judit Sándor on “The Right to Health and the Human Organ: A Rights by Consequence?”
Commentator (for the papers of Trudo Lemmens–Candice Telfer, Sándor Judit, Cole Durham–Javier Martinez Torron): Petra Bárd
June 10–11, 2011, Budapest, Hungary

11th Behavioral Studies Days: Conference titled “From Stress to Happiness”

Organized by Semmelweis University, Institute

for Behavioral Studies

Presentation by József Kovács on “Some Questions on Publication Ethics”
June 28–29, 2011, Gödöllő, Hungary

Brain In Dialogue Project Final Conference: Dialogue to Dialogue

Round table discussion
Participant: Judit Sándor
July 5–6, 2011, Brussels, Belgium

European Society for Philosophy of Medicine and Health Care (ESPMH) Annual Conference

Presentation by Péter Kakuk on “Conflict of Interests in Biomedicine: Reconfiguring the Problem”
August 20, 2011, Zürich, Switzerland

Conference of the European Group of Public Law: Public Law and the Judges

Presentation by Violeta Beširević on “The Dialogue between the Serbian Constitutional Court and the European Court of Human Rights, with T. Marinković”
September 9–11, 2011, Spetses, Greece

Bioethics from a Cross-Cultural Perspective: European Association of Centers of Medical Ethics (EACME) 25th Annual Conference

Presentation by Enikő Demény and George-Tudor Florea on “Applied Case Studies in Ethics and Medicine in Eastern Europe: The Role of Bioethics in Living Organ Donation Decision Making.”
Presentation by Péter Kakuk on “Conflict of Interests in Biomedical Sciences: Toward a New Ethical Framework.”
September 15–17, 2011, Istanbul, Turkey

4. EVENTS AND ACHIEVEMENTS

4.2. SCIENCE COMMUNICATION AND MEDIA EVENTS

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

“Bioethics in the Health Care System” [Bioetika az egészségügyben]

Interview with József Kovács by Éva Vörös
In: *Óbuda-Békásmegyer Local Governance Newspaper*,
November 5, 2010, p. 9.

“Right to Die”. Film Session followed by a Debate on Death and Soul

Participant: Judit Sándor
January 17, 2011, Budapest, Hungary

“Welcome, Umut-Talha!” [Isten hozott, Umut-Talha!]

Interview with Judit Sándor on savior siblings
In: *Elitmed, Legal Artis Medicinae*,
www.elitmed.hu/ilam/interjuk/isten_hozott_umut_talha_beszelgetes_sandor_judit_bioetikussal_a_kozep_europai_egyetem_tanaraval_7064/
February 16, 2011

“On Patient’s Rights” [A betegjogokról]

Interview with József Kovács by Köbli Anikó
In: *Átalakítás előtt a hazai betegjogvédelem rendszere. Medical Tribune*,
March 17, 2011, p. 7.

“On Abortion” [Az abortuszról]

Interview with József Kovács by Danó Anna
In: *Népszabadság*.
March 23, 2011, p. 3.

“The Ethical Aspects of Modern Genomics” [A modern genomika etikai kérdései]

Participant in the round table discussion:
Dr. József Kovács.
In: *Mindentudás Egyeteme 2.0* [Open University

TV Program], M2 [Hungarian Television 2]
April 28, 2011

“A jövő orvostudománya etikai szemmel” [The Future of Biomedical Science from an Ethical Perspective]

Interview with Judit Sándor on savior siblings
In: *Elitmed, Legal Artis Medicinae*,
www.elitmed.hu/ilam/interjuk/a_jovo_orvostudomanya_etikai_szemmel_5901/
July 7 2011

“Dying with Dignity”

Film Session and round table discussion on dying with dignity
Participants: Judit Sándor, Mihály Filó, Viktor Gábor Orosz
May 5, 2011

“On Refusing Life Saving Treatments” [Az életmentő kezelések visszautasításáról]

Interview with József Kovács by Moskovics Judit
In: *Házon kívül* [Television Program on Legislative Issues] RTL Klub
May 5, 2011.

“The Possibilities of Diminishing Aggression” [Az agresszió csökkentésének lehetőségei]

Interview with József Kovács by Bíró Szilvia
In: *Kék Fény* [Television Program on Criminal Cases], M1 [Hungarian Television 1]
May 23, 2011.

“Mihály Filó (ed): Dialogue about Death: Euthanasia on the Peripheries of the Legal System”

[Párbeszéd a Halálról: Eutanázia a jogrend peremén] – Book launch
Participant from CELAB: Judit Sándor
May 26, 2011, Budapest

“Discussion on Euthanasia”

Participants: Judit Sándor, Mihály Filó, Viktor Gábor Orosz. Reporter: Júlia Nyári
In: *Adó-vevő. Fogyasztóvédelmi magazin* [Program on Consumer Protection], Radio Q 99.5.
June 9, 2011

4.3. PUBLICATIONS

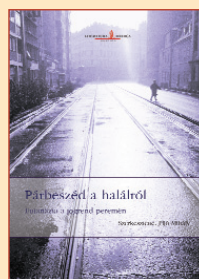
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4. EVENTS AND ACHIEVEMENTS

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Biobanks and
Tissue Research
– book



Párbeszéd
a halálról – book



Adolescent et acte
médical – book

4.4. AWARDS, APPOINTMENTS AND SPECIAL EVENTS

4.4.1. Awards

Petra Bárd was awarded by the Hungarian Society of Criminology with the *Rusztém Vámbéry II. Award*.



4.4.2. Appointments



Judit Sándor was appointed as member of the International Advisory Board of DRZE (Das Deutsche Referenzzentrum für Ethik in den Biowissenschaften or German Reference Centre for Ethics in the Life Sciences), which was established by the Federal Ministry of Research and Education in Germany.



József Kovács received the degree “Academic Doctorate” on December 1, 2010 and was appointed “Egyetemi Tanár” (university full professor) at the Semmelweis University on September 1, 2010.



Péter Kakuk was appointed “Egyetemi Adjunktus” (assistant professor) at the Medical and Health Sciences Center of the University of Debrecen.

Péter Kakuk was appointed as Editor at *Meditor* (a new Hungarian journal for applied ethics).



György Kovács was appointed in 2011 to the post of Board member at the Hungarian Fulbright Association.



Éva Földes joined CELAB as a Research Associate, starting with the academic year of 2010–2011.

4. EVENTS AND ACHIEVEMENTS

4.4.3. Acknowledgements

A paper written by *Violeta Beširević*, “End-of-Life Care in the 21st Century: Advance Directives in Universal Rights Discourse,” and published in *Bioethics*, vol. 24, no. 3 (March 2010), pp. 105–112, was one of the five most visited articles during 2010–2011 on the Wiley-Blackwell website.



One of the most prominent newspapers in the Czech Republic, *Lidové noviny*, published an article on law faculties in Central Europe in which CEU’s Department of Legal Studies ranked first. CEU’s Center for Ethics and Law in Biomedicine (CELAB) was also pointed out for its excellence in research on biobanks.



4.4.4. Special Events

On November 2, 2010 Petra Bárd gave life to her son, Patrik. In the academic year of 2010–2011, Petra was on maternity leave.



On December 13, 2010 Márton Varju’s daughter, Zsuzsi was born. In the academic year of 2010–2011, Marci was on paternity leave.



5. BUDGET.....

5.1. REVENUES IN AY 2010-2011

Approved Budget from CEU	Amount in Euro
C-5036 Total	56,460

External Funding	Amount in Euro
RemediE	26,122
Tiss.EU	654
EULOD	42,360
Total	69,136

5.2. SPENDING IN AY 2010-2011

C-5036 – CELAB MAIN BUDGET CODE

Budget category	Amount in Euro
Personnel cost	55,019
Other costs	0
Total	55,019

C-8341 – TISS.EU PROJECT

Budget category	Amount in Euro
Personnel cost	0
Other costs	654
Total	654

C-8340 – REMEDIE PROJECT

Budget category	Amount in Euro
Personnel cost	24,611
Other costs	1,511
Total	26,122

C-8336 – EULOD PROJECT

Budget category	Amount in Euro
Personnel cost	39,890
Other costs	2,470
Total	42,360



