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# CENTER FOR ETHICS AND LAW IN BIOMEDICINE

ANNUAL REPORT

2011-2012

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© December 2012 Center for Ethics and Law in Biomedicine (CELAB)

ISSN 1992-4038

CELAB Report is published annually

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Design and layout: Zsolt Sándor Printed in Hungary by FOM kft.

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# 1. FOREWORD

Recent developments in the natural and biomedical sciences have confronted us with new challenges and opportunities in various areas of life and, consequently, opened up new fields of governance. The Central European University acknowledged the need to explore the direct and indirect social, ethical, and legal implications of new technological advances and to understand them from a multidisciplinary perspective when it established the Center for Ethics and Law in Biomedicine (CELAB), in 2005.

Since its foundation, one of the major activities of the Center has been the participation in various European research and policy projects investigating the social, ethical and legal implications of contemporary biotechnologies and biomedicine. As a consequence, CELAB has completed several research projects sponsored by the European Union, such as PUG, PRIVIREAL, PRIVILEGED, GeneBanC, Tiss.Eu, NANOPLAT, RemediE, or EULOD, and participated as advisor or as expert in several others, such as NMD-CHIP, EURECA and, most recently, EpiHealth. Between 2009 and 2011 we focused on a range of studies including privacy protection in biobanks and in genetic databases; access and safety issues involving nanotechnology; ethical and legal policy questions of organ donation; the moral and security challenges posed by organ trafficking; the new interpretations of kinship and reproduction in the age of biotechnology; and the protection of intellectual property rights within stem cell research. As a result of these projects, several publications have been produced, including books, book chapters, and articles in various refereed journals, including the *Journal of Medical Ethics* and *Common Market Law Review*.

We realize that all those new technologies that we have studied in our projects require a multidisciplinary approach. For example, the intersection between human rights and bioethics creates a unique opportunity to combine, in quite original ways, the theoretical and policy-based approaches to some of our most vexing social problems. We have to see that bioethics, as a discipline, has been traditionally interested in questions of the beginning, the end, and the value of life, as well as, more recently, in problems concerning the enhancement of human life. As Sheila Jasanoff notes, discourses related to the governance of science are "shifting and fluid, subject to place-specific histories, memories, and intellectual traditions, but there are some constant elements of this relation: forces of convergence that propel governments to speed innovation and create jobs. Science is increasingly produced in application, it

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#### FOREWORD

"Today, four decades after the birth of the neuromolecular gaze, we are seeing a concerted attempt, across Europe and North America at least, to argue that the discoveries of these neurosciences hold the key to the management of all manner of human activities and experiences, from psychiatric illness to economic behavior, from human sociality to spirituality and ethics. It remains to be seen whether these attempts to translate from the molecular understanding of the nervous system to the molar management of human affairs represent a genuine advance in our understanding of the kinds of creatures we human beings are, or a premature and unwise extrapolation to society of the modest and always uncertain and correctible knowledge of the laboratory sciences."

Joelle M. Abi-Rached and Nikolas Rose, "The Birth of the Neuromolecular Gaze," *History of the Human Sciences*, vol. 23 no. 1 (February 2010), 11–36.

is transdisciplinary, and ... scien[tists] have grown more aware of the social implications and assumptions of their work more than ever before."

In the autumn of 2012, we continued our successful CELAB Distinguished Lecture Series at the Central European University. This series had started in the fall of 2011 with the presentations of Prof. John Harris, Prof. Inez de Beaufort, and Prof. Donna Dickenson. Our guests' lectures explored the frontiers of contemporary biomedical sciences and their applications from three different angles: the possibilities of enhancement, the consequences of longevity, and the commercialization of scientific results.

This year the Distinguished Lecture Series focuses on the human brain. On October 12, 2012 Nikolas Rose, professor of sociology and head of the Department of Social Science, Health and Medicine at King's College London gave a lecture at CEU titled "Our Brains, Our Selves? The Social Implications of the New Brain Sciences." Contemporary developments in the neurosciences raise numerous old and new ethical questions Professor Rose addressed: Are enhancement technologies safe? Are they effective? Do they have any harmful effects on those who apply them? How should they be regulated, if at all? Who should benefit from these new technologies and how should we protect the rights of people whose lives they affect?

This Report is the Seventh Annual Report of the Center for Ethics and Law in Biomedicine (CELAB). Looking back at the past 12 months, one the most important achievements of the 2011–2012 academic year has been the completion of the EULOD project. CELAB associates completed an extensive report on the patterns of organ trafficking cases and explored the possibilities of new law enforcement policies. A book chapter has also been prepared and further publications will follow as contributions to this FP7 European research project.

During this research cooperation, we learnt a lot about the difficulties of law enforcement in the increasingly globalized world. Although organ trafficking is prohibited universally, when it comes to a concrete case it seems that many techniques of enforcement are still inefficient. Countries and their citizens that can benefit from organ trade and trafficking are in very different socio-economic conditions compared to the countries where organs are coming from. Globalization has created tensions between developed and less developed countries, which resulted in a division between typical "organ recipient" and "organ donor" countries.

By the twenty-first century, neither the number of available organs, nor the infrastructural and financial means could keep pace with the increasing need and technological capacity for transplantation in developed countries. National waiting lists have become full and long, and the number of people who die while waiting has also increased.

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Patients' mobility has also increased and in many countries patients no longer feel bound to the capacity of one health care sector. It is easier to travel and it is no longer regarded as a luxury to seek health care beyond the national frontiers.

During the two-year tenure of the EULOD project, CELAB's work focused on mapping national laws, legal cases and practices with regard to organ transplantation and organ trafficking. From the minor violation of law in selecting a donor target for the recipient to more severe forms of violation of human rights, such as organ trafficking, cases were collected and analyzed. We also examined selected laws and practices in order to develop recommendations for legislators and research ethics committees. When it comes to trafficking in persons, it is now a commonplace to say that it has become the third most lucrative criminal activity, right after drug trafficking and arms dealing.

WHO first declared the prohibition of organ trade in 1987, affirming that such trade is inconsistent with the most basic human values and contravenes the Universal Declaration of Human Rights. Later on the WHO Guiding Principles explained the reason why organ sales are prohibited. The Commentary to Principle No. 5 states: "Payment for [...] organs is likely to take unfair advantage of the poorest and most vulnerable groups, undermines altruistic donation, and leads to profiteering and human trafficking. Such payment conveys the idea that some persons lack dignity, that they are mere objects to be used by others." The crime of human trafficking leads to the direct infringement of a number of the victims' human rights, including the right to life, the right to human dignity, to their freedom of movement, the prohibition of torture and other cruel, inhuman and degrading treatments, the right to health and the prohibition of discrimination. As it follows, several human rights instruments, including the Oviedo Convention states a categorical ban on the commercialization of organ donation in Article 21 by saying "The human body and its parts shall not, as such, give rise to financial gain." The convention is based on broad consensus in Europe as more than twenty countries have ratified it so far. It follows from the text that both commercialization and commodification are covered by this prohibition. In our Final Report to the European Commission we made important legal and policy recommendations based on our legal analysis of laws and collected cases.

In addition to the public lecture series and the major European research projects, we continue to participate in other long-lasting collaborations, such as the francophone network of biomedical lawyers and social scientists (Réseau Universitaire International de Bioéthique, RUIB). The topic of the annual workshop of RUIB this year, held in Rio de Janeiro, was the effect of new biotechnologies on the notion of kinship. This research cooperation has been

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#### 1. FOREWORD

very fruitful over the years, as the number of books published from the conference proceedings shows. By the end of 2012 two new books have been prepared for publication, and this new topic will be the basis of further publications projected for 2013–2014.

During the 2011–2012 academic year, we also participated in several important international conferences, including the 19th World Congress on Medical Law, a key scientific event of the World Association for Medical Law, organized in Maceió, Brazil.

It is an encouraging fact that we have more and more visiting fellows coming to CELAB who want to spend their short research leave with us. In order to respond to this increasing interest in the activities and resources of CELAB we have mobilized external financial assistance, or at least offered our research facilities to the guest researchers.

In the upcoming year, besides continuing the CELAB Distinguished Lecture Series, we have already set out to participate in new EU sponsored research consortia. Within the framework of a new research initiative called NERRI, in 2013 CELAB will launch a new type of research project that is going to explore the social implications of recent developments in the neurosciences. One of the most important implications of contemporary neuroscience is that it promises to give us a better understanding of human behavior and to help us apply this knowledge to various practical fields, such as politics, education and the criminal justice system.

It is important to note that the major organizing theme of the public lecture series is in line with the research focus of this new project. The kick-off meeting of NERRI is scheduled for March 2013. In addition to NERRI, there are other European research projects in the pipeline. Thus, we are looking forward to yet another busy year.

For more information about CELAB, we recommend that you read this Annual Report and consult the CELAB website at celab.ceu.hu; 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

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## 2. RESEARCH AND POLICY ACTIVITIES .....

#### 2.1. PARTICIPATION AND COLLABORATION IN RESEARCH NETWORKS

#### 2.1.1. EULOD: Living Organ Donation in Europe



#### Partners:

Erasmus University Medical Center, the Netherlands (Coordinator)

European Society for Organ Transplantation (ESOT), The Netherlands

University of Gothenburg, Sweden University of Münster, Germany

Catholic University of Leuven, Belgium

Center for Ethics and Law in Biomedicine, Central

European University, Hungary

Bulgarian Center for Bioethics, Bulgaria

Kidney Foundation, Moldova

Tartu University Hospital, Estonia

Academic Society for the Research of Religions and Ideologies, Romania

Polish Transplant Coordinating Center, Poland

The project on living organ donation in Europe (EULOD), completed in the spring of 2012, was a coordination action aiming 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 set out to achieve broad European coverage with a specific focus on the new EU Member States. It drew 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 contained two scientific research packages. The first package focused on living-unrelated donation practices in Europe. The second focused on legal restrictions and safeguards for living donations in Europe. The remaining three work packages ensured the coordination of this work, the dissemination of project results, and the organization of meetings. The most important goal of the project was to exchange best practice and effective organizational models to promote and safequard living donation in Europe.

The CELAB team contributed to WP3 part II, which focused 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.

One of the main project events in the academic year of 2011–2012 was the Fourth ELPAT conference and project meeting, organized on November 3–6, 2011, in Berlin, Germany. The CELAB team members presented their papers in the "Organ Tourism and Paid Donation" Working Group of ELPAT. Judit Sándor delivered a presentation on "Scales and Patterns of Organ Transplantation Violations," Violeta Beširević on "Eyes Wide Shut: Organ Trafficking in Kosovo," while Enikő Demény and George Florea on "Assessing Structural and Institutional Deficiencies in the Implementation of Romanian Legal Policies."

#### 2. RESEARCH AND POLICY ACTIVITIES



Teddy Florea and Enikő Demény at EULOD workshop, November 3–6, 2011, Berlin, Germany

After mapping the literature and the regulatory framework of organ trafficking, tourism and paid donation, the CELAB team analyzed organ trafficking cases identified in the region, based on the templates and questionnaire developed by the project principal investigator Judit Sándor, assisted by Violeta Beširević. The questionnaire was sent out to various stakeholders identified in the previous phase of the project, and its results were analyzed and evaluated in the academic year of 2011-2012. Our research across a wide range of European countries has confirmed that while legal provisions repeatedly emphasize and reinforce the principles of non-commercialization, law is not an omnipotent tool. In the lack of appropriate control and follow-up mechanisms within the organ transplantation system and without the support of the professional bodies of medical practitioners, the growing economic tension between the poor and the rich may lead to finding legal loopholes and organizational gaps within the enforcement mechanism.

There is also the added risk of developing illegal networks that clearly distinguish between organ supply and organ demand countries, as well as institutionalize the exploitation that comes with this distinction. However, we have also identified good practices and promising efforts in regional cooperation that have contributed to the enhancement of existing organ transplantation systems.

The results of this two-year research project have been materialized in a report titled *Improving the Effectiveness of the Organ Trade Prohibition in Europe, in Living Organ Donation in Europe: Scientific Report (2012),* 

and in the book chapter "Organ Trafficking, Organ Trade: Recommendations for a More Nuanced Legal Policy" published in an edited book of the EULOD project. The CELAB team has also been involved in the dissemination of the project results. In this context, CELAB Researchers presented the results of their research at international conferences in Helsinki, Sibiu, Cluj-Napoca, Strasbourg, Belgrade, and Budapest.

CELAB participants in the project: Judit Sándor, Enikő Demény, Violeta Beširević and George-Tudor Florea

Duration of the project: 2010–2012

Webpage: www.eulod.eu

# 2.1.2. Equal Opportunities for Heath: Action for Development



#### Partners:

Doctors with Africa – Cuamm, Italy
Department of Medicine and Public Health, University of
Bologna, Italy
Italian Global Health Watch, Italy
Italian Secretariat of Medical Students, Italy
Region of Vento, Italy
Transilvania University of Brașov, Romania
Medicine Students Scientific Association of Brasov,

Redemptoris Missio Foundation, Poland Poznan University of Medical Sciences, Poland International Federation of Medical Students' Association, Poland

Papardes Zieds Association, Latvia Medical University, Pleven, Bulgaria

#### In association with:

Romania

Central European University (CELAB), Hungary Association of Medical Students in Bulgaria, Pleven Branch, Bulgaria

Personality Development of and Human Communities Association, Bulgaria

Latvian Medical Students' Association, Latvia University of Latvia, Latvia

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Malta Medical Students' Association, Malta National Federation for the Orders of Doctors and Dentists, Italy

Universities, organizations and student associations from seven European countries are involved in this project, united by a common interest in global health and its teaching. "Equal Opportunities for Health: Action for Development" is an education and awareness-building project designed to highlight the importance of approaching health as a fundamental human right closely related to individual social development.

The aim of the project—of which Doctors with Africa is the lead organization—is to make European public opinion aware of the close link between health and development and to make the medical and health community—doctors, health providers, lecturers, trainers, and medical students—responsible for taking action.

Another aim is to promote discussion and dissemination of the global health paradigm, understood as a "panoramic" approach to health, which is able to theoretically transpose into practice social determinants of health, the values of justice and equity identified in the Declaration of Almaty. In addition, the growing interdependence between populations and countries determined by processes of globalization and their impact on health and health inequalities both in and among countries are to be analyzed.

Project activities include training; public activities and communication; networking; as well as studying and research. Among training activities, academic courses are offered for students of medicine and other faculties; workshops are organized for doctors and healthcare professionals in collaboration with health and hospital authorities and medical associations; and trainers (academic and teaching staff) are trained on content and teaching methods.

Among the public awareness and communication activities, a website is dedicated to the project, containing uploaded documents and references; the Health and Development journal is published and also made available online; video documentaries are produced; an international conference is planned; and different meetings and events are organized for the public. Among the networking activities, national and international meetings are prepared for project partners, experts, professionals, trainers, teaching staff and students; new synergies are developed among

stakeholders in global health, at the national and regional European levels.

Studying and research activities include mapping academic courses on global health; updating the standard curriculum on global health; participating in conferences and focus sessions; conducting research on the African health system; and publishing scientific articles and joint international studies.

Acting as an Associate Partner, CELAB participates in partnership meetings organized in the framework of the project. The 3rd Partnership Meeting took place in Poznań, Poland on May 11, 2012. Enikő Demény represented CELAB at the meeting and gave a presentation on our Center's activities in the field of global health and ethics. Two more partnership meetings will take place in the academic year of 2012–2013.

CELAB participants in the project: Judit Sándor and Enikő Demény

Duration of the project: 2011-2014

Website: http://www.educationglobalhealth.eu/en/

#### 2.1.3. Bio-Archaeological Heritage Project

This is an interdisciplinary research project that intends 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 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.

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 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 reg-

#### RESEARCH AND POLICY ACTIVITIES

ulations, research protocols and guidelines as a repository for working out best-practice reference materials.

In the academic year of 2011–2012, CELAB participated in this project in the form of lectures given by Judit Sándor and Enikő Demény in the framework of the Seminar Cycle: Caring for Dead Bodies from Medieval to Contemporary Society, organized by CEU Department of Medieval Studies. On March 20, 2012 Enikő Demény presented on "Dissecting the Dead for Medical Purposes: Attitudes towards Deceased Organ Donations" examining the extent to which the medieval cult of relics influences the dissection of bodies in modern societies, and discussing how they impact modern donations of organs. On May 15, 2012 Judit Sándor presented on "The Human and the Person—Legal Dilemmas on the Human Body in Research."

CELAB participants in the project: Judit Sándor and Enikő Demény

Duration of the project: 2011-2013

Website: medievalstudies.ceu.hu/projects/ceu-20th-anniversary-postdoctoral-fellowship-to-make-dead-bodies-talk

#### 2.1.4. International Academic Network on Bioethics (IANB)



Réseau Universitaire International de Bioéthique (RUIB, in English, the International Academic Network on Bioethics or IANB)

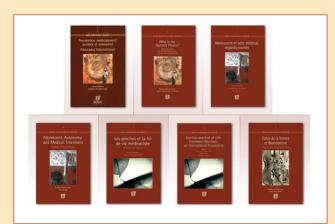
Scientific advances in biomedicine generally contribute to human well-being, but they may also have dangerous consequences threatening fundamental human rights. Facing this possibility, the International Academic Network on Bioethics (IANB) has decided to tackle these issues in a systematic manner. IANB is unique in that it involves the participation of legal scholars, lawyers, and social scientists from many different countries. Consequently, its major specialty is to develop international and multidisciplinary perspectives on research with bioethics implications.



Judit Sándor at IANB meeting, December 8–9, 2011, Tozeur, Tunisia

Although steered predominantly by academics, the network actively collaborates with other, non-academic professionals and legal experts who specialize in the field of biomedicine. During the thematic annual workshops, various complex, bioethics-related issues are discussed and analyzed through the prism of a wide range of disciplines, such as anthropology, philosophy, sociology, medicine, psychoanalysis, and even economics. Focusing on cases from different countries also involves a comparative study on the cultural determinants of the social perception of bioethical issues. Therefore, laws and legal provisions are examined also cross-culturally; the chosen themes thus allow an exploration of the legal regimes in each country and assist our understanding of the different underlying cultural and religious foundations. Each study is presented by a minimum of the eighteen permanent members of the IANB (from the countries of Belgium, Brazil, Chile, France, Germany, Greece, Holland, Hungary, Italy, Japan, Portugal, Senegal, Spain, Switzerland, Tunisia, Turkey, UK, and USA). Hungary and CELAB has been represented in this network by Judit Sándor since 2006.

The fourth annual workshop of the network convened in Tozeur, Tunisia in December 2011, and focused on the uses and visions of the woman's body in biomedicine under the title "Women's Body and Biomedical Intervention." Professor Judit Sándor, member of the Steering Committee of IANB, gave a presentation on the legal and political questions of home birth in Hungary. In November 2012, the fifth workshop was held Rio de Janeiro. Prof. Sándor submitted a paper on the "Transformation of Families and New Biomedical Technologies in Hun-



#### IANB book covers

gary." The topic of the workshop was "Parenthood and Biomedical Interventions."

The major output of this international network is a book series titled Droit, Bioéthique et société (Law, Bioethics and Society), edited by Brigitte Feuillet-Liger and published in Belgium by Bruylant. Four edited books have been completed, two in French and two 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 medical, regards croisées; and the English version came out in early 2012, with the title Adolescents, Autonomy and Medical Treatment. The proceedings of the Tozeur and Rio de Janeiro workshops are also going to be published both in French and English.

For more information please consult: rui-bioethique.univ-rennes1.fr/themes/LavieduRUIB/

# 2.1.5. Forthcoming Project: Neuro-Enhancement: Responsible Research and Innovation (NERRI)



Type of funding scheme: Coordination and Support

Actions (Supporting)

Starting date: March 15, 2013

#### Participating Institutions:

Ciencia Viva—National Agency for Scientific and Technological Culture, Portugal

London School of Economics and Political Science, United Kingdom

Radboud University, the Netherlands
Austrian Academy of Sciences, Austria
International School of Advanced Studies, Italy
Institute of Cellular and Molecular Biology, Portugal
Tilburg Law School, Tilburg University, the Netherlands

Johannes Gutenberg University, Germany Johannes Kepler University, Austria King's College, United Kingdom European Brain Council, Belgium Pompeu Fabra University, Spain Central European University, CELAB, Hungary

This new project aims to contribute to the new field of Responsible Research and Innovation (RRI) in Neuroenhancement (NE) in the European Research Area and to the shaping of a normative framework underpinning the governance of NE technologies. This will be achieved through mobilization and mutual learning (MML) activities engaging scientists, policy-makers, industry, civil society groups, patients and the wider public.

To structure this complex socio-technical domain this project will propose an analytic classification of NE technologies into currently available methods, experimental and hypothetical technologies. Each of the types raises some fundamental ethical, legal, social and economic issues, which have different relevance to various societal groups, point to different methods of stakeholder engagement, and may require different regulatory approaches. Over the course of the project, the analytic classification of NE technologies will be developed and extended in the work packages.

Mobilization will form the central commitment of the project from the outset to the conclusion. The consortium will stimulate and organize a broad societal dialogue employing state-of-the-art engagement methodologies tailored to specific contexts (education, health, work and research) and stakeholders (producers, users and intermediaries). Furthermore, the project participants will synthesize the national experiences, map the contours of a normative framework as

#### 2. RESEARCH AND POLICY ACTIVITIES

it emerges from societal engagement and dialogue and elaborate the concept of RRI in Europe. The consortium comprises experts in the neurocognitive sciences, the social sciences, law, philosophy, communication science and public engagement with science and technology. Many have prior experience in EC projects and in successful collaborations with other members of the consortium.

Duration: 2013-2016

CELAB participants in the project: Judit Sándor and Már-

ton Varju

#### 2.2. POLICY AND OUTREACH ACTIVITIES

#### 2.2.1. CEU Public Health Research Group



The Public Health Research Group at CEU was initiated in the academic year of 2011–2012 by Visiting Research Fellow at the Center for Policy Studies, Thomas Lynch, a Canadian medical sociologist with an interest and expertise in public health delivery and policy issues. Mr. Lynch spent most of his career working in the Canadian public policy environment. His principal interests in sociology are the sociology of academic medicine, theory, health inequality and the determinants of health, and the "greening" of medicine in response to changes brought by societal responses to climate change.

In his efforts to organize the research group, Thomas Lynch has been supported by CEU Professors Judit Sándor, Director of CELAB and Péter Mihályi from the Department of Economics and by CEU's Human Rights Initiative (HRSI). CELAB has been involved in the activity of this research group both by regularly attending its meetings and by Enikő Demény, Junior Researcher at CELAB offering logistic support in maintaining the group's webpage.

The creation of this group at CEU meant to encourage the development of an inter-disciplinary community of faculty and students with interests in public health research, meeting collegially, discussing planned or ongoing research, promoting a greater understanding of public health as a research theme, identifying opportunities for collaboration and cooperation between disciplines, scholars and students and fostering an international perspective on public health issues.

The meetings of the research group were open. Any CEU scholar or student was free to attend meetings of the research group or present on a public health topic. Any non-CEU scholar with an interest in the public health topic under discussion at a meeting or public health NGO representative may attend a research group meeting. Non-CEU scholars or NGO staff who wishes to present a public health topic of interest are invited to do so.

Meetings have been publicized to interested parties outside the immediate CEU community too. Involvement of colleagues from other universities, from the Open Society Institute, and from NGO's with interests in public health issues is encouraged.

Given the reality of CEU's scholarly base and the need to attract presenters and interest from that base, the following themes have been pursued in a flexible manner: research on the determinants of health, on health economics, on health inequities and inequality, and on public health ethics; the history of public health; human rights and public health; and health of vulnerable populations.

Webpage: http://phrg.ceu.hu/

#### PHRG Meetings in the academic year 2011–2012

Introductory Meeting of the Public Health Research Group

Discussion topics: Public Health Research and an Open Global Community Agenda

Presenter: Tom Lynch, Post-doctoral Research Fellow in Public Health and Development Center for Policy Studies, CEU

December 6, 2012, CEU

Marriage Counseling and Anti-VD Policies in Hungary, 1920 to 1950s

Presenter: Gábor Szegedi, Ph.D. student, CEU Department of History January 31, 2012, CEU

Effective HIV/AIDS Advocacy as a Catalyst for Social and Political Change

Presenter: Gregg Gonsalves, Open Society Foundations Fellow February 29, 2012, CEU

Ending the HIV/AIDS Epidemic in Sub-Saharan Africa
Presenter: Mark Schoofs, Senior Editor at ProPublica,
teaching journalism at Yale University
March 13, 2012, CEU

Health and New Media, Expanding Frontiers of Medicine in Digital Space

Presenter: Dr. Bertalan Meskó, Founder and Managing Director of Webicina.com June 13, 2012, CEU

Spending Cuts and Centralization in Hungarian Healthcare as a Response to the International Financial Crisis Presenter: Dr. Péter Mihályi, Professor of Economics at CEU June 19, 2012, CEU

#### 2.2.2. 19th World Congress on Medical Law

Between August 7 and 10, 2012 the 19th World Congress on Medical Law was hosted by APEDIMES (Pernambuco's Association of Medical and Health Law) at Maceió in Brazil. The congress of the World Association for Medical Law focused on the dialogue between biomedical sciences and the law with special emphasis on health law, legal medicine and bioethics, representing a unique opportunity to exchange knowledge and multidisciplinary experiences from all across the globe. It was an important event especially because this was the first time that the World Congress on Medical Law was held in Latin America. As a result, numerous experts, lawyers, health care professionals from Latin America participated at the panels of the conference creating a truly inter-cultural dialogue. Judit Sándor participated both at the special symposium of the European health lawyers, which included a round table discussion between Andre den



Judit Sándor at 19th World Congress on Medical Law, August 7–10, Maceió, Brazil

Exter, Jean Herveg, Vugar Mammadov and Diederik van Meersbergen, and also presented a paper on "Embryos and Genes on Trial."

More information available at http://www.2012wcml.com/

# 2.2.3. Rethinking the Self: Transnational and Transdisciplinary Bioethical and Biopolitical Concerns

"Rethinking the Self: Transnational and Transdisciplinary Bioethical and Biopolitical Concerns" was an International Symposium hosted by the Helsinki Collegium for Advanced Studies, University of Helsinki, and took place on April 10-12, 2012. The symposium aimed to address how cultural, medical and political understandings of the self are shifting and changing in contemporary societies. It explored how humanness is imagined and conceived in various symbolic systems of knowledge, and how gender, disability, class and ethnicity articulate these understandings. With a particular focus on how ideas of the flesh and national identity reconfigure experiences of the embodied self, the symposium brought together scholars whose work engages with issues ranging from medical and cultural technologies, globalization, migration and neoliberalism to phenomenology and ethics, political ideologies and subjectivities, and theories of social transformation.

Enikő Demény, Junior Researcher at CELAB, offered a presentation at the Symposium on "Bioethics and the

#### 2. RESEARCH AND POLICY ACTIVITIES

Vulnerable Selves in the Context of Living Organ Donation", a paper co-written with Teddy Florea, a Ph.D. student and Research Assistant in the EULOD project. The researchers aimed to add value to the recent developments in theoretical approaches of the body by focusing on the role of bioethics in the context of living organ donation. The empirical material of the study was gathered in Romania within the framework of the Living Organ Donation in Europe (EULOD) EU FP7 project. Based on the analysis of this material, the researchers argued that a theoretical approach based on the concept of embodied relational self, recognizing the vulnerability of the self is more suitable to addressing the challenging ethical issues in living organ donation than the model of autonomous, sovereign subject. They also pointed out that the vulnerability of the relational embodied self does not make autonomy impossible, but they claimed that autonomy is always relational and contextual. Therefore, they argued, the principle of vulnerability shall be the underlying principle of any ethical framework that addresses the issue of living organ donation.

#### 2.2.4. DNA on Trial

On May 30 the guest of the Brown Bag Lunch Series organized by the OSF-CEU Liaison Office was Prof. Judit Sándor. On this occasion, she spoke about recent theoretical and legal questions of the various kinds of human DNA applications. It is a challenging task to explore and to analyze the dialogue between law and science in a complex way and to peel off the legacy of an older, paternalistic professional tradition, and to deflect eugenic and reductionist thinking.

The joint CEU-OSF Brown Bag Lunch program offers a valuable forum for an informal and interactive discussion among CEU faculty, OSF staff, fellows and invited third parties. Topics have ranged from public health, through the future of the European Union, to investigative journalism. The program's goal is to identify thought-provoking and relevant subjects that focus on and complement the existing themes that are important for CEU faculty and OSF staff. Previous speakers have included *Tom Carothers* (CEU School of Public Policy and International Affairs, Carnegie Endowment), *Jonathan Cohen* (OSF Public Health Program), *Péter Balázs* (CEU IRES), *Gregg Gonsalves* (OSF Fellow, Yale University), *Rebecca MacKinnon* (former OSF Fellow, New America Foundation), and *Mark Schoofs* (OSF Fellow, Pro Publica).

#### 2.2.5. Policies and Practices of Health and Illness

The panel titled "Policies and Practices of Health and Illness" was organized at the 2012 International Congress on Romanian Studies: "Europeanization and Globalization: Romanians in Their Region and the World." Teddy Florea, a CEU Ph.D. student and research assistant at CELAB in the EULOD project attended the panel, where he presented a paper prepared with Enikő Demény on "The Globalization of Organ Transplantation Policies in a Regional Context: An Analysis of the Domestic Application of International Frameworks on Living Organ Donations' Selection Process in Romania."

The context of the paper was the increasing international involvement in domestic European legal systems in the field of organ transplantation, and specifically in the living donors' selection process. Various legal directives and recommendations have been adopted at the international level over the last two decades in an attempt to create a safe and transparent system of access and fairness to such life saving surgical procedures. One very important role has been given to the presence of bio-ethics committees in supervising the living organ donation process. With the Council of Europe, the World Health Organization, and the European Union all adopting legal instruments stipulating the presence and practice of such ethics committees, one would expect that the domestic law creation and implementation to follow the international model. However, throughout Europe, there have been different domestic applications of the general principle of equal access and fairness with varying degrees of success in the creation and activity of bioethics committees.

The paper presented at this panel was based on an indepth analysis of the law creation and implementation concerning bio-ethics committees within the domestic transplantation system in Romania. Based on an indepth case study analysis of the law and practice, through purely objective criteria the paper shows that the practice is far from being unitary in translating the law into practice. The authors argue that an enhanced international supervision of the practice of ethics committees is necessary in order to establish the population's trust in their formal decision-making. Furthermore, the objective criteria by which international frameworks in organ transplantation could be implemented in Romania and elsewhere in Europe could be improved through signing

regional agreements and membership in organizations such as EuroTransplant, whose role would be to add an extra level of monitoring and transparency to living organ donations.

# 2.2.6. ESF Exploratory Workshop New Perspectives on Gamete and Embryo Donation: Ethics, Kinship and Citizenship in a Globalized World

This workshop held in Essex on September 10–12, 2012 aimed to explore the theoretical, ethical and policy issues that arise from gamete (eggs and sperm) and embryo donation. The objective of the workshop was to bring together academics, policy makers, organizations and practitioners working on gamete and embryo donation in order to: identify common interests and themes; encourage interdisciplinary and international discussion of the issues raised; and review existing legislation and regulation in order to inform future research and policy agendas. The workshop proceedings and a collection of recommendations for practitioners will be published in an edited book.

CELAB was represented in the workshop by Judit Sándor and Enikő Demény. Prof. Judit Sándor gave a presentation with the title "Assisted Reproduction: Through the Lens of the Court." In reflecting on the regulation of assisted reproduction, she pointed out that law has proven to be a double-edged sword: on the one hand, it has repeatedly made attempts to restrict the application of certain contested techniques and, on the other hand, it has provided a tool to remove existing obstacles to a wider ranging use of other technologies that had been available to a select few and thus involved some form of discrimination. As a result, new groups of individuals can claim access to assisted reproduction and to the use of pre-implantation diagnostics. She analyzed recent legal debates, through the practice of the European Court of Human Rights, and made an attempt to explore the current legal frontiers of the technology of assisted reproduction.

Enikő Demény, Junior Researcher offered a presentation on "Networks of Reproduction in the Globalized World" which addressed the issue of transnationalizing reproduction through the analysis of a controversial



Enikő Demény presenting at ESF workshop, September 11-12, 2012, Essex, UK

transnational ova "donation" case. The researcher employed the perspective of critical and empirical bioethics, and used the method of contextualization for demonstrating how both normative and empirical arguments have to be considered in order to make sense of how certain "technological applications" are working in real life and what type of moral, ethical and ontological concerns they raise. Thus in her analysis she paid attention not only to the standard principles of bioethics invoked in such cases (for example, informed consent or autonomy) but also to the local and global context in which the analyzed phenomenon took place. She started with pointing out how some reported transnational commercial ova "donation" cases involving Romanian women challenged the existing national regulatory framework concerning these issues even to the extent that the Romanian state was sued at the European Court of Human Rights as a consequence of this case. Then the position of the various actors involved in this network of reproduction (donors, receivers, their families, intermediaries, fertility clinics and MDs, state institutions and agencies, the media, etc.) was analyzed. The researcher highlighted how some generally shared bioethical principles were employed (or not) in this context and argued that if we neglect the context in which people make moral decisions, we run the risk of reinforcing further injustices against already vulnerable groups.

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#### 3. ACADEMIC ACTIVITIES

# 3. ACADEMIC ACTIVITIES

#### 3.1. PUBLIC LECTURES

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.

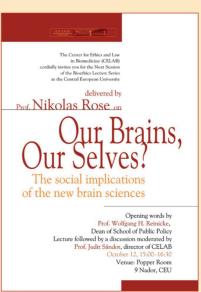
The lectures, which took place between September 30 and October 14, 2011 in the Auditorium of the Central European University, focused on the ethical, legal, and social implications of recent scientific advances in the field of life sciences. The three main topics—enhancement of the bodily capacities, 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. Detailed information about these lectures was presented in the CELAB Annual Report 2010–2011.

The CELAB Bioethics lecture series continued in the academic year of 2011–2012 with a public lecture offered by Prof. Nikolas Rose.

# 3.1.1. "Our Brains, Our Selves? The Social Implications of the New Brain Sciences" by Professor Nikolas Rose

On October 12, 2012 Professor Nikolas Rose, at the invitation of CELAB offered a very interesting public lecture at CEU on the social implications of the new



The poster of Nikolas Rose's lecture

brain sciences. The public lecture was opened by Prof. Wolfgang H. Reinicke, Dean of the School of Public Policy. In his introductory remarks Prof. Reinicke raised some preliminary policy questions of neurosciences related to the possible implications of this technology for people, societies, governments, researchers, and academic communities.

In his lecture, Prof. Nikolas Rose provided an overview of the history of neurosciences. Since the 1990s, at least in the United States and Western Europe, we have seen the proliferation of brain based explanations of human behavior. Neuroscience has escaped the laboratory, and has gained traction far beyond the field of psychiatric research and the widespread use of psychiatric drugs. Brain based explanations are supplementing and often displacing psychological explanations of human volition, action and emotion in criminal behavior, sociality, marketing and consumption practices and in our understanding of personhood itself. In his presentation Professor Rose accounted for the birth of this developing configura-





Audience at Nikolas Rose's public lecture, October 12, 2012

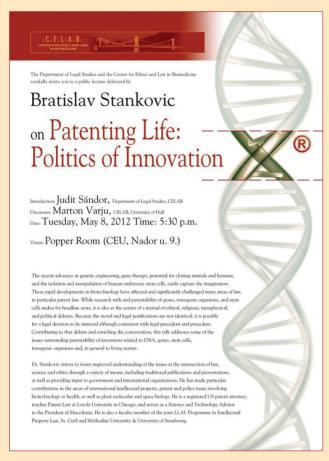
tion, explored the role of neuroscience in the government of human conduct, and examined the implications, and the limitations, of the growing belief that what makes us humans is our brains.

The full video typed version of the lecture can be found at the CELAB web page: celab.ceu.hu/events/2012-10-12/our-brains-our-selves-the-social-implications-of-new-brain-sciences

Nikolas Rose is Professor of Sociology and Head of the Department of Social Science, Health and Medicine at King's College, London. He was previously Martin White Professor of Sociology and Director of the BIOS Centre for the Study of Bioscience, Biomedicine, Biotechnology and Society at the London School of Economics and Political Science. His most recent books are The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century (Princeton, 2006); Governing the Present (with Peter Miller, Polity, 2008) and Neuro: the New Brain Sciences and the Management of the Mind (with Joelle Abi-Rached, Princeton, forthcoming, 2012). He is co-editor of BioSocieties: an interdisciplinary journal for social studies of the life sciences, Chair of the European Neuroscience and Society Network, and a member of numerous advisory groups including the Nuffield Council on Bioethics.

Nikolas Rose

#### 3. ACADEMIC ACTIVITIES



#### The poster of Bratislav Stankovic's lecture

# 3.1.2. "Patenting Life: Politics of Innovation" by Professor Bratislav Stankovic

On May 8, 2012 Bratislav Stankovic, Visiting Research Fellow at CEU Department of Law and CELAB in Spring 2012 held a public lecture at CEU on Patenting Life: Politics of Innovation. The introduction was presented by Judit Sándor, and the discussant was Márton Varju, from the University of Hull, and CELAB Researcher (in REMEDIE project).

The recent advances in genetic engineering, gene therapy, the potential for cloning animals and humans, and the isolation and manipulation of human embryonic stem cells easily capture the imagination. These rapid developments in biotechnology have affected and significantly challenged many areas of law, in particular patent law. While research with and patentability of genes, transgenic organisms, and stem cells makes for headline news, it is also at the center of a myriad of ethical,



Márton Varju, Bratislav Stankovic and Judit Sándor at the public lecture, May 8, 2012, Budapest, Hungary

religious, metaphysical, and political debates. Because the moral and legal justifications are not identical, it is possible for a legal decision to be immoral although consistent with legal precedent and procedure. Contributing to that debate and enriching the conversation, Bratislav Stancovic's lecture addressed some of the issues surrounding the patentability of inventions related to DNA, genes, stem cells, transgenic organisms and, in general, to living matter.

Following the lecture, Márton Varju made germane comments from a European regional perspective. He emphasized that European law has been the most comprehensive in incorporating ethical principles related to the treatment of the human body and human biological material: objects of utility and of commercial relevance by the patent system is provided in European patent law, harmonized by European Union Directive 98/44/EC. The Directive was to respond to a number of different demands, such as those of European Union economic and innovation policy envisioning a dynamic and competitive European biotechnology sector, those of European Union market regulation aiming at the reduction of regulatory differences in national patent laws, and the social demands for delineating the boundaries of patenting the human body and biological material harvested from it. The Directive guaranteed a priority posi-

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tion for the relevant bioethical principles and set out to achieve its regulatory and policy objectives having regard to those principles.

#### 3.1.3. "Human Reproduction and Beyond: Embryos, Genes, and Tissues on Trial" by Professor Judit Sándor

The public lecture was delivered in the framework of the Department of Gender Studies' Lecture Series: Voicing Genders, Engendering Voices. This lecture series was a joint celebration of the Department's 15th anniversary and the 20th anniversary of CEU. The lecture series shared with the wider academic community the faculty's most recent research and showcased the multiple and interdisciplinary ways in which the field of gender studies contributes to the themes of CEU's university-wide celebrations: disciplinary self-reflexivity and academia's social responsibility. Thus

the lecture series intended to contribute to the larger intellectual debates initiated in celebration of CEU's 20th anniversary.

The public lecture offered by Prof. Judit Sándor focused on the topic of human reproduction. Advances in assisted reproduction, genetic testing, embryonic stem cell research, synthetic biology, and other fields in contemporary biotechnology have generated considerable attention among legal scholars as many contested cases in relation to them have already reached the courts. Legal interest in these scientific developments has emerged also because they challenge our taken-forgranted understanding of the relationship between the body and the mind, between natural and artificial, or between private and public domains. Prof. Sándor analyzed some of these recent legal debates, and explored the current legal frontiers of the technology of assisted reproduction.

#### 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 academic year of 2011–2012

Petra Bárd

EU constitutional law
EU criminal justice
Department of Legal Studies

Judit Sándor

Privacy and Data Protection in Biotechnology Health and Human Rights Department of Legal Studies Human Rights and Biopolitics
Department of Political Science and Department of Gender Studies

Body, Gender and Commercialization of Human Body
Department of Gender Studies and Department of
Political Science

#### 3.2.2. Teaching and Lecturing at Other Institutions

In the academic year of 2011–2012 CELAB, represented by *Péter Kakuk*, Research Associate, participated in establishing a new network of bioethics educators: the Hungarian Working Group of the Cambridge Consortium on Bioethics Education (BOMM). Collaborating with the University of Debrecen as a host institution, and joining the international network of the Cambridge Consortium on Bioethics Education, the working group aims at improving ethics education across the country. The working group's mission is to improve the quality of bioethics education, to develop and adapt innovative methods in bioethics education, to

#### 3. ACADEMIC ACTIVITIES

preserve and transfer education related experiences and knowledge to the community of scholars.

#### 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

Ethical issues in Health Care Management course, Postgraduate Program for Health Care Management Biotechnology Ethics course, Biotechnology MSc Health Care Ethics and Law, Health Policy MSc Ethics in Medical Rehabilitation, Medical Rehabilitation MSc

Ethics of Science: Responsible Conduct of ResearchResearch Ethics: RCR Education (elective course)

#### József Kovács

"Ethical Questions of Psychotherapy"

Lecture held for clinical psychologists in postgraduate training, organized by the Department of Clinical Psychology of the Semmelweis University October 4, 2011, Budapest, Hungary

"Introduction to Bioethics"

Lecture organized by the Hungarian Association of Bioethics

October 5, 2011, Budapest, Hungary

"Bioethical Aspects of Dealing with Aggressive Patients"

Lecture delivered at the CME course *The Possibilities* of the Prevention and Treatment of Aggression in Clinical Practice

October 6, 2011, Budapest, Hungary

"Ethical Questions in Health Insurance"

Lecture held in the course I-II. *Postgraduate Training Course in Health Insurance* 

October 6, 14, 2011, Budapest, Hungary

"Introductory Thoughts relating to the Birth of HGPM" Lecture delivered at the conference of the Hungarian Group for Philosophy, Medicine and Mental Health October 14, 2011, Budapest, Hungary

"Ethical Approach to Social Values I.-II."

Lecture held at the Institute of Mental Hygiene of the Semmelweis University on the Postgraduate Course of Mental Hygiene)

October 28, November 25, 2011, Budapest, Hungary

"Bioethical Questions of Suicide"

Lecture delivered on the scientific meeting of the Hungarian Association of Phenomenology November 17, 2011, Budapest, Hungary

"Ethical Questions in Psychotherapy"

Lecture held for clinical psychologists in postgraduate training (grade 2), organized by the Department of Clinical Psychology of the Semmelweis University February 13, 2012, Budapest, Hungary

"The Ethical and Legal Principles of Informed Consent" Lecture held at the CME course Information Disclosure and Consent in Everyday Medical Practice from an Ethical and Legal Point of View February 17, 2012, Budapest, Hungary

"Ethical Questions of Competency"

Lecture held at the CME course Information Disclosure and Consent in Everyday Medical Practice—from an Ethical and Legal Point of View
February 18, 2012, Budapest, Hungary

"Do we Need a New World-Ethics to Solve the Ecological Crisis?"

Lecture delivered on the scientific meeting held at the 70th birthday of Prof. Maria Kopp February 24, 2012, Budapest, Hungary

"Applied Ethics I.-II.-III"

Postgraduate lecture delivered at Pázmány Péter Catholic University on the MSc course *Philosophical Practice* 

February 25, March 10, April 14, 2012, Piliscsaba, Hungary

"Ethical Questions in the Management of Medical Mistakes"

Lecture delivered on the CME course *Errors and Mistakes in Medical Practice* organized by the Institute of Behavioral Sciences of Semmelweis University—Budapest and by Medicontext for Medical Communication Ltd. March 3, 2012, Budapest, Hungary

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"Ethical Questions of Human Research"
Lecture delivered at the Institute of Forensic
Medicine of the Semmelweis University in the postgraduate training course of *Health Care Engineering Training*April 27, 2012, Budapest, Hungary

"Reason-Centered Personality Development I–II."
Postgraduate lecture delivered at Pázmány Péter
Catholic University on the MSc course *Philosophical Practice*September 28, 2012, Piliscsaba, Hungary

Imre Szebik

Bioethics course at Semmelweis University, Budapest, Hungary Bioethics for Medical Students Lectures and seminars in the Hungarian, German and English Programs

Bioethics course at Evangelical-Lutheran Theological University, Budapest, Hungary Research Ethics, Lecture at Ph.D. Course October, 2012

#### 4. RESEARCH FELLOWS

## 4. RESEARCH FELLOWS

In the academic year of 2011–2012 CELAB hosted four Research Fellows: Bratislav Stankovic, Mihaela Frunză, Adina Rebeleanu and Slavica Karajičić. In the academic year of 2012–2013 CELAB will host two Research Fellows: László Fosztó and Imre Bárd.

#### BRATISLAV STANKOVIC

Bratislav Stankovic got in contact with CELAB in March 2011, when he participated in the week-long workshop, titled "From Trash to Gold? Contemporary Ethical Chal-



lenges to the Use of Human Tissues and Organs in Biotechnology" organized by CELAB in collaboration with the Curriculum Research Center (CRC). Then from March to May 2012 Bratislav Stankovic visited CELAB again, this time as a joint Senior Research Fellow of the Department of Legal Studies and the Center for Ethics and Law in Biomedicine.

In his work Dr. Stankovic strives to foster improved understanding of the issues at the intersection of law, science and ethics through a variety of means, including traditional publications and presentations, as well as providing input to government and international organizations. He has made particular contributions in the areas of international intellectual property, patent and policy issues involving biotechnology or health, as well as plant molecular and space biology. He is a registered US

patent attorney, teaches Patent Law at Loyola University in Chicago, and serves as a Science and Technology Advisor to the President of Macedonia. He is faculty member of the joint LL.M. Programme in Intellectual Property Law, St. Cyril and Methodius University and University of Strasbourg.

During his Fellowship at CELAB, on May 8, 2012, Bratislav Stankovic held a public lecture at CEU on *Patenting Life: Politics of Innovation*. He addressed some of the issues surrounding patentability of inventions related to DNA, genes, stem cells, transgenic organisms and, in general to living matter. More details about the public lecture are included in 3.1.2. of the present Report.

During his Fellowship at CELAB, Bratislav Stankovic also participated in the Fifth International Research and Practice Conference in Medical Law, April 26–27, 2012, Lvyv, Ukraine, where he delivered two presentations: one on "The Politics of Biotech Patents" and another on "The Importance of Research Ethics for Medical Law."



#### MIHAELA FRUNZĂ

Mihaela Frunză was a Visiting Research Fellow at CELAB in her capacity as Postdoctoral Researcher at the Center for Ethics in Health Policies (CEHP), Grigore T. Popa Uni-

versity of Medicine and Pharmacy, Iași. She stayed at CELAB between June 15 and September 13, 2012 with

the main purpose to deepen and enrich the research carried out at CEHP on ethical aspects of transplantation.

Mihaela Frunză (PhD, Lecturer) teaches courses on Ethics, Medical Ethics, Applied Ethics at the Faculty of History and Philosophy, Babes-Bolyai University, Cluj. She is editor of the Journal for the Study of Religions and Ideologies and is currently involved in several research projects on transplantation ethics and organ trafficking. Some of her relevant publications are: Mihaela Frunză, "Case Studies in Teaching Euthanasia. Ethical and Pedagogical Aspects" in the *Romanian Journal of Bioethics*, vol. 9, no. 1 (January–March 2011), pp. 108–113; Mihaela Frunză, Sandu Frunză, Cătălin Vasile Bobb, Ovidiu Grad, "Altruistic Living Unrelated Organ Donation at the Crossroads of Ethics and Religion. A Case Study," in the *Journal for the Study of Religions and Ideologies*, vol. 9, no. 27, (Winter 2010), pp. 3–24.

#### ADINA REBELEANU

Adina Rebeleanu was a Visiting Research Fellow at CELAB in her capacity as Postdoctoral Researcher at the Center for Ethics in Health Policies (CEHP), Grigore T. Popa University of



Medicine and Pharmacy, Iași. She stayed at CELAB between July 12 and October 12, 2012. The Fellow's research topic was vulnerability in health care systems.

Adina Rebeleanu is Associate Professor at the Department of Social Work, Faculty of Sociology and Social Work, Babes-Bolyai University in Cluj-Napoca. She graduated from the Faculty of Social Work and the Faculty of Law, and took her PhD in Sociology. The topic of her dissertation was: health policies in the framework of Romanian social reform. Her research interests and fields include: comparative research in the field of social problems and social policies (especially the social health policies, vulnerable persons exposed to the risk of marginalization and/or social exclusion), theories, models and methods in social work, the analysis of the legislation in the field of social work and social protection (intentions and outcomes), community development, alternative strategies and the possibility of increasing

their efficacy. Some of her relevant publications are: Soitu Daniela, Rebeleanu, Adina, "Vulnerabilities of the Socio-Medical Legal Framework for Elderly," *Revista de Asistenta Socială*, 2011, pp.137-152; Rebeleanu, Adina, 2010, "Vulnerability in the Romanian Health Care System," in Bourdelais P., Chircop, J. (eds.) *Vulnerability, Social Inequality and Health*, Editiones Colibri, pp:141-158.; Rebeleanu, Adina, 2008, "Characteristics of the Social Health Insurance System in Romania: Past, Present and Trends," in Abreu, L. Boudelais, P (eds.), *The Price of Life. Welfare Systems, Social Nets and Economic Growth*, Editiones Colibri; Rebeleanu, Adina, "Health Policy in Post-Socialist Romania—Intentions vs Achievements," *Studia Sociologia* no.(2008), pp.5-21.

During their stay at CELAB, the Post-doctoral Fellows from the Center for Ethics in Health Policies (CEHP), University of Medicine and Pharmacy "Gr. T. Popa", lasi collected articles for their research in the CEU Library and in the international databases that the CEU is subscribing to. They met regularly with CELAB staff, discussed their research, planned for future common activities and explored the possibilities for building a continuous partnership between their center (CEHP), their university (Babes-Bolyai University, Cluj) and CELAB/CEU. The Fellows also took part in the public meetings organized at CEU. Mihaela Frunză for example participated at the conference organized by the CEU's Public Health Research Group on June 19, 2012. On this occasion the speaker was Dr. Péter Mihályi from the CEU Department of Economics, who delivered a presentation on "Spending Cuts and Centralization in Hungarian Healthcare as a Response to the International Financial Crisis." Adina Rebeleanu participated in the Bioethics Lecture Series organized by the Center for Ethics and Law in Biomedicine (CELAB) at CEU on October 12, 2012. The public lecture was offered by Prof. Nikolas Rose on "Our Brains, Our Selves? The Social Implications of the New Brain Sciences."

The results of the Fellows' research stay at CELAB were presented at conferences such as the *National Conference on Bioethics* and the *International Conference - PR Trend. New Media, Challenges and Perspectives* both organized at Cluj, Romania (see details at 5.1. in this Report), and the following papers got published/were accepted for publication: Cristina Gavriluță, Mihaela Frunză (2012) "Four Anthropological and Religious Arguments in Favor of Organ Donation,"

#### 4. RESEARCH FELLOWS

European Journal of Science and Theology, vol.8, no.3, pp. 47–57; Mihaela Frunză, Enikő Demény, Judit Sándor, Beatrice Ioan "To Share or not to Share Your Donor Status on Facebook: Public Benefits, Private Risks", accepted for publication in Gurch Randhawa & Silke Schicktanz (eds.) Public Engagement in Organ Transplantation, Pabst Publisher Lengerich (2013); and Mihaela Frunză, Cristina Gavriluță, Beatrice Ioan "Stem Cells Transplantation from Romania. A Media Analysis with Focus on the Ethical Aspects", accepted for publication in the journal Organ, Tissues and Cells (due to appear in March 2013).

#### SLAVICA KARAJIČIĆ

Slavica Karajičić spent a one month Fellowship at CELAB, in July 2012, with a CEU Fellowship Grant, and the topic of her research was legal, social and ethical aspects of



reproductive technologies. The Junior Fellow worked under the supervision of CELAB Director Judit Sándor, and was also assisted in her work by CELAB Researcher

Enikő Demény. The result of the Fellowship was a working paper titled *Perspectives of IVF/ICSI Methods in Serbia and Hungary: Comparative Analysis.* 

Slavica Karajičić is a graduate political scientist. After completion of the Faculty of Political Science at Department of Political Science, University of Belgrade, she successfully completed her Master studies in the field of Public Administration and Local Self-government on the topic City Manager, a new model of organization of local government in Serbia. Currently, she is an Erasmus Mundus student of the European Master in Sustainable Regional Health System. She was working for the National Assembly and People's Office of the President of the Republic of Serbia. She took part in "1000 young leaders" program of Serbia in the cross-border cooperation field. For over three and a half years she was working in the Gynecological Hospital "Jevremova" in Belgrade, dealing with one important aspect of public health, namely reproductive and in vitro fertilization. She took part in many different programs, seminars and trainings and is a member of the Serbian Green Youth. Her fields of interest are: In-vitro fertilization, biomedicine and bioethics, health economy and finances, health technology assessment, health ecology and sustainability, health politics and policy, patient safety and risk management, cross-border cooperation.

# 5. EVENTS AND ACHIEVEMENTS IN CHRONOLOGICAL ORDER ....

#### 5.1. PARTICIPATION AT CONFERENCES

During the 2011–2012 Academic Year, CELAB staff and fellows took part in the following academic and scientific events:

Fourth ELPAT Conference and EULOD meeting Presentations by:

Judit Sándor on "Scales and Patterns of Organ

Transplantation Violations"

Violeta Beširević on "Eyes Wide Shut: Organ Trafficking in Kosovo"

Enikő Demény and George Florea on "Assessing Structural and Institutional Deficiencies in the Implementation of the Romanian Legal Policies" November 3–6, 2011, Berlin, Germany

German-Hungarian Dialogue on Bioethical Issues

Organizer: Bioethics Research Group of the Research University of Debrecen

Presentation by József Kovács on "Ethical Issues in Human Stem Cell Research"

November 5, 2011, Debrecen, Hungary

Fourth European Public Health Conference: Public Health and Welfare—Welfare Development and Health

Presentation by Mária Éva Földes (with Hancher, L.) on "Empowering Patients' Access to Information on Prescription Medicines: the Reform Proposed by the European Commission"

November 9-12, 2011, Copenhagen, Denmark

Conference on Suicide and Law

Organizer Mihály Filó

Presentation by József Kovács on "Az öngyilkosság a bioetika nézőpontjából" [On Suicide from a Bioethical Point of View]

November 18, 2011, Budapest, Hungary

Fourth International Workshop of the International Academic Network on Bioethics (IANB): "The Female Body in Biomedicine"

Participant Judit Sándor

December 8-9, 2011, Tozeur, Tunisia

Department of Gender Studies Lecture Series: Voicing Genders, Engendering Voices

Public lecture by Judit Sándor on "Human Reproduction and Beyond: Embryos, Genes, and Tissues on Trial"

January 31, 2012, CEU, Budapest, Hungary

CEU 20th Anniversary Postdoctoral Fellowship: To

Make Dead Bodies Talk

Seminar Cycle: Caring for Dead Bodies from

Medieval to Contemporary Society

Organized by CEU Department of Medieval Studies

Presentation by Enikő Demény on "Dissecting the

Dead for Medical Purposes: Attitudes towards

Deceased Organ Donations"

March 20, 2012, CEU, Budapest, Hungary

#### 5. EVENTS AND ACHIEVEMENTS

Twenty-First Scientific Conference of the Medical and Pharmaceutical Section of the Transylvanian Museum Society

Presentation by Mária Éva Földes on "Orvosilag indokolt, jogos és mégsem mindenki számára elérhető ellátás? Prioritásképzés és rangsorolás a gyógyításban" [Medically Necessary but not Equally Accessible? Priority-setting and Rationing in Healthcare] April 7–9, 2012, Satu Mare, Romania

Rethinking the Self: Transnational and Transdisciplinary Bioethical and Biopolitical Concerns
International Symposium organized by the Helsinki
Collegium for Advanced Studies, University of Helsinki
Presentation by Enikő Demény (with Teddy Florea) on
"Bioethics and the Vulnerable Selves in the Context
of Living Organ Donation"
April 10–12, 2012, Helsinki, Finland

Second Meeting of the Cambridge Consortium on Bioethics Education Participant Péter Kakuk April 11–13, 2012, Paris, France

Fifth Annual CEE & CIS Clinical Trials Forum
Presentation by József Kovács on "Topical Questions
of Clinical Research in Central and Eastern European
Countries"
April 19, 2012, Vienna, Austria

Twelfth AWID International Forum: Transforming Economic Power to Advance Women's Rights and Justice
Session: Resisting Exploitation of Women's Reproductive Health and Human Rights
Participants Enikő Demény and Hedva Eyal (Representing the International Coalition for Reproductive Justice)
April 19–22, 2012, Istanbul, Turkey

and Pharmaceutical Section of the Transylvanian Museum Society
Presentation by Mária Éva Földes on "Vényköteles gyógyszerekkel kapcsolatos betegtájékoztatás: az Európai Bizottság által javasolt reform' [Information to Patients on Prescription Medicines: the Reform Proposed by the European Commission]
April 19–21, 2012, Sovata, Romania

Twenty-Second Scientific Conference of the Medical

Conference on the Situation of Patients' Rights in a Transforming System
Presentation by József Kovács on "A betegjogok magyarországi helyzete a bioetika szemszögéből"
[The Situation of Patients' Rights in Hungary from a Bioethical Point of View]
April 26, 2012, Budapest, Hungary

Biotechnology and Bioethics: Contemporary Problems
Organized by Semmelweis Genomic Network
Presentations by József Kovács on "Ethical Issues of
Synthetic Biology", and by Judit Sándor on "Genetics
Test and Stem Cell Lines as Intellectual Properties:
Bioethical Challenges"
May 9, 2012, Budapest, Hungary

Equal Opportunities for Health: Action and Development
3<sup>rd</sup> Partnership Meeting
Presentation by Enikő Demény on "Global Health and Ethics at CEU-CELAB"
May 10–11, 2012, Poznań, Poland

CEU 20th Anniversary Postdoctoral Fellowship: To
Make Dead Bodies Talk
Seminar Cycle: Caring for Dead Bodies from
Medieval to Contemporary Society
Organized by CEU Department of Medieval Studies
Presentation by Judit Sándor on "The Human and the
Person—Legal Dilemmas on the Human Body in
Research"
May 15, 2012, CEU, Budapest, Hungary

OSF-CEU Brown Bag Lunch Series
Presentation by Judit Sándor on "DNA on Trial"
May 30, 2012, OSF-CEU, Budapest, Hungary

Human Rights in Childbirth Conference
Presentation by Imre Szebik on "Justice and Home
Birth in Hungary Show Trials in the 21st Century"
May 31–June 1, 2012, The Hague, the Netherlands

#### Ninth Internal Medicine Days

Presentation Péter Kakuk on "A hálapénz rendszer elemzése a hivatásetika szempontjából" [An Analysis of the System of Informal Payments from the Perspective of Professional Ethics] June 4–8, 2012, Debrecen, Hungary

#### Twelfth Behavioral Studies Days

Presentation by Péter Kakuk on "Módszertani újdonságok a bioetika oktatásában és a rejtett curriculum" [Methodological Innovations in Bioethics Education and the Hidden Curriculum] Presentation by Imre Szebik on "Nocebo Profession? Problems of Accepting Bio-psychosocial Model in Obstetric Practice" June 16–17, 2012, Szeged, Hungary

Biobanks and Biomedical Collections: an Ethical Framework for Future Research
Conference organized at Council of Europe
Participant Judit Sándor
June 19–20, 2012, Strasbourg, France

Policies and Practices of Health and Illness
Panel at the 2012 International Congress on Romanian Studies: Europeanization and Globalization:
Romanians in Their Region and the World
Presentation by Teddy Florea (with Enikő Demény) on
"The Globalization of Organ Transplantation Policies in a Regional Context"
July 2–4, 2012, Sibiu, Romania

19th World Congress on Medical Law
Presentation by Judit Sándor on "Embryos and
Genes on Trial"
August 7–10, 2012, Maceió, Brazil

European Society for Philosophy of Medicine and Health Care (ESPMH) Annual Conference Presentation by Péter Kakuk on "Teaching Responsible Conduct of Research in the Life Sciences and the Hidden Curriculum" August 21–24, 2012, Nazareth, Israel

New Perspectives on Gamete and Embryo Donation:
Ethics, Kinship and Citizenship in a Globalized World
European Science Foundation Exploratory Workshop
Presentation by Judit Sándor on "Kinship and
Gamete Donation: How Far Can Courts Go?"
Presentation by Enikő Demény on "Networks of
Reproduction in the Globalized World"
September 11–12, 2012, Essex, UK

#### Eighth National Conference on Bioethics

Organized by the Romanian Society of Bioethics, the Romanian College of Physicians, the Center for Health Policy and Ethics at the Grigore T. Popa University of Medicine and Pharmacy, Iaşi, Center of Ethics at the Babes-Bolyai University, Cluj-Napoca, and the UNESCO National Commission of Bioethics, Romania Presentation by Adina Rebeleanu (with Mihaela Frunză and Enikő Demény) on "Vulnerability in the Reforming Health Systems Process—Legal vs. Ethical Perspectives"

Presentation by Mihaela Frunză (with Enikő Demény, Judit Sándor and Beatrice Ioan) on "Ethical Perspectives on Facebook Organ Donation Campaign" September 13–16, 2012, Cluj, Romania

Comparative embryonic stem cell research in mammalians

Yearly Open Workshop of the Partners in FP7 project Participant Judit Sándor September 25, 2012, Budapest, Hungary

PR Trend. New Media, Challenges and Perspectives - International Conference

Presentation by Mihaela Frunză, Enikő Demény, Judit Sándor and Beatrice Ioan on "Ethical Challenges of the Facebook Campaign in Promoting Organ Donation" October 19–20, 2012, Cluj, Romania

Les incidences de la biomédecine sur la parenté -Workshop

Organized by the International Academic Network on Bioethics

Presentation by Judit Sándor on "The Transformation of Families and New Biomedical Technology in Hungary"

October 29-30, 2012, Rio de Janeiro, Brazil

#### Embedding Ethics in Scientific Practice

Expert Meeting at the Hungarian Academy of Sciences Participant Judit Sándor November 6–7, 2012, Budapest, Hungary

Hungarian Skeptic Society Meeting

Presentation by Imre Szebik on "Evidence Based Medicine and Obstetrics"
November 18, 2012, Budapest, Hungary

#### EVENTS AND ACHIEVEMENTS

EpiHealth Project Steering Committee Meeting -Roundtable

Participant: Judit Sándor, as Member of the Ethics Advisory Board

November 22, 2012, Gödöllő, Hungary

TILEC-EUR Health Workshop

Presentation by Mária Éva Földes on "Information to Patients on Medicinal Products and Medical Devices: EU Law Developments"

December 7, 2012, Tilburg, the Netherlands

Bioethics & Genetics: Dilemmas of Genetic Diagnosis and Consultation

Conference organized by: The Bioethics Committee of the Polish Academy of Sciences, The Institute of Philosophy of the University of Warsaw, and The Editorial Board of a Scientific Journal "Ethics" Keynote Speakers:

Prof. Søren Holm, University of Manchester, UK, University of Oslo, Norway

Prof. Judit Sándor, Central European University, Budapest, Hungary

December 7-8, 2012, Warsaw, Poland

#### 5.2. 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.

"Discussion on Euthanasia"

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

June 9, 2011

"Person charged with manslaughter would save lives" [Emberöléssel vádolják, életet mentene] Interview with Petra Bárd by Adrienn Vona In: *Magyar Nemzet* October 17, 2011, p.4.

"Ova Trade and Surrogacy"

Interview with Prof. Donna Dickenson and Prof. Judit Sándor by Júlia Gímes In: *Radio Kossuth*, "Kihívás"

in: Radio Nossutii, Ninivas

http://www.petesejtdonor.hu/discussion/63/kihivas-

mr1-kossuth-radio-2011-11-24-1515-felvetele/p1 November 24, 2011, 15:15-15:30.

"20 Years from Now: A Therapeutic Future" [20 év múlva: terápiás jövő] Interview with József Kovács by László Bán In: *Reader's Digest* (Hungarian edition) November, 2011, pp. 42–43.

"The Road to Good Death has not yet been Found]" [Még keresik az utat a szép halálhoz Magyarországon] Interview with József Kovács by Anita Vorák In: *Origo*, www.origo.hu November 27, 2011.

"The "Uzsoki" Affair. It was Probably not the Mengeles who have United" [Uzsoki ügy: Valószínűleg nem Mengeléék fogtak össze].
Interview with József Kovács by Anna Danó In: Népszabadság
November 28, 2011, p.7.

"The Expectable Life-span at Birth was Read out for the First Time: the Genetic Crystal Sphere [Először olvasták ki génekből a születéskor

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várható élettartamot: genetikai kristálygömb] Interview with József Kovács by Tamás Simon In: *Origo*, www.origo.hu/tudomany/20120110-telomerok-kromoszomak-dns-oregedes-zabrapintyekalapjan-elore-jelezheto-az-elethossz.html January 11, 2012.

- "Can a Transgendered Man Give Birth to a Child?" [Szülhet-e transznemű férfi gyereket? Etikai kérdések] Interview with József Kovács by Orsolya Molnár In: *Origo*, www.origo.hu February 17, 2012
- "Without Deception: Treat Patients as Partners, Right over Genes" ["Becsapás nélkül" Sándor Judit a partnerként kezelt betegekről, és a gének tulajdonjogáról] Interview with Judit Sándor by Csaba Molnár In: Magyar Nemzet March 10, 2012
- "From May Regional Waiting Lists May be Introduced. Ethical and Professional Dilemmas." [Májustól jönnek a térségi várólisták. Etikai és szakmai dilemmák] Interview with József Kovács by Anikó Köbli In: *Medical Tribune*, vol.10. no.5., p. 5. March 22, 2012
- "Each and Every Man is of Jewish and Gipsy Origin a Little Bit" [Minden ember zsidó és cigány is egy kicsit] Interview with József Kovács by Tamás Simon In: *Origo*, www.origo.hu May 16, 2012
- "Bad Science, Good Science?" [Rossz tudomány, jó tudomány?]
  Interview with József Kovács by Dorottya Vizi In: *Radio Kossuth*, "Közelről"
  May 17, 2012, 16.00–16.45.

- "The Side Effect of the Abortion Pill: Intimidated Hospital Directors" [Az abortusztabletta mellékhatása: megfélemlített igazgatók]
  Interview with József Kovács by Anna Danó
  In: Népszabadság
  May 24, 2012
- "Give me Your Gene but do not Ask" [Add a géned, és ne kérdezz!] Interview with Judit Sándor by István Palugyai In: *Népszabadság*, http://nol.hu/tud-tech/20120623add\_a\_gened\_es\_hallgass June 25, 2012
- "Ethical Questions of the Diagnosis of Down Syndrome from the Blood Sample of the Mother" [A Down-kór anyai vérből való korai diagnosztizálásának etikai kérdései]
  Interview with József Kovács by Dorottya Vizi In: *Radio Kossuth*, "Közelről"
  September 24, 2012, 16.00–16.45.
- "On Placebo" [A placebóról] Interview with József Kovács by Júlia Gímes In: *Radio Kossuth*, "Tér-idő." September 28, 2012, 14.15–15.00.
- "Ethical Questions in Animal Treatment [Az állatokkal való bánásmód etikai kérdései]
  Interview with József Kovács by Júlia Gímes
  In: Radio Kossuth, "Tér-idő."
  October 5, 2012, 14.15–15.00.
- "Reproductive Rights" [Reprodukciós jogok]
  Discussion with Judit Sándor by Julia Nyári and
  Mihály Filó
  In: *Radio Q 99.5.*November 17, 2012, 19.00–20.00.

#### 5. EVENTS AND ACHIEVEMENTS

#### 5.3. PUBLICATIONS

#### 5.3.1. Books

Filó Mihály, ed. (2011) Conversation about Death: Euthanasia on the Edge of Law. Budapest: Literatura Medica Kiadó Kft.

Sándor, Judit with Róza Ádány, and Angela Brand (eds.) (2013) Népegészségügyi genomika [Public Health Genomics]. Budapest: Medicina.



Sándor, Judit with Christian Lenk, and Bert Gordijn (eds.) (2011) Biobanks and Tissue Research: The Public, the Patient and the Regulation. Dordrecht: Springer.



#### 5.3.2. Book Chapters and Journal Articles

Bárd, Petra (2011) The Fight Against Terrorism: European Data Protection Standards and the Establishment of a Surveillance Society. In Luciana Caenazzo, Renzo Pegoraro (eds.) Biobanks in the Mediterranean Area. Procurement, Storage and Transfer of Tissue and Cells for Non Clinical Purposes in the Eastern Mediterranean Area: Legal and Ethical Perspectives. Padova: PROGET Edizioni, pp. 143–150.

Bárd, Petra with Judit Sándor (2011) Anonymization and Pseudonymization as Means of Privacy Protection (Second International Workshop of the Tiss.EU Project). In Katharina Beier, Silvia Schnorrer, Nils Hoppe, Christian Lenk (eds.) *The Ethical and Legal Regulation of Human Tissue and Biobank Research in Europe—Proceedings of the Tiss.EU Project.* Göttingen: Universitätsverlag Göttingen, pp. 2025–2034.

Beširević, Violeta (2012) Bioethics in Democracy: Transforming the Clash of Absolutes into Human Rights Issues. In Walter Schweidler (ed.) *Bioethik—Medizin—Politik/Bioethics—Medicine—Politics*. Sankt Augustin, Germany: Academia Verlag, pp. 79–89.

Beširević, Violeta with Judit Sándor *et al.* (2012) Improving the Effectiveness of the Organ Trade Prohibition in Europe. In *Living Organ Donation in Europe: Scientific Report.* Authors of the chapters: 1.1, 1.2, 2.5, 3.5 and 4. Available at:

http://www.eulod.org/Files/Eulod/Content\_Files/Hwc OgEULOD.WP3.ImprovingTheEffectiveness.pdf

Demény, Enikő, Judit Sándor and Péter Kakuk (2012)
Experiments with Cross National Deliberative Processes within the 6th and 7th Framework Program of the EU: The Convergence Seminar, the DEMOCS Card Game, and Nanologue. In Harald Throne-Holst, Gerd Scholl, Eivind Stø and Pål Strandbakken (eds.)

Consumers and Nanotechnology—Deliberative Processes, Social Barriers and Methodologies. Singapore: Pan Standford.

Demény, Enikő with Judit Sándor *et al.* (2012) Improving the Effectiveness of the Organ Trade Prohibition in Europe. In *Living Organ Donation in Europe: Scientific Report.* Authors of the chapters: 2.4, 3.4, 4. Available at: http://www.eulod.org/Files/Eulod/Content\_Files/Hwc OgEULOD.WP3.ImprovingTheEffectiveness.pdf

Filó, Mihály (2012) Death in Custody by Hungarian Law. In Tag Brigitte, Gross Dominik (ed.) *Tod im Gefängnis: Hungerstreik, Suizid, Todesstrafe und "normaler" Tod aus rechtlicher, historischer und ethischer Sicht.*Frankfurt, New York: Campus Verlag, pp. 209–226.

Filó, Mihály (2011) Way to Clean Talking. In Filó Mihály (ed.) Conversation about Death: Euthanasia on the Edge of Law. Budapest: Literatura Medica Kiadó Kft., pp. 9–12.

Földes, Mária Éva with A. Covaci (2012) Research on Roma Health and Access to Healthcare: State of the Art and Future Challenges. *International Journal of Public Health*, vol. 57, no. 1, pp. 37–39.

Földes, Mária Éva (2012) Transparency—An Essential Requirement in Medical Device Regulatory Reform.

- In SSRN Series, TILEC Discussion Paper No. 2012-022. Tilburg: University of Tilburg, June 2012.
- Földes, Mária Éva (2011) Orvosilag indokolt, jogos és mégsem mindenki számára elérhető ellátás? Prioritásképzés és rangsorolás a gyógyításban [Medically necessary but not equally accessible? Priority-setting and rationing in healthcare]. *Orvostudományi Értesítő* (Bulletin of Medical Sciences), vol. 84, no.2, pp. 107–113.
- Hancher, L. with Mária Éva Földes, (2011) Push or Pull?— Information to patients and European Law. European Journal of Consumer Law/ Revue Européenne de Droit de la Consummation, vol.4, pp, 749–776.
- Kakuk, Péter (2012) Genetic Exceptionalism. In Chadwick, Ruth (ed.) *Encyclopedia of Applied Ethics*, 2<sup>nd</sup> edition. Oxford: Academic Press, pp. 445–452.
- Kakuk, Péter (2012). A szemfényvesztő impakt faktor [Delusive impact factor]. *Orvostovábbképző Szemle*, vol.19, nos. 7–8, pp. 74–77.
- Kakuk, Péter (2011) Publikációs etika: a pénzügyi érdekkonfliktusok szabályozása az orvosi folyóiratokban. [Publication Ethics: Regulating Financial Conflict of Interests in Biomedical Journals]. *Lege Artis Medicinae*, vol. 21, no.1, pp. 65–71.
- Bánfalvi, A. & Kakuk, P. (2011). Pénzügyi tevékenységek és az orvosi hivatás: az érdekkonfliktusok etikai problémája. [Financial Activities and the Medical Profession: Conflicts of Interest as an Ethical Problem.] *Orvostovábbképző Szemle*, vol. 18, nos. 6–8 (June–August 2011), pp. 77–82.
- Kovács, József (2012) (ed.): Biotechnológiai etika. [Biotechnology Ethics] Manuscript (p. 360) (Accepted for publication as an e-book by Semmelweis Kiadó.)
- Kovács, József (2012) Honorary Authorship Epidemic in Scholarly Publications: How the Current Use of Citation-based Evaluative Metrics Make (Pseudo)Honorary Authors from Honest Contributors of Every Multi-Author Article, *Journal of Medical Ethics Online* [First published on August 3, 2012] as doi: 10.1136/medethics-2012-100568.
- Kovács, József (2012) Response to the Commentaries of Melissa S Anderson and Murray J Dyck. *Journal of Medical Ethics Online* [First published on October 4, 2012] as doi: 10.1136/medethics-2012-101016.
- Kovács, József (2012) A pszichoterápia etikai és jogi kérdései. [Ethical and Legal Questions of Psychotherapy]. In Zsolt Unoka, György Purebl, Ferenc

- Túry, IstvánBitter, (eds.) A pszichoterápia alapjai. Budapest: Semmelweis Kiadó, pp. 266–273.
- Kovács, József (2012) Az emberen végzett kutatás és szabályozásának története etikai szemszögből [The History of Human Research and its Regulation]. *Lege Artis Medicinae (LAM)*, vol.22, no. 3, pp. 226–231.
- Kovács, József (2012) Etikai kérdések a pszichoterápiában I. rész [Ethical Questions in Psychotherapy. Part I.]. *Lege Artis Medicinae (LAM)*, vol.22, no.4, pp. 310–315.
- Kovács, József (2012) Etikai kérdések a pszichoterápiában II. rész [Ethical Questions in Psychotherapy. Part II.]. *Lege Artis Medicinae (LAM)*, vol.22, no.5, pp. 388–391.
- Sándor, Judit (2012) Bioethics and Basic Rights: Persons, Humans, and the Boundaries of Life. In Michel Rosenfeld, András Sajó (eds.) *The Oxford Handbook of Comparative Constitutional Law.* Oxford: Oxford University Press, pp. 1142–1165.



- Sándor, Judit with Petra Bárd (2011) Anonymization and Pseudonymization as Means of Privacy Protection (Second International Workshop of the Tiss.EU Project). In Katharina Beier, Silvia Schnorrer, Nils Hoppe, Christian Lenk (eds.) The Ethical and Legal Regulation of Human Tissue and Biobank Research in Europe Proceedings of the Tiss.EU Project. Göttingen: Universitätverlag, pp. 25–34.
- Sándor, Judit and Petra Bárd (2011) Anonymity and Privacy in Biobanking. In Judit Sándor, Christian Lenk, and Bert Gordijn (eds.) *Biobanks and Tissue Research: The Public, the Patient and the Regulation.* Dordrecht: Springer, pp. 213–230.
- Sándor, Judit (2012) Adolescents and Medical Law in Hungary. In Brigitte Feuillet-Liger, Ryuichi Ida, Therese Callus (eds.) *Adolescents, Autonomy and Medical Treatment*. Bruxelles: Bruylant, pp. 189–199.
- Sándor, Judit (2011) L'adolescent et le droit médical en Hongrie. In Brigitte Feuillet-Liger, Ryuichi Ida (eds.) Adolescent et Acte Médical, Regards Croisés. Bruxelles: Bruylant, pp. 195–205.
- Sándor, Judit (2011) Az eutanázia mint politikai kérdés [Euthanasia as a Political Issue]. In Mihály Filó (ed.) Párbeszéd a halálról: Eutanázia a jogrend peremén [Dialogue on Death: Euthanasia on the Peripheries of

... www.ceu.hu/celab

#### 5. EVENTS AND ACHIEVEMENTS

the Legal System]. Budapest: Literatura Medica Kiadó, pp. 83–95.

Sándor, Judit with Márton Varju (2012) Patenting Stem Cells in Europe: The Challenge of Multiplicity in European Union Law. *Common Market Law Review*, no. 3, pp. 1007–1037, available at SSRN: http://ssrn.com/abstract=2072255

Sándor, Judit, Petra Bárd, Claudio Tamburrini, and Torbjörn Tännsjö (2012) Law, Ethics and Medicine. The Case of Biobank with the Law: Between a Legal and Scientific Fiction. *Journal of Medical Ethics Online* [First published on September 24, 2011] as doi:10.1136/jme.2010.041632

Szebik, Imre (2012) Gondolatok az egészségügy finanszírozási kérdéseiről antropológiai szemmel.

[An Anthropologist's Ideas on Financing the Health Service] In Lázár and Pikó (eds.) *Orvosi Antropológia* [Medical Anthropology]. Budapest: Medicina, 2012.

Varju, Márton with Judit Sándor (2012) Patenting Stem Cells in Europe: the Challenge of Multiplicity in European Union Law. *Common Market Law Review*, no. 3, pp. 1007–1037.

Varju, Márton (2012) European Human Rights Law as a Multilevel Human Rights Regime. In Jan Wetzel (ed.) *The EU as a* 'Global Player' in Human Rights? London and New York: Routledge.



#### 5.4. AWARDS, APPOINTMENTS

Prof. Judit Sándor has become a member of the Editorial Board of CEU Press, member of the Editorial Board of the journal *Studia humana* (SH) and member of the Editorial Board of *Medicine*, *Health Care*, *and Philosophy*.

Studia humana is a multi-disciplinary peer reviewed journal in Poland publishing valuable contributions to any aspect of the human sciences. Medicine, Health Care and Philosophy: A European Journal is the official journal of the European Society for Philosophy of Medicine and Health Care. It provides a forum for international exchange of research data, theories, reports and opinions on bioethics, and the philosophy of medicine and health care in general.

Prof. Violeta Beširević was awarded the *Fulbright Stipend* and admitted as a Global Research Fellow at the NYU School of Law, for the Fall semester of the academic year of 2012–2013.

Enikő Demény was appointed member of the editorial board of the *International Journal: Ethics and Bioethics* (in Central Europe).

Mihály Filó and Imre Szebik joined CELAB as a Research Associates, starting with the academic year of 2011–2012. Éva Földes was appointed as Coordinator of the Special



CELAB End of Year Lunch, December 19, 2011

Edition on 'Consumer Choice: New Developments in the Health Care Sector in Europe' of the Revue Européenne de Droit de la Consommation /European Journal of Consumer Law (R.E.D.C.), 4/2011.

György Kovács was appointed to the post of Vice President of the Board of the Hungarian Fulbright Association in the Spring of 2012.

# 6. BUDGET.....

#### 6.1 REVENUES IN AY 2011-2012

Approved Budget from CEU	Amount in Euro
C-5036 Total	55,739
External Funding	Amount in Euro
EULOD	27,020
Total	27,020

#### 6.2 SPENDING IN AY 2011-2012

#### C-5036 - CELAB MAIN BUDGET CODE

Budget category	Amount in Euro
Personnel cost	55,019
Other costs	720
Total	55,739

#### C-8336 - EULOD PROJECT

Budget category	Amount in Euro
Personnel costs	26,597
Other costs	423
Total	27,020

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