

celab.ceu.hu/



| C | E | L | A | B |

CENTER
FOR ETHICS AND LAW
IN BIOMEDICINE

ANNUAL REPORT

2013–2014



Editor-in-chief: Judit Sándor
Executive editor: Enikő Demény

© December 2014
Center for Ethics and Law
in Biomedicine (CELAB)

ISSN 1992-4038

CELAB Report is published annually

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

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

TABLE OF CONTENTS

1. FOREWORD	2
2. RESEARCH AND POLICY ACTIVITIES	6
2.1. PARTICIPATION AND COLLABORATION IN RESEARCH NETWORKS	6
2.1.1. Neuro-Enhancement: Responsible Research and Innovation (NERRI)	6
2.1.2. Cell-Based Regenerative Medicine: New Challenges for EU Legislation and Governance (EUCeLLEX)	11
2.1.3. Equal Opportunities for Health: Action for Development	13
2.1.4. Infertility and the Socio-Technical Practice of Assisted Reproductive Technologies	13
2.1.5. International Academic Network on Bioethics (IANB-RUIB)	14
2.1.6. Disaster Bioethics	15
2.2. POLICY AND OUTREACH ACTIVITY	16
2.2.1. Globalization and Commodification of the Human Body: A Cannibal Market?	16
2.2.2. Bioethics and Biopolitics—28th European Conference on the Philosophy of Medicine and Health Care	17
2.2.3. International Forum on Intercountry Adoption and Global Surrogacy	18
2.2.4. The 3rd Central European Dictionary of Political Concepts Conference	18
3. ACADEMIC ACTIVITIES	20
3.1. PUBLIC LECTURES ORGANIZED BY CELAB	20
3.1.1. Public Lecture: European Legal Policy on Biotechnology and Intellectual Property: Competition and Responsible Innovation	20
3.2. TEACHING	21
3.2.1. Teaching at CEU	21
3.2.2. Teaching and Lecturing at Other Institutions	21
3.2.3. Bioethics Teaching Network (BOMM)	22
4. EVENTS AND ACHIEVEMENTS IN CHRONOLOGICAL ORDER	24
4.1. PARTICIPATION IN CONFERENCES	24
4.2. SCIENCE COMMUNICATION AND MEDIA EVENTS	26
4.3. PUBLICATIONS	28
4.4. AWARDS, APPOINTMENTS AND SPECIAL EVENTS	31
5. BUDGET	36
5.1. REVENUES IN AY 2013/2014	32
5.2. SPENDING IN AY 2013/2014	32

1. FOREWORD

In the above quote Sheila Jasanoff distinguishes between two bodies of writing, the social and the biological, and claims that the two are now linked more than ever before. When we set out the interdisciplinary mission of CELAB at the beginning of its activities nine years ago, we had exactly this connection in mind and intended to build a bridge between the social sciences, the natural sciences, and law in our research. This is an especially demanding work at an internationally known, prestigious university, with an almost exclusive focus on social sciences and humanities.

In the rich repertoire of research subjects that we have addressed there is a recurrent reference to the issues of privacy in the field of biomedicine. Privacy was an important focus of our research in several CELAB projects: previously on genetic databases and biobanks; and most recently on neuroscience. Promoting the right to privacy in these fields may diminish the consequences of the increasing medical gaze and surveillance that developed with the emergence of new techniques of biomedicine, such as genetic testing and the self-monitoring of health parameters. In the new world of personalized medicine the individual is the main target of medical intervention. As a result, this model focuses on solving medical problems on the individual, and not on the social level. Our bioethical and legal research at CELAB continues to investigate the consequences of increasing medicalization and the strengthening of medical surveillance; and to explore the bioethical problems related to the emergence of personalized medicine, the individualization of health, and the prospects of enhancement beyond therapy. Within this complex field of research interest, our main focus was the NERRI project over the past academic year.

During the 2013–2014 academic year the CEU–CELAB team carried out multiple tasks within the NERRI project. First, our researchers set out to identify the ethical and legal principles that could serve as potential *normative anchors* for the conceptualization and regulation of new neurotechnologies in developing and rethinking the ethical and legal framework of human rights law and private law applied to this field. Our report on normative anchors was discussed extensively at the Barcelona and the Nijmegen consortium meetings in 2013 and 2014.

Second, our researchers conducted sixteen *interviews* during the summer and autumn of 2013 with various stakeholders that we had previously identified: neuroscientists, psychologists, clinicians and clinical researchers, patient groups, ethicists, as well as commercial users and operators. The interviews focused on the main themes of NERRI: exposure, knowledge,

1. FOREWORD

3

“Two encyclopedic bodies of writing—one social, the other scientific—define the meaning of life in our era. Encompassing, respectively, law and biology, these intertwined, mutually supporting, indeed coproducing textual projects frame the possibilities, limits, rights, and responsibilities of being alive—most especially for the species we call human.”

Sheila Jasanoff (2011) Introduction: Rewriting Life, Reframing Rights, in *Reframing Rights: Bioconstitutionalism in the Genetic Age*, p.1.

evaluation, moral issues, and governance. Our attempts to secure interviews with representatives of government administration and regulation failed owing to the particular Hungarian circumstances. Generally, we had to address the suspicion of interviewees towards the concept of neuro-enhancement, which does not have an unequivocal translation into the Hungarian language. Moreover, because of the novelty of the concept and the surrounding ideas in the Hungarian context, most of our interviewees preferred to discuss the traditional questions of neurological diseases and their social environment. We found that most stakeholders were concerned with the most immediate issues linking them to neurological diseases, and had difficulty imagining the technical and therapeutic opportunities promised by neuro-enhancement.

Third, we organized four so-called “*mobilization and mutual learning exercise*” (MML) events in Hungary. The first MML was organized in April 2014 with the participation of groups representing patients of neurological illnesses and the disabled. For this occasion we selected a documentary film titled *Fixed* for screening it to the participants of the workshop. With the permission of Ms. Regan Brashear, the director of the film, we produced the Hungarian subtitled version of the movie after translating its narrative and dialogues. This helped a lot to stimulate the debate on the access and limitation to new, enhancement technologies. The second MML, also in April 2014, focused on the possibilities and threats of neuro-enhancement and performance enhancement in education, and university students were invited to take part in the discussion. We launched an essay competition on the topic and several Ph.D. students submitted insightful essays. Then in September 2014, the third MML investigated the responsibility of scientists involved in neurobiological research and we invited prominent experimental and clinical neuroscientists and psychologists. The fourth MML was held in October 2014 and it addressed regulatory issues with the participation of representatives of government agencies, NGOs, and other experts on legal regulation.

Work on the mobilization and mutual learning exercises (MMLs), which were extremely resource intensive and required significant planning and organization efforts, started as early as the Barcelona consortium meeting in 2013. In order to achieve the objective to deliver the desired outputs, we had to tailor the workshops according to the special needs of the participating stakeholders. Therefore, in each case the MMLs contained activities or program components that addressed specific stakeholder groups: for example, documentary and feature film screening (including the production of Hungarian subtitles) on human enhancement for patient groups and university students; a nation-wide essay competition on enhancement in education for high school and university students; short keynote lectures delivered by prominent researchers and experts; and screening of short clips from our video recorded interviews to policymakers.

Fourth, with the help of Imre Bárd and Gabriella Göbl, a *new website* (nerri.hu) was launched for this project in Hungarian. While CELAB shared the English language overview of the interviews with the NERRI consortium, the video or audio-recorded original interviews were made available on the Hungarian webpage.

We also participated in workshops held in Barcelona, Nijmegen, and Porto. All these events were aimed to harmonize the various research activities conducted at different partner institutions.

The other main line of our activities concentrated around the *EUCeLLEX* project, which started in October 2013. During the first few months of the project we had a kick-off meeting in Paris, conducted interviews with stakeholders in Madison, Wisconsin (United States), and several webinars were also organized. In the first full year of this research CELAB associates had two major tasks: first, to perform a comprehensive mapping of stakeholders on the procurement side of human stem cell technologies in the countries involved in the research, and second, to conduct a comparative legal analysis of legal and other regulation of stem cell procurement in the relevant states. In 2015 CELAB will organize a workshop in Budapest.

In 2013–2014 we also continued our cooperation within the Francophone network of research on bioethics and medical law, the Réseau Universitaire International de Bioéthique (with French Acronym: RUIB). In this long-term project, which started in 2006, representatives from 20 countries are involved—including Belgium, Brazil, Chile, Canada, China, Egypt, France, Germany, Greece, Hungary, Italy, Japan, Senegal, Spain, Switzerland, Taiwan, Tunisia, Turkey, the United Kingdom, and the United States. The December 2013 workshop was held in Brussels on the legal protection of the human body, and in November 2014 another workshop focused on the relevance of human dignity in different jurisdictions. In addition to the annual workshops organized, the network is also very productive in publishing academic books. Over the past two years, four books have been published by Bruylant in Brussels: in 2013, *Corps de la femme et biomédecine: Approche internationale* (in French) and *The Female Body: A Journey through Law, Culture and Medicine* (in English), then in 2014 *Les incidences de la biomédecine sur la parenté: Approche internationale* (in French) and *Reproductive Technology and Changing Perceptions of Parenthood: Around the World* (in English).

In 2014 we also participated in a Hungarian project financed by OTKA, the Hungarian Social Scientific Research Fund, focusing on the transformation of reproductive technologies. The regulation of reproduction is a very dynamic legal field: new and new groups claim access to reproduction and technological advances improve the success rates, but these developments also pose further ethical and legal challenges to decision-makers. Within the framework of this research project we have conducted interviews with stakeholders to clarify the current dilemmas in clinical practice and started to map out the relevant literature and legal framework.

CELAB has also organized several smaller research seminars, one with the lecture of a visiting fellow, György Kovács, who currently works at the European Commission, and another with the participation of our new fellow, Emma Cecilia Bullock. Péter Kakuk, CELAB research associate, organized a workshop with the

1. FOREWORD

5

participation of all instructors and professors who teach bioethics and related subjects at Hungarian universities.

During the past twelve months CELAB research associates participated in several important events that are listed in the section of conferences of this *Annual Report*. Péter Kakuk and Judit Sándor participated at the European Conference of the Society of Philosophy of Health Care held in Debrecen on August 27–30, 2014. At this conference, which focused on the topic of Biopolitics and Bioethics, Judit Sándor delivered the keynote speech titled “Me Molecule,” on August 27. Several keynote speeches were given by CELAB members. Violeta Beširević gave a keynote lecture on “Unlocking Organ Donation Euthanasia: Legal Perspective” at the Institute of Bioethics of the University of Zürich on May 15, 2014. Judit Sándor explored the question “Is Commodification of the Human Body a Gender Issue?” in her presentation at the Symposium on Globalization and Commodification of the Human Body, held at the Brocher Foundation, in Geneva, on February 6–7, 2014. Professor Sándor also delivered an invited speech at the New York University Law School, in New York, on March 5, 2014, with the title “Commodification of the Human Body: Global Challenges to Biomedical Law.” Enikő Demény participated at the International Forum on Inter-Country Adoption and Global Surrogacy in the Hague, Netherlands.

CELAB researchers regularly appear in the international and local scientific media, as well. Mihály Filó produced a radio series on bioethics, while Judit Sándor launched an opinion column in *Magyar Narancs*, a political-cultural weekly, in which she publishes essays on bioethics and human rights topics on a monthly basis.

While CELAB has a very small staff, we have always been proud of the external scholars who have been working with us for the nine years of CELAB’s operation and without whom we would not be where we are now. Over the past academic year, a policy research team led by Péter Kakuk coordinated the official translation of the latest text of the Helsinki Declaration, and added commentaries to the translation. Andrea Domján, Péter Kakuk and Judit Sándor took part in this project.

Further information on our activities can be found in our Annual Reports; and the Facebook page www.facebook.com/Center.CELAB; and posted to the CELAB subsite of the CEU website celab.ceu.hu/.

Judit Sándor

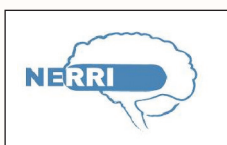
Director of the Center for Ethics and Law in Biomedicine (CELAB)

celab.ceu.hu/

2. RESEARCH AND POLICY ACTIVITIES

2.1. PARTICIPATION AND COLLABORATION IN RESEARCH NETWORKS

2.1.1. Neuro-Enhancement: Responsible Research and Innovation (NERRI)



Type of funding scheme: EU FP7 Coordination and Support Actions (Supporting)

Starting date: March 15, 2013

Duration: 2013–2016

Participating Institutions:

Ciência Viva—Agência Nacional para a Cultura Científica e Tecnológica, Portugal
 London School of Economics and Political Science, United Kingdom
 Radboud University Nijmegen, the Netherlands
 Austrian Academy of Sciences, Austria
 Scuola Internazionale Superiore di Studi Avanzati, Italy
 Instituto de Biologia Molecular e Celular, Portugal
 Tilburg Law School, Tilburg University, the Netherlands
 Johannes Gutenberg Universität, Mainz, Germany
 Johannes Kepler Universität, Linz, Austria
 Kings' College, United Kingdom
 European Brain Council, Belgium
 Universitat Pompeu Fabra, Catalonia, Spain
 Center for Ethics and Law in Biomedicine, Central European University, Hungary

This project aims to contribute to the new field of Responsible Research and Innovation in Neuro-Enhancement (NE) in the European Research Area and to the shaping of a normative framework underpinning the governance of NE technologies. These will be achieved through so-called “mobilization and mutual learning” (MML) activities engaging scientists, policymakers, industrial and commercial stakeholders, 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 (1) currently available methods, (2) experimental technologies, and (3) hypothetical techniques. Each of these types raises 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 is developed and extended into Work Packages. Mobilization and mutual learning forms the central commitment of the project from the outset to the conclusion. Based on the analytic classification this mobilization is seen as stimulating a broad societal dialogue that employs 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 have assumed the task to synthesize national experiences, to map the contours of a normative framework as it emerges from societal engagement and dialogue,

2. RESEARCH AND POLICY ACTIVITIES



József Kovács



Csaba Pléh



Zoltán Nádasdy

and to elaborate the concept of Responsible Research and Innovation in Europe. The consortium comprises of experts in the neuro-cognitive sciences, the social sciences, law, philosophy, communication science, and intermediaries that facilitate public engagement with science and technology. Many experts have prior experience with European Union projects and have successfully collaborated with other members of the consortium.

In the 2013–2014 Academic Year CELAB organized four Mobilization and Mutual Learning (MML) events in Budapest. In the four MMLs we covered the topics most relevant for Hungary and the choice of these themes were informed by the outcomes of the interviews conducted by the CELAB team in 2013.

The four MMLs addressed different technologies and disciplines in neuro-enhancement. Our choice was determined by the subject matter of the MMLs and the orientation of the expected audience. MML1 addressed patient groups and discussed neuro-enhancement from their perspective, MML2 dealt with neuro-enhancement and 'smart drugs' in higher education, MML3 focused on responsible research, and MML4 discussed regulation and the role of regulators in neuro-enhancement.

The first MML event was organized on April 11, 2014, addressed different patients groups, and dealt with *cutting-edge and future technologies of neuro-enhancement*. The aim of this meeting was to bring together individuals, patients groups, patient's rights organizations, paralympians, social scientists, bio-ethicist, and the public to discuss the possibilities and the personal and social implications of new, frontier technologies in the treatment of these devastating diseases and disabilities. The event began with the screening of *Fixed: The Science/Fiction of Human Enhancement*, a documentary directed by Regan Brashear, and it was the premier of the film in Hun-

gary. The film explores the boundaries of 'normalcy' and 'disability', and raises the question of what makes us human. The screening was followed by the personal account of one of the participants, Benjamin Lebor on his life before and after he received a cochlear implant, an electronic device that provides direct electrical stimulation to the auditory (hearing) nerve in the inner ear. After Lebor's account the floor was opened for comments and questions. Some of the comments reflected on the huge gap between the concepts of trans-humanism and bionic men discussed in the documentary and the reality people with disabilities have to face in Hungary. A member of the audience questioned the philosophy of enhancement; another noted the role of control, saying that "one has to be mature enough to be able to make responsible decisions. One has to know how to use technology, and also, technology is not a solution for everything." Pál Szekeres, deputy state secretary at the Ministry of Human Resources and paralympian fencer, noted that despite advances in technology, there will always be new disabilities but he sees hope for the disabled. "Once we accept ourselves, we can be accepted by society." Reflecting on the film and the ensuing discussion, CELAB Researcher Márton Varju concluded the first MML meeting noting that scientists have a responsibility in what they're researching and therefore they should participate more actively in science communication.

The second MML was organized on April 29, 2014 and dealt with neuro-enhancement in higher education, focusing on the use of 'smart drugs' and conventional *cognitive performance enhancing substances*. The event aimed to explore the attitudes of higher education students towards the enhancement of neuro-capabilities and capacities (cognition, memory, communications skills, etc.) for the purpose of achieving better in school and in the workplace, and it

Still from the Documentary *Fixed*

Audience at the MML 1 Event



Bejamin Lebor at the MML 1 Event

provided an opportunity to examine the participants' understanding of the social, ethical, and economic implications of neuro-enhancement for non-therapeutic purposes. After the presentation of the winners of the national essay competition "Neuro-Enhancement in Education: How Far Would You Go To Achieve Your Best?" the MML session started with screening an excerpt of the movie *Limitless*, based on Alan Glynn's novel *The Dark Fields*, and directed by Neil Burger. The film's tagline: "What if a pill could make you productive, rich and powerful?" served as a conversation starter. CELAB Director Judit Sándor moderated the discussion in which the invited participants were Attila Gulyás, associate professor at the Department of Cellular and Network Neurobiology at the Institute of Experimental Medicine in Budapest, and József Kovács, Head of the Department of Bioethics and Deputy General Director of the Institute of Behavioral Sciences at Semmelweis University, Budapest.

On September 26, 2014 the Center for Ethics and Law in Biomedicine hosted the third mobilization and mutual learning (MML) session. The third MML covered very diverse areas of research in neurosciences (psychology, cognitive sciences, brain research, neural stem cell science) with the involvement of prominent researchers, who discussed the role and responsibility of researchers in neuro-enhancement. The purpose of the third meeting was to seek preliminary inspiration and analysis from scientific and societal stakeholders, in order to make the project's understanding of the *responsibility and role of researchers* more relevant and precise. The event was opened by Prof. Judit Sándor who summed up the current stage of the NERRI project and the purpose of the third event. The first presentation, titled "Neural Plasticity: Psychological Interpretations" was given by Prof. Csaba Pléh (Chair of the Department of Cognitive Science at the Budapest University of Technology and Economics). Professor

2. RESEARCH AND POLICY ACTIVITIES



CELAB Associates Violeta Beširević, Enikő Demény, and József Kovács at the MML 2 Event



Judit Sándor and Attila Gulyás at the MML 2 Event

Pléh outlined three models of human thinking: (a) thinking is wholly fixed by nature; (b) thinking is wholly culturally influenced; and the more popular view that (3) thinking is partially fixed by nature and susceptible to some cultural modification. The lecturer's central thesis was that thinking should not be interpreted within the dichotomic framework of 'nature versus nurture', but instead viewed through the lens of 'nature *via* nurture'.

The next lecturer was Prof. András Dinnyés (Szent István University; Universiteit Utrecht; General Director BioTalentum) who spoke on "Stem Cell Therapy for Neurodegenerative Diseases: Possibilities and Barriers." Prof. Dinnyés began by arguing that stem cell research provides a unique opportunity for testing the effect of drugs on neural systems. Stem cell research also provides societal benefits, opening up the possibility of personalized medicine and potentially leading to the development non-invasive diagnostic and treatment techniques. Prof. Dinnyés explained that there is a specific problem for regenerative neural therapy: namely, that the neural stem cells, unlike other stem cell types, do not have much plasticity. For this reason, regenerative neural medicine will only be possible in the distant future: at this stage neural stem-cell research is not much more than an "intellectual pursuit."

Ádám Takács (Eötvös Loránd University) rounded off the talks by giving a presentation on the problems of diagnosing Attention Deficit Hyperactivity Disorder (ADHD) with the title "Identifying at Risk Groups of ADHD." Takács argued that choosing samples for research on ADHD is problematic: partly because ADHD

has a low prevalence rate (5%), and partly because each diagnosis is temporally unstable (symptoms change unpredictably over time). Takács noted that the diagnosis of ADHD is further destabilized by its unique feature that the interpretation of the symptoms is often based on the testimony of the guardians, peers, and teachers of the patient. Takács estimated that in light of these factors around 50 percent of ADHD diagnoses are uncertain.

The meeting concluded with a lively expert panel discussion with the participation of Zoltán Nusser, Dezső Németh, Imre Szabik, as well as the CELAB fellows and members of the audience. During the debate, which was moderated by Márton Varju, it was argued that researchers are aware of and abide by the legal regulations on scientific research. However, participants were generally concerned by the variety of factors that drive scientific research and whether research can be carried out responsibly in view of them. Three forces constraining the current focus of scientific research were identified: (1) financial support from pharmaceutical industries, (2) social demand, and (3) the intrinsic value of basic research.

The fourth MML took place on October 8, 2014, and it did not address a particular technology or discipline; it focused instead on the dilemmas that neuro-enhancement in general presents for regulation. Professor Judit Sándor opened the discussion stating that neuroscience seems to be the fourth turning point in the history of humankind to shake the self-perception of human beings that they are unique creatures. The first was Copernicus' model that placed the Sun instead of the Earth in the center of



Judit Sándor Introducing the MML 3 Event



András Dinnyés, Judit Sándor, Imre Szebik, and Márton Varju at the MML 3 Event

the universe, the second was Darwin's theory of evolution that located humans among the animals, and the third was the discovery that the genetic composition of humans is almost identical with that of many animal creatures. Recent discoveries in neuroscience have shed light on how, besides the brain, other parts of the neural system contribute to the processing of information and revealed that both the functional organization and physical structure of the brain changes throughout a person's lifetime.

Prof. Sándor described her experiences of the mutual learning process thus far, noting that there is still no consensus on how neuro-enhancement should be defined, let alone translated into Hungarian. The audience was shown three video clips which underlined the fact that medical professionals themselves are perplexed by the concept of neuro-enhancement. In one of the clips the bioethicist, József Kovács, highlighted the difference between treatment and enhancement, noting that while treatments lead from sickness to health, enhancements enables perfection beyond the human condition. In another clip, Kovács took this distinction further, saying that neuro-enhancement could allow for wealth to create a "biological inequality, with obsolete 'Trabant-bodied' humans, and enhanced, superhuman 'Audi-bodied' humans" (referring to the popular difference made between the durable but low technology East German car and its hi-tech West German counterpart). The cognitive scientist, Csaba Pléh, noted that the plasticity of the brain is often left out from the discussion of neuro-enhancement, even though not

only the functioning but also the structure of the brain is affected by hormonal and cultural factors, including the various ways of improving cognitive capacities and performance.

After showing the video clips, the philosopher László Nemes gave a short lecture on "Neuroethics and New Paternalism," then Marianna Nagy, Deputy Dean of the Faculty of Law at Eötvös Lóránd University in Budapest, discussed the difficulties of regulating scientific results in particular and the relationship between law and cognitive science in general. Nemes discussed how the concept of free will and autonomy has changed through the history of bioethics, how it's been affected by libertarianism and paternalism in the past few years, and how traditional Kantian ethics are in conflict with modern, more paternalistic ethics.

"The study of law is the most conservative science," Marianna Nagy began her talk, noting that new approaches from various perspectives are needed when creating legislation. The law does not reflect on psychology, cognitive sciences and the individuals' decision-making processes, but presumes a direct timeline from decision to action, Nagy said. "The concept of causative action is completely different in the study of law and cognitive science." Still, she warned against rushing the process of aligning the two, as science hasn't yet reached the point when its results should appear in legislation, although they should be considered in jurisprudence. "We can't *not* reflect and react to the results of cognitive science," Nagy concluded. The talks on the issues of decision-

2. RESEARCH AND POLICY ACTIVITIES



Presentations at the MML 4 Event

making, legislation and regulation generated a lively discussion session with the participation of lawyers, economists, stakeholders, and interested parties.

CELAB participants in the project: Judit Sándor, Márton Varju and Enikő Demény
NERRI project on the internet: www.nerri.eu, www.nerri.hu

2.1.2. Cell-based Regenerative Medicine: New Challenges for EU Legislation and Governance (EUCeLLEX)



Type of funding scheme: EU FP7
Starting date: October 1, 2013
Duration: 2013–2016

Participating Institutions:

Institut National de la Santé et de la Recherche
 Médicale (INSERM), Paris, France
 Gottfried Wilhelm Leibniz Universität, Hannover,
 Germany
 Center for Ethics and Law in Biomedicine, Central
 European University, Budapest, Hungary
 Legal Pathways BV, Aerdenhout, the Netherlands
 The Chancellor, Masters and Scholars of the
 University of Oxford, United Kingdom

Medizinische Universität, Graz, Austria
 Fondation Nationale des Sciences Politiques
 Sciences Po, Paris, France
 Katholieke Universiteit, Leuven, Belgium
 Royal Institution for the Advancement of Learning,
 McGill University, Montréal, Canada

The European EUCeLLEX Project brings together experts from various disciplines and jurisdictions to deliver an overall review of the current landscape of regulating and governing the procurement, use, and applications of stem cells in Europe, as well as to identify the future challenges for regulation. The project thus involves a comprehensive examination of the application of European legal instruments on regulating stem cell banks as well as a mapping of the current practices with respect to the therapeutic use of human cells in the different countries taking part in the project. The purpose is to develop recommendations for the European Commission to draw up legislative measures in line with medical advances in this field. The coordinator of this project is the Institut National de la Santé et de la Recherche Médicale (INSERM). The project started in October 2013, the kickoff meeting was held in Paris, in December 2013.

Within the EUCeLLEX Project CELAB contributes prominently to Work Package 2 on Stem cell sources and procurement. In this WP our team focuses on two main research questions: (1) what are the interactions between EU legislation and the procurement of human (embryonic, fetal, and adult) stem cells for research and innovation? And (2) what are the effects of the application and implementation of EU legislation on the procurement of human (embryonic, fetal, and adult) stem cell research and/or innovation. We seek to answer these questions using scientific and legal analysis, based on facts and figures, and with the goal in mind to inform the evidence base that will help the European Commission optimize the innovative potential, the efficacy, and the ethicalness of future EU legislation in this area of research and innovation.

In the EUCeLLEX project, the CELAB team worked on two larger tasks this year. The first was a comprehensive mapping of stakeholders on the procurement side of human stem cell technologies in the relevant states. We produced a nearly one-hundred-page report listing the regulatory and administrative stakeholders of stem cell procurement, the relevant public and private biobanks, the



EUCelLEX Kickoff Meeting in Paris

major funding and umbrella organizations, and the most important stakeholders in basic and applied stem cell research. The report provides a clear indication of the scale and range of activities in stem cell procurement, and it also gives an accurate picture of the major geographical hubs of stem cell related work. The second task was a comparative legal analysis of legal and other regulation of stem cell procurement in the relevant states. The comparative report identified the main concepts and the main components following which regulatory regimes are constructed. It focused, in particular, on the silences and gaps of the regulatory environment as well as on the substantive and formal-technical regulatory differences in the different states. Our analysis revealed clear regulatory patterns, and suggested potential avenues for regulatory changes following different potential regulatory strategies.

In 2013 Judit Sándor conducted several preliminary interviews with stakeholders in Madison (Wisconsin). Márton Varju and Judit Sándor explore and contact the main stakeholders and map out the relevant legal frameworks in Austria, Canada, Belgium, France, Germany, Hungary, the Netherlands, the United Kingdom, and the United States. The next workshop of this project will be held in Budapest in May 2015.

CELAB participants in the project: Judit Sándor and Mátyás Varju

EUCelLEX Websites:

www.eucellex.eu

twitter.com/Inserm_EN

www.horizonhealth.eu/project/cell-based-regenerative-medicine-new-challenges-eu-legislation-and-governance/270

twitter.com/horizonhealtheu

2. RESEARCH AND POLICY ACTIVITIES

2.1.3. Equal Opportunities for Health: Action for Development



Duration of the project: 2011–2014

Partner Institutions:

Doctors with Africa—CUAMM, Italy
 Department of Medicine and Public Health
 (Dipartimento di Medicina e Sanità Pubblica),
 Università di Bologna, Italy
 Italian Global Health Watch (Osservatorio Italiano
 sulla Salute Globale, OISG), Italy
 Italian Secretariat of Medical Students (Segretariato
 Italiano Studenti di Medicina, SISM), Italy
 Regione Veneto, Italy
 Transilvania University of Braşov, Romania
 Medicine Students Scientific Association of Braşov
 (ASSM), Romania
 Redemptoris Missio Foundation, Poland
 Poznań University of Medical Sciences, Poland
 International Federation of Medical Students'
 Association (IFMSA), Poland
 Papardes Zieds Association, Latvia
 Medical University of Pleven, Bulgaria

In association with:

Center for Ethics and Law in Biomedicine, Central
 European University (CELAB), Hungary
 Association of Medical Students in Bulgaria—Pleven
 Branch, Bulgaria
 Association for the Development of Personality and
 Human Communities, Pleven, Bulgaria
 Latvian Medical Students' Association (LaMSA),
 Latvia
 University of Latvia, Riga, Latvia
 Malta Medical Students' Association, Malta
 National Federation for the Orders of Doctors and
 Dentists (Federazione Nazionale Ordine Medici
 Chirurghi e Odontoiatri), Italy

This project ended on February 2014 with an international conference held in Padua, Italy. CELAB was represented at this event by CELAB Research Associate Péter Kakuk. Universities, organizations and student associations from seven European countries were involved in this project, united by a common interest in global health education. Equal Opportunities for Health: Action for Development was an edu-

cational and awareness-building project designed to highlight the importance of viewing health as a fundamental human right, closely related to individual and social development.

The project promoted the discussion and dissemination of the Global Health paradigm, understood as a broad interdisciplinary approach to health that takes a position in favor of equity, fairness, social justice, and cooperation on both the local and the global levels. The aim of the project was 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.

As associate partner, CELAB participated in the partnership meetings organized within the framework of the project. The last partnership meeting took place on January 31 in Padova, Italy, and it was followed by an international conference titled A Decent Life for All: Equal Opportunities for Health on February 1, 2014, also in Padova. In discussing sustainable developmental goals, the presentations at the conference moved away from the dominant approach of focusing on social determinants of health to the global perspective that views health as a universal human right and a determinant of economic and social development.

CELAB participants in the project: Judit Sándor, Enikő Demény and Péter Kakuk

Website: www.educationglobalhealth.eu/en/

2.1.4. Infertility and the Socio-Technical Practice of Assisted Reproductive Technologies

Type of funding scheme: OTKA

Starting date: October 1, 2013

Duration of the project: 2013–2017

The aim of this project, financed by OTKA (National Social Scientific Research Fund), is to investigate issues that are relevant both on the academic and the policy level. The overall purpose is to conduct cutting edge research, the results of which are important for international audiences and can be published in leading international journals, whilst at the same time being of practical relevance. The pilot phase of research consisted of literature review and qualitative data analysis. In the first phase, which started with a

little delay in the spring of 2014, 40 semi-structured interviews are made with various stakeholders: experts, law-makers, medical practitioners, women engaged in IVF treatment, etc. In the second phase 40 semi-structured interviews will involve men and women with infertility problems who have decided to take part in assisted reproductive technology treatments.

Participants in the research: Lilla Vicsek (the project coordinator focusing on social aspects), Judit Sándor (ethical and legal aspects), Gábor Király (theories of science and technology studies), Zoltán Navratyil (legal aspects) Zsófia Bauer (PhD student, social aspects of biotechnologies) and Veronika Paksi, (PhD student). The project started October 2013 and will be completed in September 2017, and the preliminary results will be discussed at a small-scale seminar in 2015.

CELAB participant in the project: Judit Sándor
Information on the project:

nyilvanos.otka-palyazat.hu/index.php?menuid=930&num=108981&lang=EN

2.1.5. International Academic Network on Bioethics (IANB–RUIB)



Based on the idea of Professor Brigitte Feuillet-Liger of the University of Rennes, France, an inter-university research network—titled Réseau Universitaire International de Bioéthique (or RUIB) in French and International Academic Network on Bioethics (IANB) in English—was created in 2006 to study various general topics at the intersection of bioethics and family law, medical law and human rights, from an interdisciplinary and intercultural perspective. Although the network includes mainly lawyers, it also engages social scientists whose research focuses on the social implications of biomedicine, family law, and medical ethics. In the framework of this cooperation, therefore, the thematic workshops and the resulting publications aim to explore cultural differences in the social perception of bioethics through the analysis of local laws.

Individual members of the network are Brigitte Feuillet-Liger, Pénélope Agallopoulou, Amel Aouij-Mrad, Thérèse Callus, Maria-Claudia Crespo-Brauner, Françoise Furkel, Dominique Gobau, Carmen Domínguez Hidalgo, Yao-Ming Hsu, Ryuichi Ida, Francis Kernaleguen, Dominique Manaï, Kristina Orfali, Saibe Oktay-Özdemir, Véronica San Julian, Geneviève Schamps, and Judit Sándor, representing twenty countries: Belgium, Brazil, Chile, Canada, China, Egypt, France, Germany, Greece, Hungary, Italy, Japan, Senegal, Spain, Switzerland, Taiwan, Tunisia, Turkey, the United Kingdom, and the United States. Prof. Judit Sándor, the director of CELAB, has been a member of the Advisory Board and the network since the beginnings.

After a preparatory meeting held in Paris in 2007, workshops have been organized every year with a focus on a specific thematic field. The first workshop in Rennes, France, in December 2007 explored ethical issues related to assisted reproduction and donor anonymity from a cross-cultural perspective. The Kyoto meeting in January 2009 focused on the autonomy of choice for adolescents in medical treatment. The second Rennes meeting in May 2011 discussed the cultural differences in the end-of-life decisions within the family. The following workshop in Tozeur, Tunisia in December 2011 explored the various culturally specific ways biomedicine looks at the female body. The next meeting was held in Rio de Janeiro in November 2012 and was dedicated to the changing perceptions of parenthood around the world, as a result of the emerging reproductive technologies. The December 2013 workshop in Leuven and Brussels focused on the principles of protecting personhood and the body under powerful biomedical regimes. The most recent meeting was held in Monaco, on November 26–29, 2014, and explored how the principle of human dignity is respected in various biomedical contexts and jurisdictions. Future workshops will be organized in Istanbul, Santiago de Chile, and Dakar.

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. Two books are the outcome of each thematic workshop: one in French and one in English. By the end of 2014, Bruylant has published ten books from the conference proceedings, including four volumes over the past two years: in 2013, *Corps de la femme et biomédecine: Approche internationale (in French)*

2. RESEARCH AND POLICY ACTIVITIES



IANB-RUIB Workshop in Leuven

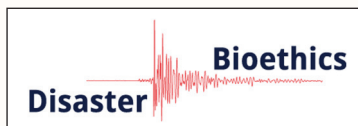
and *The Female Body: A Journey through Law, Culture and Medicine* (in English), then in 2014 *Les incidences de la biomédecine sur la parenté: Approche internationale* (in French) and *Reproductive Technology and Changing Perceptions of Parenthood: Around the World* (in English). The outcomes of the 2013 workshop will be published in 2015.

CELAB participant in this project: Judit Sándor is a member of the Steering Committee and a contributor to the workshop meetings and publications.

Duration of the project: Ongoing.

Project website: rui-bioethique.univ-rennes1.fr/versions+etrangeres/English/

2.1.6. Disaster Bioethics



Type of funding scheme: COST IS1201

Starting date: April 1, 2013

Duration of the project: 2012–2016

Disaster Bioethics is a European Cooperation in Science and Technology (COST) project that intends to develop effective ways to address ethical issues triggered by disasters. This COST Action runs from 2012 to 2016 and bring together scholars and humanitarian relief workers and agencies to deal with

the ethical issues arising in disaster relief and disaster planning. At the time of the kick-off meeting in October 2012, 19 countries were involved, and Dónal O'Mathúna was elected Chair of the Action.

Disasters have become more frequent and more costly, and these trends are predicted to continue. As a result, disaster risk reduction and management are important priorities for national, European, and global agencies. Ethical decisions must be made throughout disaster planning and in relief responses. High level statements stress the importance of disaster ethics and the principle of putting people first in disasters. Yet few resources are available for disaster ethics decision-making. Policymakers, humanitarian agencies and individual responders seek ethical guidance and training materials to better address the challenging and distressful ethical dilemmas arising in disasters. Evidence-based knowledge is required to promote high-quality ethical decision-making.

This COST Action aims to improve ethical decision-making for disasters by gathering knowledge of the ethical dilemmas and issues, carefully examining them, and developing training materials and publish resources to address disaster ethics. These outputs will assist policy-makers, humanitarian organizations, healthcare professionals, researchers and the public. The will benefit European citizens and organizations, and especially those lower income countries that are affected by disasters disproportionately and the more vulnerable within those regions.

The scientific kickoff meeting of the project was held at Dublin University on April 25–26, 2013. In the 2013–2014 academic year, two project conferences were organized. The first meeting, titled Inclusion or Exclusion: Responding Ethically to Disaster Refugees, was held at the Valetta Campus of the University of Malta, on April 24–25, 2014. The second conference bore the title Bioethical Decision-Making in Disasters, and it convened at the Faculty of Medicine, University of Porto, Portugal on October 9–10, 2014. CELAB research associate Péter Kakuk attended these meetings.

CELAB participant in this project: Péter Kakuk is a member of the Management Committee and serves as the Financial Rapporteur for the project

Project website: disasterbioethics.eu

2.2. POLICY AND OUTREACH ACTIVITY

2.2.1. Symposium on Globalization and Commodification of the Human Body: A Cannibal Market?

It is now obvious that the emergence of new bio-medical technologies has resulted in an increasing demand for health care. However, for various economic, legal, or ethical reasons, or due to shortages in human resources, public health services, even in developed countries, cannot respond to this growing demand—leaving the needs of some patients unmet.

Liberalization of the international healthcare market and rationalization of public health expenditure over the past twenty years have resulted in two fundamental changes in the organization of healthcare services on the global level. On the one hand, some emerging countries have developed private, highly specialized health services particularly designed to meet foreign demand at low cost. This new type of medical supply has a growing influence on the behavior of relatively wealthier patients who are more and more willing to go abroad for treatment. On the other hand, liberalization has allowed greater workforce mobility, allowing health professionals in poor regions to look for better-paid jobs outside their countries. This two-way migration of health professionals and patients is one of the most noteworthy features of the new globalized healthcare industry. Traveling for medical care, known as medical tourism, has recently grown in fields such as oncology, cardiovascular surgery, medically assisted reproduction, as well as organ and tissue transplantation.

In the last two of these fields, development of medical services is supported in some countries by flexible legislation and the existence of a large number of socially vulnerable people. The result is a wide availability of low-cost resources needed for specific treatments (organs, human material, surrogate mothers, etc.). Human body parts of socially disadvantaged persons are rented or purchased on a more or less legal basis in order to meet the needs of patients who can afford the

costs of those medical services. Commodification of human body parts is another feature of the global healthcare market. A new type of trade based on increasing social inequalities in most societies and between countries is developing. The result is an economy that is comparable not only to a neo-colonial one, but also to a kind of 'cannibal market'.

The previous thoughts introduced the major themes of an international and multidisciplinary symposium that took place in Geneva, Switzerland on February 6–7, 2014. It was called together in order to better understand the various aspects of this new neo-colonial or 'cannibal' market and to assess its implications for the future. The main objectives of the symposium were: (1) to analyze, from a social sciences perspective, the *globalized development of the commodification of the human body* for medical purposes; (2) to develop the outline of a research agenda based on key ideas and findings that emerge from the discussions; and (3) to create an international network of social scientists on this topic.

The discussions were based on four case studies: (1) the unregulated market of assisted reproduction technology and in particular the development of *commercial surrogacy*; (2) the conditions for *organ harvesting* that feeds the market for transplantation; (c) the *'brain drain' of health professionals* which



The Geneva Symposium on the Commodification of the Human Body

2. RESEARCH AND POLICY ACTIVITIES

reduces the capacity of poor countries to respond to their own health challenges; and (d) the development of private institutions that *collect, store, and sell human material* (gametes, embryos, blood, tissues, etc.). These represent the four areas in which the growth of this market has significant human, social, medical, economic, legal, religious, and ethical implications.

The Symposium was organized by the Institute for Global Studies, Fondation de la Maison des Sciences de l'Homme (FMSH), Paris, with the generous support of the Brocher Foundation, Geneva; the Swiss Academy of Medical Sciences, Basel; the National Fund for Scientific Research, Brussels; the Royal Academy for Overseas Sciences, Brussels; the Institute of History of Medicine and Public Health, Lausanne; the Center of Studies on International Cooperation and Development (CECID); ULB, Brussels; and the Institute for Biomedical Ethics, Geneva.

The Director of CELAB, Judit Sándor participated at this event and delivered a lecture titled "Is Commodification of the Human Body a Gender Issue?" In her presentation, Prof. Sándor pointed out that inserting gender aspects into the analysis of the commodification of the human body and body parts has proven to be fruitful since the current trends in such commodification reproduce the challenges that gender studies have already identified, criticized, and fought against in other fields.

CELAB participant in the symposium: Judit Sándor as invited presenter

Information on the Symposium: www.brocher.ch/en/events/68/globalisation-and-commodification-of-the-human-body-a-cannibal-market/

2.2.2. Bioethics and Biopolitics—28th European Conference on the Philosophy of Medicine and Health Care

The international conference of the European Society for the Philosophy of Medicine and Health Care (ESPMH), titled Bioethics and Biopolitics, was held in Debrecen, Hungary on August 27–30, 2014. The organizers of the 28th Annual Conference of the ESPMH invited presentations and plenary discussions to focus on bioethics and biopolitics. The term 'biopolitics' is either used as a philosophical or sociological term referring to the works of Negri, Agamben, Rose,



Keynote Speakers Judit Sándor and Attila Bánfalvi at the Conference



Audience at the Debrecen Conference

or especially Foucault, who focused on the contemporary style of governing populations through 'bio-power', or as a more general umbrella concept referring to the public policies regulating the applications of biotechnological innovations and research results in the life sciences.

These usages suggest that biopolitics is a central concept for modern societies. At the same time, bioethics has become increasingly interdisciplinary and

ever more politicized. Bioethical issues figure in presidential campaigns and parliamentary elections. Bioethicists are advisors for governments and frame recommendations for public policies. Bioethics and biopolitics have become deeply interwoven activities.

If bioethics and biopolitics are highly interwoven, then how should we understand their relationship? Does politics corrupt bioethics? How does bioethics influence policymaking? How has bioethics been affected by its role in policymaking? The invitation to reflect on these concepts and issues and to assess their relationship was successful as more than a hundred and forty researchers participated in the event. A selection of presentations will be published in a book format by Springer in the Global Bioethics Series in 2015.

CELAB participants at the conference: Judit Sándor gave a presentation titled "The 'Me Molecule'" and Péter Kakuk was the organizer of the conference.

The conference in the media: www.dehir.hu/video-galeria/az-ember-mint-teremto-etikai-kerdesek-az-orvostudomanyban/
www.unideb.hu/portal/hu/node/13495

2.2.3. International Forum on Intercountry Adoption and Global Surrogacy

The International Forum on Intercountry Adoption and Global Surrogacy was held in The Hague, on August 11–13, 2014. The purpose of the forum was to provide an opportunity for women's health advocates, scholars, policy experts, and legal practitioners to come together and generate an evidence base for international adoption and surrogacy problems and collect best practices that might inform policymakers and authorities working within the framework of the Hague Convention on Intercountry Adoption (HCIA). Cross-cutting themes reflected topics pertinent to the HCIA special commission on the practical operation of the convention. The Forum was divided into five thematic areas: (1) HCIA Implementation and the Best Interests of the Child; (2) Inter-country Adoption, Countries of Origin, and Biological Families; (3) Inter-country Adoption Agencies and the HCIA; (4) Force, Fraud, Coercion; and (5) Global Surrogacy Practices.

Enikő Demény was invited to participate on the Global Surrogacy Practices panel that was chaired by Marcy Darnovsky from the Center for Genetics and



Participants at the Hague Forum

Society, Berkeley, California. This section addressed topics such as women's experiences as surrogates; impacts of race, class, gender, and power on women's decisions, on their health, human rights, and well-being; experiences of children, intended parents, and egg providers in surrogacy arrangements; understanding the range of surrogacy regulations and practices in different jurisdictions (including 'best practices' and 'most problematic practices'); similarities and differences between intercountry surrogacy and intercountry adoption, and lessons learned from the latter. Enikő Demény contributed to the discussion and gave an overview of commercial surrogacy in the region of Central and Eastern Europe. The results of the forum are included in a report edited by Marcy Darnovsky and Dianne Beeson.

CELAB participant at the forum: Enikő Demény
Information on the forum: www.iss.nl/research/conferences_and_seminars/periodic_conferences_debates_and_seminars/international_forum_on_intercountry_adoption_global_surrogacy/about_the_forum/

2.2.4. Third Annual Conference of the Central European Dictionary of Political Concepts

Enikő Demény presented a paper titled "From Eugenics and 'Race Protection' to Preventive Medicine and Family Planning in Hungary" at the Third Annual Conference of the Central European Dictionary of Political Concepts held on April 26–27, 2014 in Prague, Czech Republic. The conference was divided into four sessions: Participatory Democracy; Politics of Health in Central Europe; Internet and Politics; and Politics of

2. RESEARCH AND POLICY ACTIVITIES



Enikő Demény at the Prague Conference

Arts Languages in Central Europe. The conference was organized by the association *Res Publica Nowa*, from Warsaw, Poland in cooperation with the Centre français de recherche en sciences sociales (CEFRES), the Bratislava School of Liberal Arts (BISLA), and

Magyar Lettre Internationale, and it was supported by the International Visegrad Fund.

The Central European Dictionary of Political Concepts is a novel approach to the exploration and mapping of political discourses in Central Europe. Gathering the work of scholars, writers, and journalists, the dictionary works in two directions: it provides an analysis of concepts and terms that are considered universal in modern politics—such as ‘the welfare state’, ‘totalitarianism’, ‘Left and Right’, ‘East and West’—and examines these concepts through the unique context provided by Central Europe. The intention of the editors is to provide readers with a companion of short essays illustrating the political language of Central Europe and its reference to universalized concepts.

CELAB participant at the conference: Enikő Demény
Information on the conference:

publica.pl/teksty/central-european-dictionary-of-political-concepts-3rd-edition-41056.html

3. ACADEMIC ACTIVITIES

3.1. PUBLIC LECTURES ORGANIZED BY CELAB

The lecture series of CELAB continued in the 2013–2014 academic year with a public lecture offered by György Kovács.

3.1.1. Public Lecture: European Legal Policy on Biotechnology and Intellectual Property—Competition and Responsible Innovation

On April 4 György Kovács, Legal and Policy Officer at the European Commission, Directorate General Internal Market and Services, and Visiting Research Fellow at CELAB, delivered a public lecture at the Central European University on “European Legal Policy on Biotechnology and Intellectual Property: Competition and Responsible Innovation.” In his presentation, Kovács pointed out that it is necessary to establish an efficient and balanced intellectual property infrastructure in order for innovation, competition, and creation to flourish in the single market. A joint study of the European Patent Office and the Office of Harmonization on the Internal Market published last year demonstrates the important role intellectual property plays in the European economy. More than one third of the jobs in Europe (77 million) depend either directly or indirectly on sectors making intensive use of intellectual property. In these IP intensive sectors remuneration is 40% above other sectors.

The lecture covered the recent policy initiatives of the European Commission on intellectual property, with special focus on the pharmaceutical sector, on personalized medicine, and biotechnology. Efficient enforcement of intellectual property rights is crucial in order to keep Europe attractive for innovation and investments. The presentation

also provided an update on the ongoing copyright consultation and the possible next steps in harmonizing copyright law.

The strategy of the European Commission to enforce intellectual property rights is characterized by the ‘follow-the-money’ approach. Instead of pursuing harsh and repressive punishments on individual infringers, the European Commission’s balanced enforcement strategy is focusing on commercial scale infringements by encouraging voluntary cooperation of key stakeholders to eliminate counterfeits from the supply chains and to create alternative business models to provide better legal protection for consumers.



György Kovács

3. ACADEMIC ACTIVITIES

3.2. TEACHING

CELAB's staff and fellows are involved in teaching both at the CEU and at other universities in Hungary and in the other Central and Southeastern European countries. 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 2013–2014 Academic Year at CEU

Petra Bárd

EU Constitutional Law
EU Criminal Justice

Judit Sándor

On sabbatical leave in the 2013–2014 academic year

3.2.2. Teaching and Lecturing at Other Institutions

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)

"Right to Die with Dignity: Euthanasia in Modern Legal Discourses"

Lecture at the Belgrade Youth Center
April 7, 2014, Belgrade, Serbia

"'Thou Shalt Not Kill'—Except from Mercy: Euthanasia in Modern Legal Discourse"

Lecture at the University of Niš, School of Law,
April 10, 2014, Niš, Serbia

"Unlocking Organ Donation Euthanasia: Legal Perspective"

Lecture at the Institute of Bioethics, University of Zürich
May 15, 2014, Zürich, Switzerland

Péter Kakuk

Bioethics Courses at University of Debrecen, Medical and Health Science Centre, Debrecen, Hungary

Bioethics (course offered in the General Medical Program, in Hungarian and English)

Bioethical Cases (elective course offered in Hungarian and English)

Bioethics & Dental Ethics (course in the Dentistry Program, in Hungarian and English)

Bioethics (course offered for Medical Diagnostic Laboratory Analysts)

Ethics in Pharmacy (course in Hungarian and English)

Research Ethics: RCR Education (elective course, in Hungarian and English)

Ethical Issues in Health Care Management (course offered in the Postgraduate Program on Health Care Management)

Selected issues in bioethics (For Ph.D students)

József Kovács

"The Fundamental Issues of Bioethics"

Postgraduate lecture delivered at the Pázmány Péter Catholic University
December 14, 2013, Budapest, Hungary

"Ethical Questions of Psychotherapy"

Lecture held for sophomore year clinical psychologists, organized by the Department of Clinical Psychology of the Semmelweis University
February 10, 2014, Budapest, Hungary

"Ethical Questions of Psychotherapy"

Lecture held in the framework of CBT consultation program, Psychotherapeutic Ambulance of the Psychiatric and Psychotherapeutic Clinique, Semmelweis University
March 10, 2014, Budapest, Hungary

"Solving the Typical Problems of Ethics Commissions I."

Invited lecture at the Psychology Institute of Eötvös Lóránd University
March 28, 2014, Budapest, Hungary

“Evidences and Ethical Questions in Clinical Psychology”

Lecture held for the compulsory training of clinical psychologists at International Business School (IBS)
April 23, 2014, Budapest, Hungary

“Anatomy and Neuroethics”

Lecture held at CME postgraduate training program, at the Psychiatric Clinique of the Szeged University
(<http://www.diagnozis.eu/adas/2014.-junius-4-i-adas.html>)
May 14, 2014, Szeged, Hungary

“Solving the Typical Problems of Ethics Commissions II.”

Invited lecture at the Psychology Institute of Eötvös Lóránd University
May 30, 2014, Budapest, Hungary

“Psychologist Ethics and Ethical Questions in Psychotherapy”

Lecture held at the Ethics course of the Clinical and Health Psychology Specialization, Psychology Institute
September 12, 2014, Budapest, Hungary

“The Ethical Questions of Euthanasia in Hungary”

Invited lecture at the Budapest Rotary Club
September 23, 2014

“Ethical Principles of Informed Consent”

Lecture held at the compulsory CME course *Information Disclosure and Consent in Everyday Medical Practice—From an Ethical and Legal Point of View*, Semmelweis University
September 26, 2014, 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*, Semmelweis University
September 27, 2014, Budapest, Hungary

“Current Ethical Questions in Psychotherapy”

Lecture held at the compulsory training of the Psychiatric and Psychotherapeutic Clinic, Semmelweis University
October 4, 2014, Budapest, Hungary

Imre Szezik

Bioethics courses at Semmelweis University, Budapest, Hungary

Bioethics for Medical Students (Lectures and seminars in the Hungarian, German and English Programs)

Research Ethics (Lectures in the PhD Program)

Bioethics courses at Lutheran Theological University, Budapest, Hungary

Research Ethics (Lectures in a CME course for physicians, February and September, 2014)

Bioethics lectures at University of Vienna

Six Lectures in Bioethics and Research Ethics, April, 2014.

3.2.3. Bioethics Teaching Network (BOMM)



Although as bioethicists we represent a variety of disciplines, there are certain truths we hold in common: (1) that the future of our field rests on the foundation of Bioethics Education and (2) ensuring the strength of this foundation requires a bold look at where we are now and what future directions should be pursued. In April 2010, Cambridge University Press held the first Cambridge Consortium for Bioethics Education in New York. Leaders in the field were invited to initiate a shared dialogue addressing such questions as: Why are we doing this? What goals are we trying to achieve? Where is bioethics education taking place? How well are we doing? What next? Tackling those questions and finding practical answers continues to be the aim of our subsequent meetings. To date, delegates from 29 countries have participated in the Cambridge Consortium and brought their successes—and challenges—into teaching bioethics around the world. Expanding our work together continues as we focus on “how to” methods of teaching bioethics. Through our collective information and shared experiences we are moving forward as an international community of bioethics

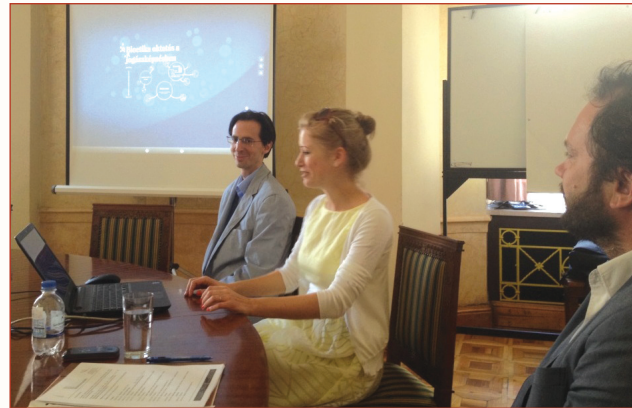
3. ACADEMIC ACTIVITIES

educators.

In the 2012–2014 Academic years CELAB, represented by Péter Kakuk, CELAB Research Associate participated in establishing a new network of bioethics educators: the *Hungarian Working Group of the Cambridge Consortium on Bioethics Education (BOMM—Bioetika Oktatás Magyarországi Munkacsoportja)*. Collaborating with the University of Debrecen, Department of Behavioral Sciences 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 preserve and transfer education related experiences and knowledge to the community of scholars.

The objectives of BOMM are to join the international network of the Cambridge Consortium on Bioethics Education, to establish a Hungarian network for professionals involved in bioethics education, to organize a yearly workshop focusing on bioethics education and to build a web-based platform for our activities and interests. Its mission is to improve the quality of bioethics education in the country, to develop and adapt innovative methods in bioethics education, to preserve and transfer education related experiences and knowledge to the community of scholars.

This professional group is open to professionals working in the field of bioethics education in institutions of higher learning. There are more than 30 educators already joined, and we had our first workshop at the University of Debrecen on June 4, 2013. The Second Annual Meeting was hosted by CELAB and took place on June 13, 2014. The workshop started with the opening remarks made by CELAB Director Judit Sándor. The first presentation was offered by Orsolya Varga (Assistant Professor at the University of



Tamás Barcsi, Judit Zeller and Péter Kakuk at the BOMM Meeting

Debrecen) who introduced the audience to an online educational platform on animal ethics. In the next presentation, Judit Zeller and Tamás Barcsi (Assistant Professors from University of Pécs) discussed their experiences of bioethics teaching at the law school. The last lecture in the morning session was offered by Gusztáv Kovács (Assistant Professor at the Theological College of Pécs) on "Knowledge from the Heavens, or Elephant Memory? Teaching Bioethics within Moral Theology." The morning lectures were followed with a lively debate on the situation of bioethics teaching across various academic fields. The afternoon session started with a presentation by Vera Szántó (Assistant Professor at Eötvös Lóránd University, Budapest) on "Cloning at the Faculty of Humanities: Challenges of Bioethics Education in the Humanities Program," then Péter Kakuk (Assistant Professor at University of Debrecen, CELAB Research Associate) gave a talk on "Bioethics in Films—Experiences and Perspectives for Development." The session ended with a debate on the conditions and contexts of bioethics teaching in Hungary and with plans for the forthcoming annual meeting.

4. EVENTS AND ACHIEVEMENTS IN CHRONOLOGICAL ORDER

4.1. PARTICIPATION IN CONFERENCES

During the 2013–2014 Academic Year, CELAB staff and fellows took part in the following academic and scientific events

EuCellLEX Kickoff Meeting

Presentation by Judit Sándor on the Work Package on Stem Cell Procurement
December 4, 2013, Paris, France

Les Principes de Protection du Corps dans le Cadre de la Biomédecine

(The Principle of the Protection of Human Body in Biomedicine)

7th Workshop of the International Academic Network on Bioethics (RUIB)

Participant: Judit Sándor

December 16–17, 2013, Brussels, Belgium

Eighth National Conference of the Hungarian Psychiatric Association

Within the framework of the World Association of Psychiatric Rehabilitation (WAPR) Symposium

Lecture by József Kovács on the “Psychiatry and Human Rights from the Perspective of Bioethics” and on “Communication as Bridge: Communication and Bioethics”

January 22–25, 2014, Budapest, Hungary

Globalization and Commodification of the Human Body: A Cannibal Market?

International Conference organized by Institute

for Global Studies, Fondation de la Maison des sciences de l’homme (FMSH)

Presentation by Judit Sándor on “Is Commodification of the Human Body a Gender Issue?”

February 6–7, 2014, Paris, France

Commodification of the Human Body:

Global Challenges to Biomedical Law

Organized by the New York University, Law School

Presentation by Judit Sándor

March 5, 2014, New York, United States

European Legal Policy on Biotechnology and Intellectual Property: Competition and Responsible Innovation

Lecture by György Kovács

Organized by the Center for Ethics and Law in Biomedicine (CELAB) at the Central European University

April 4, 2014, Budapest, Hungary

Neuro-Enhancement: Access to New Technologies—The NERRI Project’s Mobilization and Mutual Learning (MML) Event No. 1

Organizers and participants: Judit Sándor,

Márton Varju, Enikő Demény and Gabriella Göbl

April 11, 2014, Budapest, Hungary

European Union and Rising Populism: A Challenge for Democracy

Institute of European Democrats

4. EVENTS AND ACHIEVEMENTS

Presentation by Petra Bárd on Populism and the Chances of Minority Protection
April 24–25, 2014, Bratislava, Slovak Republic

Third Conference on the Central European Dictionary of Political Concepts

Presentation by Enikő Demény on “Old and New Eugenics in Central and Eastern Europe”
Organized by *Res Publica Nowa*, Warsaw, Poland
April 25–27, 2014, Prague, Czech Republic

Smart Drugs and Fairness in Education—The NERRI Project’s Mobilization and Mutual Learning (MML) Event No. 2

Organizers and participants: Judit Sándor, Márton Varju, Enikő Demény, and Gabriella Göbl
April 29, 2014, Budapest, Hungary

Attitudes, Parties, Citizens: Facing the 2014 European Parliament Elections in Hungary in Regional and European Contexts
Roundtable Discussion at the Hungarian Europe Society on “Hungary inside the European Union for Ten Years: Parties, Citizens, Political and Economic Trends”
Participant: Petra Bárd
May 15, 2014, Open Society Archives, Budapest, Hungary

Normative Aspects of Neuro-Enhancement. NERRI Project Conference
CELAB participant: Judit Sándor
May 26–28, 2014, Nijmegen, Netherlands



NERRI Project Participants in Nijmegen

Old and New Issues Concerning the New Criminal Code of Hungary: I. The Foundations of Culpability

Presentation by Petra Bárd on “Preventive Self-Defense”
June 25, 2014, Budapest, Hungary

International Forum on Intercountry Adoption and Global Surrogacy

Organized by the International Institute of Social Studies, The Hague
Panel discussion participant: Enikő Demény
August 11–14, 2014, The Hague, Netherlands

Bioethics and Biopolitics—28th European Conference on the Philosophy of Medicine and Health Care

Organized at the University of Debrecen
Lecture by Judit Sándor on “The ‘Me Molecule’”
Lecture by József Kovács on “(Bio)ethical and (Bio)political Questions of Measuring Scholarly Performance”
August 27–30, 2014, Debrecen, Hungary

Alpbach Summer School on European Integration (ASSEI) on “EU Internal Market & External Relations”

Presentation by Petra Bárd on “Fundamental Rights Protection in the EU”
Club Alpbach Belgrade, Serbia
September 18, 2014

The Role and Responsibility of Researchers in Neuro-Enhancement—The NERRI Project’s Mobilization and Mutual Learning (MML) Event No.3

Organizers and participants: Judit Sándor, Márton Varju, Enikő Demény and Gabriella Göbl
September 26, 2014, Budapest, Hungary

24th International Conference of the Hungarian Bioethics Association

Lecture by József Kovács on “Bioethics Studies at the Semmelweis University”
September 26, 2014, Budapest, Hungary

19th Conference of the Hungarian Medical Society of Life and Health Insurance (MÉBOT)

Lecture by Imre Szebik on “Analysis of Ethical Concerns of Health and Life Insurance Policies”
September 12, 2014, Budapest, Hungary

Debating the Complicated Relationship between Science and the Law—NERRI Project's Mobilization and Mutual Learning (MML) Event No. 4

Organizers and participants: Judit Sándor, Márton Varju, Enikő Demény and Gabriella Göbl
October 10, 2014, Budapest, Hungary

eHealth—Advantages, Possibilities and Challenges of Using ICT and Mobile Technology in Healthcare Conference

Lecture by József Kovács on "The Ethics of eHealth. Does Ethics Prevent the Development of Technology?"
October 10, 2014, Budapest, Hungary

International Day of Polio

Presentation by Judit Sándor and discussion about the documentary film *Fixed*
October 24, 2014, Budapest, Hungary

Fundamental Rights:

Justification and Interpretation Conference
Organized at the University of Belgrade School of Law
Lecture by Violeta Beširević on "Mission (Im)possible: Defending a Right to Die"
October 24–25, 2014, Belgrade, Serbia

Workshop on Health Diplomacy

Organized by the Institute of Public Health at the University of Debrecen
CELAB participant: György Kovács
October 29–31, 2014, Debrecen, Hungary

Hungarian Science Festival 2014—Far Seeing Science: Responsible Answers for the Future; Fixed—The Science/Fiction of Human Enhancement

Film screening and debate organized by CEU Department of Philosophy and CELAB in the frame of the Hungarian Science Festival 2014
Participants from CELAB: Emma Bullock and Judit Sándor
November 24, 2014, Budapest, Hungary

Où va l'humanité? La réalité du principe de respect de la dignité humaine (Human Dignity and Biomedicine)

8th Workshop of the International Academic Network on Bioethics (RUIB)
Organized by the l'Université de Monaco, Monaco
Presentation by Judit Sándor on
November 27–28, 2014, Monaco, Monaco

4.2. SCIENCE COMMUNICATION AND MEDIA EVENTS

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

"Tens of Thousands of Frozen Embryos are Stored"
[Több tízezer embriórt raktározna lefagyasztva]
Article by Veronika Munk, interview with Judit Sándor
Index.hu, index.hu/belfold/2013/06/25/tobb_tiz-ezer_embriot_raktaroznak_lefagyasztva/
June 25, 2013

"Courage or Privilege? Angelina Jolie's Struggle with Breast Cancer" [Bátorság vagy kiváltság? Angelina Jolie küzdelme a mellrákkal]
Article by Judit Sándor, www.magyarnarancs.hu/publicisztika/batorsag-vagy-kivaltsag-84970
Magyar Narancs, vol. 25, no. 22.
May 30, 2013

"The First Design Baby is Born" [Megszületett az első dizájnbébi]
Article by Zoltán Ötvös, interview with Judit Sándor
Népszabadság, July 11, 2013
nol.hu/tud-tech/20130711-megszuletett_az_elso_dizajnbebi

4. EVENTS AND ACHIEVEMENTS

"Baby Born to Brain-Dead Mother Three Months after Woman's Brain Death"
TV talk with Judit Sándor and József Kovács
ATV, November 19, 2013

"Homeless in Hungary"
Article by Petra Bárd
BBC World News, January 23, 2014
www.bbc.co.uk/programmes/p01q1bq4

"On the Belgian 'Child Euthanasia' Act" [A belga „gyermek-eutanázia” törvényről]
Interview with József Kovács by Dorottya Vizi
Radio Kossuth, "Tér-idő" Program
February 26, 2014, 14:34–15:00

"The Acceptability of the Belgian 'Child Euthanasia' Act in Hungary" [A belga „gyermek-eutanázia” megengedhetőségéről Magyarországon]
Interview with József Kovács by Sándor Friderikusz
ATV, "Friderikusz" Program
February 26, 2014, 22:20–23:00

"Poison into the Veins" [Méreg a vénába]
Interview with József Kovács by Anita Élő
Heti Válasz, Issue 19/9. pp. 23–25.
February 27, 2014

Interview with József Kovács by Judit Sándor (NERRI Neuro-Enhancement Responsible Research and Innovation Project)
February 28, 2014
www.nerri.eu/eng/news-highlights/nerri-news/interview-with-prof-Jozsef-Kovacs-aspx

"Patients Must Not be Left out of Decision Making"
A beteget nem lehet kihagyni a döntésből]
Interview with József Kovács by Orsolya Tarcza
eLitMed.hu
February 28, 2014

"When Surgery is Inevitable" [Mikor muszáj kés alá feküdni?]
Interview with József Kovács by Albert Ákos
Origo
March 19, 2014

"The Gender Pay Gap—The Cost of Motherhood"
[Fizetési különbségek—az anyaság bírsága?]
Article by Petra Bárd and Szilvia Bakóczy

Nők Lapja Café,
www.nlcafe.hu/ezvan/20140320/fizetesi-kulonb-segek---az-anyasag-birsaga/
March 20, 2014

"On Bioethical Questions of Rejecting Medical Treatments" [Az orvosi kezelések visszautasításának etikai kérdéseiről]
Interview with József Kovács by Izabella Kálló
Info Rádió, "Paragrafus" Program
March 27, 2014

"The Bioethics of the Mitochondrion" [A sejtszervecske bioetikája]
Article by Judit Sándor
HVG extra: Jövő, 2014/2, pp. 106–108.

"Technology on Itself is Not Enough [A technika önmagában nem elég]
Article by István Palugyai about CELAB
Népszabadság, p. 19., nol.hu/tud-tech/a-technika-onmagaban-nem-eleg-1458161
April 24, 2014

"For Better or Worse" [Holtomiglan, holtodiglan]
Article by Judit Sándor in the essay series *Body-talk* [Testbeszéd]
Magyar Narancs, vol. 26, no. 27, p. 26.
July 3, 2014

"The International Handmade Tale [A távoli szolgálólány meséje]
Article by Judit Sándor in the essay series *Body-talk* [Testbeszéd]
Magyar Narancs, vol. 26, no. 31, p. 49.
July 31, 2014

"Sex and Pension—On the Recommendation of the Demographic Roundtable"
[Szex és nyugdíj]—A Népesedési Kerekasztal javaslatáról]
Article by Judit Sándor
Magyar Narancs, vol. 26, no.35, p. 50–51.
August 28, 2014

"The Princess and the Pea and the Fundamental Rights" [A göröngyös vánkös és az alapjogok]
Article by Judit Sándor in the essay series *Body-talk* [Testbeszéd]
Magyar Narancs, vol. 26, no. 38, pp. 56–57.
September 18, 2014

"Can Love Be Cured?" [Lehet-e gyógyítani a szerelmet?]

Article by Judit Sándor in the essay series *Body-talk* [Testbeszéd]

Magyar Narancs, vol. 26, no. 41, p. 49.

October 9, 2014

"Bioethics Studies within Medical Training" [Bioetika oktatás az orvoscépzésben]

Interview with József Kovács by Ilona Keresztes
Radio Kossuth

October 24, 2014, 11:30–12:00

"The Unknown Death" [Az ismeretlen halál]

Article by Mihály Filó

HVG, www.hvg.hu/velemenypublicisztika/20141109_Az_ismeretlen_halal

November 9, 2014

"Euthanasia, Suicide with Medical Assistance"

[Eutanázia, orvos által asszisztált öngyilkosság]

Interview with József Kovács by András Simon
ATV, "Doku" Program

November 11, 2014, 20:35–21:25

"Should we Allow Euthanasia?"

Interview with Violeta Beširević

B92 TV and Radio Station, www.b92.net/mobile/info/918828

November 1, 2014

"Hibernated Motherhood, or What a Cell Can Do"

Hibernált anyaság, avagy mit tehet a sejt?

Article by Judit Sándor in the essay series *Body-talk* [Testbeszéd]

Magyar Narancs, vol. 26, no. 47, p. 40.

November 20, 2014

4.3. PUBLICATIONS

Bárd, Petra (2013) The Non-Enforcement of Strasbourg Decisions and Its Consequences. In Konrad Lachmayer, Jürgen Busch, Jennifer Kelleher, and Geanina Turcanu (eds.), *International Constitutional Law in Legal Education*. Proceedings of the Erasmus Intensive Programme NICLAS, 2007–2012. Vienna: Facultas, pp. 221–234.

Bárd, Petra (2014) Az angolszász és kontinentális büntetőeljárás eltérő igazságfelfogása [Different Understandings of the Truth in Common Law and Continental Criminal Procedures]. In Petra Bárd, Péter Hack, Katalin Holé (eds.), *In Memoriam László Pusztai*. Budapest: P-T, pp. 33–44.

Beširević, Violeta, with Judit Sándor, Enikő Demény, George Tudor Florea, and Natalia Codreanu (2013) Organ Trafficking, Organ Trade. Recommendations for a More Nuanced Legal Policy. In Frederike Ambagtsheer and Willem Weimar (eds.), *The EULOD Project: Living Organ Donation in Europe: Results and Recommendations*. Lengerich: Pabst Science Publishers, pp. 147–174.

Bullock, Emma C. (2014) Free Choice and Patient Best Interests. *Health Care Analysis*; 22, first published online on July 18, 2014.

Bullock, Emma C. (2014) A Normatively Neutral Definition of Paternalism. *The Philosophical Quarterly*, first published online on September 17, 2014.

Bullock, Emma C. (forthcoming) Assisted Dying and the Proper Role of Patient Autonomy. In M. Cholbi and J. Varelius (eds.) *New Directions in the Ethics of Assisted Suicide and Euthanasia* (Provisional title). Springer.

Demény, Enikő, Judit Sándor and Péter Kakuk (2013) Three 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 Stanford.

Demény, Enikő (2013) Medically Assisted Reproduction: Challenges for Regulation in Romania. In Judit Sándor (ed.), *Studies on Biopolitics*. Budapest: CELAB, pp. 91–103.

Demény, Enikő (2013) "Healthcare System in Hungary. *Health and Development*, June 2013, no. 67, pp. 8–9.

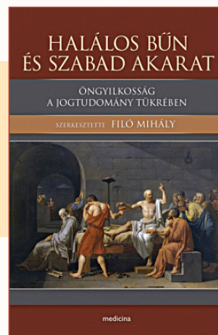
4. EVENTS AND ACHIEVEMENTS

Demény, Enikő with Slavica Karajcic and Judit Sándor (2014) Different Perspectives on Regulation of Assisted Reproduction Treatments in Serbia and Hungary: Comparative Analysis. In Ivan Humenic, Inocent-Maria V. Szaniszló, and Zuzana Zolaková (eds.), *Reprodukčné zdravie ženy v centre záujmu [Women's Reproductive Health in the Centre of Attention]*. Bratislava: MEDIUS, Insitut Aplikovanej Etiky Alexandra Spesza, pp. 122–146.

Demény, Enikő (forthcoming in 2014) "Commercial Surrogacy in Eastern European Countries" In Marcy Darnovsky and Dianne Beeson (eds.), *Global Surrogacy Practices. Report from the International Forum on Inter-country Adoption and Global Surrogacy*. Berkeley, CA: Center for Genetics and Society.

Demény, Enikő (forthcoming) From Eugenics and "Race Protection" to Preventive Medicine and Family Planning in Hungary. In Marcin Moskaliewicz and Wojciech Przybylski (eds.), *Companion to Central European Political Concepts*. Budapest: CEU Press.

Filó, Mihály (ed.) (2013) *Halálos bűn és a szabad akarat: Öngyilkosság a jogtudomány tükrében*. [Deadly Sin and Free Will: Suicide from the Perspective of Legal Science]. Budapest: Medicina.



Földes, Mária Éva and André den Exter (eds.) (2014) *Casebook on European Union Health Law*. Apeldoorn, Antwerpen, Portland: Maklu.

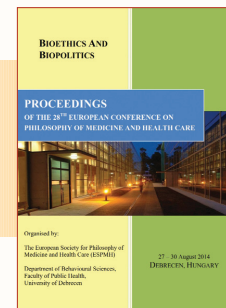
Földes, Mária Éva (2014) Addressing Equity in Health Care at the Public-private Intersection: The Role of Health Rights Enforcement in Hungary. In Colleen M. Flood and Aeyal Gross (eds.), *The Right to Health at the Public/Private Divide: A Global Comparative Study*. Cambridge: Cambridge University Press, pp. 208–235.

Kakuk, Péter (2014): Fostering Scientific Integrity and Assessing the Hidden Curriculum. In N. H. Steneck, M. S. Anderson, S. Kleinert, and T. Mayer (eds.), *Integrity in the Global Research Arena*. London: World Scientific.

Kakuk, Péter (2014) Beyond the IF Boycott: Let's Think about Counter-Incentives Against Illegitimate Co-Authorship. *EMBO Reports*, vol. 15, no. 11, 1104–1105.

Kakuk, Péter, with Andrea Domján and Judit Sándor (2014) Ötven éves a Helsinki Nyilatkozat: Kommentár a 2013-as módosításhoz. [Fifty Years of the Helsinki Declaration: Commentary to the 2013 Amendment]. *Lege Artis Medicinae*, vol. 24, no. 3, 152–158.

Kakuk, Péter with Bert Gordijn and Attila Banfalvi (eds.) (2014) *Bioethics and Biopolitics: Proceedings of the 28th European Conference on the Philosophy of Medicine and Health Care*. Debrecen: Department of Behavioral Sciences, Faculty of Public Health, University of Debrecen.



Kovács, József (2013) Etikai alapkérdések a belgyógyászatban [Basic Ethical Questions in General Medicine]. *Magyar Belorvosi Archivum*, vol. 66, pp. 310–317.

Kovács, József (2014) Tájékozott beleegyezés a sebészetben [Informed Consent in Surgery]. *Magyar Sebészet*, vol. 67, no. 1, pp. 3–8.

Sándor, Judit (ed.) (2013) *Studies in Biopolitics*. Budapest: Center for Ethics and Law in Biomedicine, pp. 1–255. (Foreword and Introduction is written by Judit Sándor pp. 1–16.)

Sándor, Judit, Violeta Beširević, Enikő Demény, George Tudor Florea, Natalia Codreanu (2013) Organ Trafficking, Organ Trade. Recommendations for a More Nuanced Legal Policy. In Frederike Ambagtsheer and Willem Weimar (eds.), *The EULOD Project: Living Organ Donation in Europe. Results and Recommendations*. Lengerich: Pabst Science Publishers, pp. 147–175.

Sándor, Judit with Mihaela Frunza, Enikő Demény and Betarice Ioan (2013) To Share or Not to Share Your Donor Status on Facebook. In Gurch Randhawa and Silke Schicktanz (eds.), *Public Engagement in Organ Donation and Transplantation*. Lengerich: Pabst, pp. 27–36.

Sándor, Judit and Márton Varju (2013) The Multiplicity of Norms: The Bioethics and Law of Stem Cell

Patents. In Andrew Webster (ed.), *The Global Dynamics of Regenerative Medicine A Social Critique*. Basingstoke: Palgrave-Macmillan, pp. 169–193.

Sándor, Judit (2013) Débats juridiques et éthiques sur la vie digne et sur l'euthanasie en Hongrie. In Brigitte Feuillet-Liger, *Les proches et la fin de vie médicalisée*. Bruxelles: Bruylant, 221–231.

Sándor, Judit (2013) Demographic Influences on the Regulation of the Female Body in Hungary. In Brigitte Feuillet-Liger, Kristina Orfali, and Thérèse Callus (eds.), *The Female Body: A Journey Through Law, Culture and Medicine*. Brussels: Bruylant, pp. 115–131.

Sándor, Judit (2014) Concilier les familles traditionnelles avec la fécondation in vitro: Le cadre juridique hongrois de la filiation à la lumière des interventions biomédicales. In *Les incidences de la biomédecine sur la parenté: Approche internationale* sous la direction de Maria-Claudia Crespo-Brauner et Brigitte Feuillet-Liger. Bruxelles: Bruylant, 145–158.

Sándor, Judit (2014) Reconciling Traditional Families with In-Vitro Assistance: The Hungarian Legal Framework on Kinship in the Light of Biomedical Intervention. In Brigitte Feuillet-Liger and Maria-Claudia Crespo-Brauner (eds.), *Reproductive Technology and Changing Perceptions of Parenthood around the World*. Brussels: Bruylant, pp. 149–163.

Sándor, Judit (accepted and forthcoming) Commodification of the Human Body: Is It a Gender Issue? In Jean-Daniel Rainhorn and Samira El Boudamoussi (eds.), *Commodification of the Human Body: A Cannibal Market?* Paris: Editions de la Fondation Maison des Sciences de l'Homme (2015)

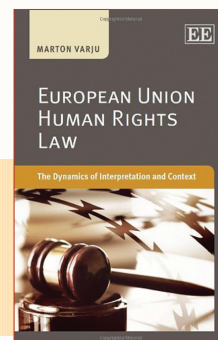
Sándor, Judit with Domján Andrea and Kakuk Péter (2014) Ötven éves a Helsinki Nyilatkozat: Kommentár a 2013-as módosításhoz. [Fifty Years of the Helsinki Declaration: Commentary to the 2013 Amendment]. *Lege Artis Medicinae*, vol. 24, no. 3, 152–158.

Szebik, Imre (2014) Neuroethics, April 2014. *Lege Artis Medicinae* (LAM) (In Hungarian).

Szebik, Imre (2014) The Notion of Futility in Medicine. In Fazakas, S, Ferencz, Á. (eds) *Time to live, time to die*. Debrecen (in Hungarian).

Szebik, Imre (2014) Questions of Responsibility of Child-birth. In *Church in the Service of the Family*. Pécs, 2014. (in Hungarian) e-book.

Varju, Márton (2014) *European Union Human Rights Law: The Dynamics of Interpretation and Context*. Edward Elgar.



4. EVENTS AND ACHIEVEMENTS

4.4. AWARDS, APPOINTMENTS AND SPECIAL EVENTS



Emma Bullock joined CELAB in August 2014 in conjunction with taking up her position as Assistant Professor at the Department of Philosophy of CEU. Her primary research interests are in medical ethics and the philosophy of medicine, especially in relation to the nature and justifiability of paternalistic interferences. Her research is motivated by the idea that debate within medical ethics has been confined to a focus on consent; instead, she argues, we should focus on the nature of patient health and the relevant harms that respect for patient free choice can bring about.

Emma completed her PhD in philosophy at the University of Birmingham in 2012. Her doctoral thesis: "Informed Consent and Justified Hard Paternalism" looks at the problems of respecting patient consent in medical practice, and concludes that in at least some cases where patient consent comes into conflict with the patient's health interests paternalistic interference is justified. During her doctoral studies she also participated with Judit Sándor on the Tiss.Eu project.

On completing her PhD Emma continued to teach medical ethics to third, fourth and fifth year medical students at the University of Southampton (2011–2013). She carried out her post-doctoral research at King's College London (2013–2014) as part of the Wellcome Trust Project 'Concepts of Health' (www.kcl.ac.uk/innovation/groups/chh/research/conceptsofhealth.aspx). Whilst at King's College London she taught an MA module in Philosophy of Medicine, and organized a number of seminars and workshops on themes in the philosophy of medicine. Emma will continue to teach a module on Philosophy of Medicine at CEU this academic year. (www.philosophy.ceu.hu/courses/20142015/philosophy-of-medicine).

Emma has delivered talks at a number of prestigious conferences, including the Tenth World Congress of Bioethics, Singapore (2010) and the Society for Women in Philosophy panel at the Joint Session of the Aristotelian Society and the Mind Association (2011). She has also been invited to speak at public lectures at Durham University (2015), the London School of Economics (2014), Manchester Metropolitan University (2014), Queen's University Belfast (2013), and the University of Liverpool (2013).

Emma plans to make the most of the resources available at CELAB in the pursuit of her academic career in medical ethics. She was a panel member on CELAB and philosophy's joint interdisciplinary event: *Fixed—The Science/Fiction of Human Enhancement* (www.ceu.hu/event/2014-11-24/fixed-sciencefiction-human-enhancement) and has contributed to workshops on the NERRI project. In the future, Emma plans to secure funding for projects centering on doctor-patient decision making, with an emphasis on the nature and legitimacy of paternalistic measures in medical practice.

Emma Bullock was awarded the Caroline Miles Visiting Scholarship at the Ethox Centre, University of Oxford (<http://www.ethox.ox.ac.uk/>) for the academic year 2014–2015, and will be visiting the center in April 2015 to carry out her current research on epistemic medical paternalism.

Petra Bárd was appointed Assistant Professor at ELTE School of Law, Department of Criminology as of October 1, 2014.

Enikő Demény became member of the ART working Group of the Center of Genetics and Society as of August 2014.

Starting from March 2014, **Mária Éva Földes** has been working as Assistant Professor/Postdoctorate Researcher at the University of Vienna, Institute for European Integration Research. She teaches courses on European Union health policy, comparative analysis of politics and minority policies in the European Union. Her research focuses on the influence of EU integration on health policy and health systems.

Péter Kakuk was appointed in 2014 Member of the Medical Research Council, Research Ethics Committee and book review editor of *Medicine, Health Care, and Philosophy*.

György Kovács was appointed Member of the Bar Exam Committee organized at the Ministry of Justice, since September 2013; He became Senior Lecturer at the public service development program organized by the National University of Public Administration since September 2014; Member of the Supervisory Board of the Hungarian-American Fulbright Foundation (renewed in 2014 for a further three years term by the Founders).

6. BUDGET

6.1. REVENUES IN AY 2013/2014

Approved Budget from CEU	Amount in Euro
C-5036 Total	54,469

External Funding	Amount in Euro
NERRI	30,444
EUCELLEX	3,753
Total	34,197

6.2. SPENDING IN AY 2013/2014

CELAB MAIN BUDGET CODE

Budget category	Amount in Euro
Personnel cost	53,749
Other costs	720
Total	54,469

NERRI PROJECT

Budget category	Amount in Euro
Personnel costs	26,405
Other costs	4,039
Total	30,444

EUCELLEX PROJECT

Budget category	Amount in Euro
Personnel costs	2,880
Other costs	873
Total	3,753



