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CENTER
FOR ETHICS AND LAW
IN BIOMEDICINE

ANNUAL REPORT

2015–2016



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TABLE OF CONTENTS

1. FOREWORD	2
2. RESEARCH AND POLICY ACTIVITIES	8
2.1. PARTICIPATION AND COLLABORATION IN RESEARCH NETWORKS	8
2.1.1. Neuro-Enhancement: Responsible Research and Innovation (NERRI)	8
2.1.2. Cell-based Regenerative Medicine: New Challenges for EU Legislation and Governance (EUCelLEX)	10
2.1.3. Infertility and the Socio-Technical Practice of Assisted Reproductive Technologies	11
2.1.4. International Academic Network on Bioethics (IANB)	12
2.1.5. Disaster Bioethics Project	13
2.1.6. RoadMAPs to Societal Mobilisation for the Advancement of Responsible Industrial Technologies (SMART map)	14
2.1.7. Joining Efforts for Responsible Research and Innovation (JERRI)	15
2.2. POLICY AND OUTREACH ACTIVITY	15
2.2.1. European Seminar on the Right to the Integrity of the Person, with a Particular Focus on the Field of Biology and Medicine	15
2.2.2. Conference on Patients' Safety in Hungary	16
2.2.3. Science Day at the University Club in Bonn	16
3. ACADEMIC ACTIVITIES	17
3.1. PUBLIC LECTURES AND CONFERENCES ORGANIZED BY CELAB	17
3.1.1. Public Lecture on 'The Genealogy of a Gene' by Prof. Myles W. Jackson	17
3.1.2. Anniversary Bioethics Debate on Gene Editing, with the Participation of John Haris and Judit Sándor	18
3.1.3. Conference on Global Justice and Vulnerability in Disaster Bioethics	19
3.2. TEACHING	20
3.2.1. Teaching at CEU	20
3.2.2. Teaching and Lecturing at Other Institutions	20
3.2.3. Bioethics Teaching Network (BOMM)	21
4. EVENTS AND ACHIEVEMENTS IN CHRONOLOGICAL ORDER	23
4.1. PARTICIPATION IN CONFERENCES	23
4.2. SCIENCE COMMUNICATION AND MEDIA EVENTS	27
4.3. PUBLICATIONS	28
4.4. VISITING FELLOWS	31
4.5. AWARDS, APPOINTMENTS AND SPECIAL EVENTS	32
5. BUDGET	33
5.1. REVENUES IN AY 2015/2016	33
5.2. SPENDING IN AY 2015/2016	33

1. FOREWORD

In December 2016 the Center for Ethics and Law in Biomedicine (CELAB) closes a very productive year full of research projects and public lectures, workshops, conferences, and seminars. Over the course of the past twelve months, we have completed two very demanding research projects and started to work in new research fields. In our research and policy analysis we apply legal, historical, and anthropological methods, combinations of desk research with fieldwork and interviews, to explore the new and exciting domains of biotechnology. We are in constant and regular interaction with scientists from various fields so that we can be freshly informed and influenced by current scientific paradigms and to reflect upon them in a timely manner.

In 2016 we had inspiring guest speakers visiting CELAB who sparked lively discussions with their thoughts on bioethics. On occasion of the tenth anniversary of CELAB's establishment, Myles W. Jackson (New York University) presented an excellent lecture titled "The Genealogy of a Gene." Professor Jackson's multidisciplinary approach to investigate the dramatic process of patenting the CCR5 gene engaged the representatives of many disciplines in the audience: historians, lawyers, anthropologists, scientists, and ethicists all found thoughts relevant to their own research in this lecture. (For more on the anniversary lecture, see Section 3.1.1 below.)

A public debate on *gene editing* between Professor John Harris (University of Manchester) and myself, and the following discussion in the CEU Senate Room, was another important event in 2016. Gene editing is one of the latest and most exciting topics of contemporary bioethics. It is not just a new technology, but it may also fundamentally change the direction of the ethical debates on gene therapy and other forms of genetic intervention. Once gene editing will be a safe and approved technology, it will be possible to "cure genetic disorders" and this new therapeutic option may also alter the notions of health and illness prevailing today. When embryos will not only be tested and screened but also "repaired" before their implantation in an artificial reproductive procedure, then this will inevitably lead to the reinterpretation of the notion of right to life and parental choices. Embryos that otherwise may not be born, could gain a chance for life by repairing their problematic genes. Immediately before our event at CELAB, John Harris had participated at the international summit on human gene editing in Washington. According to Professor Harris, scientists and other specialists who discuss the potential of powerful new technologies to make changes to human DNA should not rule out using this technology. John Harris argued that gene editing has to be pursued, and if possible, made safe enough to use in humans. Not only to pave the way for procedures on adult tissues, but also to keep open the possibility of protecting embryos from susceptibility to major diseases and preventing other debilitating genetic conditions from being passed on through them to future generations. (See Section 3.1.2 for more on this public debate.)

1. FOREWORD

“Technological advances can remake the divisions between public and private spaces in ways that affect not only personal autonomy and opportunities for public deliberation but also, and perhaps more significantly, the norms of individual and collective responsibility”

Sheila Jasanoff (2016) *The Ethics of Invention*, p. 262.

Since completing the human genome program, very few areas of debate have reached a general consensus, but one of them was an agreement on the prohibition of modifying the genome of descendants. With the introduction of pre-implantation gene editing it seems that the distinction between germ line and somatic line is getting blurred. In Europe, under Article 13 of the Oviedo Convention, an intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic, or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants. It means that *patents on gene editing* pose different problems than gene patents as such, and the main question is not whether it is similar to nature or whether it is novel. The main ethical dilemma with gene editing is whether to accept humanly made modifications of the human genome. This element is a vital part in the European patent assessment process but plays almost no role in the American debate on patentability.

Gene editing (more precisely, the CRISPR/Cas9 technology) was also the topic of a meeting held in Bonn in February. As a member of the Advisory Board of DRZE (Deutsches Referenzzentrum für Ethik in den Biowissenschaften), I was invited to participate in the events of the annual Science Day at the University Club in Bonn. On February 15, 2016 members of the DRZE Advisory Board, members of the DRZE Board of Trustees, and the scientific staff members of the IWE (Institut für Wissenschaft und Ethik) held a joint meeting in Bonn and discussed the CRISPR/Cas9 technique and germline manipulation. The Science Day started with the opening speeches of Göran Hermerén and Dieter Sturma, and they were followed by a presentation on state of the art technologies. Markus Nöthen (University of Bonn) provided a very informative presentation on the gene editing technique in a comparative context: he highlighted how gene editing differs from previously known technologies, such as gene therapy and germline interventions. Then Göran Hermerén (University of Lund) summarized the ethical arguments for or against the technology. As a member of the Advisory Board of DRZE, I participated in both the Science Day debate and then the Advisory Board meeting.

The third event that was held in this year about gene editing was at the so-called Straub Days organized by the Hungarian Academy of Sciences in Szeged on May 25, 2016.

In April CELAB held a very successful conference at CEU on *Global Justice and Vulnerability in Disaster Bioethics*. It was a new topic to most of us, but I think we managed to provide a contribution to the COST Action Project in which Péter Kakuk has been a long-term participant. He and Enikő Demény organized the conference and I contributed an introductory lecture. Hosting this conference offered us an excellent opportunity to discuss this important new field of bioethics. For more on the Disaster Bioethics project, see Section 2.1.5 below.

In addition, six other conferences and workshops have to be mentioned briefly. Three of them were held in Budapest and three abroad. First, three CELAB associates were invited to give presentations at the Hungarian National Conference on Patients' Safety, organized by the Hungarian Patient's Safety Association (Magyar Betegbiztonsági Társaság, MABEBIT), which was followed also by a radio interview (see Section 2.2.2 below). The second conference, in June 2016, was jointly organized by the Gottsegen National Institute of Cardiology and the Institute of Gynecology and Obstetrics of the Semmelweis Medical School. This workshop focused on the issues of pregnancy and heart diseases, including the possibilities of assisted reproduction and surrogacy. Third, in November 2016 the Dutch Embassy in Budapest invited József Kovács to organize a Dutch-Hungarian expert discussion on euthanasia. Péter Kakuk, László Nemes, Imre Szebik, and myself participated at this important event.

In August I was a keynote speaker at the *Dubrovnik International Bioethics Summer School (DIBSS)*, organized by the Global Bioethics Initiative, in partnership with the School of Medicine of the University of Zagreb, and CAAS at the Inter-University Centre in Dubrovnik, Croatia. The *Global Bioethics Initiative* (GBI), an organization associated with the United Nations Department of Public Information (DPI), aims to facilitate an exchange of information and development of partnerships within UN offices as well as with not-for-profit organizations around the world, to enhance interaction with and understanding of the work of the United Nations. Many of the issues addressed by GBI are relevant to the work of the UN, including reproductive and sexual rights, organ trafficking, and the ethics of population aging. This two-week long summer school proved to be very successful for students and professionals alike.

On October 6–7, 2016 the European Seminar on the Right to the Integrity of the Person, was held in Brussels, Belgium within the framework of "HELP in the 28," the Joint Programme of the European Union (EU) and the Council of Europe (CoE). The HELP network is the largest human rights training project within the EU for judges, prosecutors, and lawyers. Over 50 legal, academic, and health professionals gathered to raise awareness on the right to the integrity of the person, with a particular focus on the field of biology and medicine. I gave a presentation on the prohibition of financial gain. For more on the activities of the HELP28 network, see Section 2.2.1 below.

In November we continued our participation at the annual European Public Health Conferences. The topic for this year's meeting was "All for Health, Health for All" and it was held in Vienna, Austria. I took part in a panel discussion titled "Bridging the Gap between Knowledge and Practice in Public Health Genomics."

In 2016 we completed two European Commission financed research projects successfully: NERRI and EUCellLEX. Within the framework of the *Neuro-Enhancement: Responsible Research and Innovation* (NERRI) project, we organized dissemination events in Budapest and participated in other project partner's similar events. On February 5, 2016 CELAB hosted a panel discussion with participants of the Neuro-Enhancement Responsible Research and Innovation (NERRI) project. The panel was made up of five international members of the project: Agnes Allansdóttir (Toscana Life Sciences), Imre Bárd (LSE), Rui Vieira da Cunha (University of Porto), Judit Sándor (CEU), and Márton Varju (CEU), and was well attended by CEU faculty and students. The panel members agreed that one of the main outcomes of the project was that it uncovered the vast difference between the various stakeholders' attitudes towards neuro-enhancing technologies. The project's mobilization and mutual learning events (MML) indicated a great variety in the preferences for neuro-enhancement technologies and a wide diversity in understanding what counts as a neuro-enhancement. For instance, stu-

1. FOREWORD

dents were less interested in gaining a competitive advantage in their studies via the use of cognitive enhancements than they were in recreational mood enhancements.

The success of the NERRI project was in finding new ways of conducting a dialogue between these different stakeholders. The panel noted, however, that a lot of the information gathered about the varying interests and concerns of different stakeholders still needs to be analyzed. For partly this reason it is far too early to be considering policy recommendations. It would, for instance, be too ambitious to regulate neuro-enhancements if the term is so broad as to include mere changes in nutrition and diet. The panel thus claimed that the EU commission's call for regulatory recommendations is somewhat premature.

Two key themes emerged from the broader debate with the audience. First, discussion focused on the relation between access to neuro-enhancement technology and various forms of inequality. Panel members acknowledged that new technologies tend to favor those who are already at a social, genetic or regional advantage. Imre Bárd suggested, however, that the worry that neuro-enhancing technology will reinforce or worsen current inequalities is overstated. Firstly, new technologies could be used to compensate for inequalities. Second, enhancement technologies have a very minor influence on social inequality: the school one attends is a far greater influence on social status than access to enhancement. The meeting ended with a visit to the opening ceremony of the exhibition of the works of patients at Szentgotthárd Mental Health Institution. This exhibition took place at Brut Gallery in Budapest.

Drawing attention to the fundamental rights dimensions of neuro-enhancement is also important because the predominant engagement with regulating risk in the legal treatment of new technologies has been observed to marginalize or even exclude the moral considerations that we assume to be inherent in the law of fundamental rights. Emphasizing and explaining the fundamental rights implications of new technologies can provide a particularly useful instrument for RRI policies. Concerns about fundamental rights and their inherent value- and moral considerations may be regarded as more pressing by scientists individually or as a social group than the potential risks of their activities, and by connecting technology with issues of morality and with ideas about human nature and humanity, scientific activity can develop a more conscious relationship with these fundamental questions. This outcome may be realized despite the doubts in the fundamental rights discourse as to whether the language of rights is able to express its assumed philosophical and moral underpinnings adequately. At the end of the project NERRI consortium launched several, so-called *vignette studies*, including various themes on neuroenhancement. Through a polling company we distributed the survey to a large sample in ten participating countries. (For more on the events and achievements of the NERRI project, see Section 2.1.1 below.)

At the end of September 2016 we had the final conference of the EU Commission financed *EUCeLLEX project*. In this project we mapped the major actors in this area, conducted interviews with experts, and studied the legal systems of the participating countries: Austria, Belgium, Canada, Netherlands, France, Germany, Hungary, and the United Kingdom. During the 2015–2016 academic year the CEU–CELAB team carried out multiple tasks within the EUCeLLEX project. We participated in two conferences this year, and both were held in Paris. The first was held at SciencesPo and the other at the Institut Curie.

We aimed to explore good regulatory practices in order to develop a policy recommendation to the European Union. By the end of 2016, the consortium members will deliver their proposition for a policy framework on the regulatory aspects of stem cell research.

In our project concluding publications we have observed a wide regulatory diversity even within the European Union, where various measures are supposed to provide a common framework for regula-

tion—for instance, in the cases of regulating the procurement and use of human biological material (EU Cells and Tissues Directive) or the development of cell therapy and tissue engineered products (EU Advanced Therapies Medicinal Products Regulation). The direction and the focus of regulatory intervention may differ along both the biological and the legal dimension. There are national regulatory systems that intervene at the level of stem cells (Germany), and there are others that intervene by regulating human embryonic life in the context of human reproduction and biomedical research (Belgium, Canada, the Netherlands, the UK, and Hungary). Most national regulations approach the relevant issues from the more general questions of health care and biomedical research, if they do (e.g., in Belgium, the Netherlands, the UK, and Hungary), and states only rarely regulate—and certainly not in a comprehensive manner—from the specific angle of stem cell technologies (Germany). Although there are recurrent themes in the regulatory frameworks, the detailed regulation of these themes could considerably differ from one country to another. This leaves a patchwork rather than a uniform and comprehensive regulatory environment for stem cell technologies in the European regulatory space.

Several papers have also been produced; one that was written by Jasper Bovenberg, Alexandra Henrion, and myself, titled “Patenting the Immaculate Conception,” was published through the website of Project Syndicate in nine countries in five languages, and it has reached more than a million downloads from all around the world. With Márton Varju I also published an article in the *European Law Review* (titled Creating European Markets through Regulation: The Case of the Regulation on Advanced Therapy Medicinal Products). Preparations for an e-book has been also made. (For more on the results and outcomes of the EUCeLEX project, see Section 2.1.2 below.)

In 2015–2016 we also made a couple of research applications. As a result, in May 2016 we started a Horizon 2020 project on the *Roadmaps to Societal Mobilization for the Advancement of Responsible Industrial Technologies* (with the acronym ‘SMART-map’). The main aim of this project, coordinated by the University of Aarhus, is to design of a tool (a smart map) that helps companies to address the questions of social and environmental responsibility in their innovation processes. One of the major tasks within this project is to connect a wide range of industrial players with actors from research and civil society organizations and establish innovative formats of collaboration to jointly discuss, define, and implement concrete roadmaps (SMART-maps) for the responsible development of technologies and services in three key time-changing fields. Based on the Societal Challenges of Horizon 2020, SMART-map will address the areas of precision medicine, 3D printing in the biomedical field, and synthetic biology. In each of these areas we will pair two regions of Europe, on the north/south and east/west axes, and the unique partnership will enable a comparative assessment of these innovation fields. With regard to each theme, a SMART-map will deliver an implementation plan, to be demonstrated, tested and assessed.

Synthetic biology, personalized genetics, and 3D printing open up lots of new possibilities to science and the industry, but also constitute complex bioethical challenges. Some scientists are already trying to develop a simplified genome, designed to contain the minimal genetic code necessary to survive and replicate. This minimal genome could then be used as a chassis to which genetic material coding for particular desired traits can be added. Synthetic organisms could be designed to perform myriad functions. Scientists have already achieved the first successful transfer of a synthetic genome into a bacterial cell that has had all its original genetic information removed. Australian researchers recently were able to 3D-print brain tissue. Bio-printing and stem cell research have many common elements, aiming the regeneration of the body. However, the sources of the material they use differ in

1. FOREWORD

the two cases: stem cell research harvests stem cells from embryos and adults, whereas bio-printing applies synthetic biology's technology and develops synthetic biobricks. Consequently, using stem cells are more widely scrutinized than bioprinting. From the CELAB research associates, Enikő Demény and Péter Kakuk participate in this project. (For more on this developing project, see Section 2.1.6 below.)

We also have some projects that are not within a European research framework. In 2016 we continued our participation in the francophone International Academic Network on Bioethics. Our working method within this network is to develop research protocols: a set of questions that an upcoming workshop will discuss, and then to compare the legal, ethical, social, and cultural background of the chosen topic in the countries involved in the cooperation. The proceedings of each workshop are published in a pair of edited volumes, one in French, and the other in English. Over the past two years four books have been published in the series *Droit bioéthique et société*, by Bruylant in Brussels: in 2015, *Principes de protection du corps et Biomédecine: Approche internationale* (in French) and *Protecting the Human Body: Legal and Bioethical Perspectives from around the World* (in English), then in 2016, *La dignité de la personne: quelles réalités? Panorama international* and *Le principe de non-patrimonialité du corps humain: Approche internationale* (both in French). After the workshop held in Istanbul, Turkey in November 2015, the next meeting is coming up in December 2016 in Hikone, Japan.

We launched CELAB Faculty Seminars in 2014 with the aim of reading together and presenting on some of the seminal works in the field of contemporary bioethics. At each CELAB Seminar meeting a research fellow or a visiting fellow provides an analysis of important new pieces of bioethics literature, and may also put it in the context of his or her current research topic. Emma Bullock, Péter Kakuk, Péter Mihályi, László Nemes, and Simon Rippon gave presentations on various topics, such as ethical dilemmas in brain surgery, addiction and shame, mortality, and compromises in ethics.

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



CELAB Fellows

Judit Sándor

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

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: 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 — Lisbon, Portugal

London School of Economics and Political Science — London, United Kingdom

Radboud University — Nijmegen, the Netherlands

Österreichische Akademie der Wissenschaften — Vienna, Austria

Scuola Internazionale Superiore di Studi Avanzati — Trieste, Italy

Instituto de Biologia Molecular e Celular — Porto, Portugal

Tilburg Law School, Tilburg University — Tilburg, the Netherlands

Johannes Gutenberg Universität — Mainz, Germany

Johannes Kepler Universität — Linz, Austria

Kings' College — London, United Kingdom

European Brain Council — Brussels, Belgium

Universitat Pompeu Fabra — Barcelona, Spain

Center for Ethics and Law in Biomedicine, Central European University — Budapest, Hungary

In May 2006 we successfully completed the NERRI project. This project aimed to contribute to the new field of Responsible Research and Innovation (RRI) in Neuro-Enhancement (NE) in the European Research Area and to shape a normative framework underpinning the governance of NE technologies. This has been achieved through mobilization and mutual learning (MML) activities engaging scientists, policy-makers, industry representatives, civil society groups, patients, and the wider public.

To structure this complex socio-technical domain this project proposed an analytic classification of NE technologies into currently available methods, experimental, and hypothetical technologies. Each of the types raises some fundamental ethical, legal, social and economic issues, which have different relevance to various societal groups, point to different methods of stakeholder engagement, and may require different regulatory approaches. Over the course of the project, this analytic classification was developed and extended in the work packages. Mobilization formed the central commitment of the project from the outset to the conclusion. Based on the classification we organized a broad societal dialogue employing state-of-the-art engagement methodologies tailored to specific contexts (education, health, work, and research) and stakeholders (producers, users, and intermediaries). Furthermore, the project participants synthesized the national experiences, mapped the contours of a normative framework as it emerges from societal engagement and dialogue, and elaborated the concept of RRI in Europe. The Consortium comprised of experts in the neurocognitive sciences, the social sciences, law, philosophy, communication science and it fostered public engagement with science and technology. Many experts

2. RESEARCH AND POLICY ACTIVITIES

had prior experience in European Commission projects and had previous successful collaboration with other members of the consortium.

One of the challenging aspects of our work is that we often do something in the first time. It was in the case of ethical and legal implications of assisted reproduction, genetics, nanotechnology etc. We have never followed a paved road. Consequently, first the scientific field has to be explored, then analyzed, and then new methods may develop. We organized four stakeholder events and two dissemination events in 2014–2016. Furthermore, we attended conferences held in Rome, Vienna, Reykjavík, and Stuttgart. As a continuation of this project we submitted a project application to Horizon 2020 (PERTI).

As part of its dissemination activities, NERRI took part in the IBRO Budapest Workshop, a top neuroscience event in Europe, on January 20–22, 2016. CELAB, as NERRI partner, prepared a poster introducing the project and summarizing its main outputs. The idea of RRI and the results of the Europe-wide public engagement efforts of NERRI received considerable attention from the neuro-science community present at the workshop.

NERRI was also represented at the satellite event of the IBRO Budapest Workshop, a one-day workshop for doctoral researchers in neuroscience (HUDOC). The mini version of the poster was presented to a group of PhD students in the poster session of the workshop, which initiated a lively debate on the responsibility of researchers at the beginning of their scientific careers.

On February 5, 2016 CELAB hosted a panel discussion with participants of the Neuro-Enhancement Responsible Research and Innovation (NERRI) project. The panel was made up of five international members of the project: Agnes Allansdóttir (Toscana Life Sciences), Imre Bárd (LSE), Rui Vieira da Cunha (University of Porto), Judit Sándor (CEU), and Márton Varju (CEU), and was well attended by CEU faculty and students. Judit Sándor opened the discussion by asking panel members what they had learnt from their involvement in the NERRI project. Agnes Allansdóttir noted that at the start of the project in 2011 it was taken for granted that there was a market for neuro-enhancement. However, five years later, it seems that the anticipated technological development has not taken place. All panel members expressed a degree of skepticism about the potential for neuro-enhancement technologies and suggested that the term ‘enhancement’ might be a misnomer, generating false expectations and unwarranted fears regarding their use.

The panel members agreed that one of the main project outcomes was, instead, that it uncovered the



Judit Sándor and Márton Varju at the NERRI Dissemination Event in February 2016

many different attitudes towards neuro-enhancing technologies that the various stakeholders hold. The project’s mobilization and mutual learning events (MML) indicated a great variety in the preferences for neuro-enhancement technologies and even a wide diversity in understanding what counts as a neuro-enhancement. For instance, students were less interested in gaining a competitive advantage in their studies via the use of cognitive enhancements than they were in recreational mood enhancements. Neuroscientists had a tendency to focus on nutritional enhancements rather than on cognitive enhancers such as Modafinil. There were also geographical differences: Anglo-Saxon countries are seemingly more ready to accept new neuro-enhancing technologies than Central European countries.

The success of the project was in finding new ways of conducting a dialogue between these different stakeholders. The panel noted, however, that a lot of the information gathered about the varying interests and concerns of different stakeholders still needs to be analyzed. For partly this reason it is far too early to be considering policy recommendations. It would, for instance, be too ambitious to regulate neuro-enhancements if the term is so broad as to include mere changes in nutrition and diet. The panel thus claimed that the EU commission’s call for regulatory recommendations is somewhat premature.

Two key themes emerged from the broader debate with the audience. First, discussion focused on the relation between access to neuro-enhancement technology and various forms of inequality. Audience members reiterated a concern from one of the MML events that new technologies will in fact be unavailable to the most disadvantaged in society. There was also a concern that the use of such technologies would interfere with social approaches to alleviating discrimination.



Audience at the NERRI Dissemination Event in February 2016

Panel members acknowledged that new technologies tend to favor those who are already at a social, genetic or regional advantage. Imre Bárd suggested, however, that the worry that neuro-enhancing technology will reinforce or worsen current inequalities is overstated. Firstly, new technologies could be used to compensate for inequalities. Second, enhancement technologies have a very minor influence on social inequality: the school one attends is a far greater influence on social status than access to enhancement.

A second key theme was whether individuals should be free to choose to use neuro-enhancements that give them a competitive edge. Audience members expressed concerns that this might coerce others into using neuro-enhancements. Examples were typically taken from academia. There was some agreement from the panel that individual academics should not be prevented from using neuro-enhancements, but that such individuals should think carefully about the possible consequences of doing so. It was further noted that the 'free choice' to use a neuro-enhancement is unlikely to be adequately informed of undesirable side effects. On the other hand, it was suggested that these worries might be overstated and only really worth debating when more powerful technologies emerge.

At the meeting participants could see a small demonstration of the questionnaire, which will be distributed to each member country at the end of the project. It was followed with an opportunity to test some neuro-enhancement technologies. The meeting ended with the visit of the opening ceremony of the exhibition of the works of patients at Szentgotthárd Mental Health Institution. This exhibition took place at Brut Gallery.

On February 13, 2016 a dissemination event of the NERRI project, titled "A Clockwork Brain: How can Art Deepen the Social Discourse of Science Such as Neuro-Enhancement?", was held in Reykjavík, Iceland. The

Centre for Ethics of the University of Iceland hosted a panel discussion and an art exhibition at the Art Museum. The participants in the panel discussion were NERRI consortium specialists in the fields of social sciences and neuro-enhancement: George Gaskell, professor of Social Psychology at the London School of Economics and Political Science; Judit Sándor, professor at the Departments of Political Science, Gender Studies and Legal Studies at the Central European University; and Agnes Allansdóttir from Toscana Life Sciences. In between discussions video works by Auður Anna Kristjánsdóttir, Fritz Hendrik Berndsen, Mina Tomic and The Icelandic Love Corporation were screened. The discussion was followed by a lively debate with the audience.

CELAB participants in the project: Judit Sándor and Márton Varju

NERRI project websites: 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 — 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

In September 2016 CELAB successfully completed the EUCeLLEX project. The project's chief objective was to examine current legislation concerning the therapeutic use of somatic cells, in both the public and private sec-

2. RESEARCH AND POLICY ACTIVITIES



Participants at the EUCeLLEX Final Conference in Paris

tors and in a number of European countries. To this end, the project aimed to assess the relevance of current European legislation in order to provide the data needed to establish a European framework for the use of stem cells of every type (embryo, adult and IPS cells from cord blood) in the light of recent scientific, legal and institutional developments in Europe. To obtain a complete picture of the European situation, the legal study was complemented by an examination of current clinical practices together with the many ethical recommendations throughout Europe. Starting with the observation that the entire translational process, from research to the marketing of a product, is only partially covered by the EU rules, the teams had to examine the heterogeneous nature of legislation due to the freedom of action allowed to the member states. The ultimate objective was to make recommendations to the European Commission so as to facilitate the use of stem cells for clinical purposes in a stabilized legal context. Thus the results of the project will enable innovation in research and help the European states to implement specific legislation in this field.

In this project CELAB researchers assessed the interactions between EU legislation and the procurement of human (embryonic, fetal, and adult) stem cells for research and innovation. For the legal part of this analysis we also analyzed the legal framework of certain selected countries in more detail and the implementation of EU legislation into national law. In the analysis of the European legal debates we also looked at the opinions of the European Group on Ethics (EGE). The legal analysis was mainly carried out on the countries represented in this project (Belgium, Canada, France, Germany, Hungary, the Netherlands, and the United Kingdom) and, when it was necessary, we also looked at regulations in other countries. In the framework of this project we conducted research and made interviews with several iPS researchers in Madison in November

2013 and organized a conference at CEU in April 2015. In 2015 we also participated in two project meetings in Toulouse: one in March and one in June. A workshop was organized in Paris in May 2016 and the final conference was held also in Paris in September 2016. Several publications were completed by the end of the project, including our article in the *European Law Review*. In January 2017 an e-book will also be published.

CELAB participants in the project: Judit Sándor and Márton Varju

EUCeLLEX Websites:

www.eucellex.eu

www.horizonhealth.eu

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

twitter.com/Inserm_EN

twitter.com/horizonhealtheu

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

Type of funding scheme: OTKA

Starting date: October 1, 2013

Duration: 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 were made with various stakeholders: experts, law-makers, medical practitioners, women engaged in IVF treatment, etc. In the second phase 40 semi-structured interviews involved men and women with infertility problems who have decided to take part in assisted reproductive technology treatments.

Participants in the research are Lilla Vicsek (the project coordinator focusing on social aspects), Judit Sándor (ethical and legal aspects), Gábor Király (theories of science and technology studies), Zoltán Navratyl (legal aspects), Zsófia Bauer (PhD student, social aspects of biotechnologies), and Veronika Paksi (PhD student).

In May 2015 Judit Sándor, in collaboration with Lilla Vicsek, organized an event at CEU where Manuela Perrotta gave a public lecture on *Bio-Social*

Construction of the Human Body in Assisted Reproduction: Technology, Gender and Parenthood. A manuscript has been prepared on the non-medical egg freezing and maternity.

CELAB participant in the project: Judit Sándor

Information on the project:

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

2.1.4. International Academic Network on Bioethics (IANB)



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, Mamadou Badji, Thérèse Callus, Maria-Claudia Crespo-Brauner, Guilherme de Oliveira, Françoise Furkel, Dominique Gobau, Carmen Domínguez Hidalgo, Yao-Ming Hsu, Ryuichi Ida, Francis Kernaleguen, David Le Breton, Dominique Manăi, Kristina Orfali, Saibe Oktay-Özdemir, Véronica San Julian, Geneviève Schamps, Judit Sándor, Jaap Sijmons, Marco Ventura, representing twenty-three countries: Belgium, Brazil, Chile, Canada, China, Egypt, France, Germany, Greece, Hungary, Italy, Japan, the Netherlands, Portugal, Senegal, Spain, Switzerland, Taiwan, Tunisia, Turkey, the United Kingdom, the United States, and Vietnam. Prof. Judit Sándor, the director of CELAB, has been a member of the Advisory Board and the network since the beginnings.



Workshop members in Istanbul

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, on December 6–7, 2007 explored ethical issues related to assisted reproduction and donor anonymity from a cross-cultural perspective. The Kyoto meeting on January 5–6, 2009 focused on the autonomy of choice for adolescents in medical treatment. The second Rennes meeting on May 27–28, 2010 discussed the cultural differences in the end-of-life decisions within the family. The following workshop in Tozeur, Tunisia on December 9–10, 2011 explored the various culturally specific ways biomedicine looks at the female body. The next meeting was held in Rio de Janeiro on October 29–30, 2012 and was dedicated to the changing perceptions of parenthood around the world, as a result of the emerging reproductive technologies. The workshop in Leuven and Brussels on December 16–17, 2013 focused on the principles of protecting personhood and the body under powerful biomedical regimes. Next year the network convened in Monaco, on November 26–29, 2014, to explore how the principle of human dignity is respected in various biomedical contexts and jurisdictions. The last meeting was held on November 4–6, 2015 in Istanbul, Turkey, and discussed how the human body and its parts are protected from commodification and commercialization in the countries participating in the network. In December 2016 the group will meet in Hikone, Japan to explore the concept of death in bioethics in an international comparative perspective. Future workshops are planned to be organized in 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 2016, Bruylant has pub-

2. RESEARCH AND POLICY ACTIVITIES

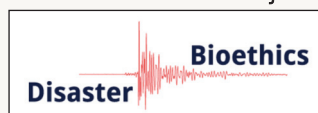
lished fifteen books from the conference proceedings, including four volumes over the past two years: in 2015, *Principes de protection du corps et Biomédecine: Approche internationale* (in French) and *Protecting the Human Body: Legal and Bioethical Perspectives from around the World* (in English), then in 2016, *La dignité de la personne: quelles réalités? Panorama international* and *Le principe de non-patrimonialité du corps humain: Approche internationale* (both in French). The English language versions of the latter two books will be published in 2017 and the proceedings of the 2016 workshop in 2018. For the list of books published in the series, see http://fr.bruylant.larciergroup.com/collections/100034_5_100050/droit-bioethique-et-societe.htm

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/

2.1.5. Disaster Bioethics Project



Type of funding scheme: COST IS1201

Starting date: April 1, 2013

Duration of the project: 2012–2016

In September 2016 we completed the Disaster Bioethics research program, which was a European Cooperation in Science and Technology (COST) project that intended to develop effective ways to address ethical issues triggered by disasters.

Disasters overwhelm local and often national capacity to respond effectively. Significant imbalances result between needs and available resources. 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 aimed 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 assist policy-makers, humanitarian organizations, healthcare professionals, researchers, and the public. The Action has benefited European citizens and organizations, as well as states—especially those lower income countries that are affected by disasters disproportionately—and the more vulnerable within those regions.

This COST Action run from 2012 to 2016 and brought 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 P. O'Mathúna was elected Chair of the Action. Four working groups were created, focusing on (1) healthcare ethics; (2) bioethics, culture, and moral theory; (3) research ethics; and (4) ethics and governance.

The first scientific conference of the project was held at Dublin University on April 25–26, 2013. Over the course of the past three years, seven project conferences, twelve workshops, a training school, and a summer school were organized. Among the conferences during the academic year of 2015–2016, the autumn meeting convened in Thessaloniki, Greece on October 1–2, 2015, and bore the title “Conceiving Disasters and Pandemics: Causes and Prevention.” The Center for Ethics and Law in Biomedicine hosted the spring conference, titled “Global Justice and Vulnerability in Disaster Bioethics,” on April 21–22 at the Central European University. The project closing conference was held in Dublin on October 3–4, 2016.

The twelve workshops were held in Copenhagen, Tartu, and Madrid (in 2014), London, Prešov, Dublin, Bilbao, and Prato (in 2015), Kraków, Belgrade, Vilnius, and Paris (in 2016). The First Summer Training School was organized on June 23–27, 2014 in Dubrovnik, for PhD students and early stage researchers, or practitioners from disaster-related fields who wished to learn about ethical issues emerging in disaster situations. The Second Disaster Bioethics Summer School was held on September 6–11, 2015 at the University of Birmingham. It targeted those who respond to humanitarian emergencies and disasters, in order to provide basic ethics training and preparation for humanitarian healthcare workers. CELAB research associate Péter Kakuk attended most of these conferences and workshop meetings.

On the conference organized by CELAB, as well as the outputs and proceedings based on the plenary meeting



Judit Sándor and Péter Kakuk opening the Conference on Global Justice and Vulnerability in Disaster Bioethics

and working group discussions, see Section 3.1.3 below.

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

2.1.6. RoadMAPs to Societal Mobilisation for the Advancement of Responsible Industrial Technologies (SMART-map)



Type of funding scheme: Horizon 2020

Starting date: May 1, 2016

Duration: 2016–2018

Participating Institutions:

Aarhus Universitet — Aarhus, Denmark (Coordinator)
The University of Manchester — Manchester, United Kingdom

Manchester Metropolitan University — Manchester, United Kingdom

Center for Ethics and Law in Biomedicine, Central European University — Budapest, Hungary

Fondazione Giannino Bassetti — Milano, Italy

Formicablu srl — Bologna, Italy

Fraunhofer Gesellschaft zur Förderung der angewandten Forschung e.V. — Germany

Zentrum für Soziale Innovation GmbH — Vienna, Austria

Instituto de Medicina Genómica — Valencia, Spain

SMART-map (RoadMAPs to Societal Mobilisation for the Advancement of Responsible Industrial Technologies) is a

coordination and support action financed by the European Commission under the Horizon 2020 Programme. Its goal is to define and implement concrete roadmaps for the responsible development of technologies and services in three key time-changing fields: precision medicine, synthetic biology, and 3D printing in biomedicine. The project will reach its goals by developing a new format for open and collaborative dialogues between industry and societal actors (Industrial Dialogues) which will allow the co-design of a tool (a smart map) that helps companies to address questions of social and environmental responsibility they face in their innovation processes. The project will test these smart maps in actual industrial settings, ensuring that innovators can use them easily within their existing processes.

The project starts with a 'baseline' survey of actors across all stakeholders to capture their understanding of responsibility in research and innovation, and levels of awareness and engagement with the European Commission's definition of Responsible Research and Innovation (RRI). Led by the Manchester partners, the survey will be repeated at the end of the project. For synthetic biology, the project design brings together industry and other stakeholders in the UK and Hungary. Following the baseline survey, the SMART-map project organises a series of Industrial Dialogues that bring together participants from industry, civil society, academia, government and innovation funding support. The project will organize two Industrial Dialogues for each of the innovation fields, which will take place in different regions of Europe to encourage exchange and mutual learning. An Industrial Dialogue focused on Synthetic Biology (within Workpackage 3) will be held in Manchester in March 2017. Its sister event will take place at CEU, Budapest in June 2017.

The project kick-off meeting took place in Aarhus, on June 14–15, 2016. The first Expert Advisory Board Meeting was organized in Budapest, on October 13, 2016, which was followed by project Executive Board meeting on October 14,



Smart Map Advisory Board Meeting

2. RESEARCH AND POLICY ACTIVITIES

2016. The aim of the Advisory Board meeting was to provide feedback to the consortium on the Industrial Dialog format developed by ZSI partner. The eight RRI Angels provided useful recommendations that were taken into account in the finalization of the Industrial Dialogue format.

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

Project website: <http://projectsmartmap.eu/>

2.1.7. Joining Efforts for Responsible Research and Innovation (JERRI)

Type of funding scheme: Horizon 2020

Starting date: June 1, 2016

Duration: 2016–2019

Participating Institutions:

FHG – Fraunhofer-Gesellschaft zur Förderung der angewandten Forschung e.V. – Germany (coordinator)
TNO – Netherlands Organisation for Applied Scientific Research – Netherlands
UNIMAN – The University of Manchester – United Kingdom
IHS – Institute for Advanced Studies – Austria

This project aims to make a substantial contribution to deeply institutionalising practices and attitudes of Responsible Research and Innovation (RRI) in the European Research Area (ERA). For this purpose JERRI is

orchestrating a deep RRI transition process within the two largest European Research and Technology Organisations (RTOs) the German Fraunhofer Gesellschaft (FhG) and the Netherlands Organisation for Applied Scientific Research (TNO) that is covering all five established RRI dimensions. The process is conceptualised as an intense mutual learning process between the two organisations, a wider circle of RTOs and R&I stakeholders across Europe. Thus, JERRI will exploit the unique mediating function of RTOs to catalyse RRI transition processes in industry, society and policy across the European research and innovation landscape.

Ethical considerations play a central role in this project. In order to adequately respond to societal challenges, research and innovation must respect fundamental rights and the highest ethical standards. Beyond the mandatory legal aspects, this aims to ensure increased societal relevance and acceptability of research and innovation outcomes. Ethics should not be perceived as a constraint to research and innovation, but rather as a way of ensuring high quality results. Within the JERRI project the focus will be set on the role of the research organizations in achieving a major transition towards incorporating ethical considerations and societal relevance through embedding the ethics dimension into its governance mechanisms in a lasting and thorough manner.

CELAB participant in the project: Enikő Demény (Member of the Project Advisory Board, responsible for the ethics dimension)

2.2. POLICY AND OUTREACH ACTIVITY

2.2.1. European Seminar on the Right to the Integrity of the Person, with a Particular Focus on the Field of Biology and Medicine

The European Seminar on the Right to the Integrity of the Person, with a Particular Focus on the Field of Biology and Medicine was organized in Brussels, Belgium on October 6–7, 2016 under “HELP in the 28,” the Joint Programme of the European Union (EU) and the Council of Europe (CoE), in collaboration with the Belgium Institute for Judicial Training (IFG-IGO) and, more particularly, the CoE Bioethics Unit.

The Seminar was opened by the IJF-IGO Director, the EC DG Justice Official (European Judicial Training), and the Deputy Head of CoE office in Brussels, all of whom highlighted the importance of the joint EU-CoE ‘HELP in

the 28’ Programme. The HELP network is the largest human rights training project within the EU for judges, prosecutors and lawyers. Over 50 judges, prosecutors and lawyers as well as academic and health professionals gathered to raise awareness on the right to the integrity of the person, with a particular focus on the field of biology and medicine. The role of legal professionals in its protection was also discussed, as well as the challenges they face. Developments in the biomedical field are definitely a potential source of great benefit for human beings, in particular human health, but they also offer more possibilities to intervene on and control human life.

Apart from EU officials from DG Justice linked to the Programme, various experts covered the subject from the legal and medical perspectives. The mutually reinforcing relationship between the CoE and EU systems was

explored by various speakers. Former CoE Human Rights Commissioner Gil-Robles closed the event inspiring attendees to continue the fight for human rights where much has been achieved over the last decades, in spite of difficult current European context. From CELAB Judit Sándor gave a keynote lecture on the prohibition of financial gain.

The Seminar indeed offered the right forum to present the achievements of the European Programme on Human Rights Education for Legal Professionals in the 28 EU countries, also known as 'HELP in the 28' and to promote its online course on *Right to the Integrity of the Person* (bioethics). The objective of this course is to assist legal professionals in the implementation of the European system of protection, based mainly on the European Convention on Human Rights and the Convention on Human Rights and Biomedicine, as well as the EU Charter of Fundamental Rights and other EU laws (*i.e.* Directives). In a practical way, the online course covers the case law of the European Court of Human Rights (ECtHR), the Court of Justice of the European Union (CJEU), pointing out to problems such as medical interventions or removal of organs or body parts without consent; medically assisted procreation; physical abuse; or end-of-life situations. This course is supposed to be piloted in Belgium, France, Italy and Poland.

CELAB participant in the event: Judit Sándor

Website: www.coe.int/en/web/help/-/safeguarding-human-rights-and-promoting-progress-in-biomedicine-an-essential-synergy

2.2.2. Conference on Patients' Safety in Hungary

The Hungarian Society on Patients' Safety, in cooperation with its Australian partner society organized its second annual conference on contemporary patient safety issues. During the three days of the meeting, some 130 speakers presented their views on a wide variety of patients' safety related topics, from hospital hygiene to emergency care, from legal and ethical challenges to financial obstacles, from the burnout syndrome among health care workers to other psychological limitations of good care, such as the fear of reporting adverse and harmful practices. The importance of the event was marked not only by the exceptionally large number of participants, but also by the current crisis in the Hungarian health care system.

In a number of presentations, the speakers urged an improvement in the quality of health care by implement-



Judit Sándor among the participants of the HELP 28 Seminar

ing a new adverse event reporting system in which providing detailed information on such events and learning from mistakes and structural errors are emphasized over blame and punishment. In this vein, some speakers discussed pharmacovigilance and the safety of medical devices, others focused on the education and training of healthcare workers on patient safety.

CELAB participants in the event: Judit Sándor, József Kovács, and Judit Zeller who presented their papers

2.2.3. Science Day at the University Club in Bonn

On February 15, 2016 members of the DRZE (Deutsches referenzzentrum für Ethik in den Biowissenschaften) Advisory Board, members of the DRZE Board of Trustees, and the scientific staff members of the IWE (Institut für Wissenschaft und Ethik) held a joint meeting in Bonn and discussed the ethical consequences of the emerging technologies of CRISPR/Cas9 and germline manipulation.

The Science Day started with the opening speeches of Göran Hermerén and Dieter Sturma, and they were followed by a presentation on state of the art technologies. Markus Nöthen (University of Bonn) provided a very informative presentation on the gene editing technique in a comparative context: he highlighted how gene editing differs from previously known technologies, such as gene therapy and germline interventions. Then Göran Hermerén (University of Lund) summarized the ethical arguments for or against the technology. As a member of the Advisory Board of DRZE, Judit Sándor participated in both the Science Day debate and then the Advisory Board meeting.

CELAB participant in the events: Judit Sándor

3. ACADEMIC ACTIVITIES

3. ACADEMIC ACTIVITIES


3.1. PUBLIC LECTURES AND CONFERENCES ORGANIZED BY CELAB

3.1.1. Public Lecture on 'The Genealogy of a Gene' by Prof. Myles W. Jackson

On January 15, 2016, at the invitation of CELAB, Myles W. Jackson, Ph.D., Albert Gallatin Research Excel-

lence Professor of the History of Science, NYU-Gallatin; Professor of History, Department of History, NYU-FAS; Director of Science and Society, NYU-CAS; and Professor of the Division of Medical Ethics, NYU-Langone School of Medicine offered a public lecture at CEU with the title "The Genealogy of a Gene." The CCR5 gene began as a small sequence of DNA, the became a patented corporate product, and when it was found to be an AIDS virus co-receptor with a key role in the immune system, it became part of the biomedical research world—and a potential money-maker for the pharmaceutical industry, Jackson said. In his lecture Myles W. Jackson used the story of the CCR5 gene to investigate the interrelationships among science, technology, and society. Mapping the varied "genealogy" of CCR5—intellectual property, natural selection, Big and Small Pharma, human diversity studies, personalized medicine, ancestry studies, and race and genomics—Jackson links a myriad of diverse topics. Prof. Myles provided examples for understanding the relationship between molecular biology, intellectual property law and race. He demonstrated how race has become a commodity in the system of financing pharmaceutical products.

The history of CCR5 from the 1990s to the present also offered a vivid illustration of how intellectual property law has changed the conduct and content of scientific knowledge, and the social, political, and ethical implications of such a transformation. The lecture was followed by a discussion moderated by CELAB Director Prof. Judit Sándor and engaged the representatives of many disciplines in the audience: historians, scientists, lawyers, ethicists, and anthropologists all found thoughts relevant to their own research in this lecture.



The Center for Ethics and Law in Biomedicine (CELAB) cordially invites you to a public lecture celebrating the 10th anniversary of CELAB in the 25th year of the Central European University

by

Myles W. Jackson, Ph.D.



Albert Gallatin Research Excellence Professor of the History of Science, NYU-Gallatin;
Professor of History, Department of History, NYU-FAS;
Director of Science and Society, NYU-CAS;
and Professor of the Division of Medical Ethics, NYU-Langone School of Medicine

with the title

"The Genealogy of a Gene"

January 15, 2016
Time: Friday, 2:30 pm - 4:00 pm
Location: Gellner Room, CEU,
9 Nádor u. Budapest

Discussion moderated by Judit Sándor, director of CELAB
Lecture followed by Reception

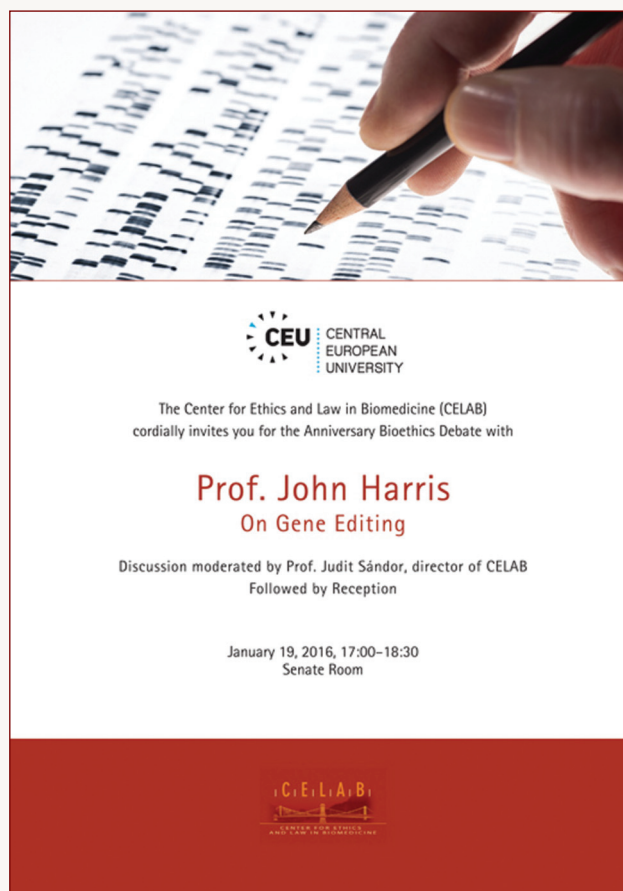
Poster inviting to Myles W. Jackson's public lecture



László Kontler Prorector opens up Myles W. Jackson's public lecture

3.1.2. Anniversary Bioethics Debate on Gene Editing, with the Participation of John Harris and Judit Sándor

On January 19, 2016 CELAB organized the Anniversary Bioethics Debate on the topic of gene editing, with the participation of Prof. John Harris and Prof. Judit Sándor. Prof. Harris called for a research-intensive society that's able to regulate itself in order to make gene editing 'safe enough' for humans. "If humankind as a species is to survive," he said, "we need to improve ourselves and introduce genes resistant to diseases like HIV." Gene editing is one of the latest and most exciting topics of contemporary bioethics. It is not just a new technology, but it may also fundamentally change the direction of the ethical debates on gene therapy and other forms of genetic intervention. Once gene editing will be a safe and approved technology, it will be possible to "cure genetic disorders"



Poster inviting to the Anniversary Debate on gene editing

When embryos will not only be tested and screened but also "repaired" before their implantation in an



John Harris and Judit Sándor at the Anniversary Debate



József Kovács and Enikő Demény at the Anniversary Debate

3. ACADEMIC ACTIVITIES

artificial reproductive procedure, then this will inevitably lead to the reinterpretation of the notion of right to life and parental choices. Embryos that otherwise may not be born, could gain a chance for life by repairing their problematic genes. John Harris argued that gene editing has to be pursued, and if possible, made safe enough to use in humans. Not only to pave the way for procedures on adult tissues, but also to keep open the possibility of protecting embryos from susceptibility to major diseases and preventing other debilitating genetic conditions from being passed on through them to future generations.

3.1.3. Conference on Global Justice and Vulnerability in Disaster Bioethics

On April 21–22, 2016 CEU hosted a conference under the same title—jointly organized by CELAB and the University of Debrecen—that also signalled the last stage of a four-year long research and networking project. The Disaster Bioethics project—COST Action No. IS1201—attempted to bring together both practitioners and researchers from a diversity of fields in order to reflect on ethical issues emerging from disaster management.

Following the welcoming and opening remarks of Dónal O'Mathúna (chair of the project) and Péter Kakuk (project member and local organizer), CELAB's director, Professor Judit Sándor gave an introductory talk on the ethical and legal complexities that we could face in disaster situations. The keynote talks had the common theme of vulnerability and justice in the global community that elaborated on a variety of topics. CEU's professor, Nenad Dimitrievic discussed collective crime and the question of responsibility. Nevena Vuckovic Sahovic explored the rights of unaccompanied children outside of their country of origin,



Disaster Bioethics Conference

in the context of the current refugee crises. Thomas Pogge talked about the issue of global justice from a philosophical perspective and Kristian Lauta approached the same question from a legal perspective.

All these presentations generated intensive discussions and the video recorded keynote talks can be accessed at www.disasterbioethics.eu. Besides these keynote speeches, the participants of the Disaster Bioethics project also convened in four working groups and each of them elaborated recommendations to international organizations, professional societies, and NGO's participating in global disaster response activities. As a concrete example for such a cooperative project output, we might mention the presentation by Andreas Reis—head of the World Health Organization's Global Health Ethics Unit—that introduced the freshly published *WHO's Training Manual: Ethics in Epidemics, Emergencies and Disasters*.

On the previous events organized within the Disaster Bioethics project, see Section 2.1.5 above.

3.2. TEACHING

CELAB's staff and fellows are involved in teaching both at the CEU and in other universities in Hungary and in other countries in the region. They offer courses that are in close connection with CELAB's main fields of inquiry. One of CELAB's goals is to develop a teaching network for bioethics and biolaw in the region.

3.2.1. Teaching at CEU

Petra Bárd

Introduction to EU Constitutional Law, at the Department of Legal Studies
EU Criminal Justice, at the Department of Legal Studies
Selected Issues of Criminology and Forensic Sciences, at the Department of Legal Studies

Emma Bullock

Critical Reasoning, at the School of Public Policy
Ethics, at the Department of Philosophy
Philosophy of Medicine, at the Department of Philosophy
Ethics, Autonomy and Paternalism, at the Department of Philosophy
Medical Paternalism
 Guest lecture at the *Political Theory, Cognitive Science, and Policy Making: Nudging* course of the Department of Political Science

Judit Sándor

Human Rights and Emerging Technologies, at the Department of Legal Studies, cross-listed with Department of Gender Studies
Human Rights in Health, at the Department of Legal Studies
Privacy Rights and Data Protection in Biotechnology, at the Department of Legal Studies
Human Rights and Biopolitics, at the Department of Gender Studies and at the Department of Political Science

Commodification of the Human Body, at the Department of Political Science

SJD Great Book Seminar — focusing on the book by Nicole A. Vincent, ed. (2013) *Neuroscience and Legal Responsibility*, Oxford: Oxford University Press, on March 23, 2016

3.2.2. Teaching and Lecturing at Other Institutions

Petra Bárd

Eötvös Lóránd University, Faculty of Law, Budapest, Hungary
Criminal policy
Data protection
EU human rights and criminal justice (in English)
 Goethe University, Frankfurt, Germany
EU integration theories, MA in Legal Theory

Violeta Beširević

Medical Law/BA 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
 School of Law, University of Lisbon, Lisbon, Portugal
 Lecture on "Deconstructing Organ Donation Euthanasia: Legal Perspective"
 April 29, 2016, Lisbon, Portugal

Éva Mária Földes

The Hague University of Applied Sciences, The Hague, Netherlands
EU Health Law
EU Decision Making and Judicial Remedies
Social and Economic Rights
Introduction to EU Law: Institutions
Consumer Protection in the EU

Péter Kakuk

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

3. ACADEMIC ACTIVITIES

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

György Kovács

National University of Public Administration,
 Budapest, Hungary
European Union Policies
Legal Framework and Characteristics of the European Union
Decision Making in the European Union
 Pázmány Péter Catholic University, School of Law,
 Budapest, Hungary
EU Intellectual Property Law
Relationship between EU Law and National Law

József Kovács

Psychiatric and Psychotherapeutic Clinique,
 Semmelweis University
 Lecture on "Ethics and Law of Psychotherapy"
 November 6, 2015, Budapest, Hungary
 Lecture on "Ethical Questions of Psychotherapy"
 September 30, 2016, Budapest, Hungary
 Lecture on "Current Ethical Questions in Psychiatry and Psychotherapy"
 October 12, 2016, Budapest, Hungary
 Department of Clinical Psychology of the
 Semmelweis University
 Lecture on "Ethical Questions of Psychotherapy"
 second year clinical psychology students
 February 8, 2016, Budapest, Hungary
 Institute for Public Health, Faculty of General
 Medicine, Semmelweis University
 Lecture on "Patient's Rights Minimum Conditions in Basic and Clinical Care"
 May 6, 2016, Budapest, Hungary

Semmelweis University
 Lecture on "Ethical Questions of Research on Human Beings"
 May 13, 2016, Budapest, Hungary
 Natural Science Research Center of the Hungarian Academy of Science
 Lecture on "Publication Ethics and Scientometry"
 November 27, 2015, Budapest, Hungary
 Józsefváros Free University
 Lecture on "The Fundamental Issues of Bioethics"
 December 2, 2015, Budapest, Hungary
 National Institute for Psychiatry and Addictology
 Lecture on "Bioethical Questions in Intensive Therapy, in Internal Medicine and in Psychiatry"
 January 27, 2016, Budapest, Hungary
 Hungarian Psychoanalytic Committee
 Lecture on "Ethical Questions of Psychoanalytic Psychotherapy"
 January 28, 2016, Budapest, Hungary
 Ethics Course of the Clinical and Health Psychology Specialization, Psychology Institute
 Lecture on "Psychologist Ethics and Ethical Questions in Psychotherapy"
 September 16, 2016, Budapest, Hungary

Imre Szabik

Bioethics courses at Semmelweis University,
 Budapest, Hungary
Bioethics for Medical Students – lectures and seminars in the Hungarian, German and English Programs at Semmelweis University, Budapest, Hungary
Research Ethics Lecture for Residents – at Semmelweis University, Budapest, Hungary
 June and August, 2015
Bioethics – course at Evangelical-Lutheran Theological University, Budapest, Hungary
Research Ethics – Lectures at CME for physicians
Research Ethics – PhD course

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) that 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, the 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 educators.

During the academic years of 2012–2014 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; and to preserve and transfer education-related expertise 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.

More than 30 educators, including CELAB Research Associates, have already joined the BOM network that held its first workshop at the University of Debrecen on June 4, 2013. The second annual meeting was hosted by CEU-CELAB and took place on June 13, 2014. This year the BOM meeting, titled “Best Practices, Innovations, Insights,” was organized by Péter Kakuk on December 1–2, 2016 at the Faculty of Public Health, University of Debrecen, with the participation of distinguished international guests—including CELAB Research Associates József Kovács and Imre Szabik.

4. EVENTS AND ACHIEVEMENTS

4. EVENTS AND ACHIEVEMENTS IN CHRONOLOGICAL ORDER

4.1. PARTICIPATION IN CONFERENCES

During the 2015–2016 Academic Year, CELAB staff and fellows took part in the following academic and scientific events

UACES Annual Conference

Presentation by Mária Éva Földes on “Extending EU-level Economic Surveillance to Health Systems of Member States: Impact of the Financial Crisis on Health Care Governance” at the Research session titled “The National Interest in EU Law and Governance: Regulatory Policies”
September 8, 2015, Bilbao, Spain

12th Annual Meeting of the Ghent Group: Network of European Forensic Psychiatrists

Presentation by József Kovács and Brigitta Baran on “Some Ethical Problems in Forensic Psychiatry”
September 17–19, 2015, Budapest, Hungary

EpiHealth Ethics Training

Presentation by Judit Sándor
September 24, 2015, Gödöllő, Hungary

CELAB Seminar Series No. 2: The Shame of Addiction

Discussion on Owen Flanagan’s article “The Shame of Addiction”—the article was presented by László Nemes, Eszterházy Károly College, Department of Philosophy
September 29, 2015, CEU, Budapest, Hungary

The Current Legal and Ethical Issues of Health Care. 4th Patients’ Rights Professional Day

Conference on the occasion of the 40th anniversary of Semmelweis University Faculty of Health Sciences

Presentation by József Kovács on “Informed Consent in Health Care Practice” and by Helga Judit Feith, Edina Gradwohl, József Kovács and Csaba Nádor on “Examining Ethical, Legal and Medical Issues Connecting to Professional Tasks of Workers in the Practice of Perinatal Intensive Care Relating to the Beginning and the End of Life” (Workshop leader: József Kovács)

October 9, 2015, Budapest, Hungary

Ninth European Public Health Conference on “Health in Europe: From Global to Local Policies, Methods and Practices”

Presentation by Mária Éva Földes on ‘Health System Governance in Times of Economic Crisis: a Growing Relevance for EU Policy and Action?’ at the session titled Health Impacts of Economic Crisis

October 16, 2015, Milano, Italy

Annual Conference of Central European Association of Bioethics

CELAB participant Imre Szebik
October, 2015, Vienna, Austria

Annual Meeting of Young Obstetricians

Presentation by Imre Szebik, Nick Rubashkin, Éva Susánszky, Zsuzsa Szántó, Anna Susánszky on "Ethical Issues of Obstetric Practice"
October 16–18, 2015, Kecskemét, Hungary

CELAB Seminar Series No. 3: Being Mortal

Discussion of the book by Atul Gawande (2014) *Being Mortal: Medicine and What Matters in the End*—the book was presented by Emma Bullock, CEU Department of Philosophy, CELAB, SPP
October 30, 2015, Budapest, Hungary

Workshop of the International Academic Network on Bioethics on "The Principle of Non-Commodification of the Human Body"

Presentation by Judit Sándor on "The Principle of Non-Commodification of the Human Body in Hungary"
November 4–8, 2015, Istanbul, Turkey

The 17th Congress of the Hungarian Transplantation Society

Presentation by Kovács József with Sándor Mihály, Anikó Smudla, Orsolya Deme, Emese Holtzinger, Ferenc Alföldy, and Dóra Sélley on "Questionnaire on the Attitude on the Organ Donation Information Process"
Presentation by József Kovács with Sándor Mihály and Anikó Smudla on "The Hungarian Specificities of the Communication Related Practices in Organ Donation"
November 19–20, 2015, Balatonfüred, Hungary

Reproductive Rights, New Reproductive Technologies and the European Fertility Market Conference

Organized by the Erasmus University Rotterdam and University of Cantabria
Presentation by Mária Éva Földes on "Transparency and Information on Medical Devices and In Vitro Diagnostic Devices: Key Elements of the EU Legislative Reform"
November 19–20, 2015, Santander, Spain

Conference on Legal Decisions at the End of Life in Hungary

Organized at the Hungarian Academy of Sciences
Presentation by Mihály Filó on "The Status of Perpetrator, Accessory, and Self-Determination: Assisted Suicide in Europe [Tetteség, részesség, örendelkezés: Az asszisztált öngyilkosság Európában]"

Presentation by József Kovács on "Restriction and Medical Ethics"

Presentation by Judit Sándor on "Life and Death at the End of Life. Pregnant Women in Persistent Vegetative State [Élet és halál az élet végén. Várandós nők perzisztens vegetatív állapotban]"
November 24, 2015, Budapest, Hungary

NERRI Vienna Workshop

Participants: Judit Sándor and Márton Varju
November 29, 2015, Vienna, Austria

Conference on Pseudo-Sciences and Evidence-Based Medicine

Organized by the Permanent Interdepartmental Committee on Health and Environment of the Hungarian Academy of Science and the Academic Committee of Pécs
Lecture by József Kovács on "Ethical Questions of Pseudo-Sciences"
December 3, 2015, Budapest, Hungary

CELAB Public Lecture Series

Lecture by Myles W. Jackson (New York University) on "The Genealogy of a Gene"
January 15, 2016, Budapest, Hungary

Anniversary Bioethics Debate on Gene Editing

Discussants: John Harris and Judit Sándor; participants: CELAB Research Associates and invited guests
January 19, 2016, Budapest, Hungary

IBRO Workshop

CELAB Participants: Judit Sándor and Márton Varju
January 20, 2016, Budapest, Hungary

Neuro-Enhancement Policies for the Future Panel Discussion

Participants: Agnes Allansdottir (Toscana Life Sciences), Imre Bárd (LSE), Rui Vieira da Cunha (University of Porto), Judit Sándor (CEU-CELAB), Márton Varju (CEU-CELAB)
February 5, 2016, Budapest, Hungary

A Clockwork Brain: How Can Art Deepen the Social Discourse of Science Such as Neuro-Enhancement?

Participation at the round-table discussion: Judit Sándor
NERRI Project Dissemination Event
February 13, 2016, Bonn, Germany

4. EVENTS AND ACHIEVEMENTS

Science Day on the CRISPR/Cas9 Technology and Germline Manipulation

CELAB participant: Judit Sándor
February 15, 2016, Reykjavík, Island

Personalized Medicine, Ethical and Legal Aspects—Conference on Patients' Safety

Presentations by Judit Sándor and József Kovács
Lecture by József Kovács on "Mistakes Committed during the Provision of Health Care and the Informed Consent [Az egészségügyi ellátás során elkövetett hibák és a tájékozott beleegyezés]"
Lecture by Judit Sándor on "Ethical and Legal Implications of the Personalized Medicine and Genetic Tests [A személyre szabott gyógyítás és a genetikai vizsgálatok etikai-jogi kérdései]"
April 1, 2016, Budapest, Hungary

Worldly Matters: 6th International Graduate Conference, Department of Philosophy, Central European University

Keynote speech by Emma Bullock on "Valid Consent and Moral Transformation"
April 1–2, 2016, Budapest, Hungary

Conference on Global Justice and Vulnerability in Disaster Bioethics

CELAB participants: Péter Kakuk, Judit Sándor, Márton Varju, Emma Bullock, Enikő Demény
April 21, 2016, Budapest, Hungary

International Conference "From Treatment to Killing. The History of Scientifically Based Eugenic Cleansing"

Presentation by József Kovács on "Bioethical Lessons of the Eugenic Movement"
April 25, 2016, Budapest, Hungary

The Art of Medical Communication: From the Medical Anamnesis to the Information Given to the Relatives of the Dying Patient

Roundtable participant: Judit Sándor
May 3, 2016, Budapest, Hungary

Straub Days: Conference of the Hungarian Academy of Science, Szeged

Presentation by Judit Sándor on "The Ethical and Legal Aspects of Gene Editing: The Textuality of Genetics [A génszerkesztés etikai és jogi aspektusai: A genetika szóbelisége]"
May 25, 2016, Szeged, Hungary

The Future of Psychiatry. Journey Time and Space. 20th Conference of the Hungarian Psychiatry Association

Presentation by József Kovács and Brigitta Baran on "The Ethics of Forensic Psychiatry"
May 25–28, 2016, Budapest, Hungary

Conference on Bioethics in a European Context

Presentation by Emma Bullock on "Valid Consent and Moral Transformation in Medical Practice"
May 19–20, 2016, Bucharest, Romania

SMART-Map Project: Kick-off Meeting

CELAB participant: Enikő Demény
June 15, 2016, Aarhus, Denmark

Third Conference on Pregnancy and Heart Disease

Presentation by Judit Sándor on "Legal Implications of Altruistic and Commercial Surrogacy and the Needs of Women with Heart Disease"
June 17, 2016, Budapest, Hungary

Dubrovnik International Bioethics Summer School (DIBSS)

Organized by the Global Bioethics Initiative, the University of Zagreb, and CAAS at the Inter-University Centre, August 5–14, 2016
Keynote speech by Judit Sándor on "Frozen Mothers and Bioethical Questions in the New Reproductive Technologies"
August 13, 2016, Dubrovnik, Croatia

Annual Conference of the Hungarian-American Medical Association

Workshop: What to Take Care of? Memorable Juristic Cases for Doctors
Presentation by György Kovács on "Liability of Doctors in the Light of Legislative Changes and the Recent Case Law of Hungarian and US Courts"
August 26–27, 2016, Balatonfüred, Hungary

International Undergraduate Conference in Moral and Political Philosophy, Central European University

Keynote talk by Emma Bullock on "Friendship and Virtuous Intervention"
September 2–3, 2016, Budapest, Hungary

EUCeLLEX Project, Final Conference

Presentation by Judit Sándor and Márton Varju on
 "Embryonic Stem Cells in Biomedicine: The
 Regulatory Tango"
 September 22, 2016, Paris, France

HELP28 Seminar on the Right to Integrity of the Person

Organized by the Judicial Training Institute
 Keynote speech by Judit Sándor on "Prohibition of
 Financial Gain"
 October 6–7, 2016, Brussels, Belgium

26th Annual Conference of the Hungarian Society of Bioethics

Participants: József Kovács, Imre Szebik
 Lecture by József Kovács on "The Ethical Issues
 of Synthetic Biology"
 October 8, 2016, Budapest, Hungary

SMART Map Project Expert Advisory Board Meeting

Participants: Enikő Demény, Judit Sándor, and
 Péter Kakuk
 October 13, 2016, Budapest, Hungary

SMART Map Project Executive Board Meeting

Participants: Enikő Demény, Péter Kakuk
 October 14, 2016, Budapest, Hungary

CELAB Seminar Series No.4: The Role of Compromise in Ethics

Presentation by Péter Kakuk
 October 21, 2016, Budapest, Hungary

Annual Conference of the Association of Bioethicists in Central Europe (BCE)

Participant: Szebik Imre
 October 23–24, 2016, Prague, Czech Republic

Ninth European Conference on Public Health

Panel on "Bridging the Gap between Knowledge
 and Practice in Public Health Genomics"
 Panelists: Róza Ádány, Stefania Boccia, Martina
 Cornel, Judit Sándor
 November 9, 2016, Vienna, Austria



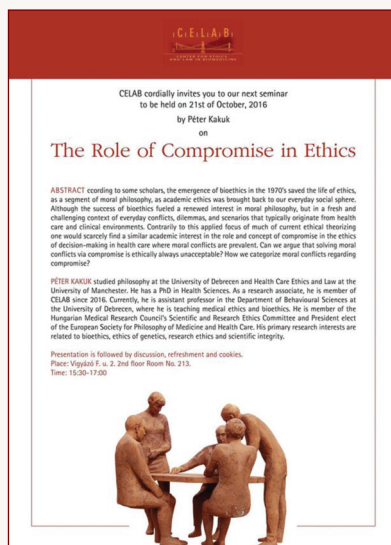
Judit Sándor among the European Public Health
 Conference panelists

CELAB Seminar Series No. 5: Disrespectful Demands

Presentation by Simon Rippon
 November 25, 2016, Budapest, Hungary

Working Group Meeting of the Cambridge Consortium for Bioethics Education: Best Practices, Innovation, Insights

Organizer: Péter Kakuk, University of Debrecen,
 Faculty of Public Health, Department of
 Behavioral Sciences
 Presentation by József Kovács on "Environmental
 Ethics in the Medical Curriculum"
 December 1–2, 2016, Debrecen, Hungary



Invitation to the
 CELAB Seminar
 'The Role of
 Compromise in
 Ethics'

4. EVENTS AND ACHIEVEMENTS

4.2. SCIENCE COMMUNICATION AND MEDIA EVENTS

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

Le style, c'est docteur [A stílus az orvos] — On the doctors' communication skills
Article by Judit Sándor in the essay series *Body Talk* [Testbeszéd]
Magyar Narancs, 2015, vol. 27, no. 39, pp. 40–41.
magyarnarancs.hu/egotripp/testbeszed-96590
September 24, 2015

Good Girl [A jó nő] — On the cultural imperative of being a good girl
Article by Judit Sándor
Magyar Narancs, 2015, vol. 27, no. 44, pp. 42–43.
magyarnarancs.hu/publicisztika/a-jo-no-97010
October 29, 2015

The Most Important of Patients' Rights [A betegjogok legfontosabbika]
Interview with József Kovács by dr. Anita Kazai
Jogorvoslap, 2015, vol. 7, no. 2, 11–14.

Me, you, she, we, you, they [Én, te, ő, mi, ti, ők] — On the dilemmas of forming groups on genetic basis
Article by Judit Sándor in the essay series *Body Talk* [Testbeszéd]
Magyar Narancs, 2015, vol. 27, no. 48, p. 56.
magyarnarancs.hu/egotripp/sandor-judit-testbeszed-97360
November 26, 2015

On the Ethical Issues of Pseudo-Sciences
Interview with József Kovács by Ágnes Veress
Radio Kossuth, 'Napközben' Program
January 7, 2016

"Just Smiles amidst This Tragic Situation"—The Doctors Do Not Care about the Patient's Sool
["Mosolyog, miközben a helyzet tragikus"—a beteg lelkével nem törődnek az orvosok]
Interview with József Kovács by Adél Hercsel

hvg.hu, online in Hungarian at
hvg.hu/plazs/20160108_cim
January 8, 2016

Emotional Studies. On the Economy of Feelings
[Szívtan. Az érzelmek gazdaságáról]
Article by Judit Sándor in the essay series *Body Talk* [Testbeszéd]
Magyar Narancs, 2016, vol. 28, no. 4, 42–43.
<http://magyarnarancs.hu/publicisztika/szivan-98036>
January 28, 2016

Gene-Edited Fetuses? [Tervezhető magzatok?]
Interview with Judit Sándor by Kata Szabó
Vasárnapi Hírek
February 20, 2016

Patenting Immaculate Conception?
Article by Jasper A. Bovenberg, Alexandra Henrion Caude and Judit Sándor
Project Syndicate
March 1, 2016

Nationalization of Women's Bodies [A női test államosítása]
Article by Judit Sándor in the essay series *Body Talk* [Testbeszéd]
Magyar Narancs, 2016, vol. 28, no. 9, 41.
<http://magyarnarancs.hu/egotripp/testbeszed-98445>
March 3, 2016

Hunting for Tumor Markers. DNA Test: Protection or Fear? [Rákvádászat. DNS-teszt: Védelem vagy félelem?]
Interview with Péter Lakatos and Judit Sándor by Júlia Gimes.
HVG, 2016, vol. 38, no. 16, 48.
April 16, 2016

Being Enhanced in Sport [Felturbózva]
Article by Judit Sándor in the essay series *Body Talk* [Testbeszéd]
Magyar Narancs, 2016, vol. 28, no. 16, 64.
<http://magyarnarancs.hu/egotripp/sandor-judit-testbeszed-99066>
April 21, 2016

The Case of Mid-Size Female Patients [A közepesen táplált nőbetegek esete] — On patient-doctor relations

Contribution by Judit Sándor

Weborvos

May 4, 2016

Surrogate Mothers' Voices [Béranyák szava]

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

Magyar Narancs, 2016, vol. 28, no. 21, 56–57.

<http://magyarnarancs.hu/egotripp/sandor-judit-testbeszed-99493>

May 26, 2016

Interview with Judit Sándor by Gabriella Nánási on the Dutch Proposal on Conducting Research on Embryos Created for Research Purposes

Radio Kossuth, 'Közelről' Program

June 1, 2016

How shall I call you? [Minek nevezzetek?] — On the many faces of the human embryo

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

Magyar Narancs, 2016, vol. 28, no. 28

<http://magyarnarancs.hu/egotripp/sandor-judit-testbeszed-100109>

July 14, 2016

Curriculum Vitae, Including Sex Discrimination

[Nemi diszkriminációs életrajz]

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

Magyar Narancs, 2016, vol. 28, no. 31, 56–57.

<http://magyarnarancs.hu/egotripp/sandor-judit-testbeszed-100354>

August 4, 2016

Interview with Judit Sándor on Personalized Medicine and Pre-implantation Genetic Testing
Reporter: Júlia Gimes

Radio Kossuth, 'Tér-idő' Program, at 2:34 p.m. and 11:36 p.m.

August 29, 2016

Borderline Cases: Intersexuality in the Global Sport
[Határhelyzetek. Az intersexuális és a globális élsport]

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

Magyar Narancs, 2016, vol. 28, no. 38, 41–43.

September 22, 2016

Piety and Reason: Life after Death [Kegyelet és ráció: Élet a halál után]

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

Magyar Narancs, 2016, vol. 28, no. 48, 58–59.

December 1, 2016

4.3. PUBLICATIONS

Bárd, Petra, Carrera, Sergio, Guild, Elspeth, Kochenov, Dimitry (2016) An EU Mechanism on Democracy, the Rule of Law and Fundamental Rights. In Center for European Policy Studies (CEPS), 234 p.

Bárd, Petra (2015) Az EU csatlakozása az Emberi Jogok Európai Egyezményéhez: A csatlakozás menete és a kutatási kérdések [EU Accession to the European Convention of Human Rights: The Process of Accession and Questions of Research]. *Fundamentum*, vol. 19, no. 4, 20–38.

Beširević, Violeta (2016) Mission (Im)Possible: Defending A Right to Die. In Kenneth Himma, Bojan Spaić (eds.), *Fundamental Rights: Justification and Interpretation*, The Hague, Eleven Publishing International, 149–177.

Bullock, Emma C. (2016) Knowing and Not Knowing For Your Own Good: The Limits of Epistemic Paternalism. *Journal of Applied Philosophy*, vol. 33 (Early view publication online on May 18, 2016).

Bullock, Emma C. (2016) Mandatory Disclosure and Medical Paternalism. *Ethical Theory and Moral Practice*, vol. 19, no. 2, 409–424.

Bullock, Emma C. (Forthcoming in 2017) Valid Consent. In Peter Schaber and Andreas Müller (eds.), *The Routledge Handbook of the Ethics of Consent*. London: Routledge.

Bullock, Emma C. (Forthcoming in 2017) The Patient-Practitioner Relationship. In Kalle Grill and Jason Hanna (eds.), *The Routledge Handbook of the Philosophy of Paternalism*. London: Routledge.

Bullock, Emma C. (Forthcoming) Moral Paternalism and Neurointervention. In David Birks and

4. EVENTS AND ACHIEVEMENTS

- Thomas Douglas (eds.) *Treatment for Crime: Philosophical Essays on Neurointerventions in Criminal Justice*. Oxford: Oxford University Press.
- Demény, Enikő (2016) The Principle of Vulnerability and its Potential Applications in Applied and Professional Ethics. In *Ethics and Bioethics (in Central Europe)*, vol. 6, no. 3–4, 181–186.
- Demény, Enikő (Forthcoming in March 2017) Networks of Reproduction: Politics and Practices Surrounding Surrogacy in Romania. In Miranda Davies (ed.) *Babies for Sale? Transnational Surrogacy, Human Rights, and the Politics of Reproduction*. London: ZED Books, 123–141.
- Demény, Enikő (Forthcoming April 2017) From Eugenics and “Race Protection” to Preventive Medicine and Family Planning in Hungary. In Marcin Moskalewicz and Wojciech Przybylski (eds.) *Understanding Central Europe*. London: Routledge.
- Filó, Mihály (2015) Die Einwilligung des Verletzten im ungarischen Strafrecht. In Christian Fahl, Eckhart Müller, Helmut Satzger, Sabine Swoboda (eds.) *Ein menschengerechtes Strafrecht als Lebensaufgabe: Festschrift für Werner Beulke zum 70. Geburtstag*. Heidelberg: C. F. Müller, 95–102.
- Filó, Mihály (2015) Anti-Drug Policies in Hungary: Towards a Punitive Approach. In Jozef Šuvada and Pavol Tománek (eds.) *Social Pathology Among Youth: International Dialogue of Aspects in Social Pathology Among Children, Youth and Young Adults*. Book of Abstracts, 143.
- Filó, Mihály (2016) Személy és személyiség mint jogi tárgy [Person and Personality as Legal Object]. In Attila Menyhárd and Fruzsina Gárdos-Orosz (eds.) *Személy és személyiség a jogban* [Person and Personality in Law]. Budapest: Complex-KJK, 269–286.
- Filó, Mihály (ed.) (2016) Special Issue on Regulating End-of-Life Decisions in Hungarian Law, *Állam- és Jogtudomány*, vol. 57, no. 4, 1–136.
- Filó, Mihály and Péter Buzás (2016) Életvégi döntések és a margin of appreciation az Emberi Jogok Európai Bíróságának gyakorlatában [End-of-Life Decisions and the Margin of Appreciation in the Practice of the European Court of Human Rights]. *Állam és Jogtudomány*, vol. 57, no. 4, 19–39. [Special Issue on Regulating End-of-Life Decisions in Hungarian Law]
- Filó, Mihály (2016) Asszisztált öngyilkosság és az életvégi döntések Európában: Tettesség, részesség, önrendelkezés [Assisted Suicide and End-of-Life Decisions in Europe: Delinquency, Compliance, and Self-Determination]. *Állam és Jogtudomány*, vol. 57, no. 4, 120–134. [Special Issue on Regulating End-of-Life Decisions in Hungarian Law]
- Földes, Mária Éva (2016) Health Policy and Health Systems: A Growing Relevance for the EU in the Context of the Economic Crisis. *Journal of European Integration*, vol. 38, no. 3, 295–309.
- Kakuk, Péter and János Kristóf Bodnár (Guest editors) (2015) Tudományetika különszám [Ethics in Science, Special Issue]. *Magyar Tudomány*, vol. 176, no. 8, 898–1025.
- Kakuk, Péter (2015) A tudomány integritásának kortárs dilemmái az orvos és egészségügyományokban [Contemporary Dilemmas of Scientific Integrity in Medical and Life-sciences]. *Magyar Tudomány*, vol. 176, no. 8, pp. 898–904.
- Kakuk, Péter with János Kristóf Bodnár and Ágoston Gajdos (2015) A Hwang botrány következményei és tanulságai [Consequences and Lessons of the Hwang Scandal]. *Magyar Tudomány*, vol. 176, no. 8, 905–916.
- Kakuk, Péter (2015) A tudományos élet egyetlen „valutája”. Interjúja Kovács József bioetikus professzorral [The Only “Currency” in the Scientific World. Interview with Professor József Kovács]. *Magyar Tudomány*, vol. 176, no. 8, 943–949.
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4. EVENTS AND ACHIEVEMENTS

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4.4. VISITING FELLOWS

Mirko Đuković works as a teaching and junior researcher at the University of Donja Gorica in Montenegro. He finished his bachelor and specialist degree at the University of Montenegro. Since 2010 he has been employed at the International law, European law and Human Rights Cathedra at the Faculty of Law. In 2012 he received his MA in European Integration Law at the Faculty of Law Belgrade University. In 2014 he started his PhD studies at the University of Donja Gorica. He is

teaching European Union Law, Non-Discrimination Law and Political System of Montenegro. His main research interests are intellectual property law, and human rights and new technologies. In his writing he primarily addresses European law, human rights, democracy, identity and constitutionalism. While visiting CEU/CELAB he will be working on correlation between Human Rights and Intellectual Property law: human right to health (life) and medical patents.

4.5. AWARDS, APPOINTMENTS AND SPECIAL EVENTS

Dr. József Kovács, Professor of Bioethics, Research Associate at CELAB has been appointed as Director of the Institute of Behavioral Sciences, Semmelweis University as of 1 July, 2016. Dr. József Kovács graduated at the Semmelweis University of Medicine in 1979. He is a physician, and a philosopher by training. He has a specialist examination in Community Medicine and in Psychotherapy (Cognitive and Behavioral Therapy). He is a bioethicist and a psychotherapist. At present he is Professor of Bioethics and the head of the Department of Bioethics. His research covers patient rights, ethical questions of human research and research integrity, and ethics

in psychiatry. He has a PhD degree in Medicine (The Hungarian Academy of Sciences; Title of his thesis is "Justice in Health Care: The Ethical Questions of Macro Allocation"). He habilitated at the Semmelweis University in 2006, and he became Academic Doctor of Philosophy (D.Sc.) in 2010 (The Hungarian Academy of Sciences; Title of thesis is "Bioethical Questions in Psychiatry and in Psychotherapy"). He wrote three books in Hungarian, and published several book chapters and scientific articles in bioethics.

Éva Mária Földes was appointed as lecturer in EU Law, The Hague University of Applied Sciences, The Hague, Netherlands.



CELAB end of year lunch

On the August 19, 2016 CELAB's research associate, Péter Kakuk was elected as the next president of the European Society for Philosophy of Medicine and Healthcare (www.espmh.org). He was elected during the Society's general assembly meeting in Zagreb that was held as part of their 30th annual scientific conference. Péter will serve the ESPMH Board for three years as President-elect, then another three years as President of Society. ESPMH was established 30 years ago, currently it has more than three hundred members and an well-established academic journal (Medicine, Health Care and Philosophy) that is globally ranked as the 24th in the category of "Ethics" journals and the 9th within the category of "History and philosophy of science."

5. BUDGET

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5.1. REVENUES IN AY 2015/2016

Approved Budget from CEU	Amount in Euro
C-5036 Total	58,400

External Funding	Amount in Euro
NERRI	57,083
EUCeLLEX	29,263
SMART Map	464
Total	86,810

5.2. SPENDING IN AY 2015/2016

CELAB MAIN BUDGET CODE

Budget category	Amount in Euro
Personnel cost	57,680
Other costs	720
Total	58,400

NERRI PROJECT

Budget category	Amount in Euro
Personnel costs	49,759
Other costs	7,324
Total	57,083

EUCeLLEX PROJECT

Budget category	Amount in Euro
Personnel costs	26,486
Other costs	2,777
Total	29,263

SMART-MAP PROJECT

Budget category	Amount in Euro
Personnel costs	0*
Other costs	464
Total	464

*spending on personal costs started after August 2016

EU PROJECTS (NERRI, EUCeLLEX, SMART-MAP) IN TOTAL

Budget category	Amount in Euro
Personnel costs	76,245
Other costs	10,565
Total	86,810

