

celab.ceu.edu



| C | E | L | A | B |

CENTER
FOR ETHICS AND LAW
IN BIOMEDICINE

ANNUAL REPORT

2016–2017



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

© March 2018
Center for Ethics and Law
in Biomedicine (CELAB)

ISSN 1992-4038

CELAB Report is published annually

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

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

TABLE OF CONTENTS

1. FOREWORD.....	2
2. RESEARCH AND POLICY ACTIVITIES	6
2.1. PARTICIPATION AND COLLABORATION IN RESEARCH NETWORKS	6
2.1.1. Neuro-Enhancement: Responsible Research and Innovation (NERRI): Project Survey Revealing Public Views on Gene Editing Published in <i>Nature</i>	6
2.1.2. Joining Efforts for Responsible Research and Innovation (JERRI)	7
2.1.3. RoadMAPs to Societal Mobilisation for the Advancement of Responsible Industrial Technologies (SMART-map)	7
2.1.4. Human Rights – Mutually Raising Excellence (HURMUR)	9
2.1.5. Infertility and the Socio-Technical Practice of Assisted Reproductive Technologies.....	10
2.1.6. International Academic Network on Bioethics (IANB)	10
2.2. POLICY AND OUTREACH ACTIVITY	11
2.2.1. Annual Congress of the Hungarian Medical Association of America	11
2.2.2. Ninth European Conference on Public Health	11
2.2.3. Twenty-Third Annual Congress of the World Association of Medical Law	11
2.2.4. Thirty-First European Conference on Philosophy of Medicine and Health Care: Emerging Technologies in Healthcare	12
2.2.6. Roundtable on Human Reproduction at the Hungarian Academy of Sciences.....	12
2.2.7. The Role of the New Technologies	13
3. ACADEMIC ACTIVITIES	14
3.1. PUBLIC LECTURES AND CONFERENCES ORGANIZED BY CELAB	14
3.1.1. CELAB Seminar Series.....	14
3.1.2. UniStem Day 2017	16
3.1.3. Bioethics Debates Series: Euthanasia	17
3.2. TEACHING	18
3.2.1. Teaching at CEU	18
3.2.2. Teaching and Lecturing at Other Institutions	18
4. EVENTS AND ACHIEVEMENTS IN CHRONOLOGICAL ORDER	20
4.1. PARTICIPATION IN CONFERENCES.....	20
4.2. SCIENCE COMMUNICATION AND MEDIA EVENTS.....	23
4.3. PUBLICATIONS.....	24
4.4. VISITING FELLOWS	27
4.5. AWARDS, APPOINTMENTS AND SPECIAL EVENTS	27
5. BUDGET	28
5.1. REVENUES IN AY 2016/2017	28
5.2. SPENDING IN AY 2016/2017.....	28

1. FOREWORD



In December 2017 the Center for Ethics and Law in Biomedicine (CELAB) closes a very productive year, full of ongoing and new research projects, public lectures and workshops, conferences and seminars. In order to explore the new and exciting domains of biotechnology we apply legal and anthropological methods, comparative ethical and historical analysis, combinations of desk research with fieldwork and interviews in our research projects and policy surveys at CELAB. 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.

After successfully completing two very demanding European research projects during the previous academic year, in 2016–2017 we started to work in new fields, as part of new research consortia. The two outgoing EU-funded projects, Neuro-Enhancement: Responsible Research and Innovation (NERRI) and Cell-Based Regenerative Medicine: New Challenges for EU Legislation and Governance (EUCeLLEX) both had their late fruits in the form of publications: in November 2017 the prestigious science journal *Nature* published the results of our extensive public survey on attitudes towards neuro-enhancement and gene editing, while the report on the findings of the EUCeLLEX project, together with some recommendations for future regulation on the cell sources of advanced therapy medicinal products, is going to be published as an E-Book by INSERM, the Toulouse-based coordinating institution of the EUCeLLEX consortium.

One of the most important projects for this academic year was SMART-map (RoadMAPs to Societal Mobilisation for the Advancement of Responsible Industrial Technologies), which 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

“A major task politicians and researchers are facing today is the need to reestablish trust between science and public opinion. This problem is often conflated with the general observation that the level of general trust, a key aspect of social capital and foundation of solidarity in Western societies, is weakening.”

Yehuda Elkana and Hannes Klöpper, *The University in the Twenty-First Century* (Budapest: CEU Press, 2016), p. 107

and collaborative dialogues between industry and societal actors (so-called 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. In the first half of 2017, the project participants organized two Industrial Dialogues for each of the three innovation fields (precision medicine, 3D printing, and synthetic biology), which took place in different regions of Europe to encourage exchange and mutual learning. Before the start of each Industrial Dialogue a ‘baseline’ survey of actors across all stakeholders was conducted to capture their understanding of responsibility in the targeted fields of 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.

In 2017 we also joined another European Commission funded project, Human Rights—Mutually Raising Excellence (HURMUR). In the framework of this research cooperation, the Tallinn University hosted the conference titled “New Human Rights of the 21st Century” on September 20–22, 2017 to explore the origins of such rights, the functions and the rhetoric of these rights, and the role such “new” rights can play in the field of human rights law. The three-day conference brought together leading researchers in the fields of rights related to identity and personality; rights to well-being; rights related to the exercise of public authority; rights related to new technologies. I took part in the conference as commentator on the genetic rights panel.

We also have some projects that are not within a European Research framework. In 2017 we continued our participation in the Inter-University Academic Network on Bioethics. This network organizes annual workshops on various bioethics-related topics

and the main purpose of these workshops is to apply a comparative perspective to the analysis of the selected topic. The workshop presentations are published in edited volumes and this research cooperation has so far yielded altogether 16 books since 2007, the start of the project. The most recent book published in the series is titled *Le principe de non-patrimonialité du corps humain: du principe à la réalité* [The Principle of Non-Patrimoniality of the Human Body: From Principle to Reality]. On November 23–25, 2017 University of Rennes hosted the, so far, last workshop with the title “Corps et Religions” in which law professors, anthropologists and philosophers from twenty different countries analyzed the role of religion in the context regulating the circumcision, blood transfusion, wearing scarf, burka, burkini, and other aspects of religious practices exercised by a minority or majority within different societies.

It is difficult to list all the events in which we participated or which we organized. Perhaps I can mention first the event that was very successful and in which we managed to include top scientists, university students, as well as students from secondary schools. UniStem, which is currently the largest educational outreach initiative on stem cells and regenerative medicine in Europe, organizes an outreach event every year to engage high school students in the field of stem cell research. In 2016 UniStem Day was organized simultaneously by 46 universities across Italy, Spain, Ireland, Sweden, and the United Kingdom. CELAB joined to this initiative in 2017 and organized the first Hungarian UniStem Day on Friday, March 12, 2017. Secondary school students and university students participated in the workshop that was coordinated by Márton Varju.

We launched CELAB Faculty Seminars in 2014 with the aim of reading together some of the seminal works in the field of contemporary bioethics. The aim of these meetings is twofold. On one hand, fellows and visiting fellows may bring with them some important new pieces of bioethics literature to provide a summary and analyze them and, on the other hand, CELAB research fellows and guest lecturers may present the results of their

current research. In the 2016–2017 academic year Mirko Đuković, János Fiala-Butora, Péter Kakuk, and Simon Rippon gave presentations on various topics, including dilemmas in brain surgery, compromise in ethics, and the organ market.

We also continued our Bioethics Film Club screenings. In April 2017 we presented and discussed the Dutch documentary film by Peter Bosch *Priscilla* in collaboration with the Dutch Embassy. The film was about the last day of Priscilla's life. She had an incurable illness and she decided to ask for a special birthday present: her euthanasia. The 55-minute-long film gave an opportunity to discuss the ethical and legal questions related to voluntary euthanasia.

We also participated at two major conferences, one was held in Baku, the Congress of the World Association of Medical Law. The other was held in Belgrade, the Conference of the European Conference on Philosophy of Medicine and Health Care. In both conferences genome editing was the main field of our contribution. We also participated in a debate organized by the Institute of Law of the Hungarian Academy of Sciences on the ethical, legal and religious implications of IVF technology.

We had a successful year in terms of publications, as well. Besides publishing our survey results on neuro-enhancement and gene editing in *Nature Biotechnology*, the conclusions of our OTKA funded research project on egg cryopreservation appeared in the journal *Medicine, Health Care, and Philosophy*.

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.

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): Project Survey Revealing Public Views on Gene Editing Published in *Nature*



Advances in biomedicine offer people with disabilities and chronic illnesses hope and choices that they did not have before—but these emerging, new options are never without controversy. Gene editing, for example, allows for specific targeted changes to the DNA of a cell and some critics label it “playing God.” CEU’s Center for Ethics and Law in Biomedicine (CELAB) was one of 18 European centers that participated in the three-year, EU-funded *Neuro-Enhancement: Responsible Research and Innovation (NERRI)* project that posed questions like: is human improvement unlimited? Can we and, more importantly, how can we employ technological innovation to better ourselves? And how imminent is the appearance of the man-machine?

The science journal *Nature* published the results of CEU Professor Judit Sándor and Márton Varju’s extensive public survey on attitudes toward gene

editing. The survey involved 1,000 participants from eleven countries, including Hungary, Austria, Germany, and the United States. Sándor and Varju found that people generally support gene editing for treatment of an illness or disease rather than for enhancement. “Similarly, there is greater support across all countries for intervention on adults than on prenatals.”

The additional comments from survey participants offer insight into why people support or do not support gene editing. “For adult therapy, 75 percent of the comments were positive evaluations of gene editing technology. In order of frequency, these comments related to the following: it led to ‘improvements to quality of life’; it would enable ‘curing dementia’; and the ‘benefits outweighing the risks,’” the study reports. “For prenatal therapy the proportion of support for gene editing declines to 60 percent. Positive comments for this type of therapy were the same as for ‘adult therapy,’ but included additional comments, such as ‘it is natural for parents to want the best for their children.’ Gene editing for adult enhancement achieves only 26 percent positive comments. On the negative side, people mention there is ‘no need; being normal or average is ok,’ and that there might be ‘risks and unknown consequences.’ Only 11 percent of comments on prenatal enhancement are positive.” (*Nature Biotechnology*, 2017, 1021–1023)

2. RESEARCH AND POLICY ACTIVITIES

2.1.2. 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 insitutionalizing 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. 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.

As member of the Advisory Board responsible for the ethics dimension Enikő Demény attended the project Advisory Board Meeting on May 10, 2017, in The Hague. Following the discussion at the Advisory Board meeting and based on the project reports, she collected responses from the two targeted organizations (Fraunhofer and TNO) and outlined recommendations concerning the implementation of the ethics dimension. The outcomes of the work done will be discussed in the next Advisory Board meeting planned on April 19–20, 2018, in The Hague.

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

Duration of the project: 2016–2019

Project website: <http://www.jerri-project.eu/jerri/>

2.1.3. RoadMAPs to Societal Mobilization 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 Mobilization 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 reaches its goals by developing a new format for open and collaborative dialogues between industry and societal actors (Industrial Dialogues) that allows 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 tests these smart maps in actual industrial settings, ensuring that innovators can use them easily within their existing processes.

The project kick-off meeting took place in Aarhus, on June 14–15, 2016. The first Expert Advisory Board Meeting was organized by CELAB in Budapest, on October 13, 2016, which was followed by project Executive Board meeting on October 14, 2016. The aim of the Advisory Board meeting was to provide feedback to the consortium on the Industrial Dialog format developed by ZSI Vienna. The eight RRI Angels provided useful recommendations that were taken into account in the finalization of the Industrial Dialogue format. The project organized two Industrial Dialogues for each of the innovation fields, which took place in different regions of Europe to encourage exchange and mutual learning. Based on the agreed format six Industrial Dialogues, two on each topic—precision medicine, 3D printing and synthetic biology—were organized in the period between January and June 2017. Before the start of each Industrial Dialogue a ‘baseline’ survey of actors across all stakeholders was conducted to capture their understanding of responsibility in the targeted fields of 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.

The CELAB team took part as observer in the first Industrial Dialogue on Precision Medicine organized on January 16–17, 2017, in Aarhus, Denmark. For synthetic biology, the project design brought together industry and other stakeholders in the UK and Hungary. The CELAB team attended the second Industrial Dialogue on Synthetic Biology organized in Manchester, United Kingdom, on March 9–10, 2017. The third Industrial Dialogue on Synthetic Biology was organized by the CELAB team and took place at Central European University, Budapest, Hungary on June 12–13, 2017. The workshop brought together 17 participants from industry, civil society, and the public sector.

The Industrial Dialogue in Budapest benefited from the participation of highly qualified experts from the National Research, Development and Innovation Office; Committee on Gene-Technology of the Ministry of Rural Development; the Hungarian Medical Research Council; the National Food Chain Safety Office; and the National Institute for Pharmacy and Nutrition—all representing the regulatory, standard setting, funding, and political sphere cluster of this ID. The industry cluster included two international guests and six representatives from Hungary. The ID benefited from the highly informed inputs of the senior representative of a UK company, and of the Senior Director of a multinational biotech company in the white biotech area, world leader in industrial enzymes. The Hungarian industry and extra-industrial research field was represented by the medical director of a multinational pharmaceutical company, by the senior representatives/scientists of two very promising start-up companies, from two different Hungarian cities, Szeged and Debrecen, and by two senior researchers from research institutes of the Hungarian Academy of Science; and one very active young scientist from University of Szeged. The civil society was represented by a dedicated blog writer/Science Meet-Up organizer; the founder of Philosophy Café and an organizer of public philosophy discussion groups; the president of a patient organization; and an Ethics Committee member of the Medical Research Council.

For the participants of the workshop, the main goal was to generate ideas and design prototypes of tools and actions that help companies to develop synthetic biology in a socially responsible way. The workshop lasted for a day and a half and followed a format of co-creation that the SMART-map consortium developed under the leadership of the Centre for Social Innovation (ZSI Vienna, consortium partner). The first day started with brief introduction on the SMART-map project offered by



the project coordinator. This was followed by a discussion on current developments in synthetic biology presented by the invited keynote speaker, Tamás Fehér from HAS-BRC, Szeged. Then the representatives of ZSI briefly introduced the concept of responsible research and innovation. In the following session, the participants introduced themselves and had the opportunity to interview each other on their backgrounds and experiences with responsible innovation. Then they formed three, mostly homogeneous groups by stakeholder category and discussed and identified opportunities, needs, and challenges for responsible innovation in synthetic biology industries. Each group presented their findings to the plenum where they were clustered by theme. In the remaining sessions of the workshop the participants developed ideas for tools and actions to meet the identified needs and challenges. A total number of thirty-five tools were generated by the participants in the Budapest dialogue during the fast prototyping session. Finally, the participants shortlisted three proposals and then worked on building physical prototypes for them. The presentation of these physical prototypes and feedback from the participants to the consortium concluded the dialogue event.

The focus on the importance of education and the persistent need for dialogue and communication between all stakeholders, were specific to the Budapest dialogue. The participants preferred those tools that enable the creation of a formal framework for RRI, such as working groups or umbrella-type webpages.

Implementing RRI in the incipient development stage of an industry, in a context where awareness of RRI is also limited, is both an opportunity and a challenge. It is an opportunity since an RRI way to develop industry could be advanced and internalized from the very early stage of development. In the same time, it is a challenge, too, since in this stage of development



industrial stakeholders are very much concentrated on business development remaining less resources and capacities for engaging with RRI discourse/practice, unless there is a dedicated ecosystem that offers framework conditions, resources and incentives for engaging with RRI.

Enikő Demény, as member of the Expert Advisory Board attended the project Joint Advisory Board meeting on July 4, 2017, organized at the Basetti Foundation in Milan, Italy.

The first results of the SMART-map project were presented at the 5th Annual Conference of the Governance of Emerging Technologies, May 17–19, 2017, Phoenix, Arizona by Sally Randles, representing the SMART-map Consortium

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

Duration of the project: 2016–2018

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

2.1.4. Human Rights – Mutually Raising Excellence (HURMUR)

Tallinn University hosted the conference 'New Human Rights of the 21st Century' on September 20–22, 2017 to explore the origins of such rights, the functions and the rhetoric of these rights, and the role such 'new' rights can play in the field of human rights law. The conference was part of the Human Rights—Mutually Raising Excellence (HURMUR) project, funded by the European Commission.

The three-day conference brought together leading researchers in the fields of rights related to identity and personality; rights to well-being; rights related to the exercise of public authority; rights related to new technologies. Judit Sandor, professor in the Depart-

ments of Legal and Gender Studies and Political Science at CEU, participated in the conference as commentator on the genetic rights panel.

CELAB participant in this project: Judit Sándor
Duration of the project: 2017–2018
Project website: hur-mur.eu

2.1.5. 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*.

The findings of this research project were published in the journal *Medicine, Health Care and Philosophy* in November 2017.

CELAB participant in the project: Judit Sándor
Duration of the project: 2013–2017
Information on the project:
nyilvanos.otka-palyazat.hu/index.php?menuid=930&num=108981&lang=EN

2.1.6. International Academic Network on Bioethics (IANB)



In 2007 based on the idea of Prof. Brigitte Feuillet-Liger, an inter-university network was created in the field of bioethics. Members of the network are: Brigitte Feuillet-Liger, Pénélope Agallopoulou, Amel Aouij-Mrad, Thérèse Callus, Maria-Claudia Crespo-Brauner, Françoise Furkel, Ryuichi Ida, Dominique Manai, Kristina Orfali, Véronica San Julian, Geneviève Schamps, and Judit Sándor. Professor Judit Sándor has been a member of the Advisory Board and the network since the beginnings.

This network organizes annual workshops on various bioethics-related topics and the main purpose of these workshops is to apply a comparative perspective to the analysis of the selected topic. The workshop presentations are published in edited volumes and this research cooperation has so far yielded altogether 16 books since 2007, the start of the project. The most recent book published in the series is titled *Le principe de non-patrimonialité du corps humain: du principe à la réalité* [The Principle of Non-Patrimony of the Human Body: From Principle to Reality]. On November 23–25, 2017 University of Rennes hosted the, so far, last workshop with the title “Corps et Religions” in which law professors, anthropologists and philosophers from twenty different countries analyzed the role of religion in the context regulating the circumcision, blood transfusion, wearing scarf, burka, burkini, and other aspects of religious practices exercised by a minority or majority within different societies.

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. RESEARCH AND POLICY ACTIVITIES

2.2. POLICY AND OUTREACH ACTIVITY

During the 2016–2017 Academic Year, CELAB staff participated in the following major conferences and roundtable discussions organized by other institutions

2.2.1. Annual Congress of the Hungarian Medical Association of America

In the workshop titled “What to Take Care of? Memorable Juristic Cases for Doctors” at the Annual Congress of the Hungarian Medical Association of America in Balatonfüred, August 26–27, 2016, CELAB Fellow György Kovács gave a presentation on the relevant legal provisions and the recent case law of the Curia of Hungary related to medical malpractice, highlighting differences and similarities in US law and court practices. The workshop following the presentation discussed with leaders from the Hungarian health sector the key requirements of providing information to the patient, as well as the legal questions and appropriate documentation of a well-informed consent. Furthermore, Mr. Kovács also raised and discussed the question of institutional liability of medical institutions and the individual liability of doctors, the various forms of medical liability insurance in Hungary and abroad, as well as the different health-care models in Hungary, the United States, and Canada.

2.2.2. Ninth European Conference on Public Health

The Ninth European Conference on Public Health was held in Vienna, on November 9–12, 2016 and provided an excellent opportunity to discuss the public health implications of new technologies. Róza Ádány from the University of Debrecen, Hungary and Stefania Boccia from the Catholic University of the Sacred Heart, Milan, Italy chaired a roundtable discussion organized by the *European Journal of Public Health* on “Bridging the Gap between Knowledge and Practice in Public Health Genomics.”

Judit Sándor gave a presentation with the title “Genetic Testing between Private and Public Interests: Ethical and Legal Implications.” In her lecture she pointed out that in Europe there is a wide variety of genetic tests that various private companies offer to patients or consumers. As a result, more and more people have become curious

about their genetic predisposition and susceptibility. However, most public health care systems are not adequately prepared for responding to the results of these genetic tests as quite often there is no available therapy for the identified genetic condition. This discrepancy between the newly emerging expectations and the insufficient responses contributes to a further rift between the public and private sectors of health care. Individual genetic test results may also trigger the need for personalized medicine and may open up a competition between the two fields in offering further genetic tests and medical exams. In this context, how should the public health system deal with the challenges of the private testing? Will private genetic testing transform health care from a solidarity-based health care to a risk-specific health care?

Prof. Sándor’s presentation was published as an open-access scientific journal article in *Frontiers in Public Health* on January 31, 2018.

2.2.3. Twenty-Third Annual Congress of the World Association of Medical Law

The WAML Annual Congresses of the World Association of Medical Law provide an international forum for discussing a broad range of issues covering health care law, forensics, medical and biotechnological law, and bioethics. Judit Sándor attended the 23rd Annual Congress in Baku Azerbaijan, on July 10–13, 2017. The title of her lecture was “Genome Editing and the Legal Editing of the New Bio-Medical Landscape.” In her presentation, she argued that the possibility of



genome editing has rapidly changed the expectations of scientists and society in the field of gene interventions, and she raised a number of questions that need to be discussed. What are the necessary elements of risks assessment and legal analysis? Can regulators uphold the delineation between somatic and germline interventions? Or can they maintain the demarcation line between therapy and enhancement? What is the proper regulatory attitude and moment in this cutting edge new technology?

According to Sheila Jasanoff, when the structure of the DNA was discovered, humanity entered into the epoch of genetic textuality. Scientists have by now acquired editorial skills and developed the technology of genome editing. When considering the normative challenges this new technology poses, we shall examine the following questions: Should regulation guarantee access to genome editing? And, if yes, on what fields? Should we consider genome editing as a form of enhancement, a therapy, or something else? Do we have to reexamine the legal issues on the chimera and hybrid models for research? Do we need international guidelines and norms in this field?

2.2.4. Thirty-First European Conference on Philosophy of Medicine and Health Care: Emerging Technologies in Healthcare

This conference was organized by the European Society for Philosophy of Medicine and Healthcare and the Belgrade Center for the Study of Bioethics and held in Belgrade, Serbia on August 16–19, 2017. The unexpectedly rapid development of various new technologies opens a variety of pressing ethical and philosophical questions. The focus of the ESPMH

conference was on *Emerging Technologies in Healthcare* and the main topics addressed were genomic medicine, gene editing, neuroengineering, enhancement, and new therapeutic solutions. CELAB was represented by Judit Sándor and Péter Kakuk at the Conference. Judit Sándor gave a presentation on “Textuality of Genome Editing: Possible Applications and their Legal Consequences.” As Professor Sándor explained, transformations of life sciences and medical technologies are altering fundamentally the ways human societies think about what it means to be alive and human, and what rights should be attached to humanness and life in general. With the discovery of the DNA structure, humankind opened up the era of genetic textuality, a new form of literacy. The next phase of this new literacy was the completion of the Human Genome Project. More recently, we reached the third phase of genetic literacy when scientists acquired editorial skills and developed the technology of genome editing. Judit Sándor’s presentation focused on the normative challenges this new technology poses. Should regulation guarantee access to genome editing? And, if yes, in which fields of intervention? Should patentability take into account moral components in this field? Furthermore, we should also reflect on the broader ethical framework that governs the ethical-legal assessment of this technology. Should we consider it an enhancement, a therapy, or something else? These were some of the most important issues raised and discussed by Prof. Sándor in her presentation.

2.2.5. Roundtable on Human Reproduction at the Hungarian Academy of Sciences

Márton Varju organized (with Sára Hungler) and moderated a round-table discussion at the Hungarian Academy of Sciences on “Assisted Reproduction, Law and Morality: A Transforming Social Consensus?” The discussion focuses on the moral interpretation and the legal regulation of assisted reproductive technologies, including *in-vitro* fertilization processes that the Catholic Church rejects on moral grounds. Imre Szezik, CELAB Fellow and Researcher at Semmelweis University, argued that the Catholic Church ties reproduction to marriage, but there is no consensus about the moral understanding of the IVF technology itself. Judit Sándor added that law changes with society, and the legal definitions of ‘the family’ also change



2. RESEARCH AND POLICY ACTIVITIES



over time. Similarly, the legal definition and regulation of trimesters during pregnancy is a legal construct that is based on various religious understandings of the status of human embryo.

2.2.6. The Role of New Technologies in Transforming Humanness in the 21st Century


Upon the invitation of Bárczy Gusztáv Faculty of Special Education of Eötvös Loránd University, Judit Sándor gave a lecture on “The Role of New Technologies in Transforming Humanness in the Twenty-First Century” on December 7, 2017. The presentation was part of a lecture series organized by the university that focuses on the various tools, technologies, innovative solutions that can change the quality of life of people living with disabilities. In her lecture, Prof. Sándor discussed the changing conceptions of therapy and enhancement; the transforming relations between them; the emergence of transhumanism and its ethical consequences; and the importance of understanding legal responsibility in utilizing enhancement technologies.

3. ACADEMIC ACTIVITIES

3.1. PUBLIC LECTURES AND CONFERENCES ORGANIZED BY CELAB

3.1.1. CELAB Seminar Series

In the 2016–2017 Academic Year we continued the CELAB seminar series with three seminars. The first seminar was held on October 21, 2016 by Péter Kakuk, CELAB Associate Research Fellow on the topic “The Role of Compromise in Ethics. According to some scholars, the emergence of bioethics in the 1970’s saved the life of ethics, as a segment of moral philosophy, as academic ethics was brought back to our everyday social sphere. The success of bioethics fueled a renewed interest in moral philosophy, but in a fresh and challenging context of everyday conflicts, dilemmas, and scenarios that typically originate from health care and clinical environments. Contrary to this applied focus of much of current ethical theorizing, one would scarcely find a similar academic interest in the role and concept of *compromise* in the ethics of decision-making in health care—where moral conflicts are prevalent. Can we argue that solving moral conflicts via compromise is ethically always unacceptable? How we categorize moral conflicts regarding compromise? In business, in politics and in law compromise is usually regarded as a valuable concept, but not in morality. We are successors of a philosophical tradition that sees compromise in moral issues as wrong, as it forms a danger to our moral life, as it is simply a betrayal of principles, and as to practice compromise is to demolish our moral integrity. With reference to the work Martin Benjamin—who confronted this tradition and attempted to introduce a positive concept of moral compromise into ethics—Kakuk’s presentation focused on the concept of integrity preserving compromise and its potential role in ethical decision-




CELAB cordially invites you to our next seminar
to be held on 21st of October, 2016
by Péter Kakuk
on

The Role of Compromise in Ethics

ABSTRACT According to some scholars, the emergence of bioethics in the 1970’s saved the life of ethics, as a segment of moral philosophy, as academic ethics was brought back to our everyday social sphere. Although the success of bioethics fueled a renewed interest in moral philosophy, but in a fresh and challenging context of everyday conflicts, dilemmas, and scenarios that typically originate from health care and clinical environments. Contrarily to this applied focus of much of current ethical theorizing one would scarcely find a similar academic interest in the role and concept of compromise in the ethics of decision-making in health care where moral conflicts are prevalent. Can we argue that solving moral conflicts via compromise is ethically always unacceptable? How we categorize moral conflicts regarding compromise?

PÉTER KAKUK studied philosophy at the University of Debrecen and Health Care Ethics and Law at the University of Manchester. He has a PhD in Health Sciences. As a research associate, he is member of CELAB since 2016. Currently, he is assistant professor in the Department of Behavioural Sciences at the University of Debrecen, where he is teaching medical ethics and bioethics. He is member of the Hungarian Medical Research Council’s Scientific and Research Ethics Committee and President elect of the European Society for Philosophy of Medicine and Health Care. His primary research interests are related to bioethics, ethics of genetics, research ethics and scientific integrity.

Presentation is followed by discussion, refreshment and cookies.
Place: Vigyázó F. u. 2. 2nd floor Room No. 213.
Time: 15:30–17:00



making. He summarized the major elements of the dominant view of compromise in ethics and assessed its relation to ethical theorizing (theories, codes, principles). After explicating the concept of integrity preserving compromise Péter Kakuk assessed the potential roles it might have in bioethics.



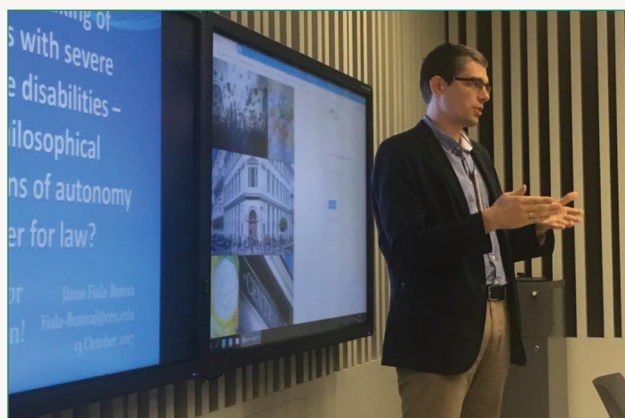
The second CELAB seminar of the academic year, titled “Organ Markets and Disrespectful Demands,” was held on November 25, 2016. Simon Rippon, Assistant Professor at the CEU Department of Philosophy and the School of Public Policy, started his lecture by asking if we can wrong others just by engaging in entirely voluntary offers and exchanges with them, of the kind that a free market permits? Rippon argues that there are various ways in which we can. He calls one type of such wronging a ‘disrespectful demand’. He shows why there is good reason to think that live donor organ markets must rely on disrespectful demands. This analysis may help explain the widespread moral repugnance people feel toward organ trading—and it provides a *prima facie*, though not decisive, case for states to prohibit such markets.

The third seminar was held on February 17, 2017 by CELAB Visiting Research Fellow Mirko Đuković on Legal and Ethical Aspects of 3D Printing (bio-printing) of Tissues and Human Organs for Transplantation. The first living transplantation of organ (kidney) was performed in 1954. In 2014, sixty years later, 119,873 organs were transplanted, according to the Global Observatory on Donation and Transplantation. Out of this number, 79,950 were kidneys (in 99 countries) and 26,150 livers (in 74 countries). Today we are facing revolutionary discovery that could determine the future of health care: the age of bioengineering. Understanding of how to engineer cells, tissues and organs is improving at a rapid pace. Using 3D printers, research centers all over the world are printing cells, muscles, blood vessels, tissues and organs. Everything we know about medicine is about to expand beyond the imaginable hence, social scientists are to be pay attention on this revolutionary



technology and discuss legal, ethical, social and other implications of it. The aim of Mirko Đuković’s presentation aimed to ask the relevant social ethical, and legal questions related to the proposed topic. The first part of his lecture focused on the legal aspects, namely on human rights issues and new technologies, IP law, data protection issues, and finally on policies, regulations, role of governments and international treaties that could regulate the rules of application of the technology. The second part of the presentation dealt with the ethical aspects, such as the questions of distributive justice, technological determinism and social determination of the technology.

The last CELAB seminar, already in the academic year of 2017–2018, was held on October 13, 2017 by János Fiala-Butora, Research Fellow at the Legal Studies Institute of the Hungarian Academy of Sciences, the Director of the Central European Program at the Harvard Law School Project on Disability, on “Decision-Making of Persons with Severe Cognitive Disabilities—Do Philosophical

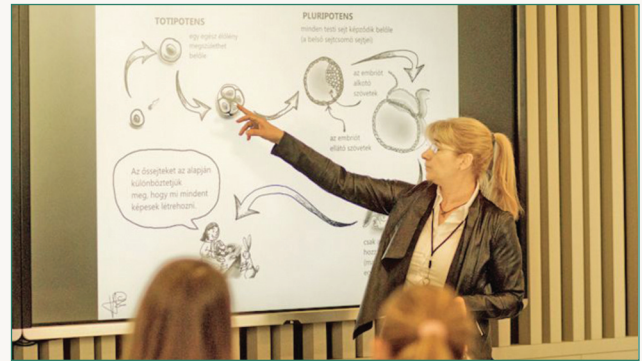


Conceptions of Autonomy Matter for Law?” The Convention on the Rights of Persons with Disabilities requires that states recognize the legal capacity of all persons with disabilities “on an equal basis with others.” Opinions differ as to what this means for persons with the most severe disabilities. How can they make their own decisions? According to a popular proposal, the independence of persons with disabilities must be re-conceptualized on the basis of ‘relational autonomy’, a concept developed in feminist literature. Fiala-Butora’s presentation analyzed whether relational autonomy is an effective tool for legal regulation of the decision-making of persons with severe disabilities, and whether there are any better-performing alternatives.

3.1.2. UniStem Day 2017

CELAB represented Hungary in UniStem Day 2017 on Friday, March 17. In seven European countries, 75 universities and research centers participated in the event which celebrates “the long and fascinating journey of stem cell research,” with seminars, roundtable discussions, and laboratory activities. Over 27,000 university and high-school students joined UniStem Day 2017.

On this occasion, CELAB hosted university students from the Faculty of Science and the Bárczi Gusztáv Faculty of Special Education of Eötvös Loránd University, as well as from the Faculty of Medicine of Semmelweis University; and high school students from the Apáczay Csere János, Szent István, József Attila, and Városmajor secondary schools. The students listened to informative presentations and discussed the hopes generated by and the obstacles to stem cell research, as well as the ethical and legal challenges involved in using stem cells for research and therapeutic purposes.



Professor Judit Sándor, the Director of CELAB, and Márton Varju, CELAB research fellow, organized the event. They have already completed two FP7 European research projects in the field of stem cell research. In both projects their contribution was to conduct a comparative legal study on fundamental normative issues, including the intellectual property aspects of stem cell research and therapy. Following this multidisciplinary tradition, CELAB organized the Hungarian UniStem Day with presentations that provided examples on the current advances in stem cell research, as well as on the controversies surrounding the use of stem cell research results, and the limitations of their applications.

After the opening remarks by Sándor and Varju, brief lectures were presented by researcher Szilvia Király, a student at Városmajori Secondary School, and then scholars from the Research Center for Natural Sciences at the Hungarian Academy of Sciences: Ágota Apáti, Elen Gócza, and Tamás Orbán.

While scientists openly discussed the current scientific, ethical and legal hurdles, lawyers and the audience engaged in a debate on the future reception and social concerns of these technologies—for instance, concerns that this expensive selective treatment would be available only to the well-off and not to the poor. By combining stem cell research with gene editing, a new avenue for human enhancement would emerge and so-called designer babies could be created. While spine injuries and several other neurological diseases may be effectively treated by stem cells based treatment in the future, hopes and expectations often result in hasty regulatory solutions. Chimeras pose also ethical questions. While animals with human genes may be useful models for understanding diseases and potential treatments they also raise the question of the human-animal delineation.



3. ACADEMIC ACTIVITIES




The presentations were followed by a panel discussion and an interactive workshop.

UniStem Day in 2017 was dedicated to Dr. Ahmadrza Djalali, who was arrested and may face the death penalty for suspected espionage in Iran. He is a researcher teaching at the European Master in Disaster Medicine (EMDM) program in Italy. A petition has been started against his possible execution. UniStem joins the appeal for his freedom and considers that concrete actions to protect him are crucial for the well-being of our democratic countries.

3.1.3. Bioethics Debates Series: Euthanasia


The Dutch Embassy has initiated a Dutch–Hungarian discussion forum on the ethical and legal aspects of end-of-life decisions. Within this framework, on November 23, 2016, CELAB fellows József Kovács and Judit Sándor participated in a panel discussion at the Embassy. The more formal presentations of the invited speakers were followed by a lively discussion. Prof.





The Center for Ethics and Law in Biomedicine (CELAB) cordially invites you to the Bioethics Film Club, co-organized by the Embassy of the Netherlands in Budapest and CELAB.

We shall screen a Dutch documentary film "*Midnight Butterfly*" directed by Peter Bosch. The film is about Priscilla who inherited her mother's terrible illness and who gives herself a special present: euthanasia. She wants to leave joyfully and on her own terms. This film gives an opportunity to discuss the ethical and legal questions on voluntary euthanasia.



Venue: CEU Nádor 11. Smart Room
Time: Friday, April 21 at 4 PM

Film screening will be followed by discussion and reception.

Sándor spoke about "The Role of Doctors in Decisions on Euthanasia."

The second event within this series on the topic of euthanasia was the screening of the film "*Midnight Butterfly: The Last Days of Priscilla*" (directed by Peter Bosch) on 21 April, 2017, at the Central European University, in the presence of the Representative of the Dutch Embassy in Hungary, CELAB Fellows and CEU Students. In the documentary film, Priscilla, who inherited her mother's terrible illness, gives herself a special present: euthanasia. She wants to leave joyfully and on her own terms. The 55-minute long film gave us an opportunity to discuss the ethical and legal questions related to voluntary euthanasia. Violeta Beširević, CELAB Associate Research Fellow and expert on the legal aspects of euthanasia, took part in the discussion and made insightful comments.

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

Judit Sándor

Human Rights and Emerging Technologies, at the Department of Legal Studies, cross-listed with Department of Gender Studies
Bioethics and Law, at the Department of Legal Studies
Human Rights and Biopolitics, at the Department of Gender Studies and at the Department of Political Sciences
Genes, Reproduction and Gender, at the Department of Gender Studies

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
 Belgrade Center for Human Rights, Visiting Lecture
Is There a Right to Die?
 November 16, 2017, Belgrade

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
Model European Parliament
 ProCuria program, The Hague University of Applied Sciences
 Training provided to members of the Indonesian Constitutional Court on the topic of the rights of people with disability in social security

Péter Kakuk

Bioethics Courses at the University of Debrecen, Medical and Health Science Centre, Debrecen, Hungary
Bioethics – course offered in the General Medical Program, in Hungarian and English
Bioethical Cases – elective course offered in Hungarian and English
Bioethics & Dental Ethics – course in the Dentistry Program, in Hungarian and English
Bioethics – course offered for Medical Diagnostic Laboratory Analysts

3. ACADEMIC ACTIVITIES

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

Clinical and Health Psychology Specialization,
Psychology Institute

Ethical Questions in Psychotherapy

Semmelweis University

Ethical Questions in Psychotherapy

The Internet and the Ethics of Psychiatry

Ethical Issues of Research on Human Beings

National Institute of Psychiatry and Addictology

Bioethics–Neuroethics

Imre Szebik

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 – Lectures at CME for physi-

cians

Research Ethics – PhD course

4. EVENTS AND ACHIEVEMENTS IN CHRONOLOGICAL ORDER

4.1. PARTICIPATION IN CONFERENCES

During the 2016–2017 Academic Year, CELAB staff and fellows took part in the following conference and workshop events:

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 József on “The Ethical Issues of Synthetic Biology”
October 8, 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: Imre Szebik
October 23–24, 2016, Prague, Czech Republic

4. EVENTS AND ACHIEVEMENTS

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

Dutch-Hungarian Expert Debate on Euthanasia

Panel Discussion

Participants: Judit Sándor and József Kovács

November 23, 2016, Budapest, Hungary

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

Annual RUIB Conference: Death and Biomedicine

Presentation by Judit Sándor on "Le mort et la biomédecine en Hongrie"

December 14–17, 2016, Hikone, Japan

Patient Centered Health Care

Panel Discussion

Participant Judit Sándor

January 19, 2017, Budapest, Hungary

CELAB Seminar Series No. 6: Legal and Ethical Aspects of 3D Printing (Bio-Printing) of Tissues and Human Organs for Transplantation

Presentation by Mirko Đuković

February 17, 2017, Budapest, Hungary

Unistem Day: A Day for Stem Cells at CELAB

Participants: Judit Sándor, Márton Varju, Enikő Demény

March 17, 2017, Budapest, Hungary

Ethical and Legal Implications of Gene/Genome Editing

Organizer: Hungarian Academy of Sciences, the Association for Innovative Agricultural Biotechnology and ELTE Institute of Biology

Presentation by Judit Sándor

March 27, 2017, Budapest, Hungary

Midnight Butterfly: The Last Days of Priscilla

CELAB Film Screening

April 21, 2017, Budapest, Hungary

Art in Therapy—The Art of Therapy (Művészet a terápiában—a terápia művészete)

Roundtable, lecture by József Kovács on "Ethical Issues in Clinical and Health Care in Child Psychiatry"

May 26, 2017, Pécs, Hungary

Conference on the Harming and Protecting Society

Organized by the Faculty of Health Sciences of Semmelweis University

Presentations by Imre Szebik:

Anna Susánszky, Éva Susánszky, Zsuzsa Szántó, Imre Szebik, and Nicolas Rubashkin on "Who's Decision? Expectations in the Decision-Making Process of Women Giving Birth in Hospitals and Those Giving Birth Outside the Institutional Context" ["Kinek a döntése? Döntésekkel kapcsolatos elvárások tervezetten kórházban és intézményen kívül szülő nők körében"]

Imre Szebik on "Ethical Questions of Mitochondrial Transplants"

Imre Szebik, Éva Susánszky, Zsuzsa Szántó, Anna Susánszky, and Nicolas Rubashkin on

"Obstetric Care and the Autonomy of the Woman in Labor" [A szülészeti ellátás és a szülő nők autonómiája]

June 8–9, 2017, Budapest, Hungary

ICON Annual Conference in Copenhagen, under the auspices of the University of Copenhagen's Faculty of Law and iCourts

Presentation by Judit Sándor on "From Checks and Balances to Caps and Gowns:

Encountering Illiberal Democracy at the European Court of Human Rights"

July 5–7, 2017, Copenhagen, Denmark

23rd WAML Annual Congress, 50th Golden Anniversary Meeting

Presentation by Judit Sándor on "Genome Editing and the Legal Editing of the New Bio-Medical Landscape"

July 10–13, 2017, Baku, Azerbaijan

Thirty-First European Conference on Philosophy of Medicine and Health Care: Emerging Technologies in Healthcare

Presentation by Judit Sándor on "Textuality of Genome Editing: Possible Applications and their Legal Consequences"

August 16–19, 2017, Belgrade, Serbia

Possibilities and Hurdles in the Personalized Medicine

Participant Judit Sándor

September 8, 2017, Galyatető, Hungary

Hungarian Philosophy at the Millenium

Presentation by József Kovács on "The Formation and Development of Hungarian Bioethics" (A magyar bioetika kialakulása és fejlődése)

September 13, 2017, Budapest, Hungary

Rights for the 21st century? Exploring the need for "new" human rights

Workshop of the EU Project "HURMUR: Human Rights – Mutually Raising Excellence"

Participant Judit Sándor

September 19, 2017, Tallin, Estonia

CELAB Seminar Series No. 7: Decision-Making of Persons with Severe Cognitive Disabilities—Do Philosophical Conceptions of Autonomy Matter for Law?

Presentation by János Fiala-Butora (Hungarian Academy of Sciences)

October 13, 2017, Budapest, Hungary

Ethics Conference of the Hungarian Medical Chamber

Presentation by József Kovács on

"Communicating Failures in Medical Care"

October 21, 2017, Budapest, Hungary

Ethical Questions of Human Research.

Lecture held by József Kovács at Semmelweis Researchers' Salon after Prof. Dr. Dietrich v. Engelhardt farewell lecture: "Ars Longa, Vita Brevis—The Meaning of Time in Medicine"

November 7, 2017, Budapest, Hungary

The Future of Free Movement in Stormy Times Conference

Paper presented by Mária Éva Földes on "Cross-Border Care and e-Health in the European Union: Challenges of the Digital Single Market"

November 21, 2017, The Hague, Netherlands

Annual RUIB Conference: Religion and Biomedicine

Participant and Presenter: Judit Sándor

November 22, 2017

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.

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 interszexualitás és a globális élsport]
Article by Judit Sándor in the essay series *Body Talk* [Testbeszéd]
Magyar Narancs, 2016, vol. 28, no. 38, p. 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, p. 58–59.
December 1, 2016

Informed Consent at Childbirth: A Moral Silver Bullet [Tájékozott beleegyezés szüléskor. A morális csodafegyver]
Article by Judit Sándor in the essay series *Body Talk* [Testbeszéd]
Magyar Narancs, 2017, vol. 29, no. 6, p. 42.
February 9, 2017

Shecherezade, or the Patient with Intellectual Needs [Seherezáde, avagy az intellektuális igényű beteg]
Article by Judit Sándor in the essay series *Body Talk* [Testbeszéd]
Magyar Narancs, 2017, vol. 29, no. 12, p. 42.
March 23, 2017

The Future Machine [A jövőgép]
Article by Judit Sándor in the essay series *Body Talk* [Testbeszéd]
Magyar Narancs, 2017, vol. 29, no. 18, p. 42–43.
May 4, 2017

When You May Give Up: Terminally Ill Children and the Limitation of Their Parents' Rights [Mikor szabad feladni? A gyerek élete és a szülők jogai]
Article by Judit Sándor in the essay series *Body Talk* [Testbeszéd]
Magyar Narancs, 2017, vol. 29, no. 37, p. 42.
September 14, 2017

Science with and for Society (SWAFS) EU Programme
Enikő Demény – presenting experience with the Science with and for Society (SWAFS) EU program, CELAB-CEU as a consortium member in the SMART Map project
Muzeuminfo (Hungarian National Museum, Budapest)
March 6, 2017

Is There a Good Death? [Létezik-e jó halál?]
Roundtable Discussion with the participation of József Kovács on Katalin Hegedűs' book with the same title
Írók Boltja (Budapest, Hungary)
April 18, 2017

4.3. PUBLICATIONS

- Bárd, Petra, Sergio Carrera, Elspeth Guild, and Dimitry Kochenov (2016) An EU Mechanism on Democracy, the Rule of Law and Fundamental Rights. *CEPS Papers on Liberty and Security in Europe*, no. 91. Bruxelles: Center for European Policy Studies.
- 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.
- Beširević, Violeta et al. (2017) *Commentary of the European Convention for the Protection of Human Rights and Fundamental Freedoms* (in Serbian). Belgrade: Sluzbeni glasnik.
- Bullock, Emma C. (2016) Knowing and Not Knowing For Your Own Good: The Limits of Epistemic Paternalism. *Journal of Applied Philosophy*, vol. 33. Online First: 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 May 2018) Valid Consent. In Peter Schaber and Andreas Müller (eds.), *The Routledge Handbook of the Ethics of Consent*. London: Routledge.
- Bullock, Emma C. (Forthcoming in January 2018) 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 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. *Ethics & Bioethics*, Volume 6, Issue 3–4, 181–186.
- Demény, Enikő (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 (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, 498–507.
- Demény, Enikő and Adina Rebeleanu (2017) Vulnerability of Health Systems: Legal Versus Ethical Perspective. Comparative Approach Hungary and Romania. *Modelling the New Europe. Interdisciplinary Studies* (Cluj: UBB), 22, 26–56.
- 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]
- Filó, Mihály (2017) Kovács Gábor: Az egészségügyi beavatkozás és kutatás rendje elleni bűncselekmények, valamint az egészségügyi önrendelkezési jog megsértése [Book Review]. *Állam és Jogtudomány*, vol. 58, no. 2, 117–121.
- Földes, Mária Éva (2017) Health Policy and Health Systems: A Growing Relevance for the EU in the Context of the Economic Crisis. In G. Falkner (ed.) *EU Policies in Times of Crisis*. London: Routledge, 77–92.

4. EVENTS AND ACHIEVEMENTS

- Kakuk, Péter (2016) Book Review: Short Literature Notices. *Medicine, Health Care, and Philosophy*, vol. 19, no. 3 (September 2016), 485–490.
- Kakuk, Péter with Signe Mezinska, Goran Mijaljica, Marcin Waligóra, and Dónal P. O'Mathúna (2016) Research in Disaster Settings: A Systematic Qualitative Review of Ethical Guidelines. *BMC Medical Ethics*, vol. 17, no. 62, 1–11.
- Kakuk, Péter (ed.) (2017) *Bioethics and Biopolitics: Theories, Applications and Connections*. Dordrecht: Springer Nature.
- Kakuk, Péter (2017) Book Review: On Complicity and Compromise. *Medicine Health Care and Philosophy*, vol. 20, no. 2, 283–284.
- Kakuk, Péter (2017) Book Review: Better Doctors, Better Patients, Better Decisions—Envisioning Health Care 2020. *Medicine Health Care and Philosophy*, vol. 20, no. 4, 573.
- Kovács, József (2016) Etikai kérdések a belgyógyászatban [Ethical Questions in Internal Medicine]. In Tulassay Zsolt (ed.) *A belgyógyászat alapjai* [Fundamentals of Internal Medicine]. Budapest: Medicina, 107–112.
- Kovács, József (2016) Az „áltudományok” etikai vonatkozásai [Ethical Aspects of Pseudoscience]. *Magyar Tudomány*, vol. 177, no. 8 (August 2016), 956–967.
- Kovács, József with Sándor Mihály and Anikó Smudla (2016) Practices around Communication of Organ Donation in Hungary. *Transplantation Proceedings*, vol. 48, no. 7 (September 2016), 2529–2533.
- Kovács, József (ed.) (2017) *A biotechnológia etikai kérdései* [Ethical Questions of Biotechnology] (E-book). Budapest: Semmelweis Kiadó.
- Kovács, József (2017) A tudomány, a technológia és az etika [Science, Technology, and Ethics]. In József Kovács (ed.) *A biotechnológia etikai kérdései* [Ethical Questions of Biotechnology] (E-book). Budapest: Semmelweis Kiadó, 19–69.
- Kovács, József (2017) Környezetetika [Environmental Ethics]. In József Kovács (ed.) *A biotechnológia etikai kérdései* [Ethical Questions of Biotechnology] (E-book). Budapest: Semmelweis Kiadó, 71–118.
- Kovács, József (2017) Az emberen végzett kutatás etikai kérdései [Ethical Questions of Research on Human Subjects]. In József Kovács (ed.) *A biotechnológia etikai kérdései* [Ethical Questions of Biotechnology] (E-book). Budapest: Semmelweis Kiadó, 245–287.
- Kovács, József (2017) Honorary Authorship and Symbolic Violence. *Medicine, Health Care and Philosophy*, vol. 20, no. 1, 51–59. [Online First Published on August 13, 2016].
- Sándor, Judit (2016) Basic Pillars of Legal Thinking on the Human Body in the Hungarian Medical Law: Dignity, Self-Determination and the Principle of Non-Commodification. In Brigitte Feullet-Liger, Geneviève Schamps, and Kristina Orfali (eds.) *Protecting the Human Body: Legal and Bioethical Perspectives from Around the World*. Droit, bioéthique et société, No. 15. Brussels: Bruylant, 169–185.
- Sándor, Judit with Márton Varju (2016) Creating European Markets through Regulation: The Case of the Regulation on Advanced Therapy Medicinal Products. *European Law Review*, vol. 41, no. 1 (February 2016), 25–43.
- Sándor, Judit, with Assya Pascalev, Kristof Van Assche, Natalia Codreanu, Anwar Naqvi, Martin Gunnarson, Mihaela Frunza, and Jordan Yankov (2016) Protection of Human Beings Trafficked for the Purpose of Organ Removal: Recommendations. *Transplantation Direct*, vol. 2, no. 2 (February 2016), e59.
- Sándor, Judit (2016) Az én molekulám. Bioetika és emberi jogok a XXI. század elején [My Molecule. Bioethics and Human Rights at the Beginning of the 21st Century]. Budapest: L'Harmattan, p. 1–228.
- Sándor, Judit (2016) La dignité humaine, fondement des droits en Hongrie. In Brigitte Feullet-Liger and Kristina Orfali (eds.) *La dignité de la personne: Quelles réalités? Panorama international*. Droit, bioéthique et société, No. 16. Brussels: Bruylant, 157–170.
- Sándor, Judit (2016) Életvégi döntés életről és halálról [End-of-Life Decisions on Life and Death]. *Állam és Jogtudomány*, vol. 57, no. 4, 40–55. [Special Issue on Regulating End-of-Life Decisions in Hungarian Law]
- Sándor, Judit, with Assya Pascalev, Kristof van Assche, Frederika Ambagtsheer, Willem Weimar, eds. (2017) *Protection of Persons Targeted or Trafficked for the Purpose of Organ Removal*. Lengerich: Pabst Science Publishers (forthcoming).
- Sándor, Judit (2017) La non-patrimonialité du corps humain: Un principe essentiel en Hongrie. In Brigitte Feullet-Liger and Saibé Oktay-Özdemir (eds.) *Le principe de non-patrimonialité du corps humain. Approches internationales*. Droit, bioéthique et société, No. 17. Brussels: Bruylant, 125–135.

- Sándor, Judit (2017) Whose Biobank? Should Biobanks Serve Research Interests or The Needs for Personalized Medicine? Analysis of the Hungarian Law. *Genetic Testing and Molecular Biomarkers*, vol. 21, no. 3 (March 2017), 140–147.
- Sándor, Judit (2017) The 'Me Molecule.' In Péter Kakuk (ed.) *Bioethics and Biopolitics: Theories, Applications, and Connections*. Cham (Switzerland): Springer International, 77–95.
- Sándor, Judit with Márton Varju (2017) Generic or Specific? The Frames of Stem Cell Procurement Regulation in Europe. *Script-ed*, vol. 14, no. 1 (June 2017), 37–80.
- Sándor, Judit with Lilla Vicsek and Zsófia Bauer (2017) Let Us Talk about Eggs! Professional Resistance to Elective Egg Vitrification and Gendered Medical Paternalism. *Medicine, Health Care, and Philosophy*, Online First: October 13, 2017.
- Sándor, Judit, with Louiza Kalokairinou, et al. (2017) Legislation of Direct-to-Consumer Genetic Testing in Europe: A Fragmented Regulatory Landscape. *Journal of Community Genetics*, Online First: November 18, 2017.
- Sándor, Judit, Márton Varju with George Gaskell, et al. (2017) Public Views on Gene Editing and Its Uses. *Nature Biotechnology*, vol. 33, no. 11 (November 2017), 1021–1023.
- Szebik, Imre, and Dániel Margócsy (2016) Commercial Visions: Science, Trade, and Visual Culture in the Dutch Golden Age. Book review. *Lege Artis Medicinae*, vol. 26, no. 3, 158–159.
- Szebik, Imre (2016) The Case of Home Birth in Hungary. *European Association of Centres of Medical Ethics Newsletter*, no. 43 (August 2016), 8–10.
- Szabik, Imre, with Petra Baji, Nicholas Rubashkin, Kathrin Stoll, Saraswathi Vedam (2017) Informal Cash Payments for Birth in Hungary: Are Women Paying to Secure a Known Provider, Respect, or Quality of Care? *Social Science and Medicine*, vol. 189, no. C (July 2017), 86–95.
- Szebik, Imre, with Nicholas Rubashkin, Petra Baji, Zsuzsa Szántó, Éva Susánszky, and Saraswathi Vedam (2017) Assessing the Quality of Maternity Care in Hungary: Expert Validation and Testing of the Mother-Centered Prenatal Care (MCPC) Survey Instrument. *Reproductive Health*, vol. 14: (152)
- Szebik, Imre (2017) A humán biotechnológia etikai kérdései I. [Ethical questions of human biotechnology I.] In József Kovács (ed.) *A biotechnológia etikai kérdései [Ethical questions of biotechnology]*. Budapest: Semmelweis Kiadó, 2017. 161–190.
- Szebik, Imre (2017) A humán biotechnológia etikai kérdései II. [Ethical questions of human biotechnology II.] In József Kovács (ed.) *A biotechnológia etikai kérdései [Ethical questions of biotechnology]*. Budapest: Semmelweis Kiadó, 191–208.
- Szebik, Imre (2017) Neuroetika [Neuroethics]. In József Kovács (ed.) *A biotechnológia etikai kérdései [Ethical questions of biotechnology]*. Budapest: Semmelweis Kiadó, 2017. 235–244.
- Varju, Márton and Judit Sándor (2016) Creating European Markets through Regulation: The Case of the Regulation on Advanced Therapy Medicinal Products. *European Law Review*, vol. 41, no. 1 (February 2016), 25–43.
- Varju, Márton and Judit Sándor (2017) Generic or Specific? The Frames of Stem Cell Procurement Regulation in Europe. *Script-ed*, vol. 14, no. 1 (June 2017), 37–80.
- Varju, Márton and Judit Sándor with George Gaskell, et al. (2017) Public Views on Gene Editing and Its Uses. *Nature Biotechnology*, vol. 33, no. 11 (November 2017), 1021–1023.

4. EVENTS AND ACHIEVEMENTS

4.4. VISITING FELLOWS

In the Academic Year 2016–2017

Mirko Đuković, Junior Researcher at the University of Donja Gorica in Montenegro

Research topic: Correlation between human rights and intellectual property law: Human rights, right to health (life) and medical patents.

In the Academic Year 2017–2018

Dr. Sabuj Kumar Chaudhuri, Assistant Professor [Senior], University of Calcutta, Department of Library & Information Science

Research topic: Intellectual property rights and bioethics; Patents on medical innovations; 'Ordre Public': Dichotomy, uncertainties, ambiguities and the role of value pluralism

Dr. Olha Nimko, Assistant Professor at the Law Department, Zhytomyr National Agroecological University, Zhytomyr, Ukraine

Research topic: Legal regulation and protection of intellectual property rights in the sphere of biotechnology

4.5. AWARDS, APPOINTMENTS AND SPECIAL EVENTS

Márton Varju presented his habilitation lecture at the University of Debrecen on November 17, 2017

Title of habilitation lecture: *Context and Interpretation before the Court of Justice of the EU: The Human Rights Jurisprudence of the Court*

Péter Kakuk presented his habilitation lecture at the University of Debrecen on December 15, 2017

Title of habilitation lecture: *Scientific Integrity and Research Ethics in the Life and Biomedical Sciences*

5. BUDGET

5.1. REVENUES IN AY 2016/2017

Approved Budget from CEU	Amount in Euro
C-5036 Total	62,056

External Funding	Amount in Euro
NERRI	47,079
EUCeLLEX	1,476
SMART Map	48,555
Total	97,110

5.2. SPENDING IN AY 2016/2017

CELAB MAIN BUDGET CODE

Budget category	Amount in Euro
Personnel cost	60,956
Other costs	1,100
Total	62,056

SMART-MAP PROJECT

Budget category	Amount in Euro
Personnel costs	35,950
Other costs	11,724
Total	47,674

NERRI and EUCeLLEX spending were completed in the Academic Year of 2015–2016, the revenue amounts represent the final installments for the two projects



