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IN BIOMEDICINE

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1. FOREWORD

Thus cites Nicolas Rose himself in his latest work, *Neuro*, and this re-confirmed statement sounds especially reassuring when we start our new research project on neuroenhancement. In March 2013 CELAB started a new European research project on neuro-enhancement with the aim to study and analyze responsible research and innovation (hence the acronym of the project: NERRI). NERRI is a Coordination and Support Actions type of project financed by the European Commission. Jointly with the Center for Ethics and Law in Biomedicine (CELAB) 18 partners from 11 countries are active within this project, coming from Austria, Belgium, Denmark, Germany, Hungary, Iceland, Italy, the Netherlands, Portugal, Spain, and the United Kingdom. The main objective of this FP7 Framework Project is to shape the future European agenda “Responsible Research and Innovation” in the field of human enhancement, through an intense “Mobilization and Mutual Learning” process that engages scientists, policy-makers, the business sector, and the wider public. Project participants will prepare, stimulate and mobilize multi-stakeholder dialogues on neuro-enhancement and explore strategies for the management of a plurality of views, needs, expectations, and fears in relation to neuro-enhancement within societies and between EU member states. It is also the intention of the project to identify specific problems at the level of individual enhancement technologies, as well as in the field of policy and regulation. In light of the principles of good-governance, outlined in EU documents, the project explores and evaluates different approaches to the funding, research, and distribution of enhancement technologies.

In the framework of this project we have conducted sixteen interviews with NGOs, groups of disabled persons, scientists (in the field of cognitive science, biology, neurology, and brain research), and members of ethical decision making bodies. Sometimes it was a challenge to persuade stake holders to speak about neuro-enhancement. But we have learnt a lot from the interviews, for instance we realized that enhancement of individual capabilities is not a generally desired aim of interventions; representatives of disability groups, for example, emphasize the need for ‘social enhancement’: the development of a tolerant and inclusive society, rather than a technocratic solution that focuses merely on some specific ‘enhanceable’ human capacity. Enhancement poses challenges also from a normative point of view. On one hand, it shakes the (in itself also contestable) dichotomy between normal and pathologic, and on the other hand, it provides a too broad approach for legal and ethical discourses. Over the course of the 20th century we witnessed the emergence of preventive medicine and the management of normality. Some have even argued that enhancement technologies may be the next step in the gradually expanding scope of medicine, as a result of which ‘normal’ functioning and the body being merely ‘healthy’ will come to be viewed as defective. The distinction between ‘normal’ and ‘non-normal’ or ‘pathological’ has long been a source of tension between the medical sciences, on the one hand, and social sciences and philosophy, on the other. As quantitative tools entered medicine, ‘normal’ became associated with ‘the

1. FOREWORD

We argue that despite their apparent contradictions, neurobiological research emphasizing the role of non-conscious neural processes and habits in our decisions and actions can—and does—happily coexist with long-standing ideas about choice, responsibility, and consciousness that are so crucial to contemporary advanced liberal societies.

(Nikolas Rose and Joelle M. Abi-Rached, *Neuro: The New Brain Sciences and the Management of the Mind*, 2013:21)

mean' and was dissociated from subjective clinical judgments. The kickoff meeting of this project was held in March in Cascais (in Portugal), followed by a special session in Lisbon organized by the Ciência Viva. The first project meeting was held in Barcelona in November, 2013. The project will last for three years.

During the 2012–2013 academic year we have participated in the preparation of another Seventh Framework Research Project, entitled “Cell-Based Regenerative Medicine: New Challenges for EU Legislation and Governance” (Acronym: EUCeLEX). In this project CELAB will assess 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 shall also analyze 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 shall also look at the opinions of the EGE. The major selection criteria of the legal analysis will be based on the countries represented in this project (Belgium, Canada, France, Germany, Hungary, the Netherlands and the United Kingdom) and when it is necessary to highlight a specific legal framework, we shall also look at the regulation in other countries. The project started in October 2013 and the kick-off meeting was held in Paris in December, 2013.

In the 2012–2013 academic year we completed a two-year European research project on organ donation and organ trafficking (EULOD). As a result of this project, two edited books have been published with project participants summarizing their main research findings in their chapters. Our team argued against the commercialization of organ trade, we developed a strong criticism against organ tourism and offered some legal solutions for the better enforcement of existing legal norms and enhancing international cooperation in this field. We have another running project on Equal Opportunities for Health: Action for Development, which is expected to be completed in January 2014.

One of our longest, still on-going international projects is the “International Academic Network on Bioethics” (French acronym: RUIB, English acronym: IANB), which conducts annual workshops of legal experts and physicians, philosophers and sociologists from seventeen countries (Brazil, Belgium, Chile, France, Germany, Greece, Hungary, Italy, Japan, Lebanon, Senegal, Spain, Switzerland, Tunisia, Turkey, U.K., and U.S.). In 2013 three books came out as a result of our collaboration in previous workshops. Two books were related to the workshop on the ethics of end-of-life treatment decisions: one in French, *Les proches et la fin de vie médicalisé*, and one in English, *Families and End-of-Life Treatment Decisions: International Perspective*. The chapters of these books analyze the current status and the role of relatives (and non-relatives) close to the patient at the end of life. Another book in French was published in October 2013, entitled *Corps de la femme et Biomédecine: Approche internationale*, edited by Amel Aouij-Mrad and Brigitte Feuillet-Liger. The English version, containing chapters elaborated at a 2011 workshop that explored the relationship between the female body and biomedicine, is expected to be published in early 2014 with the title *The Female Body: A Journey Through Law, Culture and Medicine*, edited by Thérèse Callus, Brigitte Feuillet-Liger and Kristina Orfali. Many possibilities are offered to women through biomedical techniques: from assistance to procreate (with assisted repro-

duction); to refusal to do so (contraception, voluntary sterilization, termination of pregnancy); to be informed of genetic predispositions (through the use of available genetic tests); or to improve their physical appearance with cosmetic surgery. But a recurrent question arises: with its rapid progress and its extreme medicalization of the body, can biomedicine liberate women? Or rather, given the risks of the commodification of the body or its parts, is it not a source of exploitation? These questions are explored by the authors of this work: jurists, anthropologists, philosophers, sociologists and medical doctors. The contributions to this international multidisciplinary study from nineteen countries analyze the reality of the amazing developments of biomedicine on the female body. Numerous systems are compared for the first time: European, African, North and South American, but also Chinese and Japanese. Beyond highlighting differences, and identifying similarities in the development of 'enhancement medicine', the ultimate objective of this work is to show the complexity surrounding the question of a woman's freedom over her body and the extent to which this is limited by the state. All books within this project are published by Bruylant (Brussels). The project conferences have been held so far in Rennes, France (2007), Kyoto, Japan (2009), Rennes again (2010), Tozeur, Tunisia (2011), and in Rio de Janeiro, Brazil (in 2012). The upcoming workshop will be organized in Brussels in December 2013.

The *E-Rare Project* organized a workshop on January 14, 2013 in Tel Aviv, Israel by the Chief Scientist Office of the Health Ministry of Israel, a member of E-Rare Consortium. It addressed the social, ethical and legal implications of large-scale exome/genome sequencing in the context of research on rare diseases. The planned joint publication also draws upon the contemporary debates within RD-Connect, an international project working to provide an integrated platform connecting databases, registries, biobanks and clinical bioinformatics for rare disease research.

In Hungary we participate in a research project on "Infertility and the Socio-Technical Practice of Assisted Reproductive Technologies." The aim of this project, financed by OTKA (National Scientific Research Fund), is to investigate issues that are relevant both on the academic and the policy level. The goal of 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. In the pilot phase of the research, literature review and qualitative data analysis is conducted, then in the first phase 40 semi-structured interviews are made with stakeholders (experts, law-makers and medical practitioners), and in the second phase 40 semi-structured interviews with infertility patients who have decided to take part in ART treatment.

In 2013 we continued our popular CELAB lecture series. CELAB has organized many conferences, workshops and public lectures that focused on the ethical, legal, and social challenges of the new scientific advances in the field of biomedicine. In previous Sessions distinguished speakers, such as John Harris, Inez de Beaufort, Donna Dickenson, Nicolas Rose spoke on various challenges for contemporary biomedicine. Challenges that come from the human desire and demand for enhancement, for longevity, and also for commercialization and commodification of the human body are at the core of ethical debates that engage a large range of disciplines inside and outside of the life sciences. In May 2013 Thomas Lemke, Professor of Sociology at the Faculty of Social Sciences of the Goethe-University Frankfurt am Main in Germany gave an interesting lecture entitled "Biopolitics and Beyond: Vibrant Matter and the Political Economy of Life."

Biopolitics was also the topic of a new book that we published within the CELAB Book Series. *Studies in Biopolitics* is a collection of multidisciplinary case studies on biopolitical practices and discourses contributed by political scientists and public policy experts, anthropologists and philosophers, biologists and bioethicists, legal scholars and human rights activists, as well as advanced graduate students at the Central European University (CEU). The majority of the authors have participated in graduate courses in political science and gender studies at CEU, focusing on the human rights aspects of biopolitics and the various forms of commercializing the human body. Some of the case stud-

1. FOREWORD

ies have emerged from these courses and thus the chapters of this book are not only thematically inter-related but also share similar analytical perspectives. This is the result of long hours of discussion during the classes, following film screenings or emerging after public lectures on biopolitics organized by CELAB.

The cultural diversity and multilingual academic environment that characterize CEU have made it possible to develop a pool of unique cases on biopolitics from Armenia, Georgia, Germany, Egypt, Hungary, India, Israel, Poland, Romania, Russia, Serbia, Tunisia, and Turkey. This collection of essays reflects not only the lively discussions we had during CEU courses and CELAB events, but also provides challenging cases for further comparative studies on biopolitics. There are chapters that discuss new, innovative forms of old population control policies, while others explore the consequences of the emerging biotechnologies, including stem cell research. Some of the texts in this book analyze the biopolitics of the state, while others seek to understand the 'biopractice' of traditional communities. The book is edited by the director of CELAB, Judit Sándor.

A late but very important fruit of a conference held in Rio de Janeiro in 2010, with the support of the European University Institute (Florence) and the Getúlio Vargas Foundation (Brazil), came out in 2013. The book entitled *New Technologies and Human Rights* was edited by Mario Viola de Azevedo Cunha, Norberto Nuno Gomes de Andrade, Lucas Lixinski and Lúcio Tomé Féteira, and it is a collaboration of scholars from Brazil, Hungary, Italy, and Portugal.

The final book including the main findings of the RemediE Project was also published in 2013. Edited by Andrew Webster, *The Global Dynamics of Regenerative Medicine* was published by Palgrave Macmillan.

We also participated in several summer university programs. The Riga Summer School on the European Health Law and Ethics was held in June, where in addition to one CEU faculty, four CEU students also participated. In 2013 a two-year CEU project on bio-archeological heritage came to its end. The project results were discussed at a conference and in the CEU summer university program. The closing conference was held in July with the title: "The Bodies of our Ancestors: Ancient Human Remains and the Past in the Future.

Another important event during the summer was the Galilee Colloquium in Kfar Blum, Israel about bioethics and philosophy. Scholars from Israel and other countries analyzed contemporary issues of bioethics, such as personalized medicine, pre-implantational genetic testing, organ tourism, and medical research in emergency situation. One full professor and two guest professors of CEU participated in this seminar.

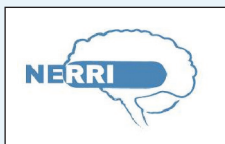
2012–2013 was an academic year with intensive research and a wide range of publications. More information about the activities of CELAB can be found at our website (celab.ceu.hu) and followed on our Facebook page (www.facebook.com/pages/CELAB/321473511079). We have many plans for the future: in the 2013–2014 academic year we are going to organize four events on the ethical and legal aspects of neuroscience and one event on stem cell research.

Judit Sándor
Director of the Center for Ethics and Law in Biomedicine (CELAB)
Central European University

2. RESEARCH AND POLICY ACTIVITIES

2.1. PARTICIPATION AND COLLABORATION IN RESEARCH NETWORKS

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



Type of funding scheme: EU FP7 Coordination and Support Actions

Starting date: March 15, 2013

Participating Institutions:

Ciência Viva—Agência Nacional para a Cultura Científica e Tecnológica, Portugal

London School of Economics and Political Science, United Kingdom

Radboud University Nijmegen, the Netherlands

Austrian Academy of Sciences, Austria

Scuola Internazionale Superiore di Studi Avanzati, Italy

Instituto de Biologia Molecular e Celular, Portugal

Tilburg Law School, Tilburg University, the Netherlands

Johannes Gutenberg Universität, Mainz, Germany

Johannes Kepler Universität, Linz, Austria

Kings' College, United Kingdom

European Brain Council, Belgium

Universitat Pompeu Fabra, Catalonia, Spain

CELAB, Central European University, Hungary

CELAB (CEU Center for Ethics and Law in Biomedicine) recently started an exciting FP7 project on neuro-enhancement: responsible research and

innovation (Acronym: NERRI). It is a project with outstanding international partners, and with a total budget of 3,287,632 € (including overheads). The CELAB research team is chaired by Prof. Judit Sándor. The project will run for three years and involves 18 research centers from across Europe. The consortium comprises experts in the neurocognitive sciences, the social sciences and humanities, and science communication. The main aim is to contribute to the introduction of Responsible Research and Innovation (RRI) perspectives in the field of neuro-enhancement (NE) and to the shaping of a normative framework underpinning the governance of NE technologies. In the field of neuro-enhancement, contemporary biomedicine has reached a crucial turning point at which it has become possible not only to restore health but also to improve it beyond its normal functioning.

To structure this complex socio-technical domain, this project will propose an Analytic Classification of NE technologies into currently available methods, experimental and hypothetical technologies. Each of the types raises some fundamental ethical, legal, social and economic issues, which have different relevance to various societal groups, point to different methods of stakeholder engagement, and may require different regulatory approaches. Over the course of the project, the Analytic Classification will be developed and extended in the work packages. Mobilization will form the central commitment of the project from the outset to the conclusion. Based on the Analytic Classification, it will stimulate and or-

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Judit Sándor and her team will participate in the identification of normative anchors that have emerged from various EU policy instruments and will conduct several interviews. Furthermore, CEU will host several so-called “Mobilization and Mutual Learning” (MML) activities in the framework of this project. In the end, from the summaries of the MML exercises participants will develop concrete options for governance, synthesizing them into a coherent framework.

The kick-off meeting of this project was held in March in Cascais (in Portugal) followed by a special session in Lisbon organized by Ciência Viva. The first project meeting was held in Barcelona at the end of November, 2013. This project will last for three years.

ganize 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, project participants will synthesize their national experiences, map the contours of a normative framework as it emerges from societal engagement and dialogue, and elaborate the concept of RRI in Europe.

The Consortium comprises experts in the neurocognitive sciences, the social sciences, law, philosophy, communication studies, and public engagement with science and technology. Many participants have prior experience of EU projects and of successful collaboration with other members of the consortium.

In the first year of this project CELAB researchers conducted sixteen interviews with NGOs, groups of disabled persons, scientists (in the field of cognitive science, biology, neurology, and brain research), and members of ethical decision-making bodies. In the interviews we learnt that enhancement of individual capabilities is not a generally desired aim of interventions; representatives of disability groups, for example, emphasize the need for ‘social enhancement’: the development of a tolerant and inclusive society, rather than a technocratic solution that focuses merely on some specific ‘enhanceable’ human capacity. Enhancement poses challenges also from a normative point of view.

Duration: 2013–2016

CELAB participants in the project: Judit Sándor, Márton Varju and Enikő Demény

2.1.2. EUCelLEX: Cell-based Regenerative Medicine: New Challenges for EU Legislation and Governance

Type of funding scheme: EU FP7

Starting date: October 1, 2013

Participating Institutions:

Institut National de la Santé et de la Recherche Médicale (INSERM), France
 Gottfried Wilhelm Leibniz Universität Hannover, Germany
 CELAB, Central European University, Hungary
 Legal Pathways BV, the Netherlands
 The Chancellor, Masters and Scholars of the University of Oxford, United Kingdom
 Medizinische Universität, Graz, Austria
 Fondation Nationale des Sciences Politiques Sciences Po, France
 Katholieke Universiteit Leuven, Belgium
 Royal Institution for the Advancement of Learning, McGill University, Canada

In April 2013, another project in which CELAB participates was also favorably evaluated by the Euro-

pean Commission with the help of independent experts. It is titled Cell-Based Regenerative Medicine: New Challenges for EU Legislation and Governance (Acronym: EUCelLEX). Accordingly, the Commission is now in the process to negotiate a Grant Agreement on the proposal. This project will last for three years, and it started officially on October 1, 2013 and the kick-off meeting was held in Paris, December 4, 2013. The coordinator of this project is the Institut National de la Santé et de la Recherche Medicale (INSERM).

The EUCelLEX Project's chief objective is to examine current legislation concerning the therapeutic use of somatic cells, in both the public and private sectors and in a number of European countries. To this end, the project aims 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 will be 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 will need to examine the heterogeneous nature of the legislation due to the freedom of action allowed to the member states.

Initially, each of the partners in the project will need to examine the legislation and the policies in their respective countries governing the use of stem cells at both national and European level. They will then compare current legislation with the practices that are due to develop stem cells in the near future, more especially in the research infrastructures to highlight the deficiencies and propose sustainable solutions. Special interest will also be paid to emerging practices such as 'cell tourism' or the use of unproven therapies. For example, in some European countries doctors propose to use regenerative medicine techniques which have yet to be scientifically validated and which do not meet the safety criteria imposed by both French and European legislation.

The ultimate objective is to make recommendations to the European Commission so as to facilitate the use of stem cells for clinical purposes in a stabilised 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 will assess 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 shall also analyze 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 shall also look at the opinions of the European Group on Ethics (EGE). The major selection criteria of the legal analysis will be based on the countries represented in this project (Belgium, Canada, France, Germany, Hungary, the Netherlands, and the United Kingdom) and, when it is necessary to highlight a specific legal framework, we shall also look at the regulation in other countries. Shortly after the project officially started in October, CELAB participants in the project conducted several preliminary interviews with stakeholders in Madison, Wisconsin, the United States on November 7–8, 2013.

Duration of the Project: 2013–2016

CELAB participants in the project: Judit Sándor and Márton Varju

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

Type of funding scheme: OTKA (National Scientific Research Fund) Research Grant

Starting date: October 1, 2013

The aim of this project, financed by OTKA (National Scientific Research Fund), is to investigate issues that are relevant both on the academic and the policy level. The goal of 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. In the pilot phase of the research, literature review and qualitative data analysis is conducted, then in the first phase 40 semi-structured interviews are made with stakeholders (experts, law-makers and medical practitioners), and in the second phase 40 semi-structured interviews with infertility patients who have decided to take part in ART treatment.

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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). The core methodology is qualitative research with active network theory. The project starts in October 2013 and will be completed on September 30, 2017.

2.1.4. Disaster Bioethics Project



Type of funding scheme: COST IS1201

Starting date: April 1, 2013

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, 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 responses. High level statements stress the importance of disaster ethics and putting people first in disasters. Yet few resources are available for disaster ethics decision-making. Policy makers, humanitarian agencies and individual responders seek ethical guidance and training materials to better address the challenging and distressful ethical dilemmas in disasters. Evidence-based knowledge is required to promote high-quality ethical decision-making.

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

The scientific kickoff meeting of the project was held at Dublin University on April 25–26, 2013.

Participant: Péter Kakuk, Management Committee Member and Financial Rapporteur

2.1.5. Equal Opportunities for Health: Action for Development



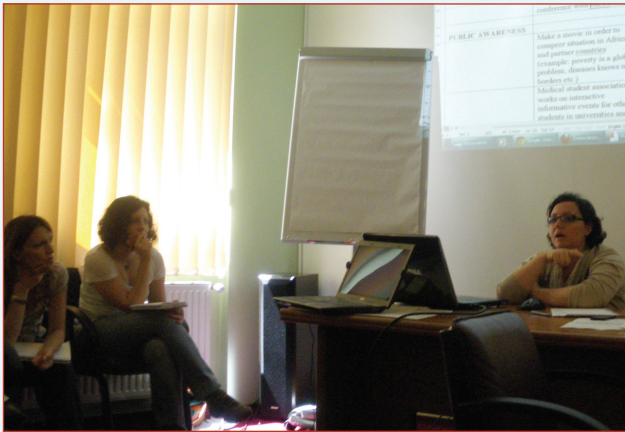
Participating Institutions:

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

In association with:

CELAB, Central European University, Hungary
 Association of Medical students in Bulgaria, Pleven branch, Bulgaria
 Personality Development and Human Communities Association, Bulgaria
 Latvian Medical Students' Association, Latvia
 University of Latvia, Latvia
 Malta Medical Students' Association, Malta
 National Federation for the Orders of Doctors and Dentists [Federazione Nazionale Ordine Medici Chirurghi e Odontoiatri], Italy

Universities, organizations and student associations from seven European countries are involved in this project, united by a common interest in Global Health and its teaching. Equal opportunities for health:



action for development is an education and awareness-building project designed to highlight the importance of approaching health as a fundamental human right closely related to individual social development.

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

To goal is to promote discussion and dissemination of the Global Health paradigm, understood as a “panoramic” approach to health, to be able to theoretically transpose into practice social determinants of health, values of justice and equity identified in the Declaration of Alma Ata, and an analysis of the growing interdependence between populations and countries determined by processes of globalization and its impact on health and health inequalities both in and among countries.

As Associate Partner CELAB participates in Partnership Meetings organized in the framework of the project. The fifth Partnership Meeting took place in Braşov, Romania on May 14–16, 2013. Enikő Demény represented CELAB and gave input for the new project that will be submitted for funding. The last project meeting will take place in January 2014 in Padua, Italy.

CELAB participants in the project: Judit Sándor and Enikő Demény

Duration of the project: 2011–2014

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

2.1.6. International Academic Network on Bioethics (IANB)



Although scientific advances in biomedicine contribute to human wellbeing, they can also lead to danger, thereby threatening fundamental human rights. As a result, the International Academic Network on Bioethics has decided to tackle these issues in a systematic manner. The IANB seeks to contribute to international reflection on biomedical questions that many countries are facing. The IANB is unique insofar as it is led by academics from many different countries. Consequently, it participates in the development of a necessary international perspective on bioethics research. However, although steered by academics, the Network actively collaborates with other non-academic professionals who specialize in the field of biomedicine.

Made up of lawyers at its core, the Network exists to conduct multidisciplinary research. The law on diverse issues in bioethics in different countries—and consequently cultures—is presented and analyzed through the prism of various disciplines. In this way, law serves to reveal the social perception of bioethical issues. The work of the Network therefore goes further than merely presenting different legal provisions: it examines the law from such diverse standpoints as anthropology, philosophy, sociology, medicine, psychoanalysis and even economics. The IANB is made up of academics belonging to different cultures. Through its comparative law publications, it furthers research on issues in bioethics between many countries of the world. The chosen themes thus allow an exploration of the legal regimes in each country and assist our understanding of the different underlying cultural and religious foundations. Each study is presented by a minimum of the eighteen permanent members of the IANB (Belgium, Brazil, Chile, France, Germany, Greece, Holland, Hungary, Italy, Japan, Portugal, Senegal, Spain, Switzerland, Tunisia, Turkey, UK, and USA). Hungary and CELAB has been represented in this network by Judit Sándor since 2006.

In November 2012, the annual RUIB workshop was held in Rio de Janeiro. The topic of the workshop was

2. RESEARCH AND POLICY ACTIVITIES

Parenthood and Biomedical Interventions. The themes of the two workshops will result in two further books each: first issued in French to be followed by the English versions. All books of the network are published in Belgium by Bruylant and all form a part of the series: “*Droit, Bioéthique et Société*” edited by Brigitte Feuillet-Liger. In 2013, three books came out as a result of our collaboration in previous workshops. Two books were related to the workshop on the ethics of end-of-life treatment decisions: one in French with the title: *Les proches et la fin de vie médicalisé*, and one in English with the title *Families and End-of-Life Treatment Decisions: International Perspective*. The chapters of these books analyze the current status and the role of relatives (and non-relatives) close to the patient at the end of life.

Another book in French was published in October 2013, entitled *Corps de la femme et Biomédecine: Approche internationale*, edited by Amel Aouij-Mrad and Brigitte Feuillet-Liger. The English version of this book, containing chapters elaborated at a workshop in 2011 that explored the relationship between the female body and biomedicine, is expected to be published in early 2014 with the title *The Female Body: A Journey through Law, Culture and Medicine*, edited by Thérèse Callus, Brigitte Feuillet-Liger and Kristina Orfali. Many possibilities are offered to women through biomedical techniques: from assistance to procreate (with assisted reproduction); to refusal to do so (contraception, voluntary sterilization, termination of pregnancy); to be informed of genetic predispositions (through the use of available genetic tests); or to improve their physical appearance with cosmetic surgery. But a recurrent question arises: with its rapid progress and its extreme medicalization of the body, can biomedicine liberate women? Or

rather, given the risks of the commodification of the body or its parts, is it not a source of exploitation? The authors of this work, jurists, anthropologists, philosophers, sociologists and doctors, have explored these questions. The contributions from nineteen countries in this international multidisciplinary study analyze the reality of the amazing developments of biomedicine on the female body. Numerous systems are compared for the first time; European, African, North and South American, but also Chinese and Japanese. Beyond highlighting differences, and identifying similarities in the development of ‘enhancement medicine’, the ultimate objective of this work is to show the complexity surrounding the question of a woman’s freedom over her body and the extent to which this is limited by the state. All books within this project are published by Bruylant (Brussels).

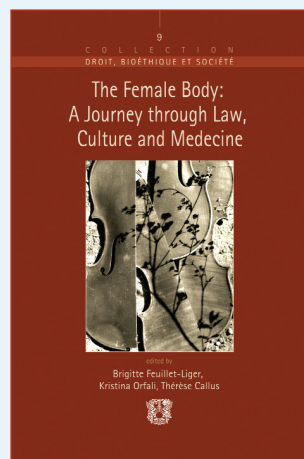
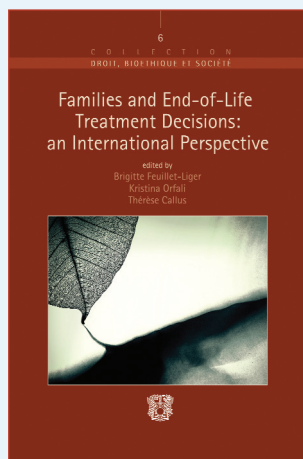
The upcoming workshop will be held in Brussels in December 2013.

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

2.1.7. Bio-Archaeological Heritage Project

This is an interdisciplinary research project that intends to confront the policy and heritage issues arising when the search for knowledge sits uncomfortably with what society regards as right and good. The project is based at the Department of Medieval Studies and involves cooperation with several CEU programs and research centers: the Department of Medieval Studies (represented by the supervisor of the project, József Laszlovszky, and Gerhard Jaritz); the Center for Law and Ethics in Biomedicine (represented by Judit Sándor); the Religious Studies Program (Matthias Riedl), the Jewish Studies Program (Carsten Wilke); the Department of History (Katalin Szende and Daniel Ziemann) and the Center for Eastern Mediterranean Studies.

The project is based on a network of physical anthropologists, bioethical and legal experts, scholars of religious studies and heritage specialists already established by an ESF project application by Irene Barbiera, an alumna of the Department of Medieval Studies who, as a research fellow, coordinates the project in the form of a CEU 20th Anniversary Postdoctoral Fellowship. The project aims to collect academic research results related to medieval and early modern human remains, policy protocols, legal regulations, research protocols and guidelines as a repository for working out best-practice reference materials. In 2013 the project



on bio-archeological heritage came to its end. The results were discussed at a conference and in the CEU summer university program (SUN) entitled: "Reading Old Bodies: New Directions in the Bio-Archaeological Heritage." The closing conference was held on July 5–6, 2013 with the title: "The Bodies of our Ancestors: Ancient Human Remains and the Past in the Future."

Duration of the project: 2011–2013

CELAB participants in the project: Judit Sándor and Enikő Demény

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

2.2. POLICY AND OUTREACH ACTIVITY

2.2.1. Third ELPAT Congress: Ethical, Legal and Psychosocial Aspects of Transplantation: Global Issues, Local Solutions

An important dissemination event of the recently finalized EULOD project took place in Rotterdam at the third ELPAT Congress: Ethical, Legal and Psychosocial Aspects of Transplantation Global Issues, Local Solutions. The project on living organ donation in Europe was a coordinated action that aimed to establish an inventory of living donation practices in Europe; to explore and promote living donation as a way to increase organ availability; and to develop tools that improve the quality and safety of living organ donations throughout Europe. This action

aims to achieve broad European coverage with a specific focus on the new EU Member States. It draws upon the support, knowledge and network of the European Platform on Ethical, Legal and Psychosocial Aspects of Organ Transplantation (ELPAT) and the European Society for Organ Transplantation (ESOT).

In Rotterdam, Judit Sándor pre-



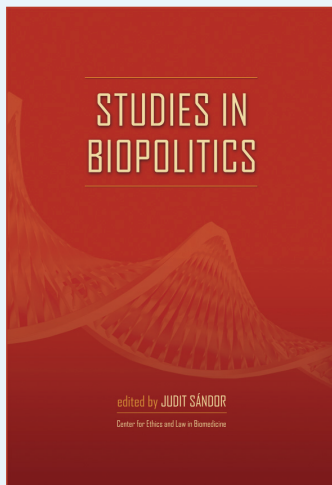
sented the main results of the CELAB team in the EULOD project. Our team argued against the commercialization of organ donation and we developed a strong criticism against organ tourism and offered some legal solutions for the better enforcement of existing legal norms and for enhancing international co-operation in this field. Tudor Florea presented a poster prepared by Enikő Demény and himself, titled "The Role of Ethics Committees in Living Organ Donations' Decision Making Process in Central and Eastern Europe." They based their analysis on empirical material acquired during the legal and field research within the EULOD. They hypothesized that the work of the committees involved in living organ donation decision making is influenced by a number of contextual variables. The question arising out of this analysis is whether best practices of such ethics committees can be translated from one cultural and



2. RESEARCH AND POLICY ACTIVITIES

legislative context to another, maintaining the same level of efficiency and if yes, what would be the aspects of the decision making process where professional guidelines could be of genuine help.

2.2.2. Studies in Biopolitics



This year we published a new book in the framework of the CELAB book series. This year the book was based on a collection of multidisciplinary case studies on biopolitical practices and discourses contributed by political scientists and public policy experts, anthropologists and philosophers, biologists and bioethicists, legal scholars and human

rights activists, as well as advanced graduate students at the Central European University (CEU). The majority of the authors have participated in graduate courses in political science and gender studies at CEU, focusing on the human rights aspects of biopolitics and the various forms of commercializing the human body. This collection of essays reflects not only the lively discussions we had during CEU courses or CELAB events, but also provides interesting cases for further comparative studies on biopolitics.

CELAB Junior Researcher Enikő Demény also contributed with a chapter to this book. She started to develop her interest in social, legal and ethical aspects of new reproductive technologies since she was an MA Student at CEU Gender Studies Department in 1997–1998 Academic Year and attended a directed seminar on this topic conducted by Prof. Judit Sándor. Enikő Demény's chapter, titled "Medically Assisted Reproduction: Challenges for Regulation in Romania," aims to present the development of the regulation regarding medically assisted reproduction in Romania and its impact on the practice of assisted reproduction. It will use the method of contextualization to highlight how the socio-cultural and economic context influences the outcomes of a technological application, and how this impacts various people in the given context. It argues that the ongoing

practice of third party reproduction in the Romanian IVF clinics and the illicit activities that are taking place in connection with these procedures in some of the clinics highlight the inadequacies of the existing regulatory framework and call for a comprehensive regulation in the field of medically assisted reproduction. The implications for individuals, family relationships or for citizenship of third party reproduction draw our attention to the broader societal issues involved in the application of this medical technology, as well as to the transnational character of such procedures and point to the necessity of a global response to this issue.

2.2.3. European Conference of the European Health Law Association

One of the key events of this year was the European Conference of the European Health Law Association. The mission of the European Association of Health Law (EAHL) is to strengthen the health and human rights interface throughout Europe, and to serve as an indispensable source of advice and guidance for the



future of health law and policies in Europe. The guiding principle of the EAHL is striving for academic excellence and the improvement of health law practice. The founding conference was held in 2008 in Edinburgh. This year the Fourth European Conference on Health Law took place in Coimbra, Portugal, on October 9–11, 2013. The Director of CELAB gave a presentation at this conference with the title: “Access to Personalized Medicine and the Case and the Case of Angelina Jolie with the Genetic Test.”

2.2.4. Ethical Thinking: Past and Present International Conference

At this conference held on May 22–23, 2013 in Prešov, Slovakia and organized by UNESCO Chair in Bioethics, at the Department of Ethics, Institute of Philosophy of Ethics, University of Prešov, Enikő Demény offered a presentation entitled: “The Principle of Vulnerability and its Potential Applications in Applied and Professional Ethics” at the session “Ethics Theories of the 20th Century.” The principle of vulnerability is a specific to European Bioethics. In contrast to the four American principles of biomedical ethics—autonomy, non-maleficence, beneficence, and justice—the four of European bioethics and bio-law principles include vulnerability along with autonomy, dignity, and integrity. According to Rendtorff and Kemp (2000, p. 274) “the principle of vulnerability is ontologically prior to the other [European] principles, it expresses better than all of the other ethical principles ... the finitude of the human condition.” On the one hand, vulnerability expresses human limits and frailty; and on the other hand it represents moral and ethical action principles. In her presentation Enikő Demény proposed a review of different theoretical approaches of the principle of vulnerability and presented case studies on its possible applications. Three fields of application from the CEE context have been considered: vulnerability in access to health-care, vulnerability in clinical ethics (example of living

organ donation decision making) and in biomedical research ethics. In conclusion she highlighted some potential benefits of applying the principle of vulnerability as well as possible difficulties in its application.

The conference proceedings will be published in the international journal *Ethics and Bioethics in Central Europe*.

2.2.5. Forthcoming Events: 28th European Conference on Philosophy of Medicine and Health Care, Bioethics and Biopolitics

Péter Kakuk is chairing the organization committee of the conference that will take place on August 27–30, 2014, in Debrecen, Hungary. This event will be organized by the European Society for Philosophy of Medicine and Healthcare (ESPMH) and the Department of Behavioral Sciences, University of Debrecen, Hungary.

‘Biopolitics’ is either used as a philosophical or sociological term referring to the works of Negri, Agamben, Rose, or Foucault, who focused on the contemporary style of governing populations through bio-power, or as an umbrella concept referring to public policies regarding applications of biotechnology and the life sciences. Both usages suggest that biopolitics is a central concept for modern societies. At the same time, bioethics has become increasingly interdisciplinary and ever more politicized. Bioethical issues figure in presidential campaigns and parliamentary elections. Bioethicists are advisors for governments and frame recommendations for public policies. Bioethics and biopolitics have become deeply interwoven activities. If bioethics and biopolitics are highly interwoven, then how should we understand their relationship? Does politics corrupt bioethics? How does bioethics affect policy-making? How has bioethics been affected by its role in policy-making?

The event may be followed on the Facebook page www.facebook.com/espmh2014

3. ACADEMIC ACTIVITIES

3. ACADEMIC ACTIVITIES

3.1. PUBLIC LECTURES

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

The lectures, which took place between September 30 and October 14, 2011 in the Auditorium of the Central European University, focused on the ethical, legal, and social implications of recent scientific advances in the field of life sciences. The three main topics of the lectures – enhancement of the bodily capacities, extension of the life span, and commercialization of the human body – are all at the core of ethical debates that engage a wide range of disciplines outside of the life sciences: from philosophy to anthropology, from ethics to law, from gender studies to public health, among others. After each lecture, and under the moderation of CELAB Director Judit Sándor, lively debates and discussions developed between the lecturers and the audience that consisted of faculty and students from various CEU depart-

ments, as well as associates and research fellows representing different CEU centers. Detailed information about these lectures was presented in the CELAB Annual Report 2010–2011. The CELAB Bioethics lecture series continued in the 2011–2012 Academic Year with a public lecture offered by *Prof. Nikolas Rose* titled “Our Brains, Our Selves? The Social Implications of New Brain Sciences.”

3.1.1. “Biopolitics and Beyond: Vibrant Matter and the Political Economy of Life” by Professor Thomas Lemke

In the academic year of 2012–2013, the CELAB Public Lecture Series continued with a lecture given by Professor Thomas Lemke. Prof. Lemke is



Thomas Lemke



a German sociologist and social theorist. He is best known for his work on governmentality, biopolitics and his readings of Michel Foucault. He is currently a Professor of Sociology with specialization in Biotechnologies, Nature and Society at the Faculty of Social Sciences at the Goethe University Frankfurt, Frankfurt am Main, Germany.

The title of the lecture, presented on May 25, 2013 was "Biopolitics and Beyond: Vibrant Matter and the Political Economy of Life." In his lecture, Prof. Lemke critically evaluated two promising areas of research that have so far received little attention in the work on biopolitics: the so-called new materialism, which shifts the accent from "life" to "vibrant matter" (Jane Bennett), and work on "biocapital" that investigates the systematic relations between (neo-liberal) capitalism, on the one hand, and the emergence of a biotech industry with new products and services based on biotechnological knowledge, on the other. The lecture inspired many students and faculty members for further debate.

The Center for Ethics and Law in Biomedicine (CELAB)
cordially invites you for the Next Session of the Bioethics
Lecture Series at the Central European University

delivered by
Prof. **Thomas Lemke** on

Biopolitics and beyond:

Vibrant matter and the
political economy of life

The talk will present and critically evaluate two promising areas of research emerged that have so far received little attention in work on biopolitics: the so-called new materialism, which shifts the accent from "life" to "vibrant matter" (Jane Bennett), and work on "biocapital" that investigates the systematic relations between (neo-liberal) capitalism on the one hand and the emergence of a biotech industry with new products and services based on biotechnological knowledge on the other.

Thomas Lemke is Professor of Sociology with focus on Biotechnologies, Nature and Society at the Faculty of Social Sciences of the Goethe-University Frankfurt/Main in Germany.

Lecture followed by discussion and reception.
May 24, 2013 15:00-16:30 p.m.
Venue: CEU Popper Room

3. ACADEMIC ACTIVITIES

3.2. TEACHING

CELAB's staff and fellows are involved in teaching both at the Central European University and at other universities in Hungary and in other countries of 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 the Central European University

Courses offered in the 2012–2013 Academic Year

Judit Sándor

Privacy Rights and Data Protection in Biotechnology

Health and Human Rights
Department of Legal Studies

Human Rights and Biopolitics
Department of Political Science and Department of Gender Studies

The Human Body on the Market
Department of Gender Studies

Petra Bárd

EU Constitutional Law
EU Criminal Justice Law
Department of Legal Studies

3.2.2. Teaching and Lecturing at Other Institutions

3.2.2.1. Bioethics Teaching Network

Although as bioethicists we represent a variety of disciplines, there are certain truths we hold in common: (1) that the future of our field rests on the foundation of bioethics education and (2) ensuring the strength of this foundation requires a bold look

at where we are now and what future directions should be pursued. In April 2010, Cambridge University Press held the first Cambridge Consortium for Bioethics Education in New York. Leaders in the field were invited to initiate a shared dialogue addressing such questions as: Why are we doing this? What goals are we trying to achieve? Where is bioethics education taking place? How well are we doing? What next? Tackling those questions and finding practical answers continues to be the aim of our subsequent meetings. To date, delegates from 29 countries have participated in the Cambridge Consortium and brought their success stories—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.

In the 2012–2013 Academic Year 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 to strengthen ethics education across the country.

Therefore, it is the organizational objective of BOMM to establish a Hungarian network for professionals involved in bioethics education, to organize an annual workshop focusing on bioethics education, and to build a web-based platform for our activities and interests. In general, 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 experiences and knowledge to the community of scholars.

This professional group is open to professionals working in the field of bioethics education in institu-



tions of higher learning. There are more than 30 educators already joined, and we had our first workshop at the University of Debrecen on June 4, 2013.

Webpage: www.mti.deoec.hu/bomm

3.2.2.2. Teaching Bioethics and Biolaw at Other Institutions

Judit Sándor

Riga University, Latvia
Summer Course on European Health Law & Ethics
 ERASMUS Lifelong Learning Programme
 June 17–28, 2013, Riga, Latvia

Petra Bárd

ELTE Faculty of Law, Criminology MA Program
Criminal Policy
Data Protection

“Mediation’s Place in Restorative Justice Regimes”
 Mediation Summer School, CEU
 June 7, 2013, Budapest, Hungary

“Freedom of Expression, Right to Privacy, Enforcement of ECtHR Judgments”
 Co-lecturing with Austrian Constitutional Court Justice Christoph Grabenwarter and chairing a session on EU accession to the ECHR
 European Forum Alpbach 2013: Experiences and Values, Seminar 09: The Role of the European Court of Human Rights in Protecting and Developing an Open Society
 August 13–16, 2013

“EU Internal Market and External Relations” and
 “Fundamental Rights Protection in the EU”
 Two lectures held at the ASSEI Alpbach Summer School on European Integration, Club Alpbach Belgrade
 September 12–21, 2013, Belgrade, Serbia

“European Judicial Training Collective”
 Training of Irish and Hungarian judges on behalf of CEU in cooperation with the Law Society of Ireland
 October 19–21, 2013

“International Cooperation in Criminal Justice”
 Lecture held at the Supreme Court/General Public Prosecutor’s Office
 December 9, 2013, Budapest, Hungary

“European Standards of Criminal Policy”
 Guest lecture held at Eötvös Loránd University (ELTE)
 December 12, 2013, Budapest, Hungary

“The EU Accession to the ECHR: Influence on Future Case-Law”
 Public lecture organized by the Interdisciplinary Association of Comparative and Private International Law at Juridikum, Vienna
 December 16, 2013, Vienna, Austria

Violeta Beširević

Medical Law Courses at Union University Law School, Belgrade, Serbia
Law and Ethics in Biomedicine (Specialized Studies in Medical Law)
Patients’ Rights (Specialized Studies in Medical Law)
 On sabbatical leave in 2012–2013

Péter Kakuk

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

3. ACADEMIC ACTIVITIES

Ethics in Pharmacy course (in Hungarian and English)

Research Ethics: RCR education (in Hungarian and English)

Ethical issues in health care management course, Postgraduate Program for Health Care Management

Selected issues in bioethics, for PhD students

József Kovács

“Reason-Centered Personality Development I–II.”

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

September 28, 2012, Piliscsaba, Hungary

“Reason-Centered Personality Development III.”

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

November 17, 2012, Piliscsaba, Hungary

“Ethical Questions in Psychotherapy”

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

February 11, 2013, Budapest, Hungary

“Ethical and Legal Principles of Informed Consent”

Lecture held at the CME course *Information Disclosure and Consent in Everyday Medical Practice—from an Ethical and Legal Point of View*, Semmelweis University

February 15, 2013, Budapest, Hungary

“Ethical Questions of Competency”

Lecture held at the CME course *Information*

Disclosure and Consent in Everyday Medical Practice—from an Ethical and Legal Point of View, Semmelweis University

February 16, 2013, Budapest, Hungary

“Psychologist Ethics and Ethical Questions in Psychotherapy”

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

March 22, 2013, Budapest, Hungary

“Patients Rights from a Bioethical Point of View”

Lecture held in the framework of lectures series organized by Semmelweis University and EDUVITAL Nonprofit Society for Health Education

April 26, 2013, Budapest, Hungary

“Ethical Questions of Psychotherapy”

Lecture held for the compulsory training course for psychotherapists *New, Evidence Based Knowledge in the Field of Psychotherapeutic Practice and Research*

November 22, 2013, Budapest, Hungary

Imre Szebik

Semmelweis University, Budapest, Hungary

Bioethics for Medical Students

Research Ethics, Lectures in Continuous Medical Education (CME) courses for physicians (February and September, 2013)

Lectures and seminars in the Hungarian, German and English language programs

Evangelical-Lutheran Theological University, Budapest, Hungary

Bioethics

4. RESEARCH FELLOWS

In the 2012–2013 Academic Year CELAB hosted two Research Fellows: Imre Bárd and László Fosztó

LÁSZLÓ FOSZTÓ

László Fosztó was a Visiting Research Fellow at the CELAB in his capacity as a postdoctoral Researcher at the Centre for Ethics in Health Politics, Grigore T. Popa University of Medicine and Pharmacy, Iași, between December 2012 and March 2013. The topic of his research was "Ethical Issues in Recent Research on the Health of the Roma Population in Eastern Europe."

László Fosztó has been a researcher at the Romanian Institute for Research on National Minorities (www.ispmn.gov.ro) since its establishment in 2007. He is an ethnographer and social anthropologist trained at the Babeș-Bolyai University of Cluj, Romania (BA 1996), Central European University in Budapest, Hungary (MA 2001), and the Max Planck Institute for Social Anthropology in Halle/Saale (PhD 2009), Germany. His training and interest encompass both 'western' and 'eastern' traditions of ethnological research. He has been doing research among different Roma/Gypsy groups in Transylvania since 1993. The fields of research he has contributed to are: the study of relations between Hungarians and Roma in Transylvanian villages, the ethnography of communicative practices, the



anthropology of religion, particularly ritual revitalization after socialism, and religious conversion among the Roma. Additionally, he is interested in the political movement of the Roma in Europe and issues of social identities, including stigma, ethnicity, diaspora, and nationalism. More recently, he started research on the local impact of the migration processes and broader issues of economic anthropology (informal economy, social capital, ritual and consumption).

He authored two volumes *Ritual Revitalization after Socialism: Community, Personhood, and Conversion among the Roma in a Transylvanian Village*, Halle Studies in the Anthropology of Eurasia, Volume 21 (Münster: LIT Verlag, 2009) and *Colecție de studii despre romii din România*, Editura Institutului pentru Studierea Problemelor Minorităților Naționale – Editura Kriterion, Cluj-Napoca 2009. His other recent publications include: "Pentecostalism in Romania. The Impact of Pentecostal Communities on the Life-Style of the Members" (co-authored with Dénes Kiss), *La ricerca folklorica*, 65 (La sfida del pentecostalismo), pp. 51–64; and "Mobilising 'Culture' and 'Religion': Ritual Practices and Social Relations among Two Minority Groups in Rural Transylvania," *Sociologie Românească*, 01/2010, pp. 132–145. He co-edited volumes: *Twenty Years After the Fall of Official Atheism: The Contemporary Romanian Religious Landscape*, Thematic Issue: Studia Universitatis Babeș-Bolyai: Sociologia, Vol. (LIV): 2, December 2009 (co-editors: Mălina Voicu and Sorin Gog) and *Spectrum. Cercetări sociale despre romi*, Editura Institutului pentru Studierea Problemelor Minorităților Naționale – Editura Kriterion, Cluj-Napoca 2011 (co-editor: Stefănia Toma).

4. RESEARCH FELLOWS

During his stay at the at the CELAB László Fosztó worked on studying the intersection of ethical problems related to research on the health of the Roma population in Eastern Europe and issues of ethics in health politics with particular focus on Romania. He worked on two studies on this topic: *Social research and Community Development in Roma communities, notes on the issues of 'vulnerability' and 'empowerment'* and *Ethical issues in recent medical research on the health of the Roma population*. The CELAB resources and the Library of the Central European University offered excellent conditions for developing these studies.

IMRE BÁRD

Imre Bárd is a PhD student at the London School of Economics & Political Science where he also works as a Research Officer. He was a Visiting Fellow at CELAB between April and December 2013. He actively contributed to the work of the FP7 project NERRI (Neuro-Enhancement: Responsible Research and Innovation) that both CELAB and the LSE are involved in. The project seeks to initiate Europe-wide societal engagement around the social, legal and ethical challenges related to neuro-enhancement technologies. In particular, he worked with Prof. Judit Sándor on conducting a series of



expert interviews and planning stakeholder events for 2014.

During his time at CELAB, Imre Bárd also worked on writing up publications: an invited chapter for Springer's forthcoming *Handbook of Neuroethics*, discussing ethical issues in novel brain-computer interfaces and their use in children with attention-deficit hyperactivity disorder (ADHD), a survey paper about students' use of cognition enhancing drugs in the United Kingdom, and a focus group study examining students' perceptions of the ethical issues related to cognition enhancement within academic environments.

In January 2013 Imre Bárd gave an evening talk about ethical issues related to human enhancement at the 'Virus Club', a highly popular weekly event in central Budapest that presents various topics of scientific or cultural significance to an interested general audience.

In July of 2013 Imre participated at Yale University's Summer Bioethics Institute where he learned more about neuroethics, bioethics in the context of US law, as well as the relationship between bioethical issues and different religious traditions. He also gave a presentation about the NERRI Project to students and faculty at Yale's Bioethics Center, and he has been invited to return in 2014 to hold a four-week a seminar on the ethics of human enhancement.

Imre sought to make the most of the resources at CELAB, he had many discussions with faculty and fellows at the Centre and he attended numerous CEU events, including the CELAB public lecture by Thomas Lemke.

5. EVENTS AND ACHIEVEMENTS

5.1. PARTICIPATION IN CONFERENCES

During the 2012–2013 Academic Year, CELAB staff and fellows took part in the following academic and scientific events:

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

Eighth National Conference on Bioethics
Organized by the Romanian Society of Bioethics; the Romanian College of Physicians; the Center for Health Policy and Ethics at the Grigore T. Popa University of Medicine and Pharmacy, Iași; the Center of Ethics at the Babeș-Bolyai University, Cluj-Napoca; and the UNESCO National Commission of Bioethics, Romania
Presentation by Adina Rebeleanu (with Mihaela Frunză and Enikő Demény) on “Vulnerability in the Reforming Health Systems Process—Legal vs. Ethical Perspectives”
Presentation by Mihaela Frunză (with Enikő Demény, Judit Sándor, Beatrice Ioan) on “Ethical Perspectives on Facebook Organ Donation Campaign”
September 13–16, 2012, Cluj, Romania

Comparative Embryonic Stem Cell Research in Mammals
Yearly Open Workshop of the Partners in FP7 project
Participant: Judit Sándor
September 25, 2012, Budapest, Hungary

PR Trend. New Media, Challenges and Perspectives—International Conference
Presentation by Mihaela Frunză, Enikő Demény, Judit Sándor, Beatrice Ioan on “Ethical Challenges of the Facebook Campaign in Promoting Organ Donation”
October 19–20, 2012, Cluj, Romania

Les incidences de la biomédecine sur la parenté [The Influence of Biomedicine on Kinship Relations]
Workshop organized by the International Academic Network on Bioethics (RUIB)
Presentation by Judit Sándor on “The Transformation of Families and new Biomedical Technology in Hungary”
October 29–30, 2012, Rio de Janeiro, Brazil

Embedding Ethics in Scientific Practice
Expert Meeting at the Hungarian Academy of Sciences
Participant: Judit Sándor
November 6–7, 2012, Budapest, Hungary

5. EVENTS AND ACHIEVEMENTS

Meeting of the Hungarian Skeptic Society

Public lecture held by Imre Szebik on "Evidence-Based Medicine and Obstetrics"
November 18, 2012, Budapest, Hungary

EpiHealth Project Steering Committee Meeting

Roundtable participant: Judit Sándor as Member of the Ethics Advisory Board
November 22, 2012, Gödöllő, Hungary

TILEC-EUR Health Workshop

Presentation by Mária Éva Földes on "Information to Patients on Medicinal Products and Medical Devices: EU Law Developments"
December 7, 2012, Tilburg, the Netherlands

Bioethics & Genetics: Dilemmas of Genetic Diagnosis and Consultation

Conference organized by the Bioethics Committee of the Polish Academy of Sciences; the Institute of Philosophy of the University of Warsaw; and the editorial board of the scientific Journal *Ethics*
Keynote Speakers: Prof. Sören Holm, University of Manchester, UK and University of Oslo, Norway and Prof. Judit Sándor, Central European University, Budapest, Hungary
December 7–8, 2012, Warsaw, Poland

Ethical Aspects of Exome and Whole Genome

Sequencing Studies in Rare Diseases Workshop
Presentation by Judit Sándor on "Ethical Aspects of Informed Consent"
January 14, 2013, Tel Aviv, Israel

18th Meeting of the Hungarian Society for Psychiatry

Presentation by József Kovács on "Some Current Issues in Neuro-ethics"
January 23–26, 2013, Győr, Hungary

Revision of Medical Devices Regulation - The Legal Challenges

organized by the Tilburg Law and Economics Center (TILEC), Lexxion the Legal Publisher, AXON Science-based lawyers and Eucomed
Participant: Éva Földes, co-organizer
January 29, 2013, Tilburg, the Netherlands

NERRI Project Kick-off Meeting

CELAB participants: Judit Sándor and Márton Varjú
March 25, 2013, Cascais, Portugal

Time to Live, Time to Die

Conference of the Faculty of Theology, University of Debrecen
Public Lecture held by Imre Szebik on "Ethical Issues at the End of Life"
April 12, 2013, Debrecen, Hungary

XVII. Pszinapszis-Budapest Psychology Days



Presentation by Enikő Demény on "The Impact of New Technologies on Identity and the Family"
April 13, 2013, Budapest, Hungary

14th Schizophrenia Academy

Presentation by József Kovács on "Current Issues in Neuro-ethics"
April 19, 2013, Budapest, Hungary

Third ELPAT Congress: Ethical, Legal and Psychosocial Aspects of Transplantation Global Issues, Local Solutions

Presentation by Judit Sándor on "Final results of the CELAB team in the EULOD project"
Poster presentation by Enikő Demény and George Tudor Florea poster presentation on "The Role of Ethics Committees in Living Organ Donations' Decision Making Process in Central and Eastern Europe"
April 20–23, 2013, Rotterdam, The Netherlands

COST IS1201, Disaster Bioethics

Scientific Kick-off Meeting
Participant: Péter Kakuk
April 25–26, 2013, Dublin, Ireland

Third World Conference on Research Integrity

Presentation by Péter Kakuk on "Fostering scientific integrity and assessing the hidden curriculum"
May 5–6, 2013, Montreal, Canada

Equal Opportunities for Health: Action for Development

CELAB participant: Enikő Demény
May 16–17, 2013, Braşov, Romania

Ethical Thinking: Past and Present

Organized by UNESCO Chair in Bioethics,
Department of Ethics, Institute of Philosophy
of Ethics at the University of Prešov
Presentation by Enikő Demény on "The
Principle of Vulnerability and its Potential
Applications in Applied and Professional Ethics",
presented at the Session: Ethics Theories of the
20th Century
May 22–23, 2013, Prešov, Slovakia

Nephrology Days

Presentation by Péter Kakuk on "The Refusal of
Dialysis at End-stage Renal Failure"
May 31, 2013, Debrecen, Hungary

*First Meeting of the Hungarian Working Group of the
Cambridge Consortium on Bioethics Education
(BOMM)*

Presentation by József Kovács on "The Present of
Bioethics Education"
Presentation by Imre Szebik on "Challenges of
Bioethics Education"
June 4, 2013, Debrecen, Hungary

Third Conference of Applied Ethics

Keynote address given by Imre Szebik on "Ethical
Questions of Gene Transfer Techniques"
June 8, 2013, Cluj, Romania

Summer Course on European Health Law & Ethics

ERASMUS Lifelong Learning
Programme
Participant: Judit Sándor
June 17–28, 2013, Riga, Latvia

*Third Cambridge Consortium for Bioethics Educa-
tion*

Presentation by Péter Kakuk on "Teaching
Responsible Conduct to Life Scientists"
Participant: Imre Szebik
June 19–21, 2013, Paris, France

*Galilee Colloquium VII. on Social, Moral and Legal
Philosophy*

Established by the Swiss-Israel Philosophy Foun-
dation
Presentation by Judit Sándor on "Novel Rights-
Based Approaches to Selective Reproduction"
June 19–23, 2013, Kibbutz Kfar Blum, Israel

Starpoint Reformed Youth Festival

Roundtable discussion with the participation of
Imre Szebik on "Ethical Issues of Human Infertility"
July 24, 2013, Mezőtúr, Hungary

Valley of Arts Festival

Public lecture held by Imre Szebik on "Ethical
Issues of Human Reproduction"
July 29, 2013, Kapolcs, Hungary

*27th European Conference on Philosophy of
Medicine and Health Care. "Innovation in Health
Care and the Life Sciences"*

Presentation by Péter Kakuk on "Innovation Cul-
ture and Mertonian Norms: Tensions in the Ethics
of Scientific Publication"
August 14–17, 2013, Basel, Switzerland

*Thirteenth Annual Conference of European Society
of Criminology, Budapest, Hungary*

Beyond Punitiveness: Crime and Crime Control in
Europe in a Comparative Perspective
Petra Bárd organized and chaired the roundtable
discussion on an emerging EU criminal justice
and policy
September 5, 2013, Budapest, Hungary

*The First Conference on Tackling Health Inequalities
in Europe - Through Human Resource Capacity
Building: "Does the Higher Education System in
the EU Respond to the Need for Ethnic Minority
Sensitive Health Assistance?"*

Co-organized by the Medical School of the Univer-
sity of Pécs and the Open Society Foundation
Co-organizer and participant: Éva Földes
September 7, 2013, Pécs, Hungary



5. EVENTS AND ACHIEVEMENTS

A Roundtable on the Implications of the Snowden Leaks
Organized by the Human Rights Initiative, with the participation of Petra Bárd, Tamás Bodoky (Atlaszo.hu) and Kate Coyer (CEU CMCS)
See www.ceu.hu/event/2013-10-02/roundtable-implications-snowden-leaks#sthash.gIDfCOsH.dpuf
October 2, 2013, Budapest, Hungary

Le droit constitutionnel national aux prises avec le droit européen: l'exemple de la Hongrie [National Constitutional Law Dealing with European Law: The Example of Hungary]
Conference held at the Université de Strasbourg
Lecture by Petra Bárd on "L'évolution constitutionnelle récente de la République de Hongrie"
October 4, 2013, Strasbourg, France

Fourth European Conference on Health Law
Presentation by Judit Sándor "Access to Personalized Medicine and the Case of Angelina Jolie with the Genetic Test"
October 9–11, 2013, Coimbra, Portugal

European Health Forum Gastein
Participant: Éva Földes as expert invited by the European Commission
October 2–5, 2013, Bad Hofgastein, Austria

Disaster Bioethics
Workshop Conference "Veterans' Voices"
Participant: Péter Kakuk
October 14–17, 2013, Tel-Aviv, Israel

Conference on EU Accession to the ECHR
Lecture held by Petra Bárd on "The Foreseeable Changes in the ECtHR's EU Law Related Case-Law as a Consequence of EU Accession to the ECHR" at the Masaryk University in Brno
October 15, 2013, Brno, Czech Republic

Meeting of the Hungarian Skeptic Society
Public lecture held by Imre Szezik on "Ethical and Critical Remarks on Evidence Based Medicine"
October 15, 2013, Budapest, Hungary

Annual Conference of the Hungarian Society for Artificial Nutrition
Presentation by Imre Szezik on "Ethical Issues of Artificial Nutrition and Hydration"
November 8, 2013, Herceghalom, Hungary

Sixth European Public Health Conference
"Health in Europe: are we there yet?"
Participant: Éva Földes as Co-chair at the workshop "Novel Ways of Improving Roma People's Health: Collaborative National, Regional and European Strategies," organized by the Open Society Foundation's Roma Health Project
November 13–16, 2013, Brussels, Belgium

Lectures at the College of Religious Studies
Presentation by Imre Szezik on "Whose Birth Is It Anyway?"
November 21, 2013, Pécs, Hungary

NERRI project meeting
Participants Judit Sándor and Márton Varju
November 25–27, 2013, Barcelona, Spain



NERRI Project Participants in Barcelona

5.2. SCIENCE COMMUNICATION AND MEDIA EVENTS

The Director and Fellows of CELAB took part in many media events and science communication activities where they contributed to 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.

“Ethical Questions of the Diagnosis of Down Syndrome from the Blood Sample of the Mother” [A Down-kór anyai vérből való korai diagnosztizálásának etikai kérdései]

Interview with József Kovács by Dorottya Vizi
Radio Kossuth, “Közletről” Program
September 24, 2012, 16.00–16.45

“On placebo” [A placebóról]

Interview with József Kovács by Júlia Gimes
Radio Kossuth, “Tér-idő” Program
September 28, 2012, 14.15–15.00

“Ethical Questions Related to Animal Treatment [Az állatokkal való bánásmód etikai kérdései]

Interview with József Kovács by Júlia Gimes
Radio Kossuth, “Tér-idő” Program
October 5, 2012, 14.15–15.00

“Reproductive Rights” [Reprodukciós jogok]

Discussion with Judit Sándor by Júlia Nyári and Mihály Filó
Radio Q 99.5
November 17, 2012, 19.00–20.00

“From Cloning to Abortion: Bioethical Issues”

[Bioetikai kérdések a klónozástól az abortuszig]
Lecture by Judit Sándor in the Science Communication Course: Bioethical Issues
ELTE, Budapest, Hungary
April 26, 2013

“Courage or Privilege? Angelina Jolie’s Struggle with Breast Cancer” [Bátorság vagy kiváltság? Angelina Jolie küzdelme a mellrákkal]

Article by Judit Sándor
Magyar Narancs, Issue 2013/22,
magyarnarancs.hu/publicisztika/batorsag-vagy-kivaltság-84970
May 30, 2013

“Tens of Thousands of Frozen Embryos are Stored” [Több tízezer embriót raktározna lefagyasztva]

Article by Veronika Munk, interview with Judit Sándor
Index.hu, index.hu/belfold/2013/06/25/tobb_tizezer_embriot_raktaroznak_lefagyasztva/
June 25, 2013

“The First Design Baby was Born” [Megszületett az első dizájnbébi]

Article by Zoltán Ötvös, interview with Judit Sándor
Népszabadság, nol.hu/tud-tech/20130711-megszuletett_az_első_dizajnbebi
July 11, 2013

“Ethical Issues Related to Designed Babies” [A „designer-baby” (a gyermektervezés) etikai kérdéseiről]

Interview with József Kovács by Dorottya Vizi
Radio Kossuth, “Közletről” Program
July 17, 2013, 16.00–16.45

“Would You Pull the Trigger? An interview on Euthanasia” [Ön meghúzná a ravaszt? Interjú az eutanáziáról]

Interview with József Kovács by Anna Danó
Népszabadság, nol.hu/archivum/20130717-on_meghuzna_a_ravaszt_
July 17, 2013

“Gene-Revolution: Do We Really Want to Know until When We Will Live?” [Génforradalom: Akarjuk-e tudni, meddig élhetünk?]

Interview with Judit Sándor by Viktória J. Kun
Vasárnapi Hírek, Issue 31, pp 6–7, www.vasarnapihirek.hu/fokusz/genforradalom_akarjuk_tudni_meddig_elhetunk
August 4, 2013

“From Two Parents: One or Three?” [Két szülőből egy vagy három?]

Interview with Judit Sándor by István Palugyai
Népszabadság Hétféje (Weekend edition),
http://nol.hu/lap/hetvege/20130810-2-szulobol_1_vagy_3
August 10, 2013

5. EVENTS AND ACHIEVEMENTS

“Brain Dead Woman Gave Birth to a Healthy Child in Debrecen” [Agyhalott nő szült egészséges babát Debrecenben]

Interview with Péter Kakuk

Origo.hu, www.origo.hu/egeszseg/20131113-agyhalott-no-szult-debrecen-transzplantacio-donacio.html

November 13, 2013

“Baby Born To Brain-Dead Mother Three Months After Woman’s Brain Death” [Három hónapja agyhalott nő szült egészséges babát]

Talk with Judit Sándor, József Kovács

ATV, “Friderikusz” Program,

www.atv.hu/videoek/video-20131120

November 19, 2013

Fagyálló a borba, áram a kerítésbe – miért nem jogos védelem? [Antifreeze in the Wine, Electric Current in the Fence – Why Is It Not Rightful Self-Defence?]

Article by Dávid Lakner, interview with Petra Bárd *Vs.hu*, vs.hu/fagyallo-borba-aram-keritesbe-miert-nem-jogos-vedelem-1204

December 4, 2013

“On the Hungarian Working Group of the Cambridge Consortium on Bioethics Education (BOMM)” [A Bioetika-oktatás Magyarországi Munkacsoportja (BOMM)]

Article by Péter Kakuk and János Kristóf Bodnár *Lege Artis Medicinae (LAM)*, 2013; 23(3–4): 224–225.

5.3. PUBLICATIONS

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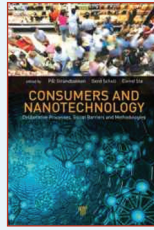
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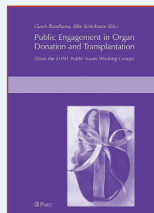
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5.4. AWARDS, APPOINTMENTS

In 2013 *Petra Bárd* became supervisory board member of the Eötvös Károly Policy Institute, she has been reelected as supervisory board member of the Hungarian Europe Society, she became member of the Society of Hungarian Lawyers for European Criminal Policy and the Codification Working Group of the European Society of Criminology. She continues to be a member of the Hungarian Society of Criminology as well.

Petra Bárd has also been invited to the CEU Research Ethics Committee; she prepared a recommendation on data protection for CEU researchers and wrote a draft of CEU's disability policy together with MDAC Director Oliver Lewis as pro bono contributions to her alma mater.

In 2012, *Violeta Beširević* was awarded a Fulbright stipend and spent the fall semester of 2012/2013 at the NYU School of Law as a Global Research Fellow

where she worked on the research “The Politics of Constitutional Courts” with a faculty mentor, Stephen Holmes, Walter E. Meyer Professor of Law.

Péter Kakuk was awarded the Magyary Zoltán Postdoctoral Scholarship for conducting a research project that has a clear educational output. The project focuses on ethical issues that challenge the integrity of the life sciences: issues of authorship and publication ethics, the regulation of financial conflict of interests and scientific misconduct.

Péter Kakuk was appointed as editor of *Meditor*, a Hungarian journal of applied ethics, and elected as Member in the Council of the School of Public Health, Member in the Council of the Medical and Health Science Centre, and Member in the Clinical Ethics Committee, Medical and Health Science Centre, University of Debrecen.

5. EVENTS AND ACHIEVEMENTS



József Kovács receives the Semmelweis Award

József Kovács was awarded the Semmelweis Award, which is conferred to those personalities who have achieved exceptionally high quality results in the field of health care, the prevention or treatment of diseases, or whose work has contributed to such results.



CELAB End of Year Lunch, December 2012

Márton Varju was appointed as convenor of the Hungarian Academy of Sciences Lendület-HPOPs Research Group on the policy opportunities of Hungary in the European Union (for further information, see jog.tk.mta.hu/en/lendulet-project-summary).

6. BUDGET

6.1. REVENUES IN AY 2012/2013

Approved Budget from CEU	Amount in Euro
C-5036 Total	55,739

External Funding	Amount in Euro
NERRI project	6,504
Total	6,504

The total funding for NERRI 2013-2016 is 175,362 EURO.

6.2. SPENDING IN AY 2012/2013

C-5036 – CELAB MAIN BUDGET CODE

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

E/R/FP7/10170– NERRI PROJECT

Budget category	Amount in Euro
Personnel costs	5,280
Other costs	1,224
Total	6,504

