Judit Sándor*

Center for Ethics and Law in Biomedicine, CEU (Budapest, Hungary)

CELAB is not just an Acronym. It represents the Center for Ethics and Law in Biomedicine in Budapest and it embraces manifold activities conducted by lawyers, philosophers, anthropologists, ethicists and other social scientists in the Center. In 2005 the idea behind establishing CELAB was related to the recognition of a new and increasingly developing interdisciplinary field: the ethical, legal, and social implications of biotechnological advances. Life sciences, especially biomedicine, traditionally focused on the restoration of health and 'normality'. However, entering the age of the human genome project, biobanks, stem cell research, and nanotechnology the role of biomedical science has shifted toward the purposeful transformation of various human capacities. For instance, while the new reproductive technologies could overcome some problems of infertility, they also pose new questions of what sexuality, gender, and kinship mean in our contemporary societies. We also have to realize that the technologies of genetic testing and preimplantation diagnosis allow for enhancement. And all these changes force the various social sciences and the practice of governance to rethink decision-making in science policy, the way resources are allocated, and the ethical and legal concerns related to the various uses of genetic data. Our Center has focused on these issues in the framework of different European research projects funded by the European Union, European Science Foundation and by UNESCO.

Our first year of operation (the 2005-2006 academic year) was dedicated to setting priorities, developing networks and creating a biomedical-legal database. In the sec-

* Director of the Center for Ethics and Law in Biomedicine, Professor at the Central European University, Budapest, Hungary.

ond year we submitted numerous applications to various research grants, and within a short time we started two new research projects. During our third year of research activities, the network of CELAB partners, associates and collaborators have become truly international, which is accentuated by our participation in five European research projects. Our small research team has been consequently expanded, and together with our new colleagues and research associates, we are working on a wide range of academic and administrative tasks. Regardless of this necessary institutional expansion, our staff has been able to preserve its original enthusiasm to work in the exciting cross-disciplinary domain of biomedical law and ethics.

CELAB works on the national, regional, and international levels. In European research consortia knowledge about the Hungarian and Central European legal system is often required while it is also essential to be familiar with other European legal and ethical approaches. Nevertheless, as international research projects have become increasingly global in their scope, we have also developed a wider comparative perspective in our work that includes studies of North American and East Asian legal and ethical discourses.

Moreover, we seek to integrate the results of these research projects into our academic teaching curricula. Therefore, we have organized workshops and seminars, film screenings and policy debates that are open to the CEU community and beyond. We also participate in legal policy development activities and provide research tools for the international scientific community. For instance, in 2007 we launched the new version of the Biolaw Database that makes it possible for researchers and students to study legal instruments and ethical norms in the field of biomedicine and biotechnology more systematically, or just to learn about the possible directions of future comparative research. In addition, we update our CELAB website on a daily basis.

At the beginning of 2008 we received a UNESCO grant. Within less than a year we completed a very ambitious project: the promotion of implementing the three bioethics-related Declarations of UNESCO in five countries – Croatia, the Czech Republic, Italy, Hungary, and Serbia. This project required legal policy work but it also gave us an opportunity to develop and reaffirm further professional contacts in the region with similar centers and scholars. As a result, CELAB published a series of booklets in five languages and organized a workshop with lectures and panels to discuss the possible methods to implement these instruments in teaching and to influence national legislation in the field of bioethics and related human rights. Although the working language of CELAB is English, this UNESCO funded project gave us the opportunity to learn about different cultural approaches to working in the field of bioethics and human rights.

Since 2007 we have also participated in the Francophone network of biomedical lawyers. This network, which has been expanded since its establishment, currently works on several thematic issues of bioethics and biomedical law and in each interdisciplinary workshop panel the participants seek to explore and understand the cultural differences behind the formulation of various bio-legal norms. The first workshop in Rennes, organized by Professor Brigitte Feuillet-Liger, was a big success and the first publication of the network on Assisted Reproduction and Anonymity has been already published. The next workshop of the network was held in Kyoto in 2009 and focused on the bioethical problems in the field of health care provided to adolescents. The third theme will elaborate the ethical issues of the death and dying with the family.

The EU project that is perhaps in the most advanced stage is called *PRIVILEGED* (Privacy in Law, Ethics and Genetic Data). The aims of this project were to make recommendations for research practice and public policy-making, including regulatory options at the national, regional, and European levels. PRIVILEGED has sought to identify, analyze and compare plural ethical, cultural, and social concepts of legitimate privacy interest engaged by research using genetic databases and biobanks. It articulates the relation between such concepts and the current regulation of research using genetic data and biobanks. PRIVILEGED focuses on the various privacy interests, particularly grounded within intimate and familial relationships in various research areas, especially in the so-called biobanking applications. This is a mega-project in which representatives of no less than thirty-two universities participate, among them not only European experts but also lawyers from Japan, Taiwan and Israel. As part of the project, two major reports have already been submitted.

The second project focuses on the governance of the so called gene-banks and the European legal and ethical framework to regulate their activities (Acronym: *GeneBanC*). Our team focuses mainly on the cases of countries that joined the European Union in 2004, most of which have not adopted legislation or guidelines in the field of classical biobanks, or have done so relatively recently without extensive experience.

In 2008 we started our third research project in this field, *TISS.EU*, mobilizing the resources of ten universities in Europe. The major aim of this project is to carry out a high-quality interdisciplinary comparative analysis of European health policies in order to assess the impact of EU legislation and to explore the relevant ethical and legal situation across the European Union. The first TISS.EU project meeting was held in Göttingen, Germany and focused on the ethical and legal challenges to conduct research on human tissues. Our Center organized the next workshop in Budapest in 2009.

Another EU funded project, *NANOPLAT* (Framing the Deliberative Process on the Responsible Development of Nanoscieneces and Nanotechnologies) also started in 2008, focusing on 'deliberative processes' in nanotechnology because these may be seen as useful, although possibly highly problematic regulatory forms supplementing democratic mechanisms. On the other hand, the conceptual shift from 'government' to 'governance' might allow for more participatory forms of shaping public policy.

The fifth EU funded research project we participate in is *RemediE* (Regenerative Medicine in Europe: Emerging Needs and Challenges in a Global Context). This project focuses on the present and future role of regenerative medicine in the health care industry, especially on the relevant intellectual property rights and patent issues. Therefore, the contributors to this project will explore and analyze international and regional policies regarding the patentability of living organisms, human genes and stem cells, as these are highly critical areas of research where market interests and ethical concerns frequently collide.

The academic year of 2008–2009 was a very intensive period for the Center for Ethics and Law in Biomedicine (CELAB). We participated, simultaneously, in five European Commission funded research projects (GeneBanC, NANOPLAT, Privileged, RemediE and the TissEu), and contributed to three more EU projects as consultants. In addition to working on these European programs, CELAB also completed a UNESCO financed project on the implementation of the three bioethics declarations in five countries of the wider Central European region (Croatia, Czech Republic, Hungary, Italy, and Serbia).

Among the EU sponsored research projects, perhaps one of the biggest achievements was to complete and publish a comparative survey of the available legal regulations of biobanks in eleven European Union member states (Cyprus, Czech Republic, Estonia, Greece, Hungary, Italy, Latvia, Lithuania, Malta, Poland and Romania). Research within the GeneBanC project required the application of interdisciplinary methods: collection of data through desk research, compiling and administering detailed questionnaires, conducting fieldwork and interviewing relevant experts in the region.

In addition to the fields in which we had conducted research before, we have developed expertise in some new research areas, such as the social-ethical aspects of nanotechnology and the intellectual property aspects of regenerative medicine.

Participation in the NANOPLAT project prompted us to accumulate knowledge on the recent advances in nanotechnology, even outside of our traditional research interest in the ethics and law of life sciences. This short but very intense project fo-

cused on the deliberative processes in shaping the contours of policies in the field of nanotechnologies.

In 2008 we started to work on another new topic within the framework of the RemediE project, which lies at the intersection of ethics and biotechnology. The emergence of biotechnology and the extension of the scope of patent rights have by now become a public concern. From genes through genetically modified plants and animals to human cells, each stage of accretion of patentability in this arena has been contested. Much of this opposition arises from cultural concerns about the moral appropriateness of property rights being applied to living, especially to human-derived cells. Because of these ethical controversies, this EU funded research project gives us an opportunity to understand the process in which biotechnological research becomes increasingly commercialized and lucrative new markets for technological advances are created.

The workshop CELAB organized in the framework of the TissEu Project was a successful event as the international experts invited analyzed a new and often misinterpreted perspective on biobanking: the questions of tissue anonymization.

During the last academic year, we also participated as consultants in several other EU projects, namely *From GMP to GBP* (From GMP to GBP: Fostering Good Bioethical Practices (GBP) in the European Biotech Industry), *NMD–Chip* (Development of Targeted DNA Chips for High Throughput Diagnosis for Neuromuscular Disorders) and *BBMRI* (Biobanking and Biomedical Resources Infrastructure).

I am very grateful to be able to work in such an inspiring field and with motivated colleagues.