

ENLSC

European Network for Life Sciences, Health and the Courts

NEXT EVENTS

- **[First International Conference on "Intellectual Property and Technology Transfer in Life Sciences: A North-South Dialogue"](#)**, 12th – 14th June, 2006
The First International Conference on "Intellectual Property and Technology Transfer in Life Sciences: A North-South Dialogue" will be held on 12-14 June 2006 at the Congress Centre of the Trieste [AREA Science Park](#). The Conference is co-organised by CIP, Center for Intellectual Property Studies (<http://www.cip.chalmers.se/>), CEI, Central European Initiative (<http://www.ceinet.org/home.php>), ICGEB, The International Centre for Genetic Engineering and Biotechnology (<http://www.icgeb.org/index.htm>), ENLSC, European Network for Life Sciences, Health and the Courts (www.unipv.it/enlsc).
- **Symposium "Biotechnology and Law"**, on June, 16th – 17th 2006, Istanbul, (Turkey), [Kadir Has University](#) – Organised by Prof. Dr. Tekin Memis – Coordinated by Prof. Dr. Jürgen Simon, Cristina Blohm-Seewald, M.A.
- **The Spanish Consejo General del Poder Judicial, approving the Comisión de Escuela Judicial's proposal, has planned the course *Ciencias de la Vida y el Derecho*, Madrid (E) on September, 25th, 26th, 27th 2006.** Coordinators: dr. Javier Hernández García and dr. Amedeo Santosuosso.

★ ***Scientific research: never ending challenge or dangerous option?***

Looking at the big picture of science and law in Europe one issue seems to gain the headlines: freedom of scientific research. The EU as a whole seems to be impaired by a misinterpreted concept of human dignity. However, dignity and human dignity are elusive concepts. Thus, the question of *what* dignity is and *how* to define it turns into constitutional terms and becomes: *Who defines dignity?* Political or religious institutions, physicians or anybody else? We cannot forget that if dignity encompasses liberty, then whoever defines dignity has in reality the power of limiting liberty.

But we believe that *dignity cannot survive without freedom*. So, from a totally different point of view, curtailing scientific inquiry needs stronger and more specific arguments than that of human dignity. This general and comprehensive principle, in fact, can be assumed as an umbrella to explain and protect other general principles and human liberties. But one of these general liberties is just scientific freedom whose limitations may be found in the principle *not to harm others*: "the principle requires liberty of tastes and

pursuits; of framing the plan of our life to suit our own character; of doing as we like, subject to such consequences as may follow; without impediment from our fellow-creatures, so long as what we do does not harm them even though they should think our conduct foolish, perverse, or wrong” (John Stuart Mill, *On Liberty*).

Otherwise, several Constitutions have specific provisions on scientific freedom. It seems to us that the proclamation of scientific freedom in Europe looks like a sample of *rights stemming from the wrongs* of Nazism. However the ghost of Nazism cannot fairly be used as a master-key to curtail the freedom of scientific research today especially if we believe that the rights of individuals involved in research activity must always be respected. However, a problem arises when powerful institutions, who act as monopolists of dignity, are against both the scientific research in critical areas (mainly embryonic stem cells research) and the autonomous decisions of the individuals in life and death matters. Notwithstanding, some countries like UK and Spain are moving faster in promoting and improving scientific research, even in the light of not violating any fundamental constitutional liberty.

I believe that science and the law in all countries and geographical realities do not have the same mutual relationship and the same place in society, but jurists and judges may find an important role in such controversial issues, even coming from different legal and social realities. The [Rome conference](#) was an important occasion to discuss in depth the reasons for and the possible limitations of scientific research and, most of all, the role that scientific, political and legal institutions may have. I think that the network ENLSC should dedicate more attention and time to the issue in order to understand why some European countries strongly affirm the freedom of scientific research while posing several and quite unreasonable limitations to its concrete practice. How can we believe that the unquestioned principle of *human dignity* may be violated by scientific research when it turns from theoretical observation into practical manipulation, when it is clear that science in itself cannot be just theoretical thinking, but it aims to modify and improve man’s environment?

Valentina Sellaroli
Prosecutor in the Juvenile Court –Torino (I)
ECLSC – University of Pavia (I)
valentina.sellaroli@giustizia.it

★ [European seminar *Hot genetic issues and the Courts* – 7th – 10th September 2005 – Pavia](#)

The science-law dialogue found an important step forward in the first international seminar for judges and prosecutors from thirteen different European countries which was held in Pavia, 7th – 10th September 2005. For the first time at such an institutional level (the seminar was co-organized with the Italian *Consiglio Superiore della Magistratura* - Judicial Superior Council), twenty-three European judges and prosecutors spent four days in the Developmental Biology Laboratory of the University of Pavia, shared the language (English) and, according to the ENLSC’s formula (*hands-on-lab* and *legal labs* activities) discussed in depth hot science-law issues such as stem cells, cloning proceedings, intellectual property rights and biotechnology, genetic data collecting and proceeding, DNA fingerprinting in criminal investigations and so on. A relevant novelty was the *press lab*: a widely socially debated scientific issue was presented by Alison Abbott (Nature) and Ananda Chakrabarty (University of Illinois in Chicago), so highlighting the correct perception and the possible misunderstanding in divulging scientific arguments.

Bringing a group of judges from such different European countries out of their usual context represented a real added value. They had a chance to overthrow their attitudes towards scientific issues and way of reasoning. Moreover, comparing different legal systems with a *case by case* approach clearly showed how judges really *make* law, also in civil law systems.

The highly active participation of the European judges and prosecutors, their enthusiastic comments regarding the [format](#) and the arguments of the seminar, the increasing interest that the participants and

some of their national scientific and judicial institutions showed towards the ENLSC's activities are the key to understand the success of this formula which was created from the first ENLSC's experiences in order to really make the European and international science-law dialogue easier and useful.

★ ENLSC in the Western Balkans

Following up the previous ENLSC's initiative in the region of Central-Southern Europe in 2004 (*"The social and cultural implications of genetics and the legal regulation. A dialogue East-Western-South Europe"*) the project carried on in 2005 aimed at improving and completing the 2004 experience in two directions. After getting into the state of the art and the needs of scientific and legal communities in countries like Serbia-Montenegro, Macedonia and Albania, the project aimed to understand the state of the art in other countries from the Balkans area such as Bosnia-Herzegovina and Croatia in order to tailor the contents of the activity to local needs. However the most important aim of the 2005 program was to start closer and more stable interactions between judges, jurists and scientists from the countries of the former Yugoslavia and the sub-region as a whole, that have shared the same political system for a long time. In order to take substantial steps forward, the 2005 activities were divided into three seminars, namely:

- *Two preparatory workshops:*

- *Pola (Croatia), 29th – 30th September, 1st October 2005*

- *[Belgrade and Valjevo \(Serbia-Montenegro\), 3rd – 5th November 2005](#) (see the program)*

aiming to select the participants for the final seminar and to define its topics, identifying the specific local interests and the accessible resources (availability of technical investigation methods, institutional framework for further scientific developments, etc.).

- *[The conclusive 1st International Seminar for judges from Serbia-Montenegro, Macedonia, Croatia and Bosnia Herzegovina on present-day biological issues – Life Sciences and the Courts in the Western Balkans – Genetics and its applications in the sphere of justice, in Sarajevo \(Bosnia-Herzegovina\) 17th – 19th November 2005.](#)*
(see the program)

The participants enjoyed the ENLSC theoretical-practical approach, had good opportunities to get in touch with the reality of scientific labs and discussed many cases from different countries on the edge of science and law.

The high number of participants from all the countries involved in all three seminars and the real interest that they showed towards all the issues dealt with represent a really good result. More comprehensive and stable projects, in co-operation with local scientific and legal partners and international institutions, are now in progress.

★ SWISS NATIONAL ETHICAL COMMITTEE'S REPORT ON EMBRYOS AND FETUS RESEARCH

The national Swiss board for ethics in medicine (a branch of the national Swiss ethics commission), dated January 2006, published the guidelines named "[Research on human embryos and fetuses](#)".

The whole document, also available in German and French, can be read in an abbreviated version in Italian and English. The forefront part of the document highlights some basic principles that inspired the suggested decisions on this sensitive matter, and this is the most relevant point of the document. It deals with the procedures that must be taken into account when gametes, embryos and fetuses (both in utero and extra utero) and embryonic stem cells are involved in bio-medical researches. Interestingly enough, while prohibiting the de novo generation of human embryo by somatic cells nuclear transfer techniques it makes a clear point on the ethics of making use of spare embryos to derive human embryonic stem cell lines. Several specific and punctual considerations, regarding the generation of parthenotes and androgenotes, deserve to be carefully considered. In fact, these techniques are prohibited, but the ethical principles which the prohibition refers to are not moral assumptions, concerning the nature of the embryos. They rather refer to the possible risks for the women's health (finally, oocytes must be available). The document is well set out and organized and it is also quite exhaustive so that the reader (even lay

people) can understand in depth the complex discussion occurred until September 2005 (deadline of the working group) and can appreciate the different opinions time by time expressed by each of the members of the commission, concerning all the issues at stake.

Silvia Garagna
ECLSC – University of Pavia (I)
silvia.garagna@unipv.it

★ **WORLD CONGRESS FOR FREEDOM OF SCIENTIFIC RESEARCH – ROME (I), February 16TH – 18TH, 2006**

The first meeting of the World Congress for Freedom of Scientific Research took place in Rome at the Campidoglio on February, 16th to 18th 2006. During the meeting emerging threats against research were discussed in order to indicate proposals and initiatives to counter them and the idea of the World Congress as a permanent forum to debate and exchange analysis, ideas and calls for action was launched. The issues debated concerned Science, Society and Politics, Science, Ethics and the Ethics of Scientific Research, Science, Technology and Economy, Stem Cell Science and Policies, Science and Law. Among participants, the *Hon. Janez Potocnik*, European Commissioner for the Advancement of Science and Medical Research, *Michael Gazzaniga* (US President's Committee on Bioethics), *Michael Sandel* (Professor at Harvard), *Colin Blakemore* (Executive Director of the UK Medical Research Council), *Bernat Soria* (Director of CABIMER, Andalusian Center for Molecular Biology and Regenerative Medicine, Sevilla, Spain), *Hon. Philippe Busquin* (former EU Commissioner for Science and Research), *Emma Bonino* (MEP, Former EU Commissioner Consumers Policy), *Dan Perry* (Vice-President, American Coalition for the Advancement of Medical Research), *Amedeo Santosuosso* (Judge and President of ECLSC), *Charles Baron* (Boston College, Law School), *Fabio Marazziti* (University of Bergamo), *Demetrio Neri* (Italian National Bioethics Committee). Before the conference there was preliminary workshop, held in Bruxelles, November 9th – 11th 2005. Related materials and a video of the whole conference are available on the website of the [World Congress for Freedom of Scientific Research](#)

★ **“AUSTRALIA ‘WELL PLACED’ TO LEAD WORLD IN PROTECTING HUMAN GENETIC INFORMATION”**

Australian Law Reform Commission (ALRC) President Professor David Weisbrot said he was “delighted with the Government's positive and comprehensive response to the ALRC/Australian Health Ethics Committee report, *Essentially yours: The protection of human genetic information in Australia*. The report, released in 2003, was hailed as the bible of human genetics protection. After the report, a new [Human genetics advisory committee](#), has been recently appointed.

So, Australia shows us how to be ready to face up to the new challenges of the post-genomic era: the report clearly assumes that the recommendations given about how Australia should deal with the ethical, legal and social implications of new genetic technologies, are not an end to these matters: they are just the right starting point for all the work still to be done, in order to create a correct and sufficient policy platform for all of these issues.

★ **ASSESSMENT OF PATERNITY AND RELATIVES' RIGHT TO PRIVACY**

According to Texas (U.S.) family code, that was first to enact in 2002 the [Uniform Parentage Act](#), paternity can be established in three ways: presumption, acknowledgment and adjudication. With the last of these a genetic test may need to be done, in order to assess who the father is. “For good cause, the court may order genetic testing on the parents, siblings, or other children of a man who may be the father of a child. (A “fatherless draw”). [TFC § 160.508]. For good cause, the court may order genetic testing of a deceased person. [TFC § 160.509]. If a man has an identical twin brother, the court

may order testing on both. If the genetic tests cannot determine which brother is the biological father of the child, the court may rely on non genetic evidence to determine paternity. [TFC § 160.510]”.

It seems to us that the issue deserves to be carefully discussed: could it be thought of as a possible unfair infringement of an individual's right to privacy? Do the parents, siblings or other children of the presumed father fairly have the duty to “discover” their personal data while they are not directly involved in the proceeding? What type of conflicts could arise from such questions and how could they be solved by the judge? Or, under a different respect, is there a scientific answer to this question: for example, could it be possible to select the kind of information to be showed by the relatives' DNA sample?

In some other countries questions such as these are not possible at all, as judges are not allowed to order genetic testing in case of the subject's refusal.

PLEASE, SEND US YOUR COMMENTS OR PERSONAL AND NATIONAL EXPERIENCES ABOUT THIS ISSUE.

We will be very happy to open a straight debate about this.

NEWS & VIEWS

★ *“Stem cells kit”: new brand gift for UK newborns*

An interesting [article](#) appeared in the Italian newspaper *Corriere della Sera* speaks about the increasing business in the UK of the extraction and collecting of cord blood in order for it to be stored and cryopreserved for future use. The whole proceeding costs about 2000 euros and the cord blood is guaranteed, by private bio-banks, to be preserved for 25 years. The journal suggests that British parents are more and more frequently buying this kind of service kit (for around 200 a month,) for the future health of their newborns.

In some other European countries, such as Italy, this could not happen: in fact, it is not allowed to buy or use these kind of biological materials privately, but they can be donated.

★ *“Click'n'clone”*

Just kidding or an easy way to talk about cloning without prejudice, too many expectations or worries?

★ *“It may look authentic...”*

Scientific frauds in the digital and photo-manipulation age. An [article](#) by George Ruhe for New York Times analyzes the most famous and recent cases of image manipulations and the means used by scientific reviews in order to catch the fraudsters.

★ *“Almost perfect crimes...”*

Three articles published by the Italian magazine “Il Sole 24ore” reveal lights and shadows of DNA and the new technologies in forensic sciences. How [DNA fingerprinting](#), [low stringency searches](#) and [forensic databases](#) can help criminal investigations in finding the guilty or proving someone's innocence. Science and technologies run fast and legal systems have to find the way to correctly balance public security and the fundamental rights of the individual. Some European countries stipulated an [agreement](#) in order to let national police enforcement straight and directly exchange information, DNA profiles and fingerprints for criminal investigations. In the meanwhile, some other countries (like Italy) do not have a DNA forensic database, yet. What perspectives or possible consequences may such a context have?

★ *“Genomics and Criminal Justice Special Issue – The [Genomics, Society and Policy Journal](#) free, online and open access. The journal provides an outlet for interdisciplinary research on the social, ethical and legal aspects of genomics and related emergent technologies such as nanotechnology and stem*

cell research. Issue 3 of Genomics, Society and Policy is now available on www.gspjournal.com. Issue 4 will be a Special Issue on the theme of Genomics and Criminal Justice. For more details and for submissions see the website

★ **Italy: Podcast Radio3 Scienza:** since February 2006, Radio 3 Scienza is available also on Podcasting. Every week the files containing the radio magazine issues will be available. They can be downloaded on the website or on the Radio 3 podcast by a free submission. For any further information see the website <http://www.radio.rai.it/radio3/podcast/podcast.cfm>

★ **“CASE OF EVANS v. THE UNITED KINGDOM”** :an interesting [judgment by the European Court of Human Rights](#) stated that: “in the absence of any European consensus on the scientific and legal definition of the beginning of life, the issue of when the right to life begins comes within the margin of appreciation which the Court generally considers that States should enjoy in this sphere. Under English law, as was made clear by the domestic courts in the present applicant’s case (see paragraphs 16 and 21 above), an embryo does not have independent rights or interests and cannot claim—or have claimed on its behalf—a right to life under Article 2”.

★ **REVIEWS:** the 2005 issues of the International Journal of Bioethics will be respectively devoted to Japan (issue 1-2) and Russia (issue 3-4). The 1st issue of 2006 will be devoted to biotechnology and biosecurity.

★ **CONFERENCES:** the International Association of Law, Ethics and Science will organize

- In Paris, on 5th – 6th May 2006, a workshop on plant and animal genomics in European Union.
- In Bucharest, on 16th – 18th November 2006, the 2nd International Bioethics Conference of French speaking countries on Bioethics, Universalism and globalization.

CALL FOR THE NEWSLETTER

★ Editorials and commentaries on news simply reflect the point of view of the authors. The ENLSC wants to offer a site for an informal and open discussion.

Please, feel free to send any kind of comment, reply or opinion about the issues discussed above. Your contribution is essential for the development of the network.

Please write to

valentina.sellaroli@giustizia.it

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How to contact us

European Network for Life Sciences, Health and the Courts (ENLSC)

- University of Pavia – Laboratory of Development Biology
Piazza Botta 9 – 27100 Pavia (I)
- Collegio Ghislieri, Piazza Ghislieri 5 – 27100 Pavia

E-mail: newsletter.enlsc@unipv.it

Tel. + 39 0382986306
Fax + 39 0382986270

The ENLSC*letter* is edited by Valentina Sellaroli: valentina.sellaroli@giustizia.it

Graphic design by Valentina Sellaroli.

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