

European Network for Life Sciences, Health and the Courts - ENLSC

Serbia-Montenegro and Macedonia

The 1st International Course for judges from Serbia, Montenegro and Macedonia (title: *Judges confront Genetics. Genetics and its applications in the sphere of justice*) will be held in Belgrade July 7th-9th, 2004. The course is organized by ENLSC with the support of the Central European Initiative (<http://www.ceinet.org/>) and in collaboration with the Ministry of Science in Belgrade, the Ministry of Justice in Belgrade and the ICgeb, Trieste (<http://www.icgeb.trieste.it>).

Seminars on case-law about life sciences (Milan, I)

After the Five conferences The Techniques of Biology and the Tools of the Law (March-May 2003: see www.unipv.it/BIOL/ENLSC.html), a new round of seminars on case-law about life sciences has been planned for 2004 (May-October) at the Justice Palace in Milan. The following issues will be discussed:

Thursday 13th May 2004

The *Sergeant* case: genetic testing and the right to privacy

Thursday 27th May 2004

The case of the sick sister: access to shared genetic data.

Thursday 10th June 2004

The *Miss B* case: Amiotrophic Lateral Sclerosis (ALS) and withdrawal of ventilation

Thursday 7th October 2004

The *Dobbiaco* case: DNA fingerprinting and criminal investigations involving population

Thursday 21st October 2004

The NIMBY (*not in my backyard*) syndrome: regarding GMOs

The seminars are organized by ENLSC (University of Pavia) and the University of Milano (Law Faculty).

Albania

The 1st Course for judges from Albania (title: *Genetics and Justice. A theoretical/practical approach*) will be held in Tirana, in October, 2004 (date to be confirmed). The course has been organized by ENLSC and the *Shkolla e Magjistratures se Republikes se Shgiperise*: <http://www.shkollaemagjistratures.org/>), with the support of the Central European Initiative (<http://www.ceinet.org/>).

A dialogue the South, East and West of Europe

"The social and cultural implications of genetics and the legal regulations: a dialogue the South, East and West of Europe" is the issue of the international conference that will be held in Pavia, November 19th - 20th, 2004. The meeting has been organized by ENLSC.

New educational programs in cooperation with ENLSC

The organization of further programs in cooperation with ENLSC in Spain, Switzerland and Chile is in progress.

The volume Science, Law and the Courts in Europe.

The volume *Science, Law and the Courts in Europe*, by A.Santosuosso - G.Gennari - S.Garagna - M.Zuccotti - C.A.Redì (eds) collects the papers of the International seminar *Science before the Courts*, 3rd - 4th June, 2003 (see **ENLSCletter** n.2, www.unipv.it/BIOL/ENLSC.html).

You can order the book writing directly to the publisher (ibisedizioni@galactica.it).

News & views

European Data Protection Working Party: Working document on genetic data (17 march 2004)

The working document adopted, on 17 March 2004, by the independent European advisory body on data protection and privacy that was set up under Article 29 of Directive 95/46/EC is incredibly interesting but does not come unexpectedly: http://www.europa.eu.int/comm/internal_market/privacy/docs/wpdocs/2004/wp91_en.pdf.

The Working document is the first practical comprehensive attempt to approach the problems arising from the use of genetic data. These problems are well known by judges, citizens and public institutions. Just think about some "classical" topics such as the problem with the "definition of scientific concepts in terms of law".

On the other Hand, new very difficult aspects are brought to the attention both of social awareness and of law-makers.

Among the most relevant issues:

- a. the reference to the biological group, a "group of related individuals", as a specific subject of rights and a "new legally relevant social group" and its correct definition in biological terms;
- b. the attempt to find criteria for a proper use of genetic data and to find the areas in which these data are more "sensible", with the relative rights to know (or not to know) them;
- c. the possibility of "exceptional cases" in which the processing of genetic data can be authorised in the employment and insurance fields.

All these issues are worthy of being discussed in depth in the light of their heavy social impact.

Bioethics in Paris

The ENM (*Ecole Nationale de la magistrature*) dedicates itself to bioethics issues and the course planned for November 22nd-26th, 2004, in Paris. The scientific director is Christian Byk, who is now in charge of the annual national bioethics training programme of the *Ecole Nationale de la magistrature*. The course was announced in the volume *Science, Law and the Courts in Europe*, by A.Santosuosso - G.Gennari - S.Garagna - M.Zuccotti - C.A.Redì (eds), p.22, and is now clearly presented in the ENM website as follows:

Bioéthique et droit - Société et questions contemporaines

« Les progrès intervenus depuis quelques années dans le domaine des sciences posent aux chercheurs, aux médecins, aux juristes et d'une façon plus générale à tous les citoyens des questions nouvelles et graves qui peuvent se résumer ainsi : Les droits de l'homme sont-ils renforcés ou menacés ? Parmi les thèmes évoqués : - l'utilisation du corps humain (prélèvement d'organes en vue de greffe, essais sur l'homme), - les débuts de la vie (assistance médicale à la procréation et filiation, embryon humain), - les tests génétiques (médecine prédictive, empreintes génétiques et procédures judiciaires), - les nouvelles thérapies (point sur les thérapies géniques, eugénisme, protection du sujet), - la mort (la médecine et le respect de la mort, euthanasie, la mort et le droit, jurisprudence), - la responsabilité (de la faute au risque, évolution du droit de la responsabilité en fonction de l'évolution des techniques, aléa thérapeutique), - l'expression de l'éthique en France et à l'étranger, les comités. »

(http://www.enm.justice.fr/formation_continue/actions/detailaction.asp?numaction=1092)

 **The previous issues of the ENLSCletter are available at**
www.unipv.it/BIOL/ENLSC.html

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