



GENINFO

Newsletter on the Ethical, Legal and Social
Issues in Human Genetics

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January-February 2007



It is already the New Year! 2006 has been a productive year for GenInfo: our readership has grown by 26% in the last 15 months.

The whole HumGen team joins me in wishing everyone peace, health, happiness and success in the coming year.

We are pleased to have you as a reader.

Emmanuelle LÉvesque, Editor-in-Chief

EDITORIAL



LAWS AND POLICIES NEW DOCUMENTS

INTERNATIONAL / REGIONAL

International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH): Draft Consensus Guideline - Terminology in Pharmacogenomics

Geneva - October 25, 2006

Link: [URL](#)

Key Words: Communication of Results - Confidentiality - Consent - Data - DNA - Pharmacogenomics - Privacy - Research - Researcher - Right of Withdrawal

International Society of Nurses in Genetics (ISONG), National Society of Genetic Counselors (NSGC): Provision of Quality Genetic Services and Care: Building a Multidisciplinary, Collaborative Approach among Genetic Nurses and Genetic Counselors
Newton - November 1, 2006

Link: [URL](#)

Key Words: Adult - Community/Population - Counseling (general) - Education - Educational Institution - Family - Genetic Services - Insurer/Insurance - Liability - Man/Paternity - Minor/Child - Patient/Participant/Individual - Professional - Standard of Care - Woman/Maternity

Universities Allied for Essential Medicines (UAEM): Philadelphia Consensus Statement on University Policies for Health Related Innovation
Philadelphia - November 13, 2006

Link: [URL](#)

Key Words: Commercialization - Data - Developing Country - Intellectual Property - Patents - Research - Researcher

European Parliament (EP): Report on the Proposal for a Decision of the European Parliament and of the Council Concerning the Seventh Framework Programme of the European Community for Research, Technological Development and Demonstration Activities (2007 to 2013)

Strasbourg - July 1, 2006

Link: [URL](#)

Key Words: Community/Population - Governance - Research

NATIONAL

American Society of Human Genetics (ASHG): ASHG Code of Ethics

Bethesda - March 1, 2006

Link: [URL](#)

Key Words: Communication of Results - Community/Population - Confidentiality - Conflict of Interest - Consultation/Collaboration - Education - Genetic Services - Integrity - Liability - Patient/Participant/Individual - Privacy - Professional - Research - Researcher - Standard of Care - Storage

Council for Responsible Genetics (CRG): Genetic Testing: Preliminary Policy Guidelines

Cambridge - July 1, 2006

Link: [URL](#)

Key Words: Cancer - Communication of Results - Counseling (general) - Education - Follow-up - Genetic Testing - Insurer/Insurance - Patient/Participant/Individual - Pharmacogenomics - Professional

GeneWatch UK: Genetic Discrimination by Insurers and Employers: Still Looming on the Horizon

Buxton - February 1, 2006

Link: [URL](#)

Key Words: Discrimination - Employer/Employment - Genetic Testing - Insurer/Insurance - Predictive Testing

Japan Pharmaceutical Manufacturers Association (JPMA): Guideline for Research Tool Patent Licensing

Tokyo - January 16, 2006

Key Words: DNA - Intellectual Property - Patents - Research

NHS Sickle Cell and Thalassaemia Screening Programmes: NHS Sickle Cell and Thalassaemia Screening Programme. Standards for the Linked Antenatal and Newborn Screening Programme

London - November 1, 2006

Link: [URL](#)

Key Words: Biobank - Counseling (general) - Education - Family - Foetus - Genetic Screening - Genetic Services - Newborn - Prenatal - Professional - Storage

Nuffield Council on Bioethics: Forensic Use of Bioinformation: Ethical Issues (Consultation Paper)

London - September 1, 2006

Link: [URL](#)


Key Words: Confidentiality - Consent - Databases - Deceased - Family - Governance - Patient/Participant/Individual - Privacy - Research - Storage

Victorian Government - Department of Human Services: Victorian Newborn Screening Review Committee - Final Report for the Minister for Health

Melbourne - August 1, 2006

Link: [URL](#)

Key Words: Access Info/Material - Biobank - Consent - Databases - Genetic Screening - Newborn - Storage

 SPECIALIZED MODULES

StemGen

For a comprehensive database of international, regional and national legislation and policies

on stem cell research and related therapies, visit [StemGen](#). A unique feature of StemGen is the [STEM CELL WORLD MAP](#), which describes the policy approaches adopted in over 50 countries.

UPCOMING EVENTS

International Stem Cell Conference

Organized by: Singapore Stem Cell Consortium

Date: February 1-2, 2007

Location: Singapour, Singapour

Information:

10th Annual Meeting: Pharmacogenomics

Organized by: National Coalition for Health Professionals Education in Genetics (NCHPEG)

Date: February 1-2, 2007

Location: Bethesda, Maryland, USA

Information:

Genomics : A Global Public Good?

Organized by: Chaire de Recherche du Canada en Droit et Médecine

Date: February 14, 2007

Location: Montréal, Québec, Canada

Information:

La santé publique est-elle éthique?

Organized by: Chaire de Recherche du Canada en Droit et Médecine

Date: March 7, 2007

Location: Montréal, Québec, Canada

Information:

Biobanking and Biorepositories 2007 Conference

Organized by: IBC Life Sciences

Date: April 26-27, 2007

Location: Amsterdam, Pays-Bas

Information:

12th Human Genome Meeting

Organized by: Human Genome Organisation (HUGO)

Date: May 21-24, 2007

Location: Montreal, Quebec, Canada

Information:

34th International Conference on Global Health : Partnerships Working Together for Global Health

Organized by: Global Health Council

Date: May 29-June 1, 2007

Location: Washington, D.C., United States

Information:

2007 Annual Meeting - International Biobanking Standards

Organized by: International Society for Biological and Environmental Repositories (ISBER)

Date: May 30-June 2, 2007

Location: Singapour, Singapour

Information:

Integrative Systems Biology for Health from First Principles to Medical Applications

Organized by: Systemoscope Consortium

Date: June 25-28, 2007

Location: Paris, France

Information:

One Origin, One Race, One Earth : Genetics, Human Rights and the Next Phase of Human Evolution

Organized by: Alberta Civil Liberties Research Centre

Date: November 15-17, 2007

Location: Calgary, Alberta, Canada

Information:



 TEAM PUBLICATIONS

Bucci L.M., "**Public Understanding of Nanotechnology**", (December 2006) *Nano and Society, A Newsletter from the Center on Nanotechnology and Society*

Abstract: Nanotechnology has emerged at a time when there is much discussion about the role of the lay public in science policy. At present, there is no doubt that very few people are familiar with nanotechnology. This is particularly disturbing because an increasing amount of public funds is being spent on nanotechnology research worldwide. There is therefore a need for national and international debate on nanotechnology to bring citizens and experts together in open, public deliberation about nanotechnology and its potential impacts on society. Using such broad-based, inclusive, and transparent initiatives will not only positively influence public understanding of nanotechnology but will also enable governments, experts, and academic communities to develop a better understanding of what the public wants and expects in the oversight of nanotechnology.

Hervé C., Knoppers B.M., Molinari P.A., Grimaud M.A., "**Systèmes de santé et circulation de l'information : encadrement éthique et juridique**", (Paris: Dalloz, 2006)

Abstract: [French version only]

Lévesque E., Petit E., "**The Legal Framework for Genetic Research in Quebec**", in Lambert R.D. and DeKoninck M. (eds.), *Responsible Conduct in Research. Normative Frameworks* (Québec: Faculty of Medicine, Université Laval, 2006), online: [URL](#)

Abstract: The objective here is to paint a general portrait of the legal framework for genetic research in Quebec. Firstly, we will consider the provisions concerning consent. In the second section, the risk/benefit analysis that precedes genetic research will be considered. The third section is devoted to the protection of the confidentiality of information in genetic research. Finally, to conclude, we will focus on the particularities of research in population genetics.

S. Jean M., "**L'UNESCO adopte la Déclaration universelle sur la bioéthique**", (2006) 46 *Les Cahiers du CCNE*, 59

Abstract: [French version only]

 EDITORIAL TEAM

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