



GENINFO

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

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January-February 2008



At the start of this new year, we would like to draw your attention to the publication of a new periodical that will reflect developments in the domain of ethics in human genetics: *Public Health Genomics*.

This periodical replaces, and takes up the mandate of the existing *Community Genetics*. An objective of *Public Health Genomics* is to integrate genomic knowledge with the development of policies and services that aim to improve population health. This new Journal will be co-edited by Bartha Maria Knoppers and Angela Brand. We invite you to look out for upcoming publications of *Public Health Genomics*!

Finally, the entire HumGen team joins me to wish all our readers Happy New Year and all the best in 2008!

Guillaume Sillon, editor-in-chief

EDITORIAL



Consent in Pharmacogenomic Research

Phillips M.S., Joly Y., Silverstein T., Avard D.

Abstract: This article analyzes the emerging ethical and legal requirements for informed consent in pharmacogenomic research. It reviews how policies at the international, regional and national levels have responded to new ethical challenges raised by genetics. It concludes that the policy framework in the field of pharmacogenomics is still in its infancy and needs to be further developed to answer the challenges raised by this important discipline.

(2007) 5:2 *GenEdit*, 1-9

LAWS AND POLICIES | NEW DOCUMENTS

INTERNATIONAL / REGIONAL

European Patent Office (EPO): *Guidelines for Examination in the European Patent Office*

Munich - November 1, 2007

Link: [URL](#)

Key Words: Intellectual Property - Patents

NATIONAL

American Society for Reproductive Medicine (ASRM), Society for Assisted Reproductive Technology: *Preimplantation Genetic Testing: A Practice Committee Opinion*

Birmingham - October 4, 2007

(2007) 88 *Fertility and Sterility* 1497-1504

Key Words: Counseling (general) - Embryo - Genetic Screening - Genetic Services - Genetic Testing - Pre-implantation

Human Genetics Commission (HGC): *More Genes Direct. A Report on Developments in the Availability, Marketing and Regulation of Genetic Tests Supplied Directly to the Public*

London - December 1, 2007

Link: [URL](#)

Key Words: Access Info/Material - Adult - Commercialization - Confidentiality - Consent - Counseling (general) - Counseling (Post-test) - Counseling (Pre-test) - Education - Genetic Testing - Minor/Child - Psychosocial Aspects - Standard of Care - Storage

Nuffield Council on Bioethics: *Public Health: Ethical Issues*

London - November 13, 2007

Link: [URL](#)

Key Words: Community/Population - Confidentiality - Consent - Data - Developing Country - Dignity - Governance - Intellectual Property - Privacy - Public Health - Respect for Human Life - Third Party

Public Health Genetics Unit (PHGU): *Moving Beyond ACCE: An Expanded Framework for Genetic Test Evaluation*

Cambridge - September 1, 2007

Link: [URL](#)

Key Words: Criteria - Genetic Services - Genetic Testing

Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS): *U.S. System of Oversight of Genetic Testing - Draft Report*

Bethesda - November 5, 2007

Link: [URL](#)

Key Words: Criteria - Genetic Testing - Governance - Pharmacogenomics

Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE): *Prise de position no.14/2007. Diagnostic préimplantatoire II - Questions spécifiques sur la réglementation légale et le typage HLA*

Berne - October 30, 2007

Link: [URL](#)

Key Words: Autonomy - Consent - Counseling (general) - Disability - Discrimination - Embryo - Eugenics - Family - Genetic Screening - Genetic Services - Genetic Testing - Integrity - Minor/Child - Pre-implantation - Research - Storage - Surplus Embryos

United States - State of New Jersey (Government): *Genetic Nondiscrimination in Employment Act P.L. 1996, c. 126*

Trenton - May 14, 2007

Assembly 4170, 212th Legislature (N.J. 2007)

Link: [URL](#)

Key Words: Confidentiality - Discrimination - Employer/Employment - Genetic Testing

United States - State of New York (Government): *An Act to Amend the Insurance Law, in Relation to Requiring Coverage for Genetic Testing in Accident and Health Insurance Policies*

Albany - January 23, 2007

Assembly 3113, 2007, 07-08 Reg. Sess. (N.Y. 2007)

Link: [URL](#)

Key Words: Genetic Testing - Insurer/Insurance

United States - State of New York (Government): *An Act to Amend the Insurance Law, in Relation to Reimbursement for Testing for Familial Dysautonomia, Canavan's Disease and Tay-Sachs*

Albany - February 2, 2007

Assembly 4447, 2007, 2007-2008 Reg. Sess. (N.Y. 2007)

Link: [URL](#)

Key Words:

Comité d'éthique de santé publique: *Avis sur le Projet-pilote d'offre de tests de porteur pour quatre maladies héréditaires récessives au Saguenay-Lac-St-Jean*

Montréal - July 1, 2007

Link: [URL](#)

Key Words: Adult - Autonomy - Beneficence - Carrier Status - Communication of Results - Community/Population - Confidentiality - Consent - Consultation/Collaboration - Counseling (general) - Databases - Discrimination - Embryo - Employer/Employment - Equity - Eugenics - Foetus - Genetic Screening - Genetic Testing - Insurer/Insurance - Justice - Patient/Participant/Individual - Population Genetics - Pre-implantation - Privacy - Public Health - Research - Right not to Know - Woman/Maternity



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

Les enjeux éthiques et juridiques en recherche populationnelle

Organized by: Regroupement des organismes de santé publique de la région de Québec (DMSP, DSP-CHUQ, DRSP, FSI, INSPQ, URESP, URSP, CSSS)

Date: February 18, 2008

Location: Québec, Québec, Canada

Information:

International Stem Cell Forum 2008

Organized by: International Stem Cell Forum

Date: February 26-27, 2008

Location: San Francisco, Californie, États-Unis

Information:

Symposium GE3DS international 2008: S'orienter dans le paysage en changement

Organized by: Génome Canada

Date: April 28-30, 2008

Location: Calgary, Alberta, Canada

Information:

Translating ELSI: Global Perspectives on the Ethical, Legal and Social Implications of Human Genome Research

Organized by: Center for Genetic Research Ethics and Law du Département de bioéthique de l'Université Case Western Reserve

Date: May 1-3, 2008

Location: Cleveland, Ohio, États-Unis

Information:

Journées Génétiques

Organized by: Réseau de Médecine Génétique Appliquée du Québec (RMGA)

Date: May 14-16, 2008

Location: Québec, Québec, Canada
Information:

XX International Congress of Genetics: Genetics - Understanding Living Systems

Organized by: International Federation of Genetics et la German Genetics Society

Date: July 12-17, 2008

Location: Berlin, Allemagne

Information:

"Point to Consider" - The Commercialization of Genomic Research in Canada

Organized by: CRDP - Université de Montréal

Date: January 30, 2009

Location: Montreal, (Quebec), Canada

Information:

 **TEAM PUBLICATIONS**

Caulfield T., Ogbogu O., Knoppers B.M., Isasi R.M., et. al., "**Stem Cell Research Ethics: Consensus Statement on Emerging Issues**", (2007) 29:10 *J. Obstet. Gynaecol. Can.* 2007, 843

Abstract: This article is a consensus statement by an international interdisciplinary group of academic experts and Canadian policy-makers on emerging ethical, legal, and social issues in human embryonic stem cell (hESC) research in Canada. The process of reaching consensus included consultations with key stakeholders in hESC research (regulators, stem cell researchers, and research ethics experts), preparation and distribution of background papers, and an international workshop held in Montreal in February 2007 to discuss the papers and debate recommendations. The recommendations provided in the consensus statement focus on issues of immediate relevance to Canadian policy-makers, including informed consent to hESC research, the use of fresh embryos in research, management of conflicts of interest, and the relevance of public opinion research to policy-making.

Isasi R.M., Knoppers B.M., "**Monetary Payments for the Procurement of Oocytes for Stem Cell Research: In Search of Ethical and Political Consistency**", (2007) 1 *Stem Cell Research*, 37

Abstract: The debate on both the appropriateness of allowing healthy women to provide oocytes for research use and the use of financial incentives is increasingly reduced to a confrontation between ethics, science, and the welfare of women. It is plausible that the expansion of national and international research efforts, paired with the growing trend toward liberalizing stem cell research policies, will inevitably result in increased demand for the materials needed to conduct such research. In this article we explore the conceptual models for categorizing oocyte donors and analyze the use of financial incentives as well as the compensation models proposed and implemented in various jurisdictions. Finally, we propose the adoption of a mixed model that both respects altruism and provides a feasible solution to an issue that could be situated only in the context of the overall acceptability of providing financial rewards to donors of human reproductive materials for assisted reproductive technologies.

Joly Y., Nycum G., "**Currents in Contemporary Ethics. The Tuberculosis Scare in Retrospect**", (2007) 35:4 *Journal of Law, Medicine & Ethics*, 734

Abstract: The '2007 tuberculosis scare', involving an international air traveller believed to have a drug resistant strain of tuberculosis, gives pause for consideration of the ethical and legal issues associated with the traveller's individual responsibility, as well as the public health response to an international health crisis. This article assesses whether there are any grounds for civil liability against the individual air traveller, or for professional disbarment given that the traveller was also a licensed attorney. It also assesses the American public health response; specifically around whether adequate information was provided to the traveller and whether the public health authorities met their obligations.

Joly Y., Wahnon F., Knoppers B.M., "**Impact of the Commercialization of Biotechnology Research on the Communication of Research Results: North American Perspective**", (2007) 8:1 *Harvard Health Policy Review*, 71

Abstract: Evidence demonstrates that academic biotechnology research has become increasingly commercial in the last twenty years in Canada and in the US. This trend is

not necessarily negative. Private funds have helped American universities to remain on the cutting edge of scientific research and to provide the best learning environment for their students. However, it would seem that this increasing emphasis on research commercialization has also created situations where university teachers and researchers could now find themselves in conflict between their traditional academic duties and the new commercial imperatives. This situation is especially worrisome in that it could lead researchers to delay the communication of important findings over substantial periods of time in order to protect commercial interests.

Kharaboyan L., Knoppers B.M., Avard D., Nisker J., "**Understanding Umbilical Cord Blood Banking: What Women Need to Know Before Deciding**", (2007) 17:5 *Women's Health Issues*, 277

Abstract: Information about umbilical cord blood (UCB) banking is surfacing at a very rapid pace. The messages, largely targeted toward women, encourage mothers-to-be to bank their child's UCB. Indeed, an evergrowing number of Internet sites and magazine advertisements are cautioning women that storing a newborn's UCB is a once-in-a-lifetime opportunity and a worthwhile investment that can save their child if it were to ever become necessary. The promise of private banking, coupled with pleas from public banks asking mothers to donate UCB for altruistic purposes, can become puzzling for pregnant women. To allow them to make an informed choice about UCB banking, it is important that women receive complete and accurate information from their obstetrical care providers. The purpose of this editorial is to raise awareness about UCB banking.

Sheremeta L., Knoppers B.M., "**Beyond the Rhetoric: Population Genetics and Benefit-Sharing**", in *Accessing and Sharing the Benefits of the Genomics Revolution*, Peter W.B. Phillips and Chika B. Onwuekwe, eds (Germany: Springer, 2007)

Abstract: Information derived from the Human Genome Project promises to inspire an array of future innovations with profound societal benefits. Population genetics research is now viewed as a necessary next step in the evolution of research based on the human genome. However, population genetic research raises numerous ethical, legal and social issues. The thesis of this chapter is that, if appropriately developed and applied to human population genetic research, a rational model of benefit-sharing can provide a mechanism that will enable cooperation between the developed world and the developing world.

 EDITORIAL TEAM

Editor-in-chief: [Guillaume Sillon](#) | **Associate editor:** [Gillian Nycum](#) | **Contributing editors:** [HumGen Team](#) | **Correctors:** [Julie Samuël](#) and [Maya Shukairy](#) | **Webmaster:** [Dan-Thanh Truong](#) | **Director:** [Bartha Maria Knoppers](#) | **Research Director:** [Denise Avard](#)

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