



## Last Issues

-  [November-December 2009](#)
-  [September-October 2009](#)
-  [July-August 2009](#)
-  [May-June 2009](#)
-  [March-April 2009](#)
-  [January-February 2009](#)

## Previous Issues

2008  
2007  
2006  
2005  
2004

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# GENINFO

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

[EDITORIAL](#) | [LAWS AND POLICIES](#) | [EVENTS](#) | [TEAM PUBLICATIONS](#)

November-December 2009



Dear Readers,

For this month's GenInfo, we highlight five important documents that have been published recently. First, the OECD published in October its *Recommendation on Human Biobanks and Genetic Research Databases*, which aims to provide guidance for the establishment, governance, management, operation, access, use and discontinuation of human biobanks and genetic research databases. Secondly, the [Canadian Stem Cell Foundation](#) has adopted a new Stem Cell Charter which advocates the advancement of stem cell research. With this objective, the Charter articulates five important principles: responsible science, protection of citizens, intellectual freedom, transparency and integrity. Thirdly, the UK Human Genetics Commission has drafted a set of principles for direct-to-consumer genetic testing in order to promote high standards and consistency among companies offering genetic tests. The document "[A Common Framework of Principles for direct-to-consumer genetic testing: Principles and Consultation Questions](#)" is available for consultation and comment until December 6, 2009.

In addition, Belgium has adopted its *Law on the Obtention and Use of Human Bodily Material for Human Medical Applications or for Scientific Research*. For their part, the Swiss federal authorities recently published a *Draft Law Pertaining to Research on Human Subjects*.

Finally, we would like to take this opportunity to congratulate two members of our team: Yann Joly, who successfully defended his thesis for a Doctorate of Civil Law (DCL) at McGill University under the supervision of Prof. Richard Gold, and Julie Samuel, who received an Erasmus Mundus grant from the European Commission. Congratulations on your achievement!

Happy reading!

Thu Minh Nguyen and Ma'n H. Abdul-Rahman






## The Risks of Nanotechnology to Human Health: A Review of International Guidelines and Policy Statements

Bucci L, Stanton-Jean M and Deschênes M

Abstract: Nanotechnology is acknowledged by the research and development community as the technology of the 21st century. Whether used for combating cancer or improving telecommunication, the scientific breakthroughs emerging from nanotechnology are significant, but it is also understood that they are not without risk. In the midst of understanding the implications of nanotechnology, it has become clear that we should not be misled about nanotechnology's impact on society. While there are many uncertainties, there is also much promise in that nanotechnology can impact many disadvantaged communities around the world. As is the case with other emerging technologies, a balance has to be found between the risks and the benefits. In this editorial, we examine the relevant international policy statements on nanotechnology and highlight how they provide guidance towards the management of the risks posed, in particular, those affecting human health.

(2009) 7:2 GenEdit

COMING SOON

### LAWS AND POLICIES NEW DOCUMENTS

#### INTERNATIONAL / REGIONAL

Organisation for Economic Co-operation and Development (OECD): *OECD Recommendation on Human Biobanks and Genetic Research Databases*

Paris - October 22, 2009

Link: [URL](#)

Key Words: Access Info/Material - Biobank - Commercialization - Community/Population - Confidentiality - Consent - Data - Databases - DNA - Donor - Ethical Review - Governance - Ownership - Population Genetics - Privacy - Research - Storage - Tissue

#### NATIONAL

Belgium/Government: *Loi relative à l'obtention et à l'utilisation de matériel corporel humain destiné à des applications médicales humaines ou à des fins de recherche scientifique*

Bruxelles - December 19, 2008

Link: [URL](#)

Key Words: Access Info/Material - Biobank - Confidentiality - Consent - Data - Databases - DNA - Ethical Review - Ethics Review Board - Governance - Privacy - Research - Storage - Tissue

Canadian Stem Cell Foundation: *Stem Cell Charter*

Ottawa - October 8, 2009

Link: [URL](#)

Key Words: Equity - Integrity - Research - Researcher - Stem Cell

France/Government - Ministère de la Santé et des sports: *Arrêté du 23 juin 2009 fixant les règles de bonnes pratiques en matière de dépistage et de diagnostic prénatals avec utilisation des marqueurs sériques maternels de la trisomie 21*

Paris - June 23, 2009

Link: [URL](#)

Key Words: Communication of Results - Consent - Disability - Foetus - Genetic Screening - Genetic Services - Genetic Testing - Minor/Child - Prenatal - Professional - Storage - Waiver of Consent - Woman/Maternity

Human Genetics Commission (HGC): *A Common Framework of Principles for direct-to-consumer genetic testing: Principles and Consultation Questions*

London - September 8, 2009

Link: [URL](#)

Key Words: Access Info/Material - Biobank - Communication of Results - Confidentiality - Consent - Consumer - DNA - Genetic Information - Genetic Services - Genetic Testing - Insurer/Insurance - Minor/Child - Predictive Testing - Professional - Storage - Third Party - Waiver of Consent

Institute for Science and Society – University of Nottingham: *The Commercial Development of Cell Therapy - Lessons for the Future?*

Nottingham - April 1, 2009

Link: [URL](#)

Key Words: Commercialization - Professional - Research - Researcher - Somatic Therapy - Stem Cell - Third Party - Tissue

Institute for Science and Society – University of Nottingham: *Barriers to the Commercialisation & Utilisation of Regenerative Medicine in the UK*

Nottingham - April 1, 2009

Link: [URL](#)

Key Words: Benefit Sharing - Educational Institution - Intellectual Property - Patents - Professional - Research - Researcher - Somatic Therapy - Tissue

National Science Foundation: *Responsible Conduct of Research*

Washington - August 20, 2009

Link: [URL](#)

Key Words: Community/Population - Education - Professional - Research - Researcher

Swiss Confederation: *Projet de la loi fédérale relative à la recherche sur l'être humain*

Bern - October 21, 2009

Key Words: Access Info/Material - Biobank - Confidentiality - Consent - Data - Databases - DNA - Ethical

Review - Liability - Research - Storage - Tissue

#### UPCOMING EVENTS

HUGO Symposium on Genomics and Ethics, Law and Society

Organized by: The Human Genome Organisation

Date: November 1-3, 2009

Location: Geneva, Switzerland

Information: <http://www.hugoevents.org/gels/index.php>

The Convention on Human Rights and Biomedicine: 10 years later

Organized by: Council of Europe

Date: November 3, 2009

Location: Strasbourg, France

Information:

[http://www.coe.int/t/dg3/healthbioethic/activities/10th\\_anniversary/default\\_FR.asp?](http://www.coe.int/t/dg3/healthbioethic/activities/10th_anniversary/default_FR.asp?)

Beyond the Embryo: Transnational, Transdisciplinary and Translational Perspectives on Stem Cell Research

Organized by: The Canadian Stem Cell Network and the Brocher Foundation

Date: November 14-15, 2009

Location: Hermance (Lake of Geneva), Switzerland

Information:

Sixteenth Session of the International Bioethics Committee (IBC)

Organized by: UNESCO - International Bioethics Committee (IBC)

Date: November 23-25, 2009

Location: Mexico City, Mexico

Information: [http://portal.unesco.org/shs/en/ev.php-](http://portal.unesco.org/shs/en/ev.php-URL_ID=12662&URL_DO=DO_TOPIC&URL_SECTION=201.html)

[URL\\_ID=12662&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/shs/en/ev.php-URL_ID=12662&URL_DO=DO_TOPIC&URL_SECTION=201.html)

Consortium Meeting

Organized by: ENGAGE

Date: May 31-June 1, 2010

Location: Helsinki, Finland.

Information: <http://www.euengage.org/events.html>

Summer Institute - Genetics, Ethics and Clinical Translation

Organized by: European Network for Genomic and Genetic Epidemiology

Date: June 22-25, 2010

Location: Egmond aan Zee, Netherland

Information: [http://www.euengage.org/Summer\\_Institute\\_2010.html](http://www.euengage.org/Summer_Institute_2010.html)

## TEAM PUBLICATIONS

Costea I., Isasi R., Knoppers B.M., Lillicrap D., "Haemophilia gene therapy: the patients' perspective", (2009) 15:5 *Haemophilia* 1159  
Abstract: Not Available.

Isasi R.M., Knoppers B.M., "Governing stem cell banks and registries: Emerging issues", *Stem Cell Res.* 2009 Sep-Nov;3(2-3):96-105., online: [URL](#)  
Abstract: The expansion of national and international research efforts in stem cell research is increasingly paired with the trend of establishing stem cell banks and registries. In jurisdictions crossing the spectrum of restrictive to liberal stem cell policies, banks and registries are emerging as an essential resource for transnational access to quality-controlled and ethically sourced stem cell lines. In this study, we report the preliminary findings of a survey of stem cell banks participating in the International Stem Cell Forum's International Stem Cell Banking Initiative (ISCBI). The questionnaire circulated to all ISCBI members addressed both general issues surrounding research policies (e.g., national policies regulating the permissibility of conducting embryonic stem cell research (hESCR)) and, more specifically, issues relating to the governance of stem cell banking projects. The results of the questionnaire were complemented by scholarly research conducted by the authors. This article provides an overview of the current international hESC banking landscape (I). For this purpose, the policy and governance approaches adopted in the surveyed stem cell banks at the national level will be analyzed and areas of convergence and variance will be identified (II). Finally, while our analysis is focused on research grade hESCs, the lessons to be gleaned from this examination will encourage further thought, analysis, and research into the issues raised in the banking and governance of other sources of stem cell lines (e.g., SCNT, parthenogenesis, iP) (IV).

Isasi, R.M., "Registration of Stem Cell-Based Clinical Trials: A Scientific and Ethical Imperative", *World Stem Cell Report 2009* (Florida: Genetics Policy Institute, 2009)

Abstract: Substantial progress in stem cell research has been made since the first report on the derivation of human embryonic stem (ES) cells.' As we celebrate the 10th anniversary of this landmark event, we also witness new scientific' and policy',4 milestones that reinvigorate hopes for moving forward the clinical translation of stem cell-based interventions. Nevertheless, stem cellbased therapies remain largely at the experimental stages and the road towards the clinical is still paved with major scientific',6 and ethical' hurdles. A positive signpost though, is the recent approval of what will be the world's first clinical trial of a hESC-derived product by the United States Food and Drug Administration(FDA).' Geron Corporation has been granted clearance for an Investigational New Drug (IND) application for the clinical trial of GRNOPC1 in patients with acute spinal cord injury.

Knoppers B.M., Bordet S., Isasi R., "The Human Embryo: Ethical and Legal Aspects", *Human Embryogenesis: Methods and Protocols* (New York: Humana Press, 2009)

Abstract: This paper analyses the status of the embryo in Canadian law. First, a brief overview of some ethical issues raised by research with embryos, focusing on the moral status of the embryo, is presented. A survey of the regulatory framework applicable to embryo research in Canada follows, so as to delineate the legal status of the embryo in Canada and its ethical underpinnings. A summary of applicable regulation in Germany, the United Kingdom, and the United States is also undertaken, illustrating the lack of consensus on this issue in Western countries. Finally, recent developments in stem cell research are considered, focusing on current alternatives to embryo destruction.

P3G Consortium, Church G., Heeney C., Hawkins N., de Vries J., Boddington P., Kaye J., Bobrow M., Weir B., "Public Access to Genome-Wide Data: Five Views on Balancing Research with Privacy and Protection", (2009) 5:10 *Plos Genetics*, 1  
Abstract: Not available.

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