



GENINFO

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

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July-August 2008



In this latest issue of GenInfo, we would like to draw your attention to a document created by the CIHR entitled *Health Services for Genetic Diseases Strategic Initiative: Success Stories*. This document provides an update on a diverse set of research projects carried out over the past few years that have enabled developments around genetic diseases. It describes, among other projects, various information tools and decision-making aids that have been developed to assist health care providers in the provision of care, as well as to aid policy makers and the public; for example, CanGeneTest, Genetikit, GenMessenger, and do not forget HumGen! Congratulations to all the research teams who contributed to these success stories by working toward improvements in the health and quality of life of Canadians.

Finally, we would like to thank Mr. Guillaume Sillon for the excellent work he has done for us as Editor-in-Chief of GenInfo, and we wish him all the best in his new position as a genetic counselor. On behalf of the entire team, congratulations Guillaume, and best wishes!

I will be taking over Guillaume's position as Editor-in-Chief of GenInfo and will work alongside Gillian Nycum, Editor-in-Chief of HumGen to bring you bi-monthly issues of GenInfo.

Happy reading!

Karine Sénécal and Gillian Nycum

▶ EDITORIAL



Involving the Public in Public Health Genomics: A Review of Guidelines and Policy Statements

Avard D., Grégoire G., Jean M.S.

Abstract: Public health genomics raises possibilities for preventing or reducing the occurrence of both rare and common disease. However, this area of research raises challenging ethical, legal and social issues that must be addressed. One way of addressing these issues is through public involvement in the policy-making process. This GenEdit reviews how international guidelines and policy statements related to public health genomics address the issue of public involvement. Key areas of discussion are the values and goals justifying public involvement, the proposed activities to increase public involvement, who is / who represents "the public", and the projected outcomes of their

involvement.

(2008) 6:1 *GenEdit*, 1-9

 LAWS AND POLICIES NEW DOCUMENTS

INTERNATIONAL / REGIONAL

The Hinxton Group, an International Consortium on Stem Cells, Ethics and Law: *Consensus Statement: Science, Ethics and Policy Challenges of Pluripotent Stem Cell-Derived Gametes*

Baltimore - April 11, 2008

Link: [URL](#)

Key Words: Consent - Data - Embryo - Gamete - Genetic Engineering - Researcher - Stem Cell - Tissue - Woman/Maternity

European Science Foundation (ESF): *Population Surveys and Biobanking*

Strasbourg - May 26, 2008

Link: [URL](#)

Key Words: Access Info/Material - Benefit Sharing - Biobank - Data - DNA - Patient/Participant/Individual - Population Genetics - Storage

NATIONAL

American Society of Clinical Oncology (ASCO): *American Society of Clinical Oncology 2007 Update of Recommendations for the Use of Tumor Markers in Breast Cancer*

New Haven - November 20, 2007

(2007) 25:33 *J. Clin. Oncol.* 5287-5311

Link: [URL](#)

Key Words: Cancer - Genetic Screening

Canadian Institutes of Health Research (CIHR): *Health Services for Genetic Diseases Strategic Initiative: Success Stories*

Ottawa - October 19, 2007

Link: [URL](#)

Key Words: Research

France/Government: *Décret no. 2008-321 du 4 avril 2008 relatif à l'examen des caractéristiques génétiques d'une personne ou à son identification par empreintes génétiques à des fins médicales*

Paris - April 4, 2008

Link: [URL](#)

Key Words: Access Info/Material - Assent/Dissent - Communication of Results - Confidentiality - Consent - Family - Genetic Screening - Genetic Testing - Incompetent Adult - Minor/Child - Newborn - Patient/Participant/Individual - Prenatal - Right not to Know

Human Genetics Society of Australasia (HGSA): *Pre-symptomatic and Predictive Testing in Children and Young People*

Sydney - February 1, 2008

Link: [URL](#)

Key Words: Autonomy - Beneficence - Confidentiality - Consent - Counseling (general) - Discrimination - Employer/Employment - Family - Genetic Testing - Insurer/Insurance - Justice - Minor/Child - Psychosocial Aspects

Human Genetics Society of Australasia (HGSA): *Genetic Testing and Life Insurance in Australia*

Sydney - February 1, 2008

Link: [URL](#)

Key Words: Communication of Results - Confidentiality - Consent - Discrimination - Family - Genetic Testing - Insurer/Insurance - Privacy - Right not to Know

Irish Council for Bioethics (Comhairle Bitheite na hÉireann): Ethical, Scientific and Legal Issues Concerning Stem Cell Research

Dublin - April 23, 2008

Link: [URL](#)

Key Words: Autonomy - Beneficence - Commercialization - Compensation for Participation - Consent - Dignity - Diversity - DNA - Donor - Embryo - Embryos (created for research) - Equity - Ethical Review - Foetus - Gamete - Genetic Engineering - Governance - Patents - Reproductive Cloning - Respect for Human Life - Stem Cell - Surplus Embryos - Therapeutic Cloning - Tissue - Umbilical Cord Blood - Woman/Maternity

Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS): U.S. System of Oversight of Genetic Testing: A Response to the Charge of the Secretary of Health and Human Services

Bethesda - April 30, 2008

Link: [URL](#)

Key Words: Communication of Results - Criteria - DNA - Genetic Information - Genetic Testing - Professional - Public Health - Researcher - Standard of Care - State

Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS): Realizing the Potential of Pharmacogenomics: Opportunities and Challenges

Bethesda - May 12, 2008

Link: [URL](#)


Key Words: Access Info/Material - Biobank - Confidentiality - Consent - DNA - Intellectual Property - Liability - Patents - Pharmacogenomics - Research - Researcher

United Kingdom/Department of Health: Our inheritance, our future: Realising the potential of genetics in the NHS: Progress Review

London - April 8, 2008

Link: [URL](#)

Key Words: Consultation/Collaboration - Education - Employer/Employment - Gene Therapy - Genetic Screening - Genetic Services - Genetic Testing - Governance - Insurer/Insurance

 **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**


XX International Congress of Genetics: Genetics - Understanding Living Systems

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

Date: July 12-17, 2008

Location: Berlin, Allemagne

Information:

 **TEAM PUBLICATIONS**

Cohen C.B., Brandhorst B., Nagy A., Leader A., Dickens B., Isasi R.M., Evans D., Knoppers B.M., "The use of fresh embryos in stem cell research: ethical and policy issues", *Cell Stem Cell*. 2008 May 8;2(5):416-21

Abstract: Fresh embryos resulting from in vitro fertilization, including many of poor quality, can provide sources of human embryonic stem cell lines. We consider why some donate such embryos for this research, address relevant ethical and policy issues, and present core guidelines for fresh embryo donation based on those of Canada.

▶ EDITORIAL TEAM

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