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GENINFO

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

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May-June 2009



Dear readers,

Recently, there have been exciting new developments in the area of stem cell research policy. Last March, US President Barack Obama issued an executive order lifting an eight-year ban on federal funding for human embryonic stem cell research. To carry out the order, the National Institutes of

Health (NIH) has adopted draft guidelines which establish policy and procedures under which the NIH will fund stem cell research. Under these draft guidelines, federal funding for research on stem cell lines created through "therapeutic cloning" or "somatic cell nuclear transfer" and the creation of human embryos solely for research purposes are banned. The NIH draft guidelines entitled, "National Institutes of Health Guidelines for Human Stem Cell Research" are currently available for consultation and comment. <http://stemcells.nih.gov/policy/2009draft.htm>

Also, we would like to highlight a special workshop entitled, "Beyond the Embryo Transnational, Transdisciplinary and the Translational Perspectives of Stem Cell Research" which is co-sponsored by the Brocher Foundation, the Stem Cell Network of Canada and the International Regulome Consortium. The main goal of this workshop is to promote reflection and discussion regarding emerging scientific and ELSI challenges in stem cell research. Abstracts are being accepted until May 30th. For more details about the workshop, please refer to <http://www.humgen.umontreal.ca/conference/en/>

Other documents of interest for this month include the Nuffield Council on Bioethic's consultation document entitled: *Medical profiling and online medicine: the ethics of 'personalised' health care in a consumer age*. This document covers ethical issues raised by commercial DNA profiling, body imaging and online health care. The Council seeks comments from anyone who is using, or contemplating using, medical profiling or online health care services, as well as from those who provide these services in the public and private sectors of health care. The Working Party also seeks opinions from researchers, academics, regulators, and policy makers. The consultation period is open until July 21st, 2009.


Furthermore, it is also a pleasure to announce a new edition to our GenEdit : "Direct to consumer genetic tests. An overview of guidelines and positions papers". At the moment, the full text is only available in French but an English version will be published in the following weeks.

Happy Reading!

Karine Sénécal and Thu Minh Nguyen

Co-Editors in Chief, HumGen International

EDITORIAL



Direct to Consumer Genetic Tests. An Overview of Guidelines and Position Papers
Karine Sénécal, Pascal Borry, Heidi C. Howard, Denise Avard

Abstract: A growing number of private companies are offering, via the Internet, genetic tests "directly to consumers". These types of genetic "services" raise a number of ethical concerns, in particular, the validity and clinical utility of these tests and the fact that they are conducted without a system in place to ensure that consumers understand the scope, limits and the basic meaning of the results. This GenEdit analyzes existing normative documents which address genetic tests offered directly to consumers. It identifies three broad approaches regarding the normative framework that should govern such testing. The first approach generally advocates for the ban of these services, while the second appears to allow them, provided that certain conditions are met. The third approach falls somewhere in the middle. These normative documents were also studied for specific information related to the roles and responsibilities of healthcare professionals, pre-test information, consent and communication of results, as well as the importance of educating the public and healthcare professionals. It concludes by stressing the scientific, social and moral necessity for a consistent and adapted normative framework, and the need to initiate activities for public education and public consultation.

(2009) 7:1 GenEdit, 1-14

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LAWS AND POLICIES NEW DOCUMENTS

INTERNATIONAL / REGIONAL

European Society of Human Genetics (ESHG): *Genetic Testing in Asymptomatic Minors*
Vienna - March 11, 2009
(2009) European Journal of Human Genetics, 1
Link: [URL](#)
Key Words: Access Info/Material - Assent/Dissent - Beneficence - Carrier Status - Communication of Results - Confidentiality - Consent - Counseling (general) - Counseling (Post-test) - Counseling (Pre-test) - Diversity - Duty to recontact - Education - Family - Genetic Screening - Genetic Testing - Liability - Man/Paternity - Minor/Child - Newborn - Patient/Participant/Individual - Pre-implantation - Preconception - Prenatal - Professional - Psychosocial Aspects - Woman/Maternity

European Society of Human Genetics (ESHG): *Genetic Testing is Asymptomatic Minors: Recommendations of the European Society of Human Genetics*
Vienna - March 11, 2009
(2009) European Journal of Human Genetics, 1
Link: [URL](#)
Key Words: Access Info/Material - Assent/Dissent - Beneficence - Carrier Status - Consent - Counseling

(general) - Counseling (Post-test) - Counseling (Pre-test) - Genetic Testing - Liability - Man/Paternity - Minor/Child - Professional - Psychosocial Aspects - Woman/Maternity

NATIONAL

Canadian College of Medical Geneticists (CCMG): *CCMG's Guidelines for DNA Banking*

Ottawa - January 23, 2008

Link: [URL](#)

Key Words: Biobank - Confidentiality - Consent - Databases - DNA - Genetic Services - Privacy - Research - Storage

Genetics and Public Policy Center: *Draft Comments on Notice of Proposed Rulemaking - Genetic Information Nondiscrimination Act (Equal Employment Opportunity Commission)*

Washington, DC - April 15, 2009

Link: [URL](#)

Key Words: Commercialization - Discrimination - Employer/Employment - Genetic Information - Genetic Screening - Genetic Testing - Newborn - Pharmacogenomics - Pre-implantation - Professional

National Consultative Ethics Committee for Health and Life Sciences (CCNE): *Opinion (No. 105) Questions for the Estates General on Bioethics*

Paris - October 9, 2008

Link: [URL](#)

Key Words: Research

Nuffield Council on Bioethics: *Medical Profiling and Online Medicine: The Ethics of 'Personalised' Healthcare in a Consumer Age*

London - April 1, 2009

Link: [URL](#)

Key Words: Communication of Results - Consumer - Follow-up - Genetic Testing - Liability - Patient/Participant/Individual - Research

PHG Foundation: *Cell-Free Fetal Nucleic Acids for Non-invasive Prenatal Diagnosis - Report of the UK Expert Working Group*

Cambridge - January 1, 2009

Link: [URL](#)

Key Words: Autonomy - DNA - Education - Foetus - Genetic Information - Genetic Screening - Genetic Services - Genetic Testing - Governance - Prenatal - Professional - Research - Researcher - Standard of Care - Woman/Maternity

PHG Foundation: *Ethical, Legal and Social Issues Arising from Cell-Free Fetal DNA Technologies (Appendix III to the Report: Cell-free Fetal Nucleic Acids for Non-invasive Prenatal Diagnosis)*

Cambridge - January 1, 2009

Link: [URL](#)

Key Words: Consent - DNA - Education - Foetus - Genetic Screening - Genetic Testing - Prenatal - Professional

Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS): *Public Consultation Draft Report on Gene Patents and Licensing Practices and Their Impact on Patient Access to Genetic Tests*

Bethesda - March 1, 2009

Link: [URL](#)

Key Words: Commercialization - Genetic Testing - Patents

Swiss Society of Medical Genetics: *Tests génétiques sur Internet*

Berne - February 1, 2009

Link: [URL](#)

Key Words: Consent - Consumer - Discrimination - Employer/Employment - Genetic Screening - Genetic Testing

The UK Biobank: *Public Attitudes to Third Party Access and Benefit Sharing: Their Application to UK Biobank*

Manchester - June 30, 2008

Link: [URL](#)

Key Words: Access Info/Material - Benefit Sharing - Biobank - Commercialization - Confidentiality - Consent - Duty to recontact - Intellectual Property - Patents

Cancer Care Ontario: *Ensuring Access to High Quality Molecular Oncology Laboratory Testing and Clinical Cancer Genetic Services in Ontario / Report of the Molecular Oncology*

Task Force

Toronto - December 1, 2008

Key Words: Cancer - Criteria - Education - Genetic Services - Genetic Testing - Patient/Participant/Individual - Professional

Gouvernement Québec - Agence d'évaluation des technologies et des modes d'intervention en santé (AETMIS): *La pertinence du dépistage néonatal urinaire des erreurs innées du métabolisme réalisé au Québec*

Montreal - February 1, 2009

Link: [URL](#)

Key Words: Access Info/Material - Beneficence - Carrier Status - Communication of Results - Community/Population - Confidentiality - Consent - Consultation/Collaboration - Discrimination - Education - Family - Follow-up - Genetic Screening - Governance - Man/Paternity - Minor/Child - Newborn - Patient/Participant/Individual - Professional - Psychosocial Aspects - Public Health - Socio-Economic Aspects - Woman/Maternity

Gouvernement Québec - Agence d'évaluation des technologies et des modes d'intervention en santé (AETMIS): *Summary - The Relevance of the Neonatal Urine Screening for Inborn Errors of Metabolism Performed in Québec*

Montreal - February 1, 2009

Link: [URL](#)

Key Words: Access Info/Material - Beneficence - Carrier Status - Communication of Results - Community/Population - Confidentiality - Consent - Discrimination - Education - Family - Follow-up - Genetic Screening - Governance - Man/Paternity - Minor/Child - Newborn - Patient/Participant/Individual - Professional - Psychosocial Aspects - Public Health - Socio-Economic Aspects - Woman/Maternity

 UPCOMING EVENTS

Genes for Health

Organized by: GRaPH-Int & Human Genetics Society of Australasia

Date: May 3-6, 2009

Location: Fremantle, Australia

Information: <http://www.graphint.org/australia2009/>

Conférence nationale pour vaincre le cancer

Organized by: Coalition priorité cancer au Québec

Date: May 14-15, 2009

Location: Montreal, (Québec), Canada

Information: <http://www.conferencecancer.com/>

Montreal Spring School of Population Genomics and Genetic Epidemiology

Organized by: CHU Sainte-Justine Research Centre

Date: May 19-22, 2009

Location: Montreal (Quebec), Canada

Information:

Food, Famine and Future Technologies: Ethical Dilemmas in a Hungry World

Organized by: American Humanist Association (Appignani Bioethics Center), in collaboration with the University of Montreal (Bioethics Program)

Date: May 22-23, 2009

Location: New York, United States

Information: <http://www.omics-ethics.org/index.cfm>

European Human Genetics Conference

Organized by: European Society of Human Genetics

Date: May 23-26, 2009

Location: Vienna, Austria

Information: <http://www.eshg.org/eshg2009/>

At the Cutting Edge of Stem Cell Science: Ethical and Policy Issues - An Intensive Seminar in Bioethics

Organized by: Harvard Stem Cell Institute and Case Western Reserve University School of Medicine

Date: June 15-19, 2009

Location: Harvard University, Cambridge, Massachusetts, United States

Information: <http://www.academicventures.com/stemcell/index.htm>

Biobank Summer School

Organized by: The Wellcome Trust and Public Population Project in Genomics (P3G)
 Date: July 1-5, 2009
 Location: Hinxton, Cambridge
 Information: <http://www.p3gobservatory.org/>, Please visit the websites of (P3G) or the (Wellcome Trust) for more details.

European Summer University - Technology and Health: Law and Ethics
 Organized by: Faculté de droit de Namur
 Date: July 6-8, 2009
 Location: Namur, Belgium
 Information: <http://www.crid.be/uee2009/home.html>, Jean Herveg,
jean.herveg@fundp.ac.be

The Age of Personalized: 5th International DNA Sampling Conference
 Organized by: Health Law Institute, University of Alberta & CRDP, Université de Montréal
 Date: September 16-18, 2009
 Location: Banff (Alberta), Canada
 Information: <http://www.genomealberta.ca/APG/>,

Beyond the Embryo: Transnational, Transdisciplinary and Translational Perspectives on Stem Cell Research
 Organized by: Brocher foundation workshop
 Date: November 14-15, 2009
 Location: Hermance (Lake of Geneva), Switzerland
 Information: <http://www.humgen.umontreal.ca/conference/en/>

▶ TEAM PUBLICATIONS

Avard D., Knoppers B.M., "Genomic Medicine: Considerations for Health Professionals and the Public", (2009) 1:2 *Genome Medicine*, 25.1
 Abstract: Advances in human genomics are ushering in a new era of predictive, preventative and personalized approaches to medicine. However, as the integration of genomic medicine progresses, the health community has a responsibility to communicate to the public the risks and challenges of genetic information. A possible knowledge transfer framework is outlined as a means to bridge the practical uses of genetics within various ethical, social and economic contexts. Tools and resources are needed to help clinicians understand genetic risks and help them inform the public appropriately and effectively.

Joly Y., "L'utilisation des ressources biologiques humaines et le partage des avantages: à la recherche d'un nouvel équilibre", *La bioéthique : Bataille autour du partage du vivant* (Éditions Autrement, 2009)
 Abstract: [Not available]

Nycum G., Avard D., Knoppers B.M., "Factors Influencing Intrafamilial Communication of Hereditary Breast and Ovarian Cancer Genetic Information", (2009) *European Journal of Human Genetics*, Advance online publication, 25 March 2009; doi:10.1038/ejhg.2009.33
 Abstract: [Not available]

Wallace S., Lazor S., Knoppers B.M., "Consent and Population Genomics: The Creation of Generic Tools", (2009) 31:2 *IRB: Ethics & Human Research*, 15
 Abstract: [Not available]

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