



May-June 2008



Providing access to an online database of normative documents related to ethical, legal and social issues in human genetics is just part of the work of the HumGen research team. Our members also research, present, and publish on a wide range of topics spanning the field of human genetics. This latest issue of GenInfo showcases the team's academic quality and diversity of research interests. Team publications announced in this edition include articles on the following topics: nanotechnology, research ethics, population genetics, and patent law, to name a few. Readers can access team publications on the HumGen database search engine by selecting relevant keywords and the "Selected literature" box!

The HumGen team is also pleased to announce in this issue of GenInfo the publication of a new edition of GenEdit for 2008 entitled "Involving the Public in Public Health Genomics: A Review of Guidelines and Policy Statements"

Happy reading!

EDITORIAL

A banner for GENEDITORIAL features a blue background with a large, stylized 'X' shape made of blue dots on the left and a rolled-up newspaper on the right. The word "GENEDITORIAL" is written in a serif font across the center.

**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

INTERNATIONAL / REGIONAL

**ECOSOC - United Nations Economic and Social Council:** *Genetic Privacy and Non-Discrimination*

Geneva - May 10, 2007

**Link:** [URL](#)

**Key Words:** Confidentiality - Discrimination - Employer/Employment - Genetic Information - Genetic Screening - Genetic Testing - Insurer/Insurance - Privacy

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

Paris - April 1, 2008

**Link:** [URL](#)

**Key Words:** Access Info/Material - Benefit Sharing - Biobank - Confidentiality - Consent - Data - Databases - DNA - Education - Governance - Intellectual Property - Population Genetics - Research - Storage - Tissue

**Action Group on Erosion, Technology and Concentration (ETC):** *Direct-to-Consumer DNA Testing and the Myth of Personalized Medicine: Spit Kits, SNP Chips and Human Genomics*

Ottawa - March 3, 2008

**Link:** [URL](#)

**Key Words:** Commercialization - Community/Population - Data - Databases - Genetic Testing - Patient/Participant/Individual - Pharmacogenomics - Research - Storage

**European Commission:** *Ethical Considerations for Clinical Trials on Medicinal Products Conducted with the Paediatric Population: Recommendations of the Ad Hoc Group for the Development of Implementing Guidelines for Directive 2001/20/EC Relating to Good Clinical Practice in the Conduct of Clinical Trials on Medicinal Products for Human Use*

Brussels - February 5, 2008

**Link:** [URL](#)

**Key Words:** Assent/Dissent - Consent - Data - Ethics Review Board - Insurer/Insurance - Man/Paternity - Minor/Child - Newborn - Pharmacogenomics - Privacy - Research - Right of Withdrawal - Socio-Economic Aspects - Tissue - Woman/Maternity

**European Society of Human Genetics (ESHG):** *Patenting and Licensing in Genetic Testing - Recommendations*

Vienna - April 1, 2008

(2008) 16:4 *European Journal of Human Genetics*, 405

**Link:** [URL](#)

**Key Words:** Beneficence - Community/Population - Genetic Testing - Intellectual Property - Patents

NATIONAL

**Agence de la biomédecine - France, French National Cancer Institute:** *Diagnostic prénatal, interruption médicale de grossesse, diagnostic pré-implantatoire et formes héréditaires de cancers*

Saint-Denis - January 1, 2008

**Link:** [URL](#)

**Key Words:** Autonomy - Cancer - Counseling (general) - Family - Genetic Testing - Patient/Participant/Individual - Pre-implantation - Predictive Testing - Prenatal - Psychosocial Aspects

**Australia/Government - Parliament of Australia:** *Explanatory Memorandum on Genetic Privacy and Non-Discrimination Bill 1998 [2008]*

Canberra - January 1, 2008

**Link:** [URL](#)

**Key Words:** Employer/Employment - Genetic Information - Insurer/Insurance - Research - Researcher

**Belgium/Government:** *Proposition de loi complétant l'article 3 de la loi du 28 janvier 2003 relative aux examens médicaux dans le cadre des relations de travail*

Brussels - July 17, 2007

**Link:** [URL](#)

**Key Words:** Confidentiality - Employer/Employment - Genetic Screening - Genetic Testing

**Belgium/Government:** *Proposition de loi modifiant la loi du 28 janvier 2003 relative aux examens médicaux dans le cadre des relations de travail*  
Brussels - October 23, 2007

**Link:** [URL](#)

**Key Words:** Confidentiality - Discrimination - Employer/Employment - Genetic Information - Genetic Screening - Genetic Testing - Privacy

**China/Government - Legislative Council:** *Patents (Amendment) Ordinance*  
Hong Kong - November 29, 2007

**Link:** [URL](#)

**Key Words:** Intellectual Property - Patents - Public Health - Research - Researcher

**National Consultative Ethics Committee for Health and Life Sciences (CCNE):** *Opinion (no 103) Ethics and Childhood Deafness: Consideration of Information Regarding Systematic Neonatal Screening and the Medical Management of Deaf Children*

Paris - December 6, 2007

**Link:** [URL](#)

**Key Words:** Beneficence - Community/Population - Consent - Foetus - Genetic Testing - Man/Paternity - Minor/Child - Professional - Psychosocial Aspects - Socio-Economic Aspects - Woman/Maternity

**United States - State of Oregon (Government):** *An Act Relating to DNA Tests - Senate Bill 244*

Salem - June 20, 2007

**Link:** [URL](#)

**Key Words:** Confidentiality - Genetic Information - Insurer/Insurance

**United States/Senate:** *Genetic Information Non-discrimination Act of 2008 (H.R. 493)*  
Washington - April 24, 2008

**Link:** [URL](#)

**Key Words:** Confidentiality - Data - Discrimination - Employer/Employment - Genetic Information - Insurer/Insurance - Privacy - Public Health

## 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

### **Canadian Workshop on Multidisciplinary Research in Nanotechnology: Gaps, Opportunities and Priorities**

**Organized by:** Canadian Institutes of Health Research

**Date:** January 22-24, 2008

**Location:** Edmonton, (Alberta), Canada

**Information:**

### **Translating «ELSI»: Ethical, Legal and Social Implications of Genomics**

**Organized by:** Case Western Reserve University

**Date:** May 1-3, 2008

**Location:** Cleveland, Ohio, Etats-Unis

**Information:**

### **Journées Génétiques**

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

**Date:** May 14-16, 2008

**Location:** Québec, Québec, Canada

**Information:**

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**Science - GE3LS Integration Workshop**

**Organized by:** Génome Québec

**Date:** May 21, 2008

**Location:** Montréal, (Qc), Canada

**Information:**

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**Managing the Uncertainty of Nanotechnologies. Challenges to Law, Ethics and Policy Making**

**Organized by:** University of Padua - Centre for Environmental Law Decisions and Corporate Ethical Certification

**Date:** May 22-23, 2008

**Location:** Rovigo, Italie

**Information:**

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**2008 International Conference: Governing Biobanks – What are the Challenges?**

**Organized by:** St. Anne's College

**Date:** June 24-26, 2008

**Location:** Oxford, United Kingdom

**Information:**

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**Supporting Policy Development in Genetics/Genomics: Where HTA, HSR, Public Health and ELSI Research Meet (pre-conference session HTAi 2008)**

**Organized by:** APOGEE-Net and Consortium CanGeneTest

**Date:** July 6, 2008

**Location:** Montreal, Quebec, Canada

**Information:**

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**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:**

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**58th Annual Meeting of the American Society of Human Genetics**

**Organized by:** American Society of Human Genetics

**Date:** November 11-15, 2008

**Location:** Philadelphia, Pennsylvania, United States

**Information:**

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 **TEAM PUBLICATIONS**

Bucci L.M., Knoppers B.M., "Toward a Canadian Policy Framework on Nanomedicine: Lessons from Reproductive Technologies", *Diritto pubblico comparato ed Europeo*, 2007 - IV (Torino: G. Giappichelli Editore, 2007)

**Abstract:** The rush toward nanomedicine has led to the burgeoning of a new market that has proceeded to expand globally without any restrictions. Adding to this is that there are still many unknown risks associated with the novel tools and applications produced with nanomedicine knowledge. Many of these risks are health-related. Impacts upon society whether ethical, legal, moral or cultural, need serious consideration as well. To encourage the development of future public policy for nanomedicine, this paper looks back to reproductive technologies to find an appropriate policy framework.

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Farmer Y., Avard D., "The Genetics of Type 2 Diabetes - a Look at the Scientific Advances of the DGDG Project", (2008) 53:1 *Diabetes Voice*, 31

**Abstract:** The International Diabetes Federation estimates that approximately 246 million people around the world have diabetes. Of this number, around 90% are people with type 2 diabetes. Given the proliferation of sedentary lifestyles, foods that are increasingly rich in sugar and fats, and the ageing of the population, it is estimated that by 2025, there will be 380 million people affected by diabetes. But the factors driving this pandemic are not only related to environment and lifestyle; genetic factors influence people's risk of developing type 2 diabetes. Yannick Farmer and Denise Avard report on the advances in our knowledge of the hereditary factors associated with the disease gained through a ground-breaking research project based in Canada and France.

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Joly Y., Schorno D., "**Le brevet : Valet ou roi du droit à la santé?**", (2006) 19:2 *Revue québécoise de droit international*

**Abstract:** There exists a vast doctrinal corpus concerning the existing tensions between intellectual property and human rights. However, few studies have thus far carried out a comprehensive analysis of the various meetings between the right to health and patent law. Does patent law thus facilitate, even indirectly, the realisation of the right to health by stimulating biomedical research or does it hinder it by privatising innovations, including the products that originate from these innovations, which are useful for healthcare? In order to bring light to these important thematic issues, the enforcement of patent law in both developed and developing countries will be discussed, in terms of access to healthcare products and innovation.

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Lacroix M., Nycum G., Godard B., Knoppers B.M., "**Should Physicians Warn Patients' Relatives of Genetic Risks?**", (2008) *CMAJ* Feb. 26;178(5):593-5

**Abstract:** When a patient refuses to disclose genetic risk information to relatives, whether the patient's physician should or may disclose such information without the patient's consent will depend on the seriousness, the imminence and the preventability of the risk. The legal landscape around the duty to warn of genetic risk is unclear in Canada, but in some cases the benefits of disclosure may be so great as to outweigh the obligation to maintain confidentiality. In this article we use a case-based approach to address the ethical and legal issues surrounding physicians' duty to warn family members of genetic risk.

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Potter B.K., Avarid D., Wilson B.J., "**Newborn Blood Spot Screening in Four Countries: Stakeholder Involvement**", (2008) 29 *Journal of Public Health Policy*, 121

**Abstract:** While newborn blood spot screening has historically been viewed as a public health success, the potential harms and benefits are more finely balanced for new conditions being considered for program expansion. We highlight complex issues that must be addressed in policy decisions, which in turn requires a consideration of many stakeholder perspectives. We describe the participation of stakeholder organizations in the newborn screening policy process, how such organizations have incorporated stakeholder views into their own policy writing, and their recommendations for inclusiveness. Differences across organizations and jurisdictions raise questions about the most effective approaches for facilitating inclusiveness, suggesting a need for formal evaluative research.

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