

WELCOME

Questions about the integration of genetics in public health are increasing. A few years ago, genetic technology belonged only to the research domain, but slowly it is entering into clinical practice. Today, we often talk about integrating genetics into public health programs. This raises specific ethical, legal and social issues.

Thus, we are proud to present the “Genetics and Public Health” contest. This contest invites university students to pose questions concerning issues related to genetics in public health and to provide answers to their own questions.

We invite you to publicize the contest, which has \$2000 in prizes, to your students: <http://www.humgen.umontreal.ca/faq>.

EDITORIAL

Consent in Pharmacogenomic Research

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

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

Organisation for Economic Co-operation and Development (OECD) : *Recommendation of the Council on the Licensing of Genetic Inventions*

Paris, February 23, 2006

<http://webdomino1.oecd.org/horizontal/oecdacts.nsf/Display/AB8F4F86943376C0C12572980057713E?OpenDocument>

Keywords: **Access Info/Material - Commercialization - Conflict of Interest - DNA - Intellectual Property - Patents - Public Health**

European Agency for the Evaluation of Medicinal Products (EMA) : *Guideline on the Ethics of Clinical Trials in Children*

London, September 18, 2006

http://ec.europa.eu/enterprise/pharmaceuticals/paediatrics/docs/paeds_ethics_consultation20060929.pdf

Keywords: **Consent - Ethics Review Board - Minor/Child - Newborn - Psychosocial Aspects - Research**

The Wellcome Trust, European Commission : *From Biobanks to Biomarkers*

London, June 1, 2006

<http://www.wellcome.ac.uk/assets/wtx032086.pdf>

Keywords: **Biobank - Community/Population - Data - Databases - Governance - Patents - Research - Storage**

European Federation of Pharmaceutical Industries and Associations (EFPIA) : *Key Messages Surrounding Pharmacogenetics*

Brussels, September 19, 2006

biozine.kribb.re.kr/kboard_trend/download.php?code=industry_new&no=4220

Keywords: **Biobank - Communication of Results - Consent - Data - Databases - DNA - Genetic Testing - Patient/Participant/Individual - Pharmacogenomics - Privacy - Professional - Research - Storage**

IPR-Helpdesk : *Licensing Biotechnology*

Alicante, September 1, 2006

[http://www.ipr-helpdesk.org/documentos/docsPublicacion/pdf_xml/8_Licensing_biotechnology\[0000006446_00\].pdf](http://www.ipr-helpdesk.org/documentos/docsPublicacion/pdf_xml/8_Licensing_biotechnology[0000006446_00].pdf)

Keywords: **Intellectual Property - Patents**

NATIONAL

Aetna Inc. : *Clinical Policy Bulletins - Genetic Counseling*

Hartford, April 11, 2006

http://www.aetna.com/cpb/medical/data/100_199/0189.html

Keywords: **Autonomy - Beneficence - Cancer - Carrier Status - Consent - Counseling (general) - Family - Genetic Screening - Genetic Testing - Male/Paternity - Minor/Child - Newborn - Patient/Participant/Individual - Professional - Waiver of Consent - Woman/Maternity**

American Academy of Pediatrics (AAP) : *Technical Report - Newborn Screening Fact Sheets*

Elk Grove Village, September 1, 2006

<http://aappolicy.aappublications.org/cgi/reprint/pediatrics;118/3/e934.pdf>

Keywords: **Follow-up - Genetic Services - Genetic Testing - Minor/Child - Newborn - Psychosocial Aspects**

American Society for Reproductive Medicine (ASRM), Society for Assisted Reproductive Technology : *Preimplantation Genetic Diagnosis (2006)*

Birmingham, November 1, 2006

(2006) 86:supp. 4 *Fertil. Steril.*, S257

http://www.sciencedirect.com/science?_ob=MIimg&_imagekey=B6T6K-4M4V2R0-1X-1&_cdi=5033&_user=789722&_orig=search&_coverDate=11%2F30%2F2006&_sk=999139994.8998&_view=c&_alid=475431943&_rdoc=2&_wchp=dGLzVzz-zSkzk&_md5=b23cddc492dde43851055e8168e347ae&_ie=/sdarticle.pdf

Keywords: **Embryo - Genetic Screening - Genetic Testing - Pre-implantation**

Australia/Government : *Statutory Review of the Gene Technology Act 2000 and the Gene Technology Agreement*

Canberra, April 27, 2006

<http://www.health.gov.au/internet/wcms/publishing.nsf/>

[Content/9F34C91EA9E219E2CA2571410009A47E/\\$File/Stat_Review_GeneTechAct.pdf](Content/9F34C91EA9E219E2CA2571410009A47E/$File/Stat_Review_GeneTechAct.pdf)

Keywords: **Genetic Engineering - Patents - Psychosocial Aspects**

Royal College of Physicians (RCP), Royal College of Pathologists, British Society for Human Genetics (BSHG) : *Consent and Confidentiality in Genetic Practice: Guidance on Genetic Testing and Sharing Genetic Information. Report of the Joint Committee on Medical Genetics*

London, July 6, 2006

<http://www.rcpath.org/resources/pdf/GeneticsConsentAndConfidentiality-JCMGreportJul06.pdf>

Keywords: **Access Info/Material - Consent - Duty to recontact - Family - Genetic Testing - Incompetent Adult - Minor/Child - Newborn - Professional - Storage - Tissue**

Council of Canadian Academies : *The State of Science & Technology in Canada*

Ottawa, September 1, 2006

<http://www.scienceadvice.ca/documents/Complete%20Report.pdf>

Keywords: **Genetic Services - Patient/Participant/Individual - Professional - Research**

Health Council of the Netherlands : *Annual Report on Screening for Disease 2006*

The Hague, June 20, 2006

<http://www.gr.nl/samenvatting.php?ID=1387>

Keywords: **Cancer - Genetic Screening - Predictive Testing - Prenatal**

Human Genetics Commission (HGC) : *Fifth Report from April 2005 to March 2006*

London, September 1, 2006

<http://www.hgc.gov.uk/UploadDocs/DocPub/Document/Final%20PDF.pdf>

Keywords: **Discrimination - Genetic Testing - Patient/Participant/Individual - Pre-implantation - Research**

March of Dimes : *Recommended Newborn Screening Tests: 29 Disorders*

White Plains, April 1, 2006

http://www.marchofdimes.com/printableArticles/14332_15455.asp

Keywords: **Genetic Screening - Genetic Services - Minor/Child - Newborn**

National Academy of Clinical Biochemistry (NACB) : *Guidelines and Recommendations for Laboratory Analysis and Application of Pharmacogenetics to Clinical Practice [draft]*

Washington, August 6, 2006

http://www.nacb.org/lmpg/LMPG_Pharmacogenetics.pdf

Keywords: **Communication of Results - Genetic Testing - Liability - Patient/Participant/Individual - Pharmacogenomics - Professional**

National Society of Genetic Counselors (NSGC) : *Code of Ethics*

Wallingford, January 1, 2006

<http://www.nsgc.org/about/codeEthics.cfm>

Keywords: **Communication of Results - Community/Population - Confidentiality - Conflict of Interest - Counseling (general) - Dignity - Discrimination - Education - Equity - Integrity - Patient/Participant/Individual - Professional - Psychosocial Aspects - Standard of Care**

Royal College of Obstetricians and Gynaecologists (RCOG) : *Opinion Paper 2: Umbilical Cord Blood Banking*

London, June 1, 2006

http://www.rcog.org.uk/resources/Public/pdf/umbilical_cord_blood_banking_sac2a.pdf

Keywords: **Access Info/Material - Autonomy - Commercialization - Consent - Donor - Family - Minor/Child - Newborn - Patient/Participant/Individual - Pre-implantation - Prenatal - Professional - Storage - Third Parties - Tissue - Umbilical Cord Blood - Woman/Maternity**

UK Pharmacogenetics Study Group : *Policy Issues in Pharmacogenetics*

Brighton, July 1, 2006

<http://www.york.ac.uk/res/pgx/publications/PGxpolicyissues2006.pdf#search=%22uk%20pharmacogenetics%20study%20group%22>

Keywords: **Genetic Testing - Pharmacogenomics - Professional**

United States - State of California (Government) : *An Act to Amend Sections 14132 and 14503 of, and to Add Sections 14105.07, 14459.6, and 14501.2 to the Welfare and Institutions Code, Relating to Family Planning*

Sacramento, September 29, 2006

http://info.sen.ca.gov/pub/05-06/bill/asm/ab_2701-2750/ab_2742_bill_20060809_amended_sen.pdf

Keywords: **Counseling (general) - Family - Genetic Services - Preconception - Prenatal**

United States - State of Idaho (Government) : *An Act Relating to Genetic Testing Privacy*

Boise, March 27, 2006

<http://www3.state.id.us/oasis/2006/S1423.html>

Keywords: **Discrimination - Employer/Employment - Genetic Testing - Insurer/Insurance - Privacy**

United States - State of Illinois (Government) : *Illinois Genetic Counselor Licensing Act, 225 Ill. Comp. Stat. 135/10-999*

Springfield, January 1, 2006

<http://www.ilga.gov/legislation/ilcs/ilcs3.asp?ActID=2632&ChapAct=225%26nbsp%3BILCS%26nbsp%3B135%2F&ChapterID=24&ChapterName=PROFESSIONS+AND+OCCUPATIONS&ActName=Genetic+Counselor+Licensing+Act%2E>

Keywords: **Community/Population - Competence - Confidentiality - Counseling (general) - Family - Genetic Services - Genetic Testing - Patient/Participant/Individual - Professional**

United States - State of Minnesota (Government) : *A Bill for an Act Relating to Data Practices, 4th Engrossment - 84th Legislative Session (2005-2006), U.S., S.F. 3132*

Saint Paul, May 21, 2006

<http://www.revisor.leg.state.mn.us/bin/bldbill.php?bill=S3132.4.html&session=ls84&print=1>

Keywords: **Biobank - Confidentiality - Consent - Data - Databases - Research - Storage**

United States - State of Oregon (Government) : *An Act Relating to Insurance Pool Governing Board*

Salem, August 17, 2005

<http://www.leg.state.or.us/05orlaws/sess0700.dir/0744ses.htm>

Keywords: **Discrimination - Employer/Employment - Insurer/Insurance**

UPCOMING EVENTS

organized by Canada Research Chair in Law and Medicine

Date: **November 1, 2006**

Location : **Montréal, Québec, Canada**

Information:

9^{ème} colloque organized by Association de thérapie génique du Québec (ATGQ)

Date: **November 3, 2006**

Location : **Montréal, Québec, Canada**

Information: , Sylvie Dupuis: sylvie.dupuis@cnrc-nrc.gc.ca

Training in Research Ethics: Social and Behavioural Sciences and Humanities Program

organized by National Council on Ethics in Human Research (NCEHR)

Date: **November 18, 2006**

Location : **Calgary, Alberta, Canada**

Information:

Patents, the Healthcare System and Benefit-Sharing organized by Canada Research Chair in Law and Medicine

Date: **November 22, 2006**

Location : **Montréal, Québec, Canada**

Information:

3^{ème} édition des journées d'étude des comités d'éthique de la recherche et de leurs partenaires

organized by Unité de l'éthique du ministère de la Santé et des Services sociaux (Québec)

Date: **November 22 - 23, 2006**

Location : **Montréal, Québec, Canada**

Information:

Frontiers in Biomedical Research, HKU 2006 organized by The University of Hong Kong Li Ka Shing Faculty of Medicine

Date: **December 8, 2006**

Location : **Hong Kong, China**

Information:

10th Annual Meeting: Pharmacogenomics organized by National Coalition for Health Professionals Education in Genetics (NCHPEG)

Date: **February 1 - 2, 2007**

Location : **Bethesda, Maryland, USA**

Information:

One Origin, One Race, One Earth: Genetics, Human Rights and the Next Phase of Human Evolution organized by Alberta Civil Liberties Research Centre

Date: **November 15 - 17, 2007**

Location : **Calgary, Alberta, Canada**

Information:

TEAM PUBLICATIONS

Joly Y., Sillon G., Knoppers B.M., "**La pharmacogénomique : nouveaux médicaments, nouvelles responsabilités?**", *1er congrès international interdisciplinaire sur la Chaîne du Médicament, "Le médicament : conception, production et consommation"*; Actes du congrès (Montréal : Groupe d'étude sur l'interdisciplinarité et les représentations sociales, 2006), 265 , online: <http://www.geirsomedicaments.uqam.ca/congres2005/ActesCongres2005.pdf>

[French version only]

Lévesque E., "**Les exigences légales entourant le consentement dans la recherche avec des enfants et des adults inaptes : une piste de solution aux difficultés posées par les art. 21 et 24 C.c.Q.**", (2006) 51:2 *Revue de droit de McGill*, 385.

Abstract : Les articles 21 et 24 du Code civil du Québec sont deux dispositions qui provoquent un grand nombre de discussions parmi les chercheurs et dans les comités d'éthique de la recherche. Les discussions suscitées par ces dispositions concernent les conditions particulières imposées à toute "expérimentation" à laquelle des enfants ou des majeurs inaptes à consentir participent. Les conditions qui posent les principales difficultés sont : (1) la nécessité d'obtenir le consentement d'une personne déterminée (parent, tuteur, curateur, mandataire) et (2) la nécessité de constater le consentement par écrit. Devant cette problématique, il est nécessaire de s'interroger sur l'interprétation des articles 21 et 24 C.c.Q. Dans son analyse, l'auteure recense les conditions auxquelles un projet de recherche est soumis aux articles 21 et 24 C.c.Q.

Poitras S., Petit E., Knoppers B.M., Godard B., "**L'industrie montréalaise des biosciences : une évaluation empirique des besoins en matières réglementaire et éthique**", *Bio-ingénierie et responsabilité sociale* (Montréal : Les Éditions Thémis, 2006) .

[French version only]

Sallée C., Knoppers B.M., "**Secondary Research Use of Biological Samples and Data in Quebec**", (2006) 85 *The Canadian Bar Review*, 137 .

Abstract : Les matières biologiques sont cueillies de façon routinière dans des établissements médicaux, et l'information amassée avec ces matières peut aussi être conservée. La valeur des échantillons biologiques et données connexes pour la recherche soulève un certain nombre de questions au sujet de la définition des conditions d'accès à ces matières ou à cette information tout en protégeant la dignité et la confidentialité des patients et patientes. Les auteures présentent une analyse critique du cadre juridique et institutionnel québécois qui régit l'utilisation secondaire des échantillons biologiques en recherche et l'accès aux données recueillies durant les soins médicaux.

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