

Close

| Welcome | News | GenEdit | New Laws & Policies | FAQ | Subscribe to GenInfo | Sponsors | Contact us |

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The last few weeks have brought success for UNESCO's International Bioethics Committee. On October 19th, the General Conference of UNESCO adopted the *Universal Declaration on Bioethics and Human Rights*. This document will undoubtedly become a crucial element in framing the ethics of human genetics.

Available at: http://portal.unesco.org/shs/en/file_download.php/bda389701d0561b79c37e0127ab255daUnivDecl_EN_fin.pdf

Emmanuelle Lévesque
Editor-in-chief



NEWS

The "News" section of GenInfo provides a brief listing of events for the coming year (if organized by our team or partner organizations). We are also pleased to include a "Publications" section with a summary of books, articles and editorials published by members of our team.

EVENTS

NOVEMBER 2005

Personal Health Information Protection Act (PHIPA) Summit 2005

Date: November 3, 2005

Location: Toronto, Ontario, Canada

Host: Information and Privacy Commissioner of Ontario

Information and registration: For additional information and to register, visit: <http://www.governmentevents.ca/phipa2005>

Congrès INRS-Armand Frappier 2005

Date: November 3, 2005

Location: Lac-à-l'Eau-Claire, Québec, Canada

Host: Student-Researchers of the INRS-Institut Armand-Frappier

Information and registration: For additional information and to register, visit: <http://www.inrs.quebec.ca/congres/index.html>

Intellectual Property: Food and Materials Research Conference

Date: November 10, 2005

Location: Montréal, Québec, Canada

Host: Advanced Food and Materials Network (AFMnet)

Information and registration: For additional information and to register, visit: http://afmnet.ca/index.php?fa=News.showNewsStory&news_id=147

McGill Bioethics Conference " Living Ethics: From Stem Cells to Life Extension "

Date: November 11-12, 2005

Location: Montréal, Québec, Canada

Host: McGill PostGraduate Student Society, McGill Alumni Association, McGill Department of Biology, Students Society of McGill University

Information and registration: For additional information and to register, visit: <http://bioethics.sus.mcgill.ca/Pages/Conference%20Welcome.htm>

9èmes journées annuelles de santé publique "Trends and Progress"

Date: November 14-17, 2005

Location: Québec, Canada

Host: Association québécoise d'établissements de santé et de services sociaux, Association des médecins spécialistes en santé communautaire du Québec, Association pour la santé publique du Québec, Agences de développement de réseaux locaux de santé et de services sociaux, Institut national de santé publique du Québec, Institut de la statistique du Québec, Ministère de la Santé et des Services sociaux du Québec.

Information and registration: For additional information and to register, visit: <http://www.inspq.qc.ca/jasp/default.asp?A=7&Lg=en>

4th Scientific Meeting - Primary Prevention of Congenital Anomalies**"Achieving Excellence in Congenital Anomalies Surveillance in Canada"**

Date: November 20-22, 2005

Location: Ottawa, Ontario, Canada

Host: Canadian Congenital Anomalies Surveillance Network (CCASN)

Information and registration: For additional information and to register, visit: http://www.phac-aspc.gc.ca/ccasn-rsac/meet_e.html

Annual general meeting 2005

Date: November 22-26, 2005

Location: Calgary, Alberta, Canada

Host: Canadian Stem Cell Network (SCN)

Information and registration: For additional information and to register, visit: <http://www.stemcellnetwork.ca/agm/index.php>

JUNE 2006**4th International DNA Sampling Conference - Genomics and Public Health**

Date: June 4-7, 2005

Location: Montréal, Québec, Canada

Host: Centre de Recherche en Droit Public (CRDP), Université de Montréal; Centers for Disease Control (CDC); Public Health Genetics Unit; Public Health Agency of Canada

Information and registration: For additional information and to register, visit: <http://www.humgen.umontreal.ca/events/dnasampling>

PUBLICATIONS**BOOK CHAPTERS & ARTICLES**

Phillips-Nootens S, Godard B, Knoppers BM, and Régnier M-H (eds), *La recherche en génétique et en génomique: droits et responsabilités*, Montréal: les Éditions Thémis, 2005, 312 p

[French version only]

Lacroix M, "The Québec Public Health System : A Modern Model", in Bailey T, Caulfield T and Ries N (eds), *Canadian Public Health Law*, Toronto: Lexis Nexis Butterworths, 2005, p. 497-518.

Abstract: The past decade has brought new challenges for public health, raising questions about the capacity of public health systems to manage and prevent threats to health and highlighting the need to modernize our public health system. This book chapter examines one modern model: Québec's Public Health Act.

Joly Y, "Biotechnologies et brevets: le cas de la pharmacogénomique" (2005) 10(2), online: Lex Electronica <<http://www.lex-electronica.org/articles/v10-2/joly.pdf>>

[french version only].

Isasi R and Nguyen M, "The Global Governance of Infectious Diseases: The World Health Organization and the International Health Regulations" (2005) 43(2) *Alberta Law Review*.

Abstract: The 2003 SARS outbreak exemplified both the porous boundaries for infectious disease due to globalization and the inadequacy of global governance of public health. The World Health Organization (WHO), whose mission it is to play a leading role in the protection and promotion of global public health, recently adopted revised International Health Regulations (IHR). It remains to be seen whether this new instrument can serve as a model for effective public health governance, thereby allowing the WHO to fulfill its mandate. The authors provide background on the role and evolution of the WHO in global health governance. They then provide a comparative analysis between the 2005 IHR with the original 1969 IHR in terms of scope, procedure, response networks, capacities and respect for human rights.



GENEDIT

The primary focus of the editorial GenEdit, which is written exclusively for HumGen, is to enhance our current understanding of policy statements related to human genetics through comparative international, legal and socio-ethical analysis.

CURRENT ISSUE

Volume III No.1 (2005)

Populational Genetic Databases: Is a Specific Ethical and Legal Framework Necessary?"

Anne Cambon-Thomsen, Clémentine Sallée, Emmanuelle Rial-Sebbag, Bartha Maria Knoppers

PAST ISSUES

Volume II No.3 (2004)

Newborn Screening, Banking and Consent

Claude Laberge, Linda Kharaboyan, Denise Avard

Volume II No.2 (2004)

Genetics and Life Insurance : A Comparative Analysis

Trudo Lemmens, Yann Joly and Bartha Maria Knoppers

Volume II No.1 (2004)

Protecting Genetic Information: A Comparison of Normative Approaches

Patricia Kosseim, Martin Letendre and Bartha Maria Knoppers

Volume I No.1 (2003)

Stem Cells in a Pluralistic Society: Consequences of Proposed Canadian Legislation

Dorothy C. Wertz, Marie-Hélène Régnier and Bartha Maria Knoppers



NEW LAWS & POLICIES

The following section contains new policy (legal, socio-ethical) statements on human genetics from international, regional and national sources.

We are constantly searching for documents to enrich our databank. If your organisation has published policy statements relating to genetics, or if you are aware of such new publications, kindly send us the relevant information and we will consider including it in the databank.

Irish government - Houses of the Oireachtas, *Disability Act 2005*, Dublin, July 8, 2005, <http://www.oireachtas.ie/documents/bills28/acts/2005/a1405.pdf> (date accessed: September 27, 2005).

Japan Society of Human Genetics, *Guidelines for Genetic Testing*, Tokyo, October 2004, http://jshg.jp/pdf/10academies_e.pdf (date accessed: September 27, 2005).

Ten genetic medicine-related societies, propose a new version of the "Guidelines for Genetic Testing" with the aim to incorporate testing in clinical practice, to expand previous guidelines established by these academic organizations, and to establish the basis of genetic medicine in the future. These guidelines concern genetic testing for gene mutations, chromosomal aberrations and their related germline abnormalities. The tests include those for clinical diagnosis, carrier detection, presymptomatic diagnosis, disease susceptibility estimation, pharmacogenetic diagnosis, prenatal diagnosis, and newborn screening for inborn errors of metabolism .

United States - Department of Health and Human Services (DHHS) - U.S. Preventive Services Task Force (USPSTF), *Genetic Risk Assessment and BRCA Mutation Testing for Breast and Ovarian Cancer Susceptibility: Recommendation Statement*, Rockville, September 6, 2005, <http://www.ahrq.gov/clinic/uspstf05/brcagen/brcagenrs.pdf> (date accessed: September 27, 2005).

This statement summarizes the U.S. Preventive Services Task Force recommendations on genetic risk assessment and BRCA mutation testing for breast and ovarian cancer susceptibility, along with the supporting scientific evidence.

Irish Council for Bioethics, *Human Biological Material: Recommendations for Collection, Use & Storage in Research 2005*, Dublin, June 29, 2005, http://www.bioethics.ie/pdfs/BioEthics_fin.pdf (date accessed: October 19, 2005).

The purpose of this report is to fill what the Council regarded as a vacuum in Ireland with a detailed report which examines multiple aspects of human biological samples within the context of medical research.

United Kingdom - Ministry of Health, *Review of the Human Fertilisation and Embryology Act - A Public Consultation*, London, August 16, 2005, <http://www.dh.gov.uk/assetRoot/04/11/78/72/04117872.pdf> (date accessed: September 27, 2005).

The Human Fertilisation and Embryology Act 1990 (the HFE Act) was a landmark piece of legislation. It followed extensive consideration of the social, ethical, and legal implications of new technologies that enabled, for the first time, observation and manipulation of the earliest stages of human development. The Government announced in 2004 that it intended to review the provisions of the HFE Act, including holding a public consultation exercise in 2005. This consultation document seeks views on whether and how the law might be updated given the rise of new technologies, changes in societal attitudes, international developments, and the need to ensure effective regulation.

United Kingdom Newborn Screening Programme Centre, *Newborn Blood Spot Screening in the UK - Implementation and Reporting Guidance*, April 2005, http://www.nelh.nhs.uk/screening/cpd/implementation_guidance.pdf (date accessed: September 27, 2005).

This document is designed to support the implementation of the Policies and Standards for Newborn Blood Spot Screening across the UK. It supplements guidance given in the Policies and Standards document. It aims to provide practical assistance for health professionals as they establish effective screening performance management groups to ensure that the core standards are being met and that an action plan, for continuous improvement and to enable the achievement of the developmental standards, is in place.

United Kingdom Newborn Screening Programme Centre, *Newborn Blood Spot Screening in the UK: Information for Parents*, London, April 2005, http://www.nelh.nhs.uk/screening/cpd/information_parents.pdf (date accessed: September 27, 2005).

This document is designed as a reference copy for health professionals to be used alongside the communication guidelines outlined in the Health Professional Handbook. Initially focusing on pre-screening information to support informed choice, this parent information will be expanded in 2005/6 to include information to support the communication of screening results to parents. Whilst the parent information contained in this document has been developed both with and for parents, it is intended to provide an evidence-based, easily accessible, summary of newborn blood spot screening for use by all those involved in newborn blood spot screening.

Health Council of the Netherlands, *Neonatal Screening*, The Hague, August 22, 2005, <http://www.gr.nl/adviezen.php?ID=1258> (date accessed: September 27, 2005).

In the Netherlands, the State Secretary for Health, Welfare and Sport has asked the Health Council to examine whether the criteria for screening newborns are still adequate and whether it would be advisable to expand the screening package. In this advisory report, the Health Council's Committee on Neonatal Screening discusses the criteria for screening newborns. The key concern is the health benefit that can be gained. The report also discusses the fact that neonatal screening detects carriers (those who have inherited a mutation but are not themselves sick) and the consequences that expanding screening would have for informing parents and requesting parental consent.

Québec - Government - Ministry of Health and Social Services, *L'évaluation et le suivi éthiques des projets de recherche multicentriques : Mieux conjuguer protection des sujets, équité et efficacité - Orientations ministérielles*, Québec, December 2004, http://www.ncehr-cnerh.org/pdf/publications/misc/Orientations_minist%20rielles_sur_les_projets_multicentriques.pdf (date accessed: September 27, 2005) [french version only].

Data Protection and Privacy Commissioners of Canada (27th International Conference), *Montreux Declaration — The Protection of Personal Data and Privacy in a Globalized World: a Universal Right Respecting Diversities*, Montreux, September 16, 2005, http://www.edsb.ch/e/links/international/konferenzen/2005/montreux_declaration_e.pdf (date accessed: October 19, 2005).

The Data Protection and Privacy Commissioners assembled for their 27th International Conference have agreed to promote the recognition of the universal character of data protection principles and have adopted this final declaration.

International Society of Nurses in Genetics (ISONG), *Informed Decision-Making and Consent: The Role of Nursing*, Newton, April 4, 2005, http://www.isong.org/about/position_statements/consent1.htm (date accessed: September 27, 2005).

Genetic testing can now be used for screening, diagnosis, management, treatment and health and reproductive decision-making. Nurses, as the omnipresent health care provider, have a central role in providing information and support to clients in the multiphase processes of genetic testing. With genetics knowledge, nurses can advocate, educate, counsel and support clients during the informed decision-making and consent process.

PricewaterhouseCoopers, *Personalized Medicine: The Emerging Pharmacogenomics Revolution*, San Jose, February 2005, <http://www.pwc.com/techforecast/pdfs/pharmaco-wb-x.pdf> (date accessed: September 27, 2005).

In this report, PricewaterhouseCoopers evaluates the effect of pharmacogenomics on the life sciences and pharmaceutical industries in the United States, highlighting the clinical impacts. This focus includes each step of the process, from clinical trial design to prescribing and monitoring treatment regimens for patients.

American College of Medical Genetics (ACMG), *Technical Standards and Guidelines: Prenatal Screening for Open Neural Tube Defects*, Bethesda, May 2005, http://www.acmg.net/resources/policies/SandG_ONTD%202005.pdf (date accessed: September 27, 2005).

These standards and guidelines are designed primarily as an educational resource for clinical laboratory geneticists to help them provide quality clinical laboratory genetic services. This specific technical standards and guidelines statement is intended to augment the current general American College of Medical Genetics Standards and Guidelines for Clinical Genetics Laboratories and to address validation guidelines specific to second trimester maternal serum screening.

Québec - Government - Commission de l'éthique de la science et de la technologie, *L'utilisation des données biométriques à des fins de sécurité: questionnement sur les enjeux éthiques (Document de consultation)*, Sainte-Foy, June 23, 2005 <http://www.ethique.gouv.qc.ca/fr/ftp/Biometrie-consultation.pdf> (date accessed: September 27, 2005) [french version only].

American College of Medical Genetics (ACMG), "Technical Standards and Guidelines: Prenatal Screening for Down Syndrome", (2005) 7:5 *Genetics in Medicine*, 344, http://www.acmg.net/resources/policies/SandG_DownSynd%202005.pdf (date accessed: October 19, 2005).

These standards and guidelines are designed primarily as an educational resource for clinical laboratory geneticists to help them provide quality clinical laboratory genetic services. This statement is intended to augment the current general American College of Medical Genetics Standards and Guidelines for Clinical Genetics Laboratories and to address validation guidelines specific to second trimester maternal serum screening for Down syndrome.

Data Protection and Privacy Commissioners of Canada (27th International Conference), *Resolution on the use of biometrics in passports, identity cards and travel documents*, Montreux, September 16, 2005, http://www.edsb.ch/e/links/international/konferenzen/2005/biometrie_resolution_e.pdf (date accessed: October 19, 2005).

Québec - Government - Commission de l'éthique de la science et de la technologie, *L'utilisation des données biométriques à des fins de sécurité: questionnement sur les enjeux éthiques (Document de réflexion)*, Sainte-Foy, June 23, 2005 <http://www.ethique.gouv.qc.ca/fr/ftp/Biometrie-reflexion.pdf> (date accessed: September 27, 2005) [french version only].

Canadian Institutes of Health Research (CIHR), *CIHR Best Practices for Protecting Privacy in Health Research*, Ottawa, September 2005.

CIHR, with the advice of its Privacy Advisory Committee, has developed Best Practice Guidelines for addressing privacy, confidentiality, and security concerns in the design, conduct and evaluation of health research.

Ombudsman Ontario, *The Right to be Impatient - Ombudsman Report*, Toronto, September 23, 2005, http://www.ombudsman.on.ca/pdf/TheRightToBeImpatient_REPORT.pdf (date accessed: October 19, 2005).

This report addresses whether the Ministry of Health and Long-Term Care has failed to properly administer Newborn Screening in Ontario.

UNESCO, *Universal Declaration on Bioethics and Human Rights*, Paris, October 19, 2005, http://portal.unesco.org/shs/en/file_download.php/bda389701_d0561b79c37e0127ab255daUnivDecl_EN_fin.pdf (date accessed: October 20, 2005).

UNESCO's General Conference, gathered in Paris for its 33rd session, adopted the Universal Declaration on Bioethics and Human Rights. The text, adopted by acclamation, "addresses ethical issues related to medicine, life sciences and associated technologies as applied to human beings, taking into account their social, legal and environmental dimensions."

Genetics and Public Policy Center, *Values in Conflict: Public Attitudes on Embryonic Stem Cell Research*, Washington DC, October 13, 2005, <http://www.dnapolicy.org/jhtml/news/October132005.pdf> (date accessed: October 19, 2005).

The Genetics and Public Policy Center released a major new report on public attitudes about embryonic stem cell research and related issues. The report, "Values in Conflict: Public Attitudes on Embryonic Stem Cell Research," reflects American attitudes about stem cell research using embryos, trade-offs between medical research and protecting embryos, and preferences for policy in embryonic research.

Organisation for Economic Cooperation and Development (OECD), *Quality Assurance and Proficiency Testing for Molecular Genetic Testing : Summary results of a survey of 18 OECD member countries*, Paris, April 25, 2005, <http://www.oecd.org/dataoecd/25/12/34779945.pdf> (date accessed: October 19, 2005).

This report presents recommendations for action to assure the quality of human genetic testing and the proficiency of those who carry out such tests. It provides the first detailed information about the availability and extent of molecular genetic testing throughout the OECD member countries as well as existing quality assurance practices in use in testing laboratories, including policies regarding samples and genetic data handling, and transborder flow of specimens.

British Medical Association (BMA), *Population Screening and Genetic Testing: A Briefing on Current Programmes and Technologies*, London, August 2005, [http://www.bma.org.uk/ap.nsf/Content/PopulationscreeninggeneticTesting/\\$file/ScreeningBriefing2.pdf](http://www.bma.org.uk/ap.nsf/Content/PopulationscreeninggeneticTesting/$file/ScreeningBriefing2.pdf) (date accessed: October 19, 2005).

This briefing paper discusses the main issues regarding population and genetic screening including areas of controversy, outlines current programmes in operation, and directs readers to useful sources of information. The aim is to provide healthcare professionals and other interested parties with the information needed to understand and explain screening programmes.

National Society of Genetic Counselors (NSGC), *NSGC Position Statement about Preconception/Prenatal Genetic Screening*, Wallingford, 2005, <http://www.nsgc.org/about/position.asp#18> (date accessed: October 19, 2005).

The Royal Society, *Personalised Medicines: Hopes and Realities*, London, September 21, 2005, <http://www.royalsoc.ac.uk/displaypagedoc.asp?id=15874> (date accessed: October 19, 2005).

The Royal Society has previously highlighted the potential for genomic technologies to improve human health (Royal Society 2002, 2003). In this report we summarise current scientific progress in pharmacogenetics and anticipate future developments in the field. The report discusses the potential role of pharmacogenetics in both clinical and public health practice, and drug development and genetic testing, and hence its likely impact on the provision of healthcare in the future. In addition, it considers some of the regulatory and ethical issues that may follow the development of this rapidly moving field.

World Health Organization (WHO), Chronic Diseases and Health Promotion, Human Genetics Programme, *Genetics, Genomics and the Patenting of DNA: Review of Potential Implications for Health in Developing Countries*, Geneva, 2005, <http://www.who.int/genomics/FullReport.pdf> (date accessed: October 19, 2005).

This report does not look to define policy, but to highlight areas of contention, suggest avenues for further investigation and stimulate dialogue among different stakeholders. Thus, the report may serve as a point of departure for professionals and public health officials to develop policies and appropriate practices.

Centre for Intellectual Property Policy (CIPP), *Genetic Patents and Health Care in Canada: an International Comparison of Patent Regimes of Canada and its Major Trading Partners*, Montreal, January 2005, <http://www.cipp.mcgill.ca/db/published/00000015.pdf> (date accessed: October 19, 2005).

The present report sets out the international context in which Canadian policy development occurs and draws on the lessons learned by Canada's major trading partners and emerging countries.

Canadian Biotechnology Advisory Committee (CBAC), *Human Genetics Materials: Making Canada's Intellectual Property Regime Work for the Health of Canadians*, Ottawa, August 2005, [http://cbac-cccb.ca/epic/internet/incbac-cccb.nsf/vwapj/CBAC_FINAL-REPORT_English_Oct14-05.pdf/\\$FILE/CBAC_FINAL-REPORT_English_Oct14-05.pdf](http://cbac-cccb.ca/epic/internet/incbac-cccb.nsf/vwapj/CBAC_FINAL-REPORT_English_Oct14-05.pdf/$FILE/CBAC_FINAL-REPORT_English_Oct14-05.pdf) (date accessed: October 19, 2005).

This report describes particular aspects of Canada's IP regime as they relate to HGM and discusses the issues and impacts of these aspects in three interconnected spheres of activity involved in making new HGM-based products and services available for use in health care: research; development and commercialization; and health services. The final sections of the report contain conclusions and recommendations.



DRAFTS

World Health Organization (WHO), *Medical Genetic Services in Developing Countries: The Ethical, Legal and Social Implications of Genetic Testing and Screening (Report - Draft 2)*, Geneva, May 23, 2005.

The final report will be published in Autumn 2005. It will focus on major ethical, social and legal issues that apply to the introduction of medical genetic services.

Working Party on Biotechnology, Committee for Scientific and Technological Policy, Organisation for Economic Co-Operation and Development (OECD), *An International Perspective on Pharmacogenetics: The Intersections Between Innovation, Regulation and Health Delivery - Issues and Background Paper for Workshop*, Paris, October 12, 2005.

The aim of this paper is to provide a short introduction to some of the key policy issues raised by current and future applications of pharmacogenetics and to stimulate debate on the topics to be considered at the workshop.

Australia - Government - Gene Technology Ethics Committees (GTEC), *National Framework for the Development of Ethical Principles in Gene Technology - Consultation Draft*, Woden, September 2005, <http://www.ogtr.gov.au/pdf/committee/ethicalprinciplesgtconsult.pdf> (date accessed: October 19, 2005).

The Gene Technology Ethics Committee has identified 10 core principles for ethical conduct in working with gene technology for scientists, research institutions, regulatory and ethics committees, and the general community.

United States - Department of Health and Human Services (DHHS) - Food and Drug Administration (FDA), *Gene Therapy Clinical Trials - Observing Participants for Delayed Adverse Events - Draft Guidance*, Rockville, August 2005, <http://www.fda.gov/cber/gdlns/gtclin.pdf> (date accessed: October 19, 2005).

This draft guidance, when finalized, will represent the Food and Drug Administration's (FDA's) current thinking on this topic. This guidance provides to sponsors of gene therapy studies recommendations regarding the design of studies : specifically, recommendations about including the collection of data on delayed adverse events in participants who have been exposed to gene therapy products.

United States - House of Representatives, *Prenatally Diagnosed Condition Awareness Act, Bill H.R. 1353 IH, 109th Congress, 1st Session (Introduced in the House of Representatives)*, Washington DC, March 16, 2005, <http://www.govtrack.us/data/us/bills.text/109/h1353.pdf> (date accessed: October 19, 2005).

A bill to amend the Public Health Service Act to increase the provision of scientifically sound information and support services to patients receiving a positive test diagnosis for Down syndrome or other prenatally diagnosed conditions.

United States - Senate, *Prenatally Diagnosed Condition Awareness Act, Bill S. 609 IS, 109th Congress, 1st Session (Introduced in Senate)*, Washington DC, March 11, 2005, <http://www.govtrack.us/data/us/bills.text/109/s609.pdf> (date accessed: October 19, 2005).

A bill to amend the Public Health Service Act to increase the provision of scientifically sound information and support services to patients receiving a positive test diagnosis for Down syndrome or other prenatally diagnosed conditions.

United States - State of Massachusetts, *An Act Promoting Stem Cell Research, Bill S. 2032*, Boston, March 30, 2005, <http://www.mass.gov/legis/bills/senate/st02/st02032.htm> (date accessed: October 19, 2005).

Swiss Academy of Medical Sciences (SAMS), *Projet de directives médico-éthiques et de recommandations - Biobanques: Prélèvement, conservation et utilisation de matériel biologique humain pour la formation et la recherche*, Basel, April 2005, http://www.samw.ch/docs/Richtlinien/f_RLBiobanken.pdf (date accessed: October 19, 2005) [French version only].

Canada - Government, *Assisted Human Reproduction Regulations (Proposed Regulations)*, Ottawa, September 24, 2005, <http://canadagazette.gc.ca/part1/2005/20050917/pdf/g1-13938.pdf> (date accessed: October 19, 2005).

The Act was built upon a framework of ethical principles consistent with the values of Canadians. These principles include the protection and promotion of human health, safety, dignity and rights, as well as the need to protect women and children from possible misuses of AHR technologies. The purpose of the proposed Regulations is to specify the basic requirements necessary to activate the section 8 prohibitions under the Assisted Human Reproduction Act and, in so doing, help to protect the reproductive autonomy of donors of human reproductive material and *in vitro* embryos. These prohibitions, approved by Parliament through its passage of the Act, would not be enforceable without regulations.

World Health Organization (WHO), *Life Science Research: Opportunities and Risks for Public Health - Mapping the Issues*, Geneva, 2005, http://www.who.int/entity/csr/resources/publications/deliberate/WHO_CDS_CSR_LYO_2005_20.pdf (date accessed: October 19, 2005).

This working paper addresses another public health implication of advances in life science research and development (R&D): its potential deliberate misuse to cause harm. Therefore, this raises the problem of how best to manage the risks associated with such research, techniques and knowledge without hindering its beneficial application to public health and welfare.

Working Party on Biotechnology, Committee for Scientific and Technological Policy, Organisation for Economic Co-operation and Development (OECD), *Explanatory Note for the BRC Activities Related to Human Derived Materials*, Paris, September 23, 2005.

These domain specific recommendations provide the basis for best practice in the management of Biological Resource Centres that hold and supply human derived material.



FAQ

The judicial, ethical and social concerns raised in the regulative texts that provide the framework for human genetics are complex. Our goal, with the Frequently Asked Questions (FAQ), is to approach these questions in such a way as to render them accessible.

Q What is the current legal framework governing cloning in Canada?

A Currently, an *Act Respecting Assisted Human Reproduction And Related Research* (2004) forbids all forms of cloning that result in the creation of a human embryo.

For more FAQs, visit HumGen's FAQ section at <http://www.humgen.umontreal.ca/int/faq.cfm?lang=1>



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