



GENINFO

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

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July-August 2007



Dear readers,

This month, the HumGen team is excited to announce the launching of its new PediaGen website (<http://www.pediagen.org/>). PediaGen provides comprehensive information including guidelines, policies, literature and news on genetic research or clinical applications involving children and minors. Topics such as genetic testing/screening, gene therapy and tissue banking are covered in this particular website.

We also invite everyone to visit our newly revised PopGen website (<http://www.popgen.info/>) (covering issues in population genetics) and StemGen website (<http://www.stemgen.org/>) (concerning stem cell research and related therapies).

These websites focus on specific issues in human genetics making the search for information more effective and efficient. We hope that the websites prove to be useful and welcome any feedback that you may have.

Thu Minh Nguyen, Editor-in-chief

EDITORIAL



Umbilical Cord Blood Banking

Bordet S., Kharaboyan L., Lebrun A.

Abstract: The umbilical cord, previously considered as waste and discarded at birth, is a source of haematopoietic stem cells. Current therapeutic uses of umbilical cord blood stem cells and the promise of these cells for the treatment of degenerative diseases in the future have led to the establishment of cord blood banks in many parts of the world. Although umbilical cord blood banking raises many ethical and legal issues, this article focuses on the controversy created by the coexistence of public and private cord blood banks in many countries. Policy statements adopted by professional associations and advisory groups indicate that, based on the current state of medical evidence, childbearing women with no

current or potential familial need of stem cell transplantation should be encouraged to donate cord blood to public banks. The authors consider that collected cord blood that does not meet standards for transplantation should be made available for research. Options should be provided to parents so that they can make informed decisions regarding which types of research they are willing to support.

(2007) 5:1 *GenEdit*, 1-7

▶ LAWS AND POLICIES NEW DOCUMENTS

INTERNATIONAL / REGIONAL

International Association for Impact Assessment: *Public Participation. International Best Practice Principles*

Fargo - August 1, 2006

Link: [URL](#)

Key Words: Community/Population - Psychosocial Aspects - Public Health - Socio-Economic Aspects

Organisation for Economic Co-operation and Development (OECD): *OECD Guidelines for the Quality Assurance in Molecular Genetic Testing*

Paris - June 1, 2007

Link: [URL](#)

Key Words: Access Info/Material - Autonomy - Benefit Sharing - Carrier Status - Community/Population - Confidentiality - Consent - Consultation/Collaboration - Counseling (general) - Data - Diversity - DNA - Duty to recontact - Education - Family - Follow-up - Genetic Testing - Governance - Minor/Child - Patient/Participant/Individual - Prenatal - Privacy - Professional - Research - Storage - Third Party - Tissue

United Nations Educational, Scientific and Cultural Organization (UNESCO): *A Cross-Cultural Introduction to Bioethics (Textbook)*

Christchurch - January 1, 2006

Link: [URL](#)

Key Words: Cancer - Confidentiality - Consent - DNA - Donor - Embryo - Eugenics - Gene Therapy - Genetic Engineering - Privacy - Reproductive

NATIONAL

American College of Obstetricians and Gynecologists (The) (ACOG): *ACOG Committee Opinion: Sex Selection*

Washington - February 1, 2007

Link: [URL](#)

Key Words: Discrimination - Eugenics - Foetus - Genetic Screening - Pre-implantation - Prenatal

American Nurses Association (ANA): *Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics*

Washington - September 1, 2006

Link: [URL](#)

Key Words: Adult - Autonomy - Consent - Counseling (general) - Counseling (Pre-test) - Education - Genetic Screening - Genetic Testing - Psychosocial Aspects

Canadian Institutes of Health Research (CIHR): *CIHR Guidelines for Health Research Involving Aboriginal People*

Ottawa - May 1, 2007

Link: [URL](#)

Key Words: Access Info/Material - Autonomy - Benefit Sharing - Biobank - Commercialization - Communication of Results - Community/Population - Confidentiality - Consent - Consultation/Collaboration - Data - DNA - Duty to recontact - Education - Ethical Review - Governance - Intellectual Property - Liability - Ownership - Population Genetics - Right of Withdrawal - Storage - Tissue

EuroGentest Network of Excellence: *Recommendations for Genetic Counselling Related to Genetic Testing (Draft 2)*

Leuven - June 1, 2007

Link: [URL](#)

Key Words: Confidentiality - Counseling (general) - Counseling (Post-test) - Counseling (Pre-test) - Genetic Screening - Genetic Services - Genetic Testing - Governance - Patient/Participant/Individual - Pre-implantation - Prenatal - Professional

Genetics and Public Policy Center: *U.S. Public Opinion on Use of Genetic Information and Genetic Discrimination*

Washington D.C. - April 25, 2007

Link: [URL](#)

Key Words: Cancer - Communication of Results - Discrimination - Employer/Employment - Genetic Testing - Insurer/Insurance - Recruitment

Human Fertilisation and Embryology Authority (HFEA): *HFEA Code of Practice (7th edition)*

London - January 1, 2007

Link: [URL](#)

Key Words: Access Info/Material - Carrier Status - Compensation for Participation - Confidentiality - Consent - Counseling (general) - Data - Deceased - Donor - Embryo - Genetic Screening - Genetic Services - Genetic Testing - Man/Paternity - Minor/Child - Pre-implantation - Professional - Research - State - Storage - Woman/Maternity

Irish Medicines Board: *Guidelines for Pharmacogenetic Research*

Dublin - November 1, 2006

Link: [URL](#)

Key Words: Commercialization - Communication of Results - Confidentiality - Consent - Counseling (general) - Data - DNA - Ethical Review - Ethics Review Board - Genetic Testing - Incompetent Adult - Minor/Child - Pharmacogenomics - Psychosocial Aspects - Research - Researcher - Socio-Economic Aspects - Storage

National Academy of Sciences (NAS): *2007 Amendments to the National Academies' Guidelines for Human Embryonic Stem Cell Research*

Washington - February 1, 2007

Link: [URL](#)

Key Words: Biobank - Confidentiality - Consent - Donor - Embryo - Embryos (created for research) - Ethical Review - Ethics Review Board - Professional - Reproductive Cloning - Research - Right of Withdrawal - Stem Cell - Storage - Surplus Embryos - Therapeutic Cloning

National Cancer Institute (NCI), National Institutes of Health (NIH), United States - Department of Health and Human Services (DHHS): *National Cancer Institute Best Practices for Biospecimens Resources (Draft)*

Bethesda - April 1, 2007

Link: [URL](#)

Key Words: Access Info/Material - Biobank - Commercialization - Confidentiality - Consent - Data - Databases - DNA - Education - Ethical Review - Governance - Intellectual Property - Liability - Privacy - Research - Storage - Tissue - Waiver of Consent

National Consultative Ethics Committee for Health and Life Sciences (CCNE): *Avis (No. 97) Questions éthiques posées par la délivrance de l'information génétique néonatale à l'occasion du dépistage de maladies génétiques (exemples de la mucoviscidose et de la drépanocytose)*

Paris - January 11, 2007

Link: [URL](#)

Key Words: Biobank - Carrier Status - Communication of Results - Consent - Databases - Genetic Screening - Newborn - Patient/Participant/Individual - Prenatal - Right not to Know

New Zealand/Government - Ministry of Health: *Antenatal Down Syndrome Screening in New Zealand*

Wellington - January 1, 2007

Link: [URL](#)

Key Words: Access Info/Material - Genetic Screening - Governance - Prenatal - Standard of Care

The American Society of Breast Surgeons: *BRCA Genetic Testing for Patients With and Without Breast Cancer*

Columbia - June 12, 2006

Link: [URL](#)

Key Words: Adult - Communication of Results - Consent - Counseling (general) - Discrimination - Education - Genetic Testing - Psychosocial Aspects

The Wellcome Trust: *Wellcome Trust Policy on Data Management and Sharing*

London - January 1, 2007

Link: [URL](#)

Key Words: Access Info/Material - Benefit Sharing - Communication of Results - Data - Databases - Ethical Review - Governance - Liability - Professional - Research - Researcher - Storage

Canada/ Government Alberta - Health and Wellness: *Alberta's Newborn Metabolic*

Screening Program Information for Health Care Providers

Edmonton - March 1, 2007

Link: [URL](#)


Key Words: Access Info/Material - Communication of Results - Consent - Family - Follow-up - Insurer/Insurance - Minor/Child - Newborn - Professional - Public Health

Fonds de la Recherche en Santé du Québec (FRSQ): *Final Report Advisory Group on a Governance Framework for Data Banks and Biobanks Used for Health Research*

Quebec - December 8, 2006

Link: [URL](#)

Key Words: Access Info/Material - Autonomy - Biobank - Commercialization - Confidentiality - Conflict of Interest - Consent - Data - Databases - DNA - Education - Ethical Review - Governance - Liability - Patient/Participant/Individual - Privacy - Recruitment - Research - Right of Withdrawal - Storage - Tissue

 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

Université Européenne d'Été: Droit de la Santé et Éthique Biomédicale

Organized by: Université Paul Sabatier & Université Complutense Madrid

Date: July 4-13, 2007

Location: Toulouse, France/Madrid, Espagne

Information:

Colloque Annuel : L'éthique du soin à son zénith

Organized by: Programmes de bioéthique, Université de Montréal

Date: September 20-21, 2007

Location: Montréal, Québec, Canada

Information:

26th Annual Education Conference

Organized by: National Society of Genetic Counselors (NSGC)

Date: October 11-16, 2007

Location: Kansas City, Missouri, États-Unis

Information:

The American Society of Human Genetics 57th Annual Meeting

Organized by: American Society of Human Genetics

Date: October 23-27, 2007

Location: San Diego, Californie, État-Unis

Information:

Visions National Health Law Conference

Organized by: Health Law Institute, Université d'Alberta

Date: November 8-10, 2007

Location: Banff, Alberta, Canada

Information:

Première table ronde canadienne sur l'éthique en santé publique : explorons les bases

Organized by: Agence de la santé publique du Canada (Facilitateur)

Date: November 8-9, 2007

Location: Montréal, Québec, Canada

Information:

1st Congress of the International Society of Nutrigenetics/Nutrigenomics

Organized by: International Society of Nutrigenetics/Nutrigenomics

Date: November 12-13, 2007

Location: Athènes, Grèce

Information:

Canadian Association of Genetic Counsellors (CAGC)

Organized by: 2007 CAGC Annual Educational Conference

Date: November 15-18, 2007

Location: Vancouver, British Columbia, Canada

Information:

2007 CAGC Annual Educational Conference

Organized by: Association Canadienne des Conseillers en Génétique

Date: November 15-18, 2007

Location: Vancouver, Colombie Britannique, Canada

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**

Bordet S., Feldman S., Knoppers B.M., "**Legal aspects of animal-human**

combinations in Canada", (2007) 1:1 *McGill Health Law Publication*, 83, online: [URL](#)

Abstract: This article examines the current legal regime applicable to animal-human combinations under the Assisted Human Reproduction Act (Canada). The Act prohibits as criminal offences the use of non-human reproductive material in humans, the use in humans of human reproductive material previously transplanted into a non-human life form, the creation of chimeras made from human embryos, and the creation for reproductive purposes of human/non-human hybrids. Additional animal-human combinations, such as transgenic life forms, may be regulated pursuant to section 11 of the Act in the future. The development of the regulatory framework under the Act will reveal how freedom of research will be balanced against the need for scientifically valid and ethically justifiable research, and whether these differences will continue to apply.

Isasi R., Nguyen T.M., "**The Rationale for a Registry of Clinical Trials Involving Human Stem Cell Therapies**", (2008) 16:2 *Health Law Review*, 56

Abstract: With the promise of new therapeutic interventions involving stem cell lines and the increasing permissibility of stem cell line procurement worldwide (from supernumerary IVF and/or cloned embryos), it is important that ethical and safety issues are not overlooked when developing public policy concerning stem cell research. All eventual stem cell clinical trials must be transparent and follow high quality standards in order to ensure the safety of human participants. In order to promote transparency and accountability with regards to all clinical trials, registries have been created internationally to disclose minimum data from human clinical trials, regardless of whether the outcomes are positive or negative. With the additional safety concerns that surround stem cell clinical trials, it is important to explore the feasibility of creating a clinical trial registry specifically for stem cell clinical research.

Knoppers B.M., Joly Y., "**Our Social Genome?**", (2007) 25:7 *Trends in Biotechnology*, 284, online: [URL](#)

Abstract: Apocalyptic views on the natural order, chimeras and genetic engineering should not detract from the fact that medical research, similar to the promotion of health, is a public good. Genomics crosses all species, thereby requiring a global approach that respects human rights and public health priorities. Public trust and public participation in research demand clear stewardship as well as transparent and accountable oversight. Characterizing fundamental genomic data as a public resource might counterbalance the current overemphasis on individual rights but this will not be simple. It is only through an attachment to justice and solidarity that the dignity and well-being of persons, both as

humans and as citizens, can truly be fostered.

Sénécal K., "**Réflexion sur la thérapie génique germinale: aspects juridiques et éthiques**", (Montréal: Les Éditions Thémis, 2007)

Abstract: [French version only]

 EDITORIAL TEAM

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