

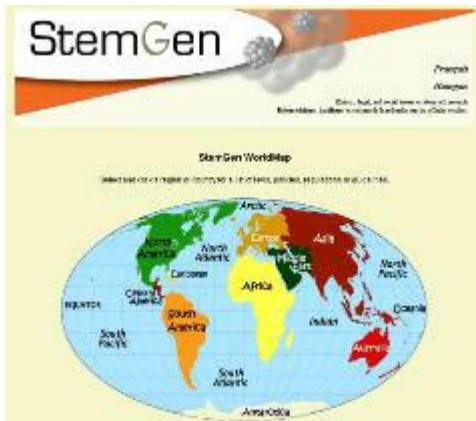


GENINFO

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

EDITORIAL | LAWS AND POLICIES | EVENTS | TEAM PUBLICATIONS

September-October 2007



Stem cells have generated much interest for researchers because of their ability to replace and repair damaged tissues. This potential raises the prospect of stem cell use for reversing and treating diseases and injuries. However, many publicized scientific studies in this field have been criticized because of the ethical and legal controversies surrounding stem cell research, particularly with respect to the derivation of stem cells from embryonic sources.

In this month's GenInfo, I invite you to consult the *Updated Guidelines for Human Pluripotent Stem Cell Research* (updated and published by the Canadian Institutes of Health Research in June 2007), the National Consultative Ethics Committee for Health and Life Sciences (CCNE) *Opinion on the Commercialisation of Human Stem Cells and Other Cell Lines* (2006) and the *Recommendations on the Ethical Review of hESC FP7 Research Projects* (2007), adopted by the European Group on Ethics in Science and New Technologies.

For a comprehensive listing of policies, laws and regulations on stem cell research adopted by different countries around the world, please visit the *Stem Cell World Map* found on our recently revamped StemGen website: www.stemgen.org

By way of information, I am off to further studies in Toronto and have delegated the responsibility for *HumGen* to Gillian Nycum, who is a new member of the team, and responsibility for *GenInfo* to Guillaume Sillon.

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

Human Genome Organization (HUGO): *HUGO Statement on Pharmacogenomics (PGx): Solidarity, Equity and Governance*
Montreal - May 1, 2007

Link: [URL](#)

Key Words: Access Info/Material - Benefit Sharing - Biobank - Community/Population - Consultation/Collaboration - Discrimination - Equity - Ethics Review Board - Governance - Justice - Pharmacogenomics - Research - Standard of Care - Storage

United Nations Educational, Scientific and Cultural Organization (UNESCO): *Educating Bioethics Committees*
Paris - January 1, 2007

Link: [URL](#)

Key Words: Autonomy - Beneficence - Benefit Sharing - Confidentiality - Consent - Discrimination - Education - Equity - Ethical Review - Ethics Review Board - Incompetent Adult - Justice - Patient/Participant/Individual - Privacy - Research - Respect for Human Life

European Group on Ethics in Science and New Technologies (European Commission) (EGE): *Recommendations on the Ethical Review of hESC FP7 Research Projects - Opinion No 22*
Brussels - June 20, 2007

Link: [URL](#)

Key Words: Biobank - Commercialization - Compensation for Participation - Confidentiality - Consent - Data - Dignity - Donor - Embryo - Ethical Review - Ethics Review Board - Governance - Pre-implantation - Privacy - Research - Researcher - Respect for Human Life - Right of Withdrawal - Stem Cell - Surplus Embryos - Umbilical Cord Blood

The European Nutrigenomics Organisation (NuGO): *Bioethics Guidelines on Human Studies*
Colney - October 1, 2006

Link: [URL](#)

Key Words: Access Info/Material - Benefit Sharing - Biobank - Consent - Databases - Research - Storage

NATIONAL

American Academy of Pediatrics (AAP): *Integrating Surveillance and Screening with the Medical home*
Elk Grove Village - August 13, 2007

Link: [URL](#)

Key Words: Communication of Results - Community/Population - Family - Genetic Screening - Genetic Services - Minor/Child - Newborn - Professional

American Cancer Society (ACS): *American Cancer Society Guidelines for Breast Screening with MRI as an Adjunct to Mammography*
Atlanta - March 1, 2007

Link: [URL](#)

Key Words: Cancer

American College of Obstetricians and Gynecologists (The) (ACOG): *ACOG*

Committee Opinion: Patents, Medicine and the Interests of Patients

Washington - May 1, 2007

Link: [URL](#)

Key Words: Beneficence - DNA - Patents - Patient/Participant/Individual - Professional

Australia/Government New South Wales - Department of Health: *Genetic Testing - Guidelines for Prioritising Genetic Tests*

North Sydney - July 6, 2007

Link: [URL](#)

Key Words: Adult - Counseling (general) - Criteria - Education - Equity - Genetic Testing - Minor/Child - Prenatal - Psychosocial Aspects

Belgium/Government: *Loi relative à la procréation médicalement assistée et à la destination des embryons surnuméraires et des gamètes*

Brussels - July 6, 2007

Link: [URL](#)

Key Words: Commercialization - Compensation for Participation - Confidentiality - Consent - Counseling (general) - Deceased - Donor - Embryo - Eugenics - Genetic Testing - Man/Paternity - Pre-implantation - Preconception - Privacy - Research - Surplus Embryos - Tissue - Woman/Maternity

Canada/Government: *Assisted Human Reproduction (Section 8 Consent) Regulations*

Ottawa - June 14, 2007

Link: [URL](#)

Key Words: Consent - Deceased - Donor - Embryo - Research - Right of Withdrawal - Stem Cell - Surplus Embryos - Third Party - Tissue

Canadian Institutes of Health Research (CIHR): *Updated Guidelines for Human Pluripotent Stem Cell Research, June 29, 2007*

Ottawa - June 29, 2007

Link: [URL](#)

Key Words: Adult - Commercialization - Compensation for Participation - Confidentiality - Conflict of Interest - Consent - Deceased - Donor - Embryo - Embryos (created for research) - Ethical Review - Ethics Review Board - Foetus - Gamete - Incompetent Adult - Privacy - Researcher - Right of Withdrawal - Stem Cell - Surplus Embryos - Therapeutic Cloning - Third Party - Tissue - Woman/Maternity

Greece - National Bioethics Commission: *Opinion on Prenatal and Pre-Implantation Diagnosis*

Athens - April 2, 2007

Link: [URL](#)

Key Words: Autonomy - Counseling (general) - Duty to Warn - Embryo - Eugenics - Family - Genetic Screening - Man/Paternity - Pre-implantation - Prenatal - Professional - Respect for Human Life - Woman/Maternity

Human Fertilisation and Embryology Authority (HFEA): *Human Tissue and Embryos (Draft) Bill - Volume I: Report*

London - August 1, 2007

Link: [URL](#)

Key Words: Consent - Embryo - Tissue

Joint Committee on the Human Tissue and Embryos: *Joint Committee on the Human Tissue and Embryos (Draft) Bill - First Report*

London - July 24, 2007

Link: [URL](#)

Key Words: Access Info/Material - Confidentiality - Gamete - Minor/Child - Privacy - Psychosocial Aspects

National Cancer Institute (NCI): *Elements of Cancer Genetics Risk Assessment and Counseling*

Bethesda - August 9, 2007

Link: [URL](#)

Key Words: Adult - Autonomy - Cancer - Communication of Results - Consent - Counseling (general) - Counseling (Post-test) - Counseling (Pre-test) - Criteria - Discrimination - Education - Genetic Testing - Privacy - Psychosocial Aspects

National Consultative Ethics Committee for Health and Life Sciences (CCNE):

Opinion (No. 93) Commercialisation of human stem cells and other cell lines

Paris - June 22, 2006

Link: [URL](#)

Key Words: Biobank - Commercialization - Consent - Dignity - Donor - Embryo - Patents - Patient/Participant/Individual - Public Health - Research - Researcher - Respect for Human Life - Stem Cell -

Therapeutic Cloning

National Council of Ethics for the Life Sciences (CNECV) - Portugal: *Opinion N. 51 on "Pre-Implantation Genetic Diagnosis"*

Lisbon - April 10, 2007

Link: [URL](#)

Key Words: Consent - Counseling (general) - Embryo - Follow-up - Genetic Testing - Pre-implantation - Psychosocial Aspects - Stem Cell

National Institutes of Health (NIH): *Policy for Sharing of Data Obtained in NIH Supported or Conducted Genome-Wide Association Studies (GWAS)*

Bethesda - August 22, 2007

Link: [URL](#)

Key Words: Access Info/Material - Benefit Sharing - Communication of Results - Confidentiality - Intellectual Property - Ownership - Patient/Participant/Individual - Population Genetics - Privacy - Public Health - Researcher

National Society of Genetic Counselors (NSGC): *National Society of Genetic Counselors Recommends Asking Questions Before Considering Genetic Testing*

Chicago - April 10, 2007

Link: [URL](#)

Key Words: Communication of Results - Counseling (general) - Education - Family - Follow-up - Genetic Services - Genetic Testing - Professional - Psychosocial Aspects - Right not to Know

NHS Sickle Cell and Thalassaemia Screening Programmes: *Sickle Cell and Thalassaemia: Handbook for Laboratories*

London - September 1, 2006

Link: [URL](#)

Key Words: Genetic Screening - Newborn - Prenatal

Nuffield Council on Bioethics: *Annual Report 2006*

London - May 24, 2007

Link: [URL](#)

Key Words: Community/Population - Ethical Review - Research

Spain/Government: *Law 14/2007, of 3 July, on Biomedical Research*

Madrid - July 3, 2007

Link: [URL](#)

Key Words: Assent/Dissent - Autonomy - Biobank - Commercialization - Compensation for Participation - Consent - Counseling (general) - Data - Databases - Dignity - Embryo - Embryos (created for research) - Equity - Ethical Review - Foetus - Genetic Screening - Genetic Testing - Germline Therapy - Incompetent Adult - Integrity - Patient/Participant/Individual - Pre-implantation - Preconception - Prenatal - Privacy - Professional - Research - Researcher - Respect for Human Life - Right not to Know - Right of Withdrawal - Stem Cell - Storage - Surplus Embryos - Therapeutic Cloning - Tissue - Waiver of Consent - Woman/Maternity

United States - Department of Health and Human Services (DHHS) - Food and Drug Administration (FDA): *Guidance for Industry and FDA Staff - Pharmacogenetic Tests and Genetic Tests for Heritable Markers*

Rockville - June 19, 2007

Link: [URL](#)


Key Words: Genetic Testing - Pharmacogenomics - Researcher

Science and Technology Ethics Committee (CEST): *Le don et la transplantation d'organes par échanges: considération éthiques sur une nouvelle option*

Québec - October 6, 2006

Link: [URL](#)

Key Words: Adult - Benefit Sharing - Commercialization - Consent - Donor - Ethical Review - Ownership - Public Health - Respect for Human Life

 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

CTS-IPITA-IXA 2007 Joint Conference

Organized by: Transplantation Society

Date: September 15-20, 2007

Location: Minneapolis, Minnesota, États-Unis

Information:

Annual General Meeting

Organized by: Académie canadienne des sciences de la santé

Date: September 17-19, 2007

Location: Montréal, Québec, Canada

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:

29e Conférence internationale des commissaires à la protection des données et de la vie privée

Organized by: Commissariat à la protection de la vie privée du Canada

Date: September 25-28, 2007

Location: Montréal, Québec, Canada

Information:

3rd Annual Clinical Trials in Canada Conference

Organized by: Insight Information

Date: October 1-2, 2007

Location: Toronto, Ontario, Canada

Information:

Gastein Forum

Organized by: European Health Forum

Date: October 3-6, 2007

Location: Bad Hofgastein, Autriche

Information:

26th Annual Education Conference

Organized by: National Society of Genetic Counselors

Date: October 12-16, 2007

Location: Kansas City, Missouri, États-Unis

Information:

2e Congrès international sur la Chaîne des médicaments « Regards interdisciplinaires sur la diversité et la complexité »

Organized by: Groupe d'étude sur l'interdisciplinarité et les représentations sociales

Date: October 14-17, 2007

Location: Montréal, Québec, Canada

Information:

Vision 2020 : L'adaptation au changement environnemental

Organized by: Génome Canada

Date: October 17-19, 2007

Location: Québec, Québec, Canada

Information:

3rd World Congress Regenerative Medicine (WCRM) : New Products for Diagnostic and Therapy

Organized by: Fraunhofer Institute for Cell Therapy and Immunology (IZI)

Date: October 18-20, 2007

Location: Leipzig, Allemagne
Information:

Public Population Project in Genomics General Meeting

Organized by: P3G Consortium
Date: October 22-23, 2007
Location: San Diego, Californie, 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:

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:

2007 CAGC Annual Educational Conference

Organized by: Association canadienne des conseillers en génétique
Date: November 15-18, 2007
Location: Vancouver, Colombie Britannique, Canada
Information:

Symposium international : "Translational Medicine and Public Health Policy: Lessons from Biobanks Ethical, Legal, Social Issues (ELSI)"

Organized by: Fondation Brocher
Date: December 6-7, 2007
Location: Genève, Suisse
Information:

 **TEAM PUBLICATIONS**

Joly Y., "**Open Source Approaches in Biotechnology: Utopia Revisited**", (2007) 59:2 *Maine Law Review*, 386, online: [URL](#)

Abstract: In the field of biotechnology, the patent system has had its share of detractors and has come under increasing criticism. It has been suggested that cooperative strategies such as open source could answer for inadequacies in the patent system. Yet, many of the presumed inefficiencies of the patent system are based merely on theoretical arguments and are not backed by evidence. Before discussing the feasibility cooperative strategies in the field of biotechnology, should we not ensure that such strategies are really needed to improve the system? Ultimately, support for open source

approaches should be based on the individual merits of these strategies rather than on the basis of theoretical inefficiencies in the patent system. Consequently, this article analyzes the claim that the patent system has created an anticommons in biotechnology and assesses the potential benefits of open source reported in the literature. The strategic use of collaborative approaches such as open source could facilitate the development of a dynamic biomedical research sector in academia and one that continues to work in the spirit of open science.

 EDITORIAL TEAM

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