



# GENINFO

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

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The development of umbilical cord blood, as a source of haematopoietic stem cells for cellular therapies or regenerative medicine, has led to the emergence of public and private cord blood banks worldwide. Umbilical cord blood cells stored in public banks are made available to any suitably matched recipient, whereas, private banks allow parents to store their newborn's cord blood for the benefit of the donor or family members. This coexistence of public and private banks has created much debate and resulted in the adoption of policy statements and opinions by professional organizations or advisory groups. Thus, the focus of this month's issue of GenInfo is on cord blood banking. I invite you to read the latest *GenEdit* issue entitled, "Umbilical Cord Blood Banking," as well as the revised policy statement on cord blood banking adopted by the *American Academy of Pediatrics*.

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

INTERNATIONAL / REGIONAL

**European Commission:** *Ethical Considerations for Clinical Trials Performed in Children - 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 - October 6, 2006

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

**Key Words:** Assent/Dissent - Consent - Ethical Review - Minor/Child - Newborn - Research

**European Commission's Joint Research Centre - Institute for Prospective Technological Studies:** *Pharmacogenetics and Pharmacogenomics: State-of-the-Art and Potential Socio-Economic Impact in the EU*

Luxembourg - April 1, 2006

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

**Key Words:** Commercialization - Education - Governance - Liability - Pharmacogenomics - Research - Researcher - Socio-Economic Aspects - State

**European Medicines Agency:** *Note for Guidance on Establishing Definitions for Genomic Biomarkers, Pharmacogenomics, Pharmacogenetics, Genomic Data and Sample Coding Categories*

London - November 1, 2006

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

**Key Words:** Access Info/Material - Confidentiality - Data - Databases - DNA - Pharmacogenomics - Research - Researcher

NATIONAL

**American Academy of Pediatrics (AAP):** *Cord Blood Banking for Potential Future Transplantation*

Elk Grove Village - January 1, 2007

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

**Key Words:** Confidentiality - Conflict of Interest - Consent - Donor - Ethical Review - Ethics Review Board - Family - Governance - Man/Paternity - Professional - Recruitment - Researcher - Storage - Tissue - Umbilical Cord Blood - Waiver of Consent - Woman/Maternity

**Health Canada:** *Guidance Document: Submission of Pharmacogenomic Information*

Ottawa - February 14, 2007

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

**Key Words:** Access Info/Material - Biobank - Community/Population - Consent - Data - DNA - Ethics Review Board - Follow-up - Genetic Testing - Patient/Participant/Individual - Pharmacogenomics - Research

**Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS):** *Realizing the Promise of Pharmacogenomics: Opportunities and Challenges [Draft Report]*

Bethesda - March 23, 2007

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

**Key Words:** Access Info/Material - Benefit Sharing - Commercialization - Communication of Results - Confidentiality - Consent - Consultation/Collaboration - Counseling (general) - Discrimination - Education - Governance - Intellectual Property - Ownership - Pharmacogenomics - Privacy - Public Health - Researcher - Socio-Economic Aspects - State

**Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS):** *Policy Issues Associated with Undertaking a New Large U.S. Population Cohort Study of Genes, Environment, and Disease*

Bethesda - March 1, 2007

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

**Key Words:** Community/Population - Consultation/Collaboration - Data - Education - Ethics Review Board - Intellectual Property - Population Genetics - Privacy - Research

**United States/House of Representatives:** *A Bill to Prohibit the Patenting of Human Genetic Material*

Washington - February 9, 2007

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

**Key Words:** DNA - Patents

**United States/House of Representatives:** *H.R. 1038: To amend the Public Health Service Act to Provide for the Licensing of Comparable and Interchangeable Biological Products, and for Other Purposes.*

Washington - February 14, 2007

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

**Key Words:** Governance - Intellectual Property - Public Health - State

**Canada/ Gouvernement Québec - Agence d'évaluation des technologies et des modes d'intervention en santé (AETMIS):** *La spectrométrie de masse en tandem et le dépistage néonatal sanguin au Québec*

Montréal - March 1, 2007

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

**Key Words:** Access Info/Material - Beneficence - Communication of Results - Confidentiality - Consent - Counseling (general) - Databases - Discrimination - Education - Family - Follow-up - Genetic Screening - Man/Paternity - Newborn - Patient/Participant/Individual - Professional - Research - Socio-Economic Aspects - Woman/Maternity

**Quebec/Government - Ministry of Health and Social Services:** *Rapports annuels des comités d'éthique de la recherche désignés, Exercice 2005-2006, Points saillants*

Québec - April 3, 2007

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

**Key Words:** Ethical Review - Ethics Review Board - Research

## 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

### **The 20th Anniversary of the DMD gene discovery: Impact on muscle biology, disease, and therapy**

**Organized by:** Institut de recherche en santé d'Ottawa (IRSO)

**Date:** May 3-5, 2007

**Location:** Ottawa, Ontario, Canada

**Information:**

### **12th Human Genome Meeting**

**Organized by:** Human Genome Organisation (HUGO)

**Date:** May 21-24, 2007

**Location:** Montréal, Québec, Canada

**Information:**

### **Atelier de formation annuel 2007**

**Organized by:** Association des conseillères et conseillers en génétique du Québec (ACCGQ)

**Date:** May 25, 2007

**Location:** Montréal, Québec, Canada

**Information:** [infoACCGQ@gmail.com](mailto:infoACCGQ@gmail.com)

### **2007 Joint Ethics Committee : 18ème conférence annuelle de la Société canadienne de bioéthique et 3ème conférence internationale sur l'éthique clinique et la consultation**

**Organized by:** Société canadienne de bioéthique

**Date:** May 30-June 3, 2007

**Location:** Toronto, Ontario, Canada  
**Information:**

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**2007 Annual Meeting - International Biobanking Standards**  
**Organized by:** International Society for Biological and Environmental Repositories (ISBER)  
**Date:** May 30-June 2, 2007  
**Location:** Singapour, Singapour  
**Information:**

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**26th Annual Education Conference**  
**Organized by:** National Society of Genetic Counselors  
**Date:** October 12-16, 2007  
**Location:** Kansas City, Missouri, États-Unis  
**Information:**

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**Visions National Health Law Conference**  
**Organized by:** Health Law Institute, Université d'Alberta  
**Date:** November 8-10, 2007  
**Location:** Banff, Alberta, Canada  
**Information:**

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**Première table ronde canadienne sur l'éthique en santé publique : explorons les bases**  
**Organized by:** Agence de santé publique du Canada (Facilitateur)  
**Date:** November 8-9, 2007  
**Location:** Montréal, Québec, Canada  
**Information:**

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**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:**

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