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## Ancestry in Health and Medicine Workshop - April 8-9th, 2008



On April 8 and 9 2008 in the heart of Toronto's downtown, a team of international and interdisciplinary leaders met to participate in the workshop *Ancestry in Health and Medicine: Expanding the Debate*.

Held in the McLaughlin-Rotman Centre for Global Health at the University of Toronto, the goal of the workshop was to explore the intersections of the notions of "race" and ancestry with population-based genetic research and medicine. Presentations focused on the science and the use of the terms race, ethnicity and ancestry in research and their social, ethical and cultural

implications. Select legal and regulatory aspects on topic, and the communication of related scientific findings both in the popular press and academic literature were also discussed.

The workshop was co-chaired by GE3LS PIs Abdallah Daar and Timothy Caulfield and was made possible by the generous support of the McLaughlin-Rotman Centre for Global Health, the Ontario Genomics Institute, AFMNet, and Genome Alberta.



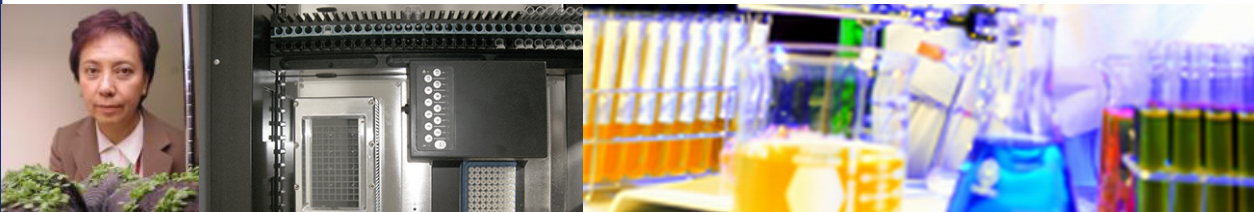
### In this Issue

1. Ancestry in Health and Medicine
2. PIs Einsiedel/Veeman: Updates
3. Nutrigenomics: Issues
4. Consensus: Research Ethics
5. Myriad and the Media
6. News from the U of Saskatchewan
7. Cord Blood Donation / Perspectives
8. Public Approval of Funds spent on GE3LS Research: PMF
9. GE3LS Alberta Upcoming Events

## Panel on Public Engagement and Biotech



On February 11th, 2008, GE3LS PI Edna Einsiedel participated in *Assessing Public Engagement Related to Biotechnology: An International Panel*, an event that explored public deliberation related to genomics and biotechnology policy in Canada and New Zealand. It was held at the University of British Columbia's W. Maurice Young Centre for Applied Ethics and was chaired by fellow GE3LS researcher Michael Burgess. In addition to Einsiedel, the panel members included Joanna Goven, University of Canterbury, Kieran O'Doherty, University of British Columbia, Conrad Brunk, University of Victoria, and Brian Wynne, Lancaster University. Einsiedel presented her recent work on Plant Molecular Farming consultation, while Goven discussed the research project "Constructive Conversations/Korero Whakaaetanga: Biotechnologies, dialogue and informed decision-making", a study in which she is a Co-PI. O'Doherty presented data from "Deliberative Democracy and Biobanks", a project that has held deliberative events on biobanks in BC and at the Mayo Clinic. Commentary was provided by Brunk and Wynne.



### PI edits new book on Emerging Technologies

The book *Emerging technologies: hindsight and foresight*, edited by GE3LS PI Edna Einsiedel and published by UBC Press will be released this Fall. The book includes contributions by various GE3LS researchers including Timothy Caulfield, Michele Veeman, Peter Phillips, Lori Sheremeta, and Rose Geransar from the GE3LS Alberta team, and Mike Burgess, James Tansey and Ed Levy from the GE3LS BC team. Other international authors are also featured. The book explores the complex and interrelated ethical, legal and social issues, in addition to policy and regulatory challenges, associated with pharmacogenomics, stem cell research, plant-made vaccines and nanotechnologies.

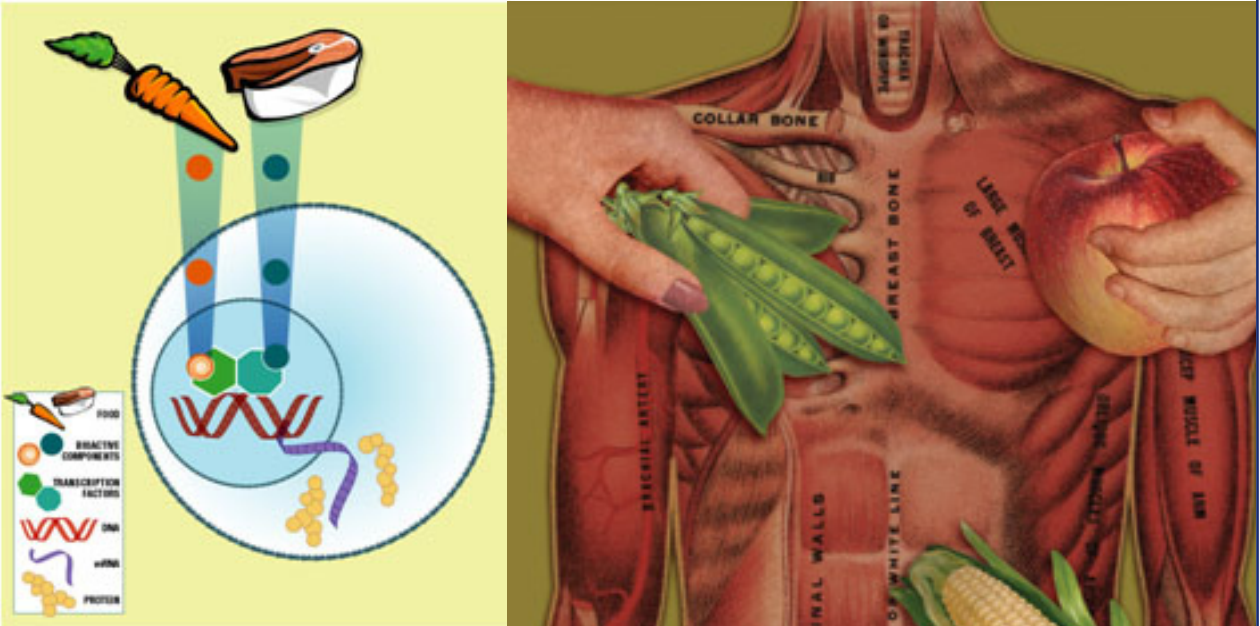
The book cover's photo also happens to be wonderfully appropriate. It is a scale of a zebrafish, and these fish are currently used in many research areas such as toxicogenomics, genetics, stem cells and regenerative medicine, some nanotechnologies, and human neuronal degenerative diseases.

### PI contributes chapter to book on 21st Century Agriculture

Michele M. Veeman, 2007. "Policy for GM Food: Why is it so hard to agree?" (Edited by R. D. Knutson S. D. Knutson and D. P. Ernstes). *Perspectives on 21st Century Agriculture: A tribute to Walter J. Armbruster*. Oak Brook: Farm Foundation. Pp.267-275.

Current international disparities in policy for food derived from modern agricultural biotechnology and the bases for these differences are overviewed in this paper. Focus is placed on policies for food labeling at the national level as well as on the international impasse that has been reached in the Codex Alimentarius food labelling process. The inability to come to a consensus on an international standard for GM food labelling through Codex reflects differences in beliefs and cultural values relative to food, challenges the WTO dispute settlement process, and has major implications for international trade in agricultural and food products.

## Regulatory & Social Issues in Nutrigenomics: Research Update



**G**E3LS researchers David Castle and Timothy Caulfield are co-investigators on a three-year research project examining regulatory and social issues in nutritional genomics. This project, now into its second year, is funded through the Advanced Foods & Materials Network (AFMNet).

**T**he research team, which includes Karine Morin (UOttawa), Nola Ries (UAlberta & UVic) and Tania Bubela (UAlberta) has focused on several key issues including regulatory framework for genetic tests and direct-to-consumer sale of tests; capacity of health care providers to integrate nutrigenomics into practice; media representations of nutrigenomics; and consumer knowledge and attitudes regarding nutrigenomics

**T**he team collaborated with the Public Health Agency of Canada in carrying out 16 focus groups across Canada with members of the public and health care providers, including dietitians, physicians, pharmacists and naturopaths. This research reveals current levels of understanding about links between nutrition, genetics and health, and perspectives of various groups on the potential benefits and harms of this area of personalized genomics.

**A** special collection of articles based on the team's research was published in the latest issue of the University of Alberta's Health Law Review. The table of contents is available at: [http://www.law.ualberta.ca/centres/hli/hl\\_review.html](http://www.law.ualberta.ca/centres/hli/hl_review.html)

**R**esearch from this project will be presented at the Genome Canada GE3LS Symposium (April 28-30th, Calgary), the "Translating ELSI" conference (May 1-3rd, Cleveland), the Asia Pacific Nutrigenomics Conference on "Diet-Gene Interaction in Human Health and Disease" (May 6-9th, Melbourne) and the Canadian Bioethics Society Annual Conference (June 18-21st, St. John's).

**D**avid Castle and Nola Ries are co-editing a book, *Nutrition and Genomics: Issues of Ethics, Law Regulation and Communication*, with contributors writing on the science of nutrigenomics; regulatory frameworks for genetic tests, foods and health products; public health dimensions; health care practice; popular representations; consumer perspectives on nutrition, genetics and health; and the relationship between food and medicine. The book will be published by Elsevier in late 2008 or early 2009.

## Whole-Genome Research Research Ethics: Consensus

T. Caulfield et al., "Research ethics recommendations for whole-genome research: consensus statement." (2008) 6(3) PLoS Biology e73.

### Synopsis:

To date, there has been only minimal consideration of the research ethics issues associated with whole genome research. Accordingly, an interdisciplinary consensus workshop was convened to develop ethically rigorous and practical guidance for investigators and research ethics boards. The four topics that were the focus of the workshop—consent, withdrawal from research, return of research results, and public data release—were selected because they were viewed as being among the most pressing research ethics issues and as representing areas where whole-genome analysis creates unique challenges. They are not, of course, intended to be framed as the only policy issues that need to be considered; commercialization, patenting, benefit sharing, and the possibility of genetic discrimination are among other topics that warrant reflection.

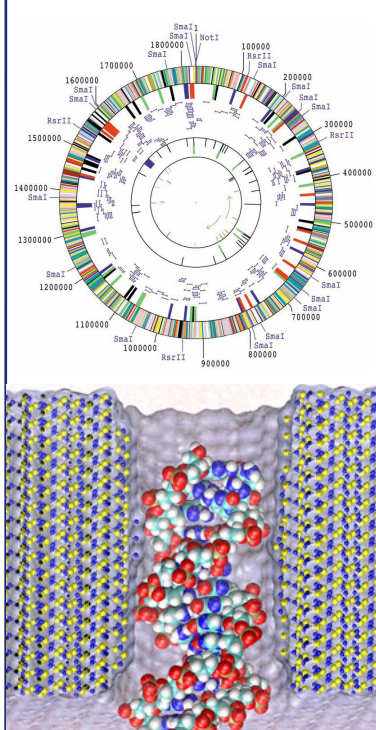
The results of the workshop were published as the above consensus statement for PLoS Biology. The paper starts with initial considerations, including general recommendations about governance and the characterization of the research activities related to the whole genome. It is important to note that while there was consensus on all recommendations, there was a good deal of debate about the degree to which they satisfy existing ethical and legal norms. All participants believed that we need both empirical research and continued conceptual analysis. These are early days in the field of whole-genome research. Research ethics guidance is needed immediately, but we should continue to explore the ethical, legal, and social implications of this rapidly evolving field.

Read the full consensus statement on PLoS Biology's website. PLoS Biology is an open-access journal: <http://biology.plosjournals.org> doi:10.1371/journal.pbio.0060073

For related articles, see:

A.L. McGuire, M.K. Cho, S.E. McGuire & T. Caulfield, "The Future of Personal Genomics". (2007) 317 Science 1687.

A.L. McGuire, T. Caulfield & M.K. Cho, "Research ethics and the challenge of whole-genome sequencing" (2008) 9(2) Nat Rev Genet 152-156.



## Featured Publication:

Timothy Caulfield, Tania Bubela & CJ Murdoch, "Myriad and the Mass Media: The Covering of a Gene Patent Controversy." (2007) 9(12) *Genetics in Medicine* 850-855.

### Abstract:

**Purpose:** We explore how the print media in four jurisdictions framed the controversy surrounding Myriad Genetic's BRCA patents and consider the possible influence of media on public perceptions and policy reform.

**Method:** We used a broad search strategy to collect newspaper articles from Factiva and Lexis/Nexis on Myriad Genetics and the BRCA gene and identified the main triggers for those articles. We then selected articles on the BRCA gene patents for coding. The coding frame queried the presence or absence of either positive or negative statements about gene patenting and a subjective assessment of the tone of the article. We compared the differences in tone and number of positive and negative statements between jurisdictions (Australia, Canada, United Kingdom, and United States).

**Results:** Myriad Genetic's BRCA1/2 gene patents sparked significant international newspaper coverage in comparison to other stories on gene patenting controversies. Only 55.9% of 143 articles presented a variety of perspectives. The majority of articles (77.6%) had a negative overall tenor; only 6.29% had a positive overall tenor, whereas 16.1% were neutral. There were significant differences in the overall tenor between jurisdictions, with Canadian coverage being overwhelmingly negative in comparison with the other three jurisdictions. The main triggers for news coverage were largely local licensing deals, actions at regional patent offices, and statements and publications by prominent figures.

**Conclusion:** Myriad's patents were largely portrayed as a negative story, except in Utah where Myriad Genetics is located, and as an example of the problems associated with gene patents. The story was primarily framed as a social dilemma that needed to be addressed. In Canada there was a disproportionate level of coverage of the political response to the threat of patent infringement action against government testing laboratories and potential impacts on public health care. In Europe and elsewhere in the United States, the opposition to gene patenting at the European Patent Office predominated. In these contexts, our data provide some support that the media coverage helped to drive the policy agenda, although the resultant policy response received almost no media attention.



**Jocelyn Orb** successfully defended her MA (Political Studies) thesis at the University of Saskatchewan in March. The thesis, entitled “The Political Economy of Public-Private Partnerships: Forestry Co-management in Northwest Saskatchewan”, examines the political economy of public-private partnerships (PPPs), specifically how power has been shared among the partners involved in the co-management of forestry lands in Northwest Saskatchewan. It uncovers the political agendas of the groups involved, how decisions have been made and costs/benefits been shared, and considers the implications this model of co-management has for the future of resource development in this province. The study reveals a complex partnership in which power is not being shared equally. A private corporation, Mistik Management Ltd., possesses power over production, knowledge and credit. It purports to be working together with stakeholders in the co-management of forestry lands in Northwest Saskatchewan, but in truth Mistik is managing this resource with minimal input from forest users and residents in the region. The company does, however, appear sincere in its consultation process with stakeholders and is trying to improve the level of their engagement in day to day forestry operations. In addition, and despite this deficiency in stakeholder engagement, Mistik is practicing what is arguably the most environmentally sustainable forestry management in the province. Ms Orb received financial support from the GELS Alberta project and Peter Phillips, Co-PI of this project, supervised the thesis. The thesis is being converted into a journal article for future publication.

**Peter Phillips** completed in March the last of three annual research visits to the Institute of Advanced Studies, University of Western Australia, in Perth, AU. During his appointment as Professor at Large at the Institute of Advance Studies he presented three public lectures, ran two master classes, consulted with the biotechnology research and policy community, and, on March 19-20, held a research colloquium on public private research and commercialization partnerships. The purpose of the 1.5-day invited symposium was to examine the methodologies and processes used to develop, manage and assess public-private partnerships (PPPs) that support knowledge translation (i.e. research design, research management and commercialization), especially for advanced scientific and technical methods and the resulting agri-food products. About 18 scholars (agricultural economics, business, and politics), practitioners (CEOs and business managers from various Australian PPPs) and policy advisors (policy advisors in the Grains Research and Development Corporation (GRDC), and a variety of other organizations) from Western Australia and the Commonwealth attended and participated in the event. Phillips made a presentation on some new primary research on public private partnerships (entitled “Public-private partnerships in the global agri-food system: An emerging Australian model?”) and more than 12 participants made informal presentations on the nature of the specific partnerships they are involved with. A summary report of the colloquium is forthcoming.

**Peter Phillips** and USask GELS research staff **Bill Boland** and **Bo Jiang** have produced a working paper entitled “Public-private partnerships in the global agri-food system: An emerging Australian model?”. The paper examines in theory and practice the model of public-private partnership. This model is being used extensively in the national and international structures and substructures of research, development, commercialization and knowledge management that have emerged in the past generation in the global agri-food system. This paper examines four functioning networks/sub-networks of RD&C—one each in Australia and Canada and then the global pulse and canola systems—and two competing knowledge management systems (PIPRA and Cambia). The networks each involve a range of 33-43 network actors, a wide range of interconnective densities and an array of central actors. While Canada and Australia exhibit many similarities, there are substantive differences. Australia appears to have a more systematic research system, with the GRDC and a few other PPPs occupying central positions in both the national and some international networks; there are not obvious central actors in Australia in the downstream development and commercialization phases. In contrast, Canada does not have the same focus to its RD&C systems (different PPPs occupy leadership roles in different stages system), but there are clear central actors in most stages of research, development and commercialization (except for canola, where the private sector has been left to lead). The different systems are weakly correlated with differential commercialization results, with the Australian system producing moderately more varieties relative to its cropped base in most crops except barley and rapeseed, where Canada has a lead. A copy of the working paper can be downloaded from [agbio-management.org](http://agbio-management.org). The paper is currently being reworked into a journal article.

## Cord Blood Donation and Canadian Parents' Perspectives: Towards a Donor-Centric Consent Process



Rose Geransar, a GE3LS Genome Alberta trainee, has recently become the recipient of a Frederick Banting and Charles Best Canada Graduate Scholarship for her Ph.D. project entitled: "Ethical and legal issues of informed consent in public umbilical cord blood banking." The award is provided by the Canadian Institutes of Health Research in honour of Sir Banting and Dr. Best's contribution to health care as co-discoverers of insulin.

Human umbilical cord blood (UCB) is a rich source of hematopoietic progenitor cells that are currently used in the treatment of various oncologic and hematologic disorders. UCB is also a source of mesenchymal progenitor cells that have shown to be promising in the field of regenerative medicine. The strong clinical and research potential of cord blood stem cells has fueled the establishment of private and public cord blood banks dedicated to its collection, storage and use worldwide.

Canada is currently moving towards developing a National Public Blood Program. Such a federally funded program is likely to utilize the existing public and private cord blood banking infrastructure in Canada and be administered through the Canadian Blood Services. However, many issues in the consent process have yet to be explored, and there is a pressing need for standardization of consent protocols across the country.

The Ph.D. project consists of three components to explore the consent process. First, a multiple case study is underway with public cord blood banks across Canada to qualitatively assess the effectiveness of the consent process for the collection, storage and use of UCB for clinical and/ or research applications from the perspective of parents who have donated UCB. Second, a mock consent process has been conducted with expectant couples in the third trimester of their pregnancies in the Calgary Health Region in order to prospectively explore key aspects of the informed consent process (who should consent, timing of consent, information provision, etc.) and whether and how informational resources for UCB donation should be incorporated in prenatal education. Third, the online literature and consent documents employed by national cord blood banks in other developed countries are being used as comparison cases to provide insight on the consent processes used in Canada.

The project began as an MSc thesis and has since expanded to a PhD project due to positive organizational and parental responses in the initial phases of recruitment and the potential for increased scope and depth of analysis. The aim is to contribute to the development of a consent process for a National Cord Blood Program in Canada.

Rose is a Ph.D. student in the Department of Community Health Sciences, Faculty of Medicine, University of Calgary. Her project is supervised by Dr. Glenys Godlovitch. She has worked with Genome Alberta GE3LS Investigator Dr. Edna Einsiedel since May 2003.

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## Update on the Plant Molecular Farming Case Study: Do Canadians approve of spending public funds on GE3LS research?



The Alberta Genome GE3LS project includes case studies of “Plant Molecular Farming” (the application, to plants, of molecular biological techniques to produce a variety of new plant-based nonfood products, such as medicines and vaccines, as well as industrial products, such as biofuels). These plant products may have many benefits, but also introduce risks from possible contamination of the food system and the natural environment, as well as posing risks to wildlife from ingestion of PMF plant materials. Analysis of some of the data from a Canada-wide survey by Genome Alberta researchers, Michele Veeman and Wiktor Adamowicz, with graduate student Shiyi Tao and Post-Doctoral Fellow Dmitry Volinski, sheds light on the question of whether Canadians would vote to fund PMF research.

Some 1500 respondents, drawn from a representative national panel, completed a stated choice experiment to express their preferences for funding different types of PMF research by choosing between a series of different research plans with different funding allocations. Research plan choices varied both in the total amount of public funds to be allocated and in their award to five different areas of PMF research. The five research areas are “Health” (to develop cheaper and more available PMF-based medicinal drugs directed to human problems of health and disease); “Industry” (to develop cheaper and more available industrial products such as alternative energy sources or fibre products); “Environment” (to assess & limit the impacts of PMF on wildlife and ecology as well as on soil, water and other components of the natural environment); “Consumer” (to develop nutritionally improved food and other products that have extra benefits to consumers that are not available through conventional food products and/or lower prices); and “Social, economic & public policy” (to identify and address public acceptance, social and ethical concerns and economic implications and to provide guidance on potential regulations (such as patents, identity preservation and labelling) that may be applied to PMF).

In each choice, respondents could choose between: the current funding level and allocations (Plan A); or choose one of two alternative plans in which total funding and the allocations to different areas were varied (plans B and C); or choose to award no public funding at all to PMF research. Many chose the status quo, few chose no funding, and some chose new research plans and allocations. From the results of conditional logit models of respondents’ choices we see general support for public research allocations to each of the five different areas of PMF applications. In simulating the preferred allocations overall of a representative individual, we find the most preferred research area to be Health, followed by Environment. Social, economic & public policy is the third favoured research area, followed by Consumer, while Industry is the least favoured research area. An extension of the analysis in this decision-making approach to one that uses individual choices as input into the preferences of a decision maker with limited information is being pursued.

Funding from Genome Alberta and the Alberta Agricultural Research Institute, with the Alberta Crop Industry Development Fund, supported this study.

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## GE3LS Alberta: Upcoming Events

1) **Popular Representations and Science Communication Workshop**  
Washington DC, June 8-9, 2008

GE3LS researcher Timothy Caulfield and the Health Law Institute's Ubaka Ogbogu are hosting a workshop in Washington D.C. on popular representations and science communications. This workshop will bring together an international group of experts to discuss the role popular/media representations of science (specifically, emerging health related biotechnologies) play in the formulation of public perceptions and policy development. Desired outcomes of this event will be the development of policy recommendations and best practices for effective and balanced communication of science stories.

2) **Imagining Science: An Artistic Exploration of Science, Society and Social Change**  
**Public Exhibition:** Art Gallery of Alberta, November 14, 2008 – February 1, 2009  
**Publication:** November 14, 2008

These additional components of the *Imagining Science* project will continue the exploration of this innovative project that began last August in Banff, AB. It is anticipated the exhibition will display a variety of media, potentially including paintings, photographs, sculptures which permit human occupation, found object installations, manipulated biological material, or teratoma meat sculptures. The accompanying publication will contain reproductions of original art exhibited in addition to short essays exploring the interface between art and science.

3) **The Age of Personalized Genomics: 5th International DNA Sampling Conference**  
Banff AB, September 16-19, 2009

Genome Alberta and Genome Quebec GE3LS researchers Timothy Caulfield and Bartha Knoppers respectively will co-chair and host the upcoming *5th International DNA Sampling Conference: The Age of Personalized Genomics*, September 16-19th, 2009 at the Rimrock Resort Hotel in Banff. This conference will focus on the rapidly emerging field of personalized genomics, with specific consideration given to the various legal, ethical and social challenges this area of research raises, in addition to its impact on health care delivery, and its representation within both the media and policy communities.

For more information regarding the above events please contact Robyn Hyde-Lay at:  
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Newsletter Compiled by Robyn Hyde-Lay and  
CJ Murdoch.

The GE<sup>3</sup>LS project is supported by Genome  
Alberta and Genome Canada, a not-for-profit  
organization which is leading Canada's na-  
tional strategy on genomics with \$600 million  
in funding from the federal government.



**Genome**Alberta