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Genome Alberta

## GE<sup>3</sup>LS Second Annual Joint Biotechnology Workshop - September 14th-16th, 2006



While rain and strong winds in the harbour ushered in the ineluctable chill of an impending fall, researchers from across Canada gathered at the Coast Harbourside Hotel in Victoria, British Columbia for the Second Annual Joint Biotechnology Workshop. This interdisciplinary event set out to provide a forum for better comprehension, debate, and analysis of the issues which arise in the junctures between science, the law, public policy, ethics, and personal health. The twenty participants, who hailed from research centers as geographically disparate as Halifax and Vancouver, were researchers and trainees from a variety of disciplines, including Law, Communications Studies, Journalism, Biology, Resource Management, Community Health Sciences,

and Ethics.

This workshop was also unique inasmuch as it was organized and implemented by student researchers at the University of Alberta's Health Law Institute. Organizers accordingly gained the valuable experience of planning, developing and hosting a highly successful academic workshop.

The event was made possible due to the generous support of Genome Alberta, Genome British Columbia, The Stem Cell Network, The Advanced Foods and Materials Network, and The Canadian Institutes of Health Research.

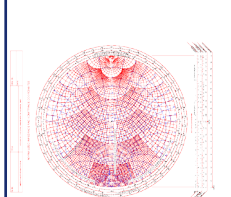
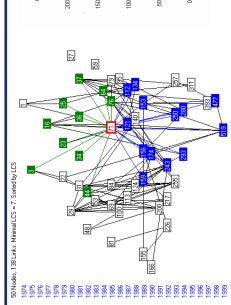
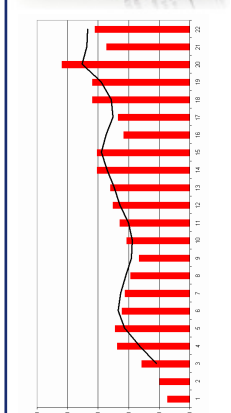
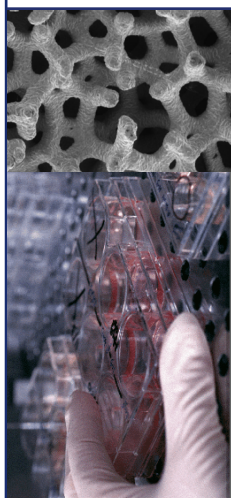
This edition of the GE<sup>3</sup>LS Newsletter includes several summaries of talks delivered by participants which showcase the breadth and depth of material covered at the event.

### Upcoming GE<sup>3</sup>LS Events

**2006.11.13-15:**  
Stem Cell Network Annual General Meeting - Ottawa, ON.

### In this Issue

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## Joint Biotechnology Workshop - Featured Presentations

### Policy Approaches to Human Embryonic Stem Cell Research and Informed Consent Guidelines

Kanchana Fernando, University of Alberta

There are few scientific discoveries which have raised more concern among scientists, government and the public than the permissibility of conducting research on embryos. In particular, research on human embryonic stem cells (hESC) challenges governments with balancing the therapeutic prospects of such research with the complex moral and ethical issues involved. Such a balancing act is achieved by various means. To articulate a taxonomy of these means, academics have identified 3 main approaches: liberal, intermediate and restrictive. These approaches are used to label the general trend of law and policy relating to hESC. But is this general trend reflected in the constituent elements of the regulations? Can a piece of legislation follow one trend, yet in the details obey another? This study begins by discussing the 3 approaches to hESC research, as developed by Isasi & Knoppers. Each approach will be examined in terms of the role of government, the justification of the policy and the details involving hESC research. Then informed consent guidelines in three jurisdictions (U.K., Canada, and U.S.), each of which follow one of the 3 approaches developed by Isasi & Knoppers, will be examined. Informed consent guidelines are particularly important in hESC research, as they act as the gateway to other legal issues such as commercialization and conflicts of interest. Where informed consent regulations/policies are particularly onerous or strict, this can negatively affect access to hESC research from a researcher perspective. The trend of the specific consent guidelines will be identified, in order to examine whether this specific part of the legislation/policy corresponds to the overall approach of hESC research.

### An Evaluation of GE3LS Public Engagement Activities

Holly Longstaff, University of British Columbia

Public engagement is a significant challenge for many social scientists, physical scientists, and policy makers involved in genetics and genomics research. Despite our commitment to public involvement and extensive research in this area, we continue to struggle with many long standing criticisms (i.e., how to achieve representativeness, sampling biases) and barriers (i.e., apathy, ignorance, funding limitations). I argue that evaluating and comparing methods is an effective way to illuminate aspects of various approaches that will help us to ultimately reach our goals. For five weeks this spring, I had the opportunity to conduct research in this area with support from the Stichting Porticus Foundation's Multidisciplinary Human Gene Technology, Research, and Therapy Project Scholarship Programme. My research resulted in a paper in which I discuss the public engagement efforts of the Genetics and Society Project at the University of Montreal (GSP) and The W. Maurice Young Centre for Applied Ethics at the University of British Columbia (CAE). I explored the strengths and limitations of all current engagement activities at each centre by comparing them against sets of pre-determined motivational and evaluation criteria. The following five questions guided this analysis: (1) what truly motivates our public engagement efforts?; (2) do our efforts meet our objectives?; (3) how do our projects fare against motivational criteria outlined by Public Agenda and the Government of Canada's evaluative criteria?; (4) what are the points of convergence and divergence between GSP and CAE projects?; and (5) how can we help each other to better serve our publics? I found that each Centre is deeply committed to GE3LS public engagement activities. The analysis I conducted provided insight into points of convergence and divergence between GSP and CAE projects and identified numerous opportunities for collaboration.

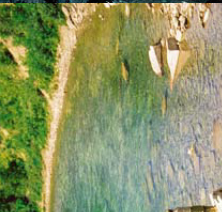
## Joint Biotechnology Workshop - Featured Presentations

### Of Hopes and Fears: Internet Direct-to-Consumer Advertising for Genetic Testing Rose Geransar, University of Calgary

The recent push towards commercialization of genetic technologies has expanded the horizons for the marketing and sales of genetic tests direct to consumers (DTC). This study on internet DTC advertising for genetic testing used a mixed method approach to assess: 1) standards of companies engaged in DTC advertisements, and 2) the way risk and benefit information was presented to consumers. Key words entered into popular internet search engines generated links to twenty-four international companies engaging in DTC advertising. Types of tests being offered were classified as: diagnostic (e.g. for cystic fibrosis), risk assessment (e.g. for breast and ovarian cancer), or enhancement (e.g. nutrigenetic and pharmacogenetic tests). Requirements for physician mediation and genetic counseling, discussion of benefits and risks were coded and themes were developed across advertisements. Companies offering risk assessment and diagnostic tests were most likely to require that tests be mediated by a clinician, and to recommend physician-arranged counseling. Companies offering enhancement tests were more likely not to require physician mediation of services, and to provide long-distance genetic counseling. Companies offering risk assessment and enhancement tests tended to have incomplete discussions of benefits and risks, and to use genetic metaphors to construct the value of their genetic tests. Discussions of health etiology were common but sometimes clouded by the use of emotive/ misleading slogans and phrases. Overall, misrepresentation or lack of information, absence of requirement for clinician mediation, and provision of long-distance genetic counseling were most commonly observed for companies offering low clinical utility tests for multifactorial health conditions.

### Learning to swim with salmon: embedding a journalist in a science project David Secko, University of British Columbia

At the 2nd Annual Joint Biotechnology Workshop, Victoria, BC, David Secko spoke on the challenges that democratic public engagement must meet in terms of coping with information. Undeniably, in the case of genomics, much of this information is scientific and hence conceptually complex, as well as riddled with technical jargon and the vested interests of experts in developing their own field. Efforts to engage citizens about genomics therefore need to gauge what information allows effective democratic deliberation, plus how to obtain, assess, and present it. Secko, a post-doctoral fellow with the Centre for Applied Ethics at the University of British Columbia, who is also a science journalist, presented experiments with the use of journalism as a way to cope with some of these challenges. The experiments are a result of collaboration between two projects: the consortium for Genomics Research on All Salmonids Project (cGRASP) and Building a GE3LS Architecture (GE3LS Arch). The work resulted in construction of sample test news stories on salmon genomics, and the suggestion that embedding journalism in a GE3LS project may be a way to: (i) critically assess the information to be used for democratic public engagement, and (ii) reflect on and sustain democratic debate.



## 2006 Meeting of the American Society of Human Genetics



The Ernest N. Morial Convention Center in New Orleans where the 2006 ASHG Annual Meeting took place.

### Event ELSI Summary by Alethea Adair

Health Law Institute Research Director and GE3LS Principal Investigator Timothy Caulfield, along with researchers Michael Sharp and Alethea Adair recently attended the American Society of Human Genetics (ASHG) annual meeting in New Orleans, Louisiana (October 9 to 13, 2006).

This year, the conference opened with sessions on ethical, legal, and social issues (ELSI) for genetic research, raising hot topics such as the current regulatory climate, personalized medicine and pharmacogenetics, and direct to consumer genetic testing. Across the board, the speakers raised difficult questions, such as the following:

- As the need for diagnostics for pharmaceuticals becomes increasingly important, should the divided regulatory processes for these heretofore separate agencies be merged? (Amelia Lissa)
- Should there be a system in place to ensure that pharmacogenetic developers can gain access to and follow up on genetic information related to their drug? (David Goldberg)
- Does focusing solely on the individual as the unit for ethical analysis occlude from view group-related risks and harms? (Sandra Soo-Jin Lee)
- Are developments in genetics ushering us into an era of consumer, rather than state-sponsored, eugenics? (Tania Simoncelli)

The ELSI sessions were matched with a number of posters displayed on point in the ASHG conference hall, including Michael Sharp and Timothy Caulfield's "The Effect of Genetic Essentialism and Exceptionalism on Law and Policy" and Alethea Adair and Timothy Caulfield's "In the Year 2020: Genotype in Representations of Personalized Medicine."

## Centenary Project: Imagining Technology



*The Rain* by Sean Caulfield. Acrylic on paper mounted to linen. Professor Caulfield's work has explored for some time the points of intersection between technology, art, socio-political issues.

As part of the University of Alberta's 2008 Centenary Celebration, Genome Alberta's GE3LS researcher Timothy Caulfield, in conjunction with his brother Sean Caulfield, Associate Professor in the U of A's Department of Art and Design, will host *Imagining Technology: An Artistic Exploration of Science, Society and Social Change Over the Past 100 Years*, a project that intends to explore the legal, social, ethical, environmental and economic issues associated with emerging technologies. The project will consist of two components, a workshop which will be held in the fall of 2007, and a public exhibition, which will take place the following November. The goal is to pair well known artists with social commentators to produce a body of artwork and complementary essays that explore, from a variety of novel perspectives, the significant challenges and controversies that arise with advancements of new technologies. Further details regarding the event will emerge as it develops.

## GE<sup>3</sup>LS Alberta Team: Notable Recent Developments

### Publications and Reports:

T. Caulfield, B. Cook-Deegan, S. Kieff, and J. Walsh. "Evidence and Anecdotes: An Analysis of Human Gene Patenting Controversies" (2006) 24 *Nature Biotechnology* 1091-1094.

E.F. Einsiedel. "TransAtlantic Perspectives on Public Engagement with Science". [Wellcome Trust publication]

W. Hu, W. Adamowicz and M. Veeman. 2006. "Labeling Context and Reference Point Effects in Models of Food Attribute Demand." *American Journal of Agricultural Economics* 88(4): 1034-1049.

W.Hu M. M. Veeman, W. L. Adamowicz and G. Gao. 2006. "Consumers' Food Choices with Voluntary Access to Genetic Modification Information" *Canadian Journal of Agricultural Economics* 54(4): 585-604.

J. Medlock. "The Role of Public Opinion Research on Biotechnology in Federal Public Policy Development". Report prepared for the Canadian Biotechnology Secretariat, Government of Canada.

S. Smyth, P. Phillips and W. Kerr. 2006. *Managing Liabilities Arising from Agricultural Biotechnology*. Chapter in R. Just, J. Alston, and D. Zilberman. Forthcoming. *Economics of Regulation of Agricultural Biotechnologies*. New York: Springer Publishers.

### Trainees:

Greg McMullen, "Dying to Live Forever: Challenging representations of radical life extension", M.A. defended August 2006. (Supervisor E. Einsiedel)

Shiyi Tao, MSc in Agricultural and Resource Economics, August 2, 2006. "Analyzing Canadian Public Preferences for Plant Molecular Farming Research Priorities." (Supervisors: M. Veeman and W. Adamowicz).

Camille Ryan accepted a post doctoral fellowship with the Faculty of Communication and Culture at the University of Calgary in October 2006.

### Awards and Recognition:

The Canadian Agricultural Economics Society's "Canadian Journal of Agricultural Economics 2005 Outstanding Journal Article Award" was awarded to W. Hu, M. Veeman and W. Adamowicz on May 26, 2006 in Montreal for their article: "Labelling Genetically Modified Food: Heterogeneous Consumer references and the Value of Information." *Canadian Journal of Agricultural Economics* 53(1, March):83-102.

M. Veeman was named an honorary life member of the International Association of Agricultural Economists (IAAE), one of only three Canadians to have ever receive this honour.

GE<sup>3</sup>LS-supported student Gloria Gao received the 2006 Food Distribution Research Society's "William Applebaum Memorial Scholarship for an Outstanding MSc Thesis" for her thesis titled: "Consumer Behaviour: Who Seeks Information about Genetically Modified Foods?" (Supervisor: M. Veeman and W. Adamowicz)

T. Caulfield in September 2006 was inducted into the Canadian Academy of Health Sciences.

T. Caulfield was asked in September 2006 to be a member of the Social Issues and Policy Advisory Board for the Archon X-Prize in Genomics, which will award \$10 million to the first group to develop rapid inexpensive whole human genome sequencing.

## CURRENT PROJECT: GE<sup>3</sup>LS Intellectual Property Survey



The Chateau Frontenac in Quebec City, QC, where the Genome Canada International Conference was held from October 25-27, 2006.

Upon arriving at the Chateau Frontenac this October, delegates for Genome Canada's International Conference found included in their conference materials the 2006 GE<sup>3</sup>LS Intellectual Property survey. The survey will also be dispatched at the Stem Cell Network Annual General Meeting in Ottawa, Ontario from November 13-15. The document in question is an anonymous survey instrument consisting of approximately 40 questions that takes about 10-15 minutes for respondents to complete. It is designed to provide key information about current trends in intellectual property protection, exploitation and transfer as well as the views of researchers on the value of patents and the practical challenges associated with protecting and using genomic inventions. Information obtained from this survey will be used to inform ongoing research about the relative benefits and harms of intellectual property protection and on researcher perceptions of the value of intellectual property protection in Canada.

For more information regarding the survey, please contact Lori Sheremeta at [lsheremeta@ualberta.ca](mailto:lsheremeta@ualberta.ca).

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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 national strategy on genomics with \$600 million in funding from the federal government.



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