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A message from Genome Alberta's new President and CEO, Dr. David Bailey



Genome Alberta's CEO and President
Dr. David Bailey.

On behalf of Genome Alberta and its Board, I am very pleased to provide a note of encouragement and congratulations to the researchers involved in our latest GE³LS Project called Translating Science: Genomics and Health Systems.

This project will investigate the broad question: "How is genomics knowledge translated in health systems and what are the consequent policy implications?" To address this question, three more specific avenues of research are being pursued which examine the translation of knowledge through intellectual property systems, the representation of genomics in the public sphere, and the policy implications of genomics translation. This work will enhance our understanding of how genomics technologies are translated and used in health systems, the socio-ethical and legal challenges around such processes, and approaches for dealing with these challenges.

We recognize that GE³LS is an intrinsic component of good scientific research and this strong team of researchers led by renowned Timothy Caulfield will continue to establish themselves as national leaders. Alberta is very fortunate to have such a strong team within our own backyard. We look forward to the project's success.

David Bailey
President and CEO
Genome Alberta

Upcoming GE³LS Events

2006.08.24-25:
Food, Health and Biotechnology:
Consumer and Social Issues in Canada's
New Food and Health Product Industries - Victoria, B.C.

2006.09.14-16:
Second Annual
GE³LS Student Joint Biotechnology
Workshop - Victoria, B.C.

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Genome Alberta

Updates from the GE³LS Team Principal Investigators



Timothy Caulfield
Health Law Institute
University of Alberta

The Genome Alberta GE³LS team has had a productive season, thanks in large part to the wonderful research team. In addition to our highly successful Banff Patent Workshop (discussed elsewhere in this newsletter) and all the research associated with it, we continued our research on media portrayals of biotechnology and on the ways in which concepts of genetics are used in policy documents (is “genetic exceptionalism” the norm?). We have also started background work on the resource allocation issues associated with the integration of genomics technologies into our health care system, and we have been working collaboratively with the BC GE³LS Arch Team on a number of policy related initiatives. All of the HLI research students have, as usual, done a spectacular job. Many have already been involved in workshops throughout Canada and we are hopeful that they will be presenting at conferences and authoring articles in the coming academic year. The student biotechnology conference, scheduled for September in Victoria, seems likely to be an interesting, productive and highly interdisciplinary event involving trainees from UofC, UBC, UVic and the UofA. Thanks to all for contributing to a highly successful start to our Genome Alberta GELS project!



Edna Einsiedel
Faculty of
Communication and
Culture
University of Calgary

Our work has focused on the role of publics and stakeholders in the shaping of new technologies. This research program has involved among other things the investigation of public engagement approaches, with emphasis on deliberative models of engagement. In 1999, we held a citizen panel of 15 Western Canadians to consider the health, regulatory, social and economic implications of genetically modified food, using the consensus conference approach. The Citizen Panel’s report was sent to various regulatory agencies. In 2001, we employed the citizen jury model for the issue of xenotransplantation, working with Health Canada and the Canadian Public Health Association as a member of their Public Advisory Group. The consultation approach we piloted in Calgary was then deployed in six regions around the country. This fall, we will reconvene our citizen panel to assess plant molecular farming, the next generation of genetically modified products. This technology uses genetically engineered plants to produce non-food products such as pharmaceuticals or industrial enzymes. In contrast with the previous consultation, policies around plant molecular farming are currently being created, so the contributions of the panel can be integrated into policy development. The process is also novel in that the same panel that had considered the first wave of biotechnology products will now also consider this new wave of applications. The panel meetings will be complemented by an on-line consultation of 500 Canadians from coast to coast. Following a survey of their views, participants will interact with one another in an on-line interactive forum, which operates like a chat room. Like the citizen panelists, the on-line participants will have the opportunity to pose questions to experts. They will also participate in the writing of the report through the use of a Wiki format.

Updates from the GE³LS Team Principal Investigators



Peter Phillips
Department of
Political Studies
University of
Saskatchewan

Peter Phillips has been on a full-year sabbatical, with visiting appointments at the London School of Economics in London (Aug-Sept, 05), the OECD in Paris (Oct-Dec), the European University Institute in Florence (Jan-Mar 06) and the Institute of Advanced Studies, U. of Western Australia, Perth (April-June 06). His main accomplishment during the year was to complete an original manuscript entitled "Who's in charge? The challenge of governing transformative technological innovation". In addition, he participated in conferences or made presentations at a number of events: these included a risk symposium at the London School of Economics, at the Final GE³LS Competition I event in Ottawa, to the Agriculture Directorate at the OECD, as an external reviewer at a European Union funded research network meeting on risk communications, at a social networks conference in Brussels, at the European Plant Science Organization conference on PMPs in Aachen, at IPGRI in Rome and at UWA in Australia. During the year he helped co-edit two research volumes: P. Phillips and Chika Onwuekwe (eds), *Assessing and sharing the benefits of the genomics revolution*; and J. Porter and P. Phillips (eds), *Public Science in Liberal Democracy*.



Michele Veeman
Department of Rural
Economy
University of Alberta

Michele Veeman's team has been conducting research based around the intersection of public attitudes towards genetically modified foods and access to information. A study was conducted in which voluntary information about GM foods was made available to assist individuals in determining purchase intentions for those foods. The study found that less than half of the participants chose to access the information made available and, of those who did, there was a tendency to be more opposed to GM foods. Veeman's team is also in the process of analyzing a significant body of data surveying the views of Canadians on the benefits and risks associated with Plant Molecular Farming (PMF). Initial findings are consistent with the hypothesis that innovations and situations which seem to provide little personal or socially accepted benefits are seen as more risky, and thus less socially acceptable, than innovations and activities that do involve socially accepted benefits. Analysis also suggests that risk perceptions are consistently associated with gender, income, and location of residence. Also during this quarter, Veeman has undertaken a contract research project for SSHRC, through the University of Alberta, on a "state of the art review of trends in North American research on ethical, legal and social aspects of genomics: agriculture, forestry and fisheries." Related to this work, she gave an invited presentation on this topic at the SSHRC-ERA-SAGE Workshop, Ottawa, May 22-23, 2006.

Abstracts for two of Professor Veeman's papers examining the two studies outlined above are provided on page 7 of the newsletter.

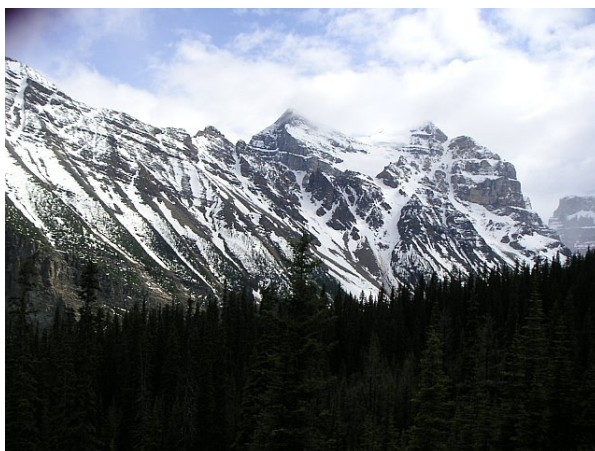
GE³LS convenes an interdisciplinary workshop in Banff, Alberta entitled "Biotechnology Patents and Policy: What's the Evidence?"

New perspectives and consensus emerge.

As a crucial step in the "Translating Science: Genomics and Health Systems" project, the GE³LS team convened an international, interdisciplinary workshop in Banff, Alberta, Canada from May 25-27, 2006. The topic of discussion was the state of knowledge about the impact of gene patents on genetics research and health service delivery.

Originally planned as a modest event with a handful of participants, the event expanded into an intensive two-day workshop that included over 35 participants including leading scholars, policymakers and industry representatives in the fields of genomics, intellectual property, sociology, philosophy, and economics. This rarefied cross-section of academics cutting across disciplines provided for powerful dialogue, argument, and sharing of research data.

GE³LS Principal Investigator Timothy Caulfield stimulated discussion about the impact that empirical studies of the consequences of gene patenting have had on policymaking. It was argued that the empirical research that is available, which tends to show that biotech patents have not had a significant effect on practice, has been often overlooked or ignored by some policymakers, and is not even on the radar of the vast majority of the public. GE³LS PI Edna Einsiedel presented valuable data on the public's perceptions relating to commercialization and intellectual property. GE³LS researcher Lori Sheremeta presented on the fact that elements of the gene patent debate are creeping into the academic discourse around nanotechnology patenting. The role of public action groups in pursuing the anti-globalization agenda was highlighted as a source of concern.



The beautiful scenery surrounding the GE³LS Workshop.

PHOTO CREDIT: Jon Merz



Dianne Nicol, Bob Cook-Deegan, and Aurora Plomer enjoy a hike around Banff after the day's events.

PHOTO CREDIT: Jon Merz

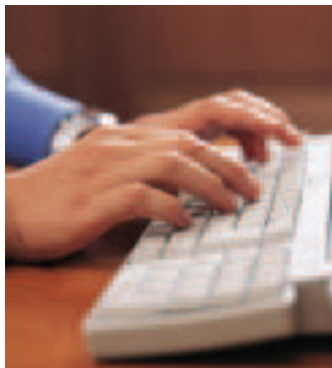
What was held to be influential on policy rather than research is the notion of an "anti-commons" in biomedical research: an unintended byproduct of the privatization of research that occurs when ownership of research inputs is fragmented over multiple parties with heterogeneous interests. The inconvenience and cost of securing multiple licenses and/or the other rights necessary to use patented research tools is predicted to skew the research agenda by blocking downstream innovation and to unduly increase the cost of clinical genetics services.

At the end of the second day, it was clear that many of the concerns that have been raised over gene patenting have not materialized to the extent predicted. Methodological challenges make it very difficult to know what the actual effect of patents is on the overall system of innovation. Several areas of future research collaboration were identified.

- Read the Complete GE³LS Team report on the Banff Workshop event:

www.law.ualberta.ca/centres/hli/r_genome.html

GE³LS Student Researchers gain valuable experience and help researchers meet publication deadlines



GE³LS Student Researchers are not only trained in interdisciplinary research techniques, but many also receive publication opportunities.

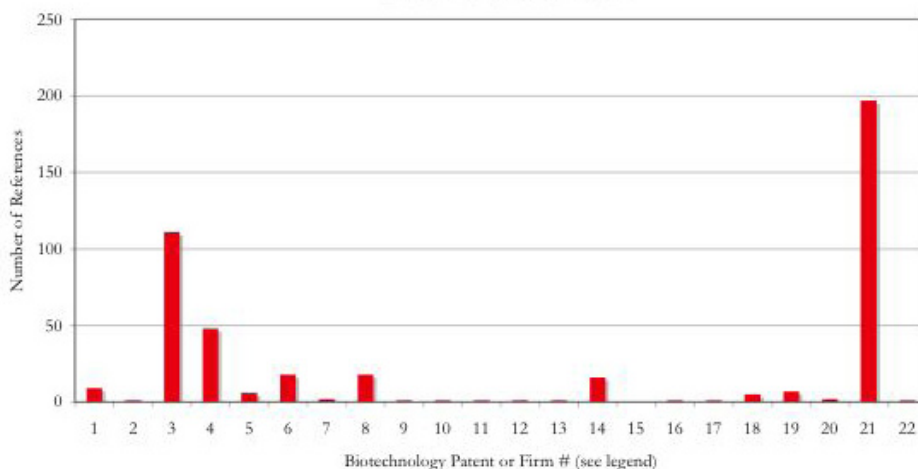


GE³LS Student Researchers are hired from among the undergraduate and graduate populations of participating universities. They work full-time over the summer and part-time during the school year in order to facilitate, supplement, develop and edit the work of the GE³LS team. One interesting example of such research was a brief inquiry conducted by HLI Student Researcher CJ Murdoch recently.

One of the fresh avenues of inquiry arising out of the Banff Workshop was to consider the impact that the Myriad Genetics controversy had on policymaking. Myriad owns patents on the BRCA1 and BRCA2 breast cancer genes, and when public healthcare in Canada attempted to implement breast cancer diagnostic testing without a proper license in 2002, Myriad sent out cease and desist orders to all provinces. A similar situation arose in Europe. These actions fomented considerable public controversy and ignited debate about the validity of gene patents. Although Myriad was in fact a relatively isolated incident in the world of biotechnology patents, its impression on the public psyche was indelible.

As an initial attempt to measure the impact of the Myriad Genetics controversy on policymaking, Murdoch simply did a citation search of ten important policy documents since 2002 for Myriad, as well as 21 other controversial biotechnology patents and companies. Although this is admittedly a limited methodology, the difference in results was so significant as to paint a suggestive preliminary picture. Between the company and its BRCA patents, Myriad was referenced explicitly over 356 times. Its closest competitor, Canavan disease, was referenced a mere 18 times. The chart below of the results graphically epitomizes the degree to which the Myriad controversy may have had an influence on policy documents.

References to Controversial Biotechnology Patents and Firms in Major Policy Documents after 2002



BIOTECHNOLOGY PATENT AND FIRM LEGEND

- | | |
|-----------------------------------------------|-------------------------------------------------------------|
| 1. Apolipoprotein E (Apo E) | 12. Spinocerebellar ataxia (SCA3) |
| 2. Hereditary breast/ovarian cancer (general) | 13. Spinocerebellar ataxia (SCA6) |
| 3. Hereditary breast/ovarian cancer (BRCA1) | 14. Adenomatous polyposis of the colon (FAP or APC) |
| 4. Hereditary breast/ovarian cancer (BRCA2) | 15. Charcot-Marie Tooth type 1A (general) |
| 5. Duchenne/Becker muscular dystrophy | 16. Charcot-Marie Tooth type 1A (CMT-1A) |
| 6. Hereditary hemochromatosis (HFE) | 17. Charcot-Marie Tooth type 1A (CMT-X) |
| 7. Myotonic dystrophy | 18. Fragile X syndrome |
| 8. Canavan disease | 19. Huntington disease |
| 9. Spinocerebellar ataxia (general) | 20. Factor V Leiden (activated protein C for thrombophilia) |
| 10. Spinocerebellar ataxia (SCA1) | 21. Myriad Genetics |
| 11. Spinocerebellar ataxia (SCA2) | 22. Cellpro |

POLICY DOCUMENTS SEARCHED

- CBAC, Human Genetic Materials, Intellectual Property and the Health Sector (2006)
- WHO, Public Health Innovation and Intellectual Property Rights (2006)
- CBAC Expert Working Party on Human Genetic Materials, Intellectual Property and the Health Sector, Human Genetics Materials: Making Canada's Intellectual Property Regime Work for the Health of Canadians (2005)
- Danish Council of Ethics, Patenting Human Genes and Stem Cells (2004)
- ALRC, Report 99 - Genes and Ingenuity: Gene Patenting and Human Health (2004)
- The Royal Society, Keeping Science Open: The Effects of Intellectual Property Policy on the Conduct of Science (2003)
- PHGU, Intellectual Property Rights (IPRs) and Genetics (2003)
- Ontario Ministry of Health, Genetics, Testing and Gene Patenting: Charting New Territory in Healthcare (2002)
- The Nuffield Council on Bioethics, The Ethics of Patenting DNA: A Discussion Paper (2002)
- OECD, Genetic Inventions, Intellectual Property Rights & Licensing Practices (2002)

We Need a Greenpeace for PMF: Industry Perspectives on Stakeholder Management in Plant Molecular Farming

The following is an abstract for a paper prepared by Jennifer Medlock, a GE³LS PhD student at the University of Calgary.

Plant molecular farming (PMF), the so-called “third generation” of GM crop techniques, uses plant systems not to produce food, but as factories to manufacture pharmaceutical and industrial products. Through a qualitative content analysis of interviews with members of the PMF industry (n=9), the objectives of the study were:

- 1) To examine how industry interviewees characterize the roles of various stakeholder groups in PMF governance arrangements in Canada; and,
- 2) To discuss the implications for future governance of PMF.

The nine PMF industry interviews discussed are a subset of a larger study of 39 structured interviews conducted with a range of PMF stakeholder groups including the food industry, government, social and advocacy groups, academia and the agricultural industry. These interviews were conducted by phone or email between April 2004 and May 2005. The interview data were originally collected to gauge opinions towards the general concept of PMF, to understand the perceptions of risks, benefits and acceptability of specific PMF applications (spanning food and non-food platforms and medicinal and industrial products), and to elicit views on how PMF should be regulated (the interview instrument appears in Appendix 1). The current work shifts the focus from evaluating perceptions of the technology itself to understanding industry perceptions of the roles and responsibilities of the various stakeholder groups in the Canadian governance environment.

The paper provides an overview of PMF technology, its applications, and the state of regulation in Canada. The concept of ‘governance’ is then presented, a term describing the changing nature of government-industry-civil society interactions. Science and technology issues are presented as a special case for governance practices and introduce the notions of pluralizing expertise and providing opportunities for new actors to participate in governance. Next, the science and technology governance discussion is placed within the context of the stakeholder management and innovation studies literatures to provide a framework for analyzing industry perceptions.



The study shows that members of the PMF industry are steeped in a technological frame advocating the benefits of PMF technologies and a sound-science regulatory framework. The interviewees understand social shaping to the extent that their technologies can be stalled or killed by sociopolitical stakeholders, but do not see most of the reasons for opposition as reasonable. Positioning themselves in a leadership position, they see cultivating relationships with public groups as educating and convincing, in the hopes of alleviating their fears. In relation to government stakeholders, the respondents see themselves as advisors for science-based regulations and partners in facilitating commercialization. NGOs such as Greenpeace are not seen as relevant, necessary stakeholders in PMF development, though their ‘tactics’ of influencing the public were seen as powerful and as ones that the industry itself should adopt.

Is information likely to change attitudes to GM foods?

Michele Veeman, Wuyang Hu and Wiktor Adamowicz (2006) are authors of a paper that will be presented to the International Association of Agricultural Economists, in Australia on August 14 2006, reporting some of their work on this issue. Their experimental survey assessed Canadians purchase intentions for a food product that could include an environmental or health benefit where this could be the result of genetic modification. An innovation in their study was to give respondents the opportunity to voluntarily access information on these innovations through hyperlinks. The information scenarios included positive information (from industry sources) and negative information (from GM opponents). The focus in this study on voluntary information access contrasts with most previous studies which usually have provided information to respondents and then assessed whether this has changed attitudes. Veeman and colleagues found that less than half of the 445 study respondents chose to access the information made available. Those who accessed information tended to be more opposed to GM food than those who did not access information. This may explain the study finding that those who accessed GM information tended to avoid choosing GM food. The results of this analysis are consistent with a finding in the social psychology literature (Scholderer and Frewer, 2003) that where negative attitudes to GM food are well-entrenched, these are unlikely to be changed by information strategies.

References:

Scholderer, Joachim and Lynne Frewer. 2003. "The biotechnology communication paradox: Experimental evidence and the need for a new strategy". *Journal of Consumer Policy*, 26: 125-157.

Veeman, Michele, Wuyang Hu and Wiktor Adamowicz. 2006. "Consumers' Preferences for GM Food and Voluntary Information Acquisition: A Simultaneous Choice Analysis." Department of Rural Economy, University of Alberta, Working Paper.

Canadians' Views of Risks From Plant Molecular Farming

Canadians' risk rankings for a variety of food and environmental issues, including the applications of modern agricultural biotechnology known as Plant Molecular Farming (PMF), were sampled by Michele Veeman and Wiktor Adamowicz using a Canada-wide survey of some 1,500 respondents in late 2005. They are working with Rural Economy MSc student Yu Li to analyze these. One interesting feature from these data is that applications of genetic modification/engineering (GM/GE) that involve production of medical products are viewed as being relatively lower risks for food and the environment than GM/GE applications that are directed at increasing crop production. Similarly PMF applications to produce industrial products or more nutritious food are also viewed as relatively lower risk than GM/GE applications to increase crop production. These assessments are consistent with the hypothesis that innovations and situations which seem to provide little personal or socially accepted benefits are seen as more risky, and thus less socially acceptable, than innovations and activities that do involve socially accepted benefits. Statistical analysis has been applied to analyze risk rankings given to these PMF applications; these suggest that risk perceptions are consistently associated with gender, income and location of residence. For example, respondents living in the Province of Quebec (QC) were much more likely to view the use of GM/GE to increase crop production as a risky issue. Having a child living in the household led to a significant but relatively small increase in the probability of higher risk ratings being chosen. In contrast, males and those with higher income tended to be less likely to rate the use of GM/GE to increase crop production as a high risk for food. Trust also seems to be associated with the risk ratings, at least in some applications.

Reference:

Veeman, Michele, Yu Li and Wiktor Adamowicz, "Consumers' assessments of food safety and environmental safety in the context of plant molecular farming" Selected paper presented at the WAEA Annual Meetings, Anchorage, Alaska, June 28-30, 2006.

Nola Ries: Update from Victoria



GE3LS Research cuts not only across disciplines, but also across provinces; some of Genome Alberta's GE3LS' Researchers work remotely from locations outside of Alberta. Nola Ries is a prominent example.

Nola Ries, Research Associate with the University of Alberta Health Law Institute, has focused much of her recent work in the emerging area of nutritional genomics. On behalf of Genome Alberta, she participated in a joint Canada-Denmark nutrigenomics workshop in Copenhagen in March, and has presented papers on GE3LS issues in nutrigenomics at the International Conference on Nutrigenomics and Gut Health (Auckland, New Zealand) and the International Consortium on Agricultural Biotechnology Research (Ravello, Italy). Nola is also part of a new three-year nutritional genomics research program funded through the Advanced Foods and Materials Network (AFMNet). This project will examine approaches to regulating nutrigenomics research and services in various jurisdictions and study public representations and understanding of nutrigenomics. Two Canadian GE3LS leaders, David Castle, University of Ottawa, and Timothy Caulfield, University of Alberta, are co-PIs on this project. In addition to her work with the U of A Health Law Institute, Nola also works as a Research Associate with the GE3LS theme of AFMNet and is organizing a GE3LS conference, Food, Health and Biotechnology: Consumer and Social Issues in Canada's New Food and Health Product Industries, to be held in Victoria on August 24 and 25.

For additional information on the conference, see: http://www.csr.s.uvic.ca/research/gels_conference.php.

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