

GE³LS

Ensuring leadership in ethical, environmental, economic, legal and social issues related to genomics

A Historic Meeting in Montreal

In early February 2003, an unprecedented number of experts on the ethical, environmental, economic, legal and social issues posed by genetic research (GE³LS) met in Montreal for the first Canadian GE³LS Winter Symposium. This historic meeting included over two hundred philosophers, lawyers, anthropologists, sociologists, geneticists, and many other scholars.

Two major themes emerged. First, there are a number of practical, concrete, social issues that must be resolved soon. That is, emerging research activities demand an immediate policy response. For example, many health researchers are contemplating the creation of large, long term, population research projects. Such studies would involve linking genetic data with other forms of personal information, such as health and socio-economic status and even ethnic and geographic information. By doing so, researchers hope to tease out the complex interplay between genes and envi-

ronment in the disease process. It seems likely that most diseases, from cancer to heart disease, involve both a genetic and environmental component. Indeed, some researchers believe that this kind of large-scale research initiative is the only way to truly understand many common diseases involving complex causal factors. Large-scale population studies appear to be emerging as an important next phase of the genome research era.

The scientific and health care payoffs of these research initiatives could be profound. However, the legal and ethical challenges are also daunting. How should researchers recruit Canadians to participate in these projects? Since genetic information is shared within families and even communities, how, and from whom,

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Symposium co-chair Timothy Caulfield, Bartha Maria Knoppers and Genome Canada President Martin Godbout.

Outreach Initiatives at Genome Canada



Genome Canada has developed several initiatives that promote public outreach in the area of genomics.

The Gee! in Genome is Canada's first exhibition on genomics. The Prime Minister of Canada, Jean Chrétien, opened it at the Canadian Museum of Nature on April 25th, 2003, the 50th anniversary

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GE³LS Websites to watch:

Genome Canada: <http://www.genomecanada.ca>
 Genome British Columbia: <http://gels.ethics.ubc.ca>
 Genome Prairie: <http://www.genomeprairie.ca/gels/>
 Ontario Genomics Institute: <http://www.utoronto.ca/cjb/genomics/index.html>
 Genome Quebec: <http://www.humgen.umontreal.ca/en/projects.cfm>

Building international leadership
 in genomics and proteomics research for Canada



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In Memoriam



Dorothy Wertz

Dorothy Wertz passed away, very suddenly, on April 29th, 2003. Genome Canada and the GE³LS community send condolences to her family and to her many friends in the United States, Canada and around the world.

A Research Professor of Psychiatry at the University of Massachusetts Medical School, in Waltham, Mass., and Senior Scientist at the American Society of Law, Medicine and Ethics in Boston, she was well-known in the scientific community for her insight, independence of mind, simplicity and sense of humour. Her contributions to several meetings undertaken by Genome Canada were refreshingly orig-

inal. She was widely respected for the quality of her research work, which included authorship of some 150 articles and book chapters on ethics, genetics and reproduction and close to two decades teaching sociology and anthropology. Moreover, she served as a member of the HUGO Ethics Committee, Genome Canada's Science and Industry Advisory Committee, as well as chair of the New England Regional Genetics Group Ethics Committee. She had received a grant from the ELSI Branch of the National Human Genome Research Institute (NIH) to study "DNA Fingerprinting and Civil Liberties" for a period of three years.

Dorothy Wertz — scholar, woman of integrity and friend to many in the GE³LS community — will be sorely missed. The next issue of the GE³LS newsletter will be dedicated to her memory.



This is the third issue of GE³LS. The entire issue is devoted to Canada's first national GE³LS Winter Symposium, held in Montreal in early February 2003. The symposium was organized by Genome Canada, in partnership with the Canadian Institutes of Health Research (CIHR), the National Sciences and Engineering Research Council (NSERC), the National Research Council (NRC), the Social Sciences and Humanities Research Council (SSHRC), Health Canada and the Canadian Biotechnology Advisory Committee (CBAC).

While we cannot hope to report on every aspect of this fascinating three-day Symposium, we hope you enjoy the overview provided in this issue! As Canada's GE³LS community grows, reaching out to researchers and diverse public audiences in Canada and other countries, we believe that the GE³LS newsletter has an important role to play. The newsletter is designed to offer public information, in French and English, on the GE³LS community, as well as on the ethical, environmental, economic, legal and social issues related to genomics.

Do you find the Newsletter interesting? What is your perspective on ethical, environmental, economic, legal and social impacts of genomics and proteomics? Drop us a line c/o Genome Canada.▶



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A Historic Meeting in Montreal



John Frank, of CIHR, addressed the future of population genetics studies in Canada.



Patricia Kosseim, of CIHR, explained the legal framework for population genetics studies in Canada's many jurisdictions.



Carleton University professor Michael Yeo addressed genomics and issues of privacy, confidentiality and control.

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should consent be obtained? Should the researchers be able to recruit newborns for the project? And how will the tremendously sensitive personal information that will be collected for these kinds of projects be protected? A 2001 survey of Canadians found that 90% believe that genetic information is different and rules governing access should be more strict (Pollara and Earncliffe). Until these legal and ethical issues are addressed, such projects will not be able to go forward.

The second major theme that emerged at the Symposium was the profound complexity of many of the scientific challenges, as well as social concerns. Now that the mapping of the human genome has been completed, the much harder task has begun of identifying which genes, or which complex interaction of genes and their environment, are related to the expression of disease. This is turning out to be far more complex than previously imagined. Similarly, the emerging GE³LS research has highlighted the complexity of the ethical and regulatory concerns. For example, the identification of the consequences associated with genetic testing and other technologies is also turning out to be more complex than originally imagined. The information produced by the science can be represented often only in terms of probabilistic algorithms that are difficult to translate into either personal or social decisions about appropriate therapy. What is the relevance of the discovery of a gene associated with a disease like cancer if it increases a person's chance of actually

getting cancer only marginally, and then only in relation to other environmental factors such as diet or life-style? How is this information to be used in a therapeutic decision?

A strong theme to emerge from the symposium concerned the need for more discussion and work on how "risk" should be understood and used in the context of genomics, at the level of both personal therapeutic and social decision making. It is increasingly clear that more sophisticated approaches to risk assessment and management will be required to keep pace with the ethical and regulatory issues posed by these technologies. There is also need for a more sophisticated understanding of how to communicate complex and ambiguous risk information to patients, publics, and decision makers.

The media play a critical role in shaping public perceptions of genomic science and technologies. The scientific and ethical complexity of the issues involved demand a level of understanding in the media that can only be accomplished by increased collaboration and dialogue between the media, scientists, and ethicists. The GE³LS Symposium was an excellent example of the value of collaboration between the latter. But, unfortunately, no one from the media attended the discussion of this issue on the final day of the Symposium. Perhaps, next year's GE³LS Symposium will find a way to remedy this situation. ■

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Population genetics



“The first Canadian GE³LS Winter Symposium shows that Canada has chosen not to duck important ethical issues, but to open them up for a frank and stimulating discussion,” said Dr. Bartha Maria Knoppers, Canada Research Chair in Medicine and Law at the Université de Montréal, and Chair of the International Ethics Committee of the Human Genome Organization. “This confirms Canada’s leadership role in this respect.”

The words “frank and stimulating” certainly applied to the opening day of the GE³LS symposium in Montreal, which was devoted to population genetics and DNA databanks. The day brought together the perspectives of genomics scientists and social science researchers on a wide range of important issues. That mix of perspectives was one of the objectives set by Symposium co-chairs Timothy Caulfield of the University of Alberta and Conrad Brunk of the University of Victoria. According to Professor Caulfield, “many lab scientists are sensitive to and interested in GE³LS issues, while GE³LS researchers need to make a real effort to reach out to the scientific community, if only to ensure that their work is properly informed.”

The perspective of genomics scientists was presented by Dr. Thomas Hudson, principal investigator of three large-scale projects supported by Genome Canada, and in particular “A Haplotype Map of the Human Genome — Biomedical Tool for Genetic Research in Canada.” According to Dr. Hudson, the International Haplotype Map Consortium, drawing in collaborators from Canada, the United States, the United Kingdom, China and Japan, aims to define 80-90% of common haplotype patterns, to dissect human diseases using haplotype information, and to develop genome-wide association studies for common diseases. During his presentation, Dr. Hudson reviewed the scientific possibilities opened up by population genetics, noting the role of single nucleotide polymorphisms (or SNPs), as well as haplotypes (strings of alleles on a specific chromosome), as they pertain to the history of disease mutation throughout a given population.

“The primary motivation of the human genome project is medical,” Dr. Hudson said. “We know we need to understand the causes of diseases. If we understand the causes, then we may be able to develop a therapy for the disease, rather than just treat symptoms... The goals of the haplotype map are to generate the map of common genetic variants in block-like structures of



and DNA

limited diversity, and to identify susceptibility genes for common diseases.”

Dr. John Frank, scientific director of the Institute of Population and Public Health at the Canadian Institutes of Health Research, also spoke from the perspective of natural science. He explained that most diseases and health conditions occur in some persons, but not others, because of intense interactions between individuals, their genetic constitutions and their social and physical environment. Indeed, early environments (social and physical) are embedded in mind and body stress and regulatory systems, such as psychological, neurological and endocrine systems. Dr. Frank expressed the hope that the Canadian National Birth Cohort will screen 10% of Canadian births, in order to provide information about population genetics on a large number of individuals, from their birth to their death.

Population genetics can be used to map common genetic disease variants, identify susceptibility genes, and screen for disease. But techniques like these also raise questions. Is the public participating in research? Is informed consent to provide genetic material freely given? Can an entire community freely give consent to provide genetic material, and how? What regulations are in effect, in different jurisdictions, to protect individual confidentiality? Population genetics also raises issues about the right to privacy, the right to know or not to know (should an individual be tested for a genetic disease if there is no therapy for that disease?), the sharing of benefits, and the different perspectives of commercial interests and the community at large.

The day saw a wide range of presentations on the ethical, environmental, economic, legal and social implications of biobanks. For example, Dr. Edna Einsiedel of the University of Calgary, principal investigator of “Commercialization and Society and its Policy and Strategic Implications”, explained that biobanks have



databanks

been defined as “a collection of physical specimens from which DNA can be derived and the data that can be derived from DNA samples.” She noted that there are four steps in the creation of biobanks: collection, physical storage, data storage and integration. She also reviewed existing data from opinion research (surveys, polls, focus groups, consultations) and gave both public and professional perspectives on the issue.

Michael Yeo of Carleton University, a philosopher who specializes in ethics, examined the possible consequences of the concentration of public biobank information in private hands. His presentation explored issues of privacy, illustrating his talk with slides of several icons of Western culture, from Jeremy Bentham’s *Panopticon* to George Orwell’s *1984*.

Mylène Deschênes and Geneviève Cardinal of the Centre de recherche en droit public at the Université de Montréal, reviewed international approaches to the development of population biobanks. According to Ms. Cardinal, “we are among the first researchers to conduct a comparative study on the different national approaches to the development of biobanks.” Ms. Deschênes added, “We are looking at Iceland, the United Kingdom and Estonia. The Icelandic government has awarded an exclusive licence for a twelve-year period to Decode, for the creation of a database of health data. In turn, Decode has awarded to Roche the possibility of extracting data from this database, in order to perform research on twelve hereditary diseases, on a commercial basis. A different approach has been taken by the United Kingdom. Indeed, the

Medical Research Council is working together with the Wellcome Trust, and is spending a good deal of time and resources on public consultation. Every possible effort has been made to inform the public. A portion of funds invested in genomics is being reserved for public information.”

Other presentations addressed issues of privacy and research ethics, the sharing of benefits in smaller markets, and the challenge of “participatory research”, where genetic research with aboriginal populations is concerned.

During this day devoted to population genetics and biobanks, two themes kept coming back: *the need to engage genomics scientists on GE³LS issues*, and *the setting of appropriate public standards*.

In the view of William Leiss, Professor of Policy Studies at Queen’s University, NSERC/SSHRC Industry

Research Chair in Risk Communication and Public Policy at the University of Calgary and Executive-in-Residence at the University of Ottawa, “in the normal form of public discourse, through the media, for example, we hear of a discovery reported in journals like *Nature* or *Science*, and if there is a GE³LS aspect, media people speed-dial the regular group of ethicists for a quick two-line quote. But you rarely get the ethics community and the scientific community to enter into a dialogue. I would like to see more scientists engaged in ethical and social issues. Genomics is not chemistry; it goes to the very heart of civilization and our values.”

“The primary motivation of the human genome project is medical,” Dr. Hudson said. “We know we need to understand the causes of diseases. If we understand the causes, then we may be able to develop a therapy for the disease, rather than just treat symptoms.”

Also attending the Symposium was Dr. Marc Saner, who leads the emerging knowledge area on ethics at the Ottawa-based Institute on Governance: “I was happy there was a mixture of genomics scientists and researchers from the social sciences and humanities at the symposium. The GE³LS symposium is a worthwhile exercise, but it is difficult to integrate ethics into the whole genomics exercise. The people who matter the most, and who should be encouraged to participate, are in three groups: the top bench scientists, the politicians and the public.”

Ultimately, the setting of appropriate public standards, both through research ethics and regulations, involves *governance*. According to Dr. Saner, “governance is the process of how communities organize themselves to arrive at decisions. Governance may be the process, but a governance regime would include standards and structure. There are lots of governance issues with genomics — such as the governance of research ethics boards; citizenship engagement and transparency; accountability for decisions is also important. Genomics is a transformative technology, like writing or electricity, which can produce unexpected results. The question becomes not so much how to govern biotechnology as how does biotechnology change our ability to maintain standards of good governance.”

The *growing need* for scientific communications

Canada's first GE³LS Symposium brought together an impressive roster of individual researchers from Canada and other countries, as well as representatives of national public institutions, some of which co-sponsored the event.

The result: a wide range of perspectives on the importance of GE³LS research, and on the best way to engage key audiences — such as genomics scientists, social science and humanities researchers, politicians and policymakers, and the general public.

“A very positive sign here,” said Dr. Harold Coward, of the University of Victoria, “is the way that genomics scientists and social science and humanities researchers have got together, to share perceptions. The scientists are showing the lead here. My model is dialogue. I believe very strongly that communication between scientists and the community has to be in both directions.”

Several people attending the GE³LS Symposium in Montreal provided examples of effective scientific communications.

According to Gijs van der Starre, of the Netherlands Genomics Initiative, “there are some very qualified researchers in the Netherlands who really put a lot of effort into informing either the general public or specific groups (e.g. patients) about their research, but a lot remains to be done in this respect. That is the reason that we specifically asked our genomics Centres of Excellence (comparable to the Genome Centres in Canada) to develop projects for public outreach, and we will hold them accountable on this matter. On top of that, we will establish a Centre for Society and Genomics, which is geared towards ‘bridging the gap’ between research and society.”

Dr. van der Starre also noted the example of Sir John Sulston of Great Britain, who in 2002 shared in the Nobel Prize in Medicine and also in Canada’s Gairdner Award. Dr. Sulston is devoting a good deal of time to scientific communications (writing books, appearing on radio and television), as a way of returning something to society. “More researchers and industry should be aware of the fact that ‘their license to develop and produce’ so to speak, depends a great deal on public support for their research and products,” Dr. van der Starre concluded.

It is not an easy task to find ways to communicate effectively. Many scientists find they have neither the time nor the interest, although some individuals have a real gift for communicating complex matters in ways that are understandable to almost everyone. Dr. Margaret Lock would like to see financial incentives given to people specifically for public dissemination of knowledge. It is also important that social science researchers gain expertise in talking about the social consideration of genomics, she said. “Canada is short of trained people in this area, as compared to the United Kingdom or the United States. Much better communication between

In line with Dr. Harold Coward’s words, a familiar theme at the Montreal Symposium was the *growing need for scientific communications*.

“I do not believe that it is necessarily a good thing to insist that *all* scientists pay attention to these ethical and public outreach issues,” said Dr. Paul Thompson, Distinguished Professor of Philosophy at Purdue University in Indiana. “Nevertheless, it is not

unreasonable to think that every scientific organization (university department, professional group, company — perhaps even every research group) should find a way to ensure that ethics and social impacts are identified and thoughtfully deliberated, and that where needed, appropriate public outreach is undertaken.”

Moreover, Dr. Thompson added, “long term, ethics and social issues must become part of scientific culture in the same way that publication and reproducible results have already. That will take generations of perseverance, but even lip service to ethics is an improvement over the past.”



The event attracted media interest. Timothy Caulfield, co-chair of the Symposium, during a press conference.

Outreach Initiatives at Genome Canada

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scientists and social science researchers is necessary, and one task for social science researchers should be to give talks in medical and basic science departments on the consequences on individuals, families and societies of the application of technologies associated with genomics."

In the experience of Dr. David Castle, people working in laboratory science are not recluses hoping the GE³LS world won't come knocking, but the opposite. In fact, scientists are often excellent sources of GE³LS issues. They are stakeholders in the process, and their intimacy with science and technology alerts them to issues that may arise.

Dr. Thompson enjoyed making contacts at the Montreal GE³LS Winter Symposium, and was delighted to find that many scientists were in the audience. He was particularly interested by sessions on population genetics and the concept of risk and its dissemination. "Next year," he said, "I would like to see sessions where social science researchers, ethicists and scientists share the same platform and do presentations on essentially the same subject matter from their differing points of view. I would also like to see a session on a project where genomics scientists and social science researchers are collaborating closely together is presented."▶

of the first scientific publication describing the double helix structure of DNA. *The Gee!* in Genome is an innovative, multi-dimensional public education project developed by the Canadian Museum of Nature, presented nationally by Genome Canada, in partnership with the Canadian Institutes of Health Research. The project includes a bilingual hands-on travelling exhibition, "suitcase" exhibits, a series of interactive public programmes, curriculum-based school programmes, youth forums, a national forum series and a dynamic Web component. The project will educate Canadians about genomics, the relevance of genomics discoveries to nature and human life, and the contributions of Canadian scientists to the field, paying particular tribute to the late Nobel-prize-winning chemist, Dr. Michael Smith.

The exhibition will close after Labour Day and launch its 3-year cross-Canada tour at Science World in Vancouver, Dr. Michael Smith's "home town." The exhibition provides an opportunity to explore the basics of cell biology, genetics and the relationship between genes and the environment. Through public forums and questions raised in the exhibition itself, *The Gee!* in Genome will also engage Canadians in the ethical issues raised by this exciting new field of science.

In addition, Genome Canada is promoting greater integration of genomics science with ethical, environmental, economic, legal and social issues related to genomics. Genome Canada insists that each project it supports puts in place an ethics strategic and communications plan, to ensure that GE³LS issues are always an integral part of scientific research.

The first national GE³LS Winter Symposium, held in Montreal, is also a sign that Genome Canada is building a national community of people from different public and professional perspectives, in the area of GE³LS. This national com-

munity welcomes the participation of international scientists and researchers in social science and the humanities.

Finally, this GE³LS Newsletter furthermore demonstrates the importance given by Genome Canada to disseminating information on ethical, environmental, economic, legal and social issues related to genomics, not only to the community of researchers across the country, but also to the public and the government.▶



How to reach the public ?



Given the wide range of issues raised during the Montreal GE³LS Winter Symposium, a key theme in the conference hall and the hotel corridors was how to inform and educate the public – and how to hear what publics have to say.

Finding a way to inform the public is one challenge and it is far from easy. The public does not always have a lot of science background, and may not be very interested in science in general. But some sub-disciplines in genomics research, such as its impact on the health care system, food safety and the environment, attract attention since they impact on every day life.

Besides, the media are sometimes given to sensationalist reporting about “miracle” cures that are just about to be delivered, or catastrophic interventions that should never have been offered, without investigating the divisions among scientists themselves, and scientific

uncertainty about conflicting claims. Public information on genomics is often lacking. For several people attending the Montreal Symposium, an important distinction should be drawn between the public at large, and strategic communities in particular.

“I would argue that it is *not* the general public that wants or needs to be informed and consulted, but the *interested* public,” said Paul Thompson, a Distinguished Professor of Philosophy at Indiana’s Purdue University, and Director of the Center for Food Animal Productivity and Well Being. “The interested public is made up of people who have identified

themselves as interested in certain special issues — certain diseases, environment, farming, etc. I believe that the best way to reach such people is through outreach designed to involve the non-governmental organizations that represent such interests.”

Dr. Conrad Brunk, of the University of Victoria and co-chair of the Montreal GE³LS Winter Symposium, agreed with this view. “Members of the public will self-select to be involved in the debate. They tend to educate themselves very well on the issues, and they raise, on the whole, very critically important questions. In some respects, these ‘informed’ publics speak

Montreal GE³LS Symposium





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for or represent the spectrum of interests in the society.” Dr. Brunk is suspicious of public policy that is driven by opinion polls and ‘focus groups’. It is primarily the informed or involved public who needs to be consulted. “This is not to say that the best efforts ought not to be made to disseminate information about genomics as widely and in as accessible a form as possible,” he added. “This is best done by media that report the full spectrum of the debate in the society — among those who are informed and/or involved. Specialized efforts to teach these issues in the schools or in specialized curricula are subject to the question of ‘who gets to write the materials and teach it?’”

According to Gijs van der Starre of the Netherlands Genomics Initiative, “public perception is not only about informing, but also about engaging the public. We have had some experience in the Netherlands with public debates about biotechnology — in 2001, there was a large public debate about genetically modified food, organized by the government — and it is hard to get people really participating in such discussions. That is not because they are not interested, but the subject is a complicated one, and it is hard to establish beforehand what the impact of the debate will be. Generally, outcomes of discussions like these are that people do support scientific research, but they also have questions about the utility of some of their applications.”

Much of what is called ‘science education’ is strongly biased in favour of science and technology, or against it, because of the reluctance to expose young people to debates within science. The scientific community itself seems to want to present the view of science as an objective, non-contested body of specialized knowl-

edge, and this is the way it is taught in high schools. So, genomics will almost always be presented in terms of ‘new knowledge with new benefits.’

In the view of Dr. Brunk, “for some reason, scientists tend to be reluctant to discuss the real uncertainties and ambiguities about their science and the related technologies in public. I am always struck by the difference in the language and discourse scientists use when they speak to the media or to lay people from the language they use among themselves. Among themselves, they speak freely of the uncertainties and the risks, but in public there is some strongly subconscious need to present science as a knowledge consensus. There is also an increasing tendency among scientists to identify themselves with the technological applications of their science. Maybe this is because the line between science and technology is increas-

ingly blurred. Maybe also it is because the real ‘payoff’ for science is increasingly in the commercializable, patentable product. As a result, scientists have tended to make broad claims about the benefit side of new developments, while depreciating the concerns about potential risks or ethics.”

Dr. Margaret Lock maintained that the media are largely responsible for publishing or broadcasting monolithic, uncritical views about scientific advances. “To date,” she said, “the media have shown a willingness to get opinions on ethical issues related to genetics, but discussion of the actual science itself, the divisions among scientists, the assumptions built into certain hypotheses, and even the most promising avenues where breakthroughs can be expected, are very rarely discussed. The media also rarely discuss the social consequences of genomics. The actual impact of genetic testing and screening on families, or empirical work on public concerns about genetically modified organisms, for example, are just two topics that social science researchers could be called upon to present to the public.”

“Everyone talks about public engagement and most people agree it is a necessary part of policy development,” said Prof. Timothy Caulfield of the University of Alberta, and co-chair of the Montreal GE³LS Symposium. “Indeed, sustainable policy demands it. However, we still aren’t sure how to do it in a meaningful way. That is one reason the British Columbia GE³LS project is so interesting. One of its explicit goals is to develop strategies to engage the public. Meantime, I think we should work with the evidence and methodologies available.”

More than two hundred researchers participated at this historic meeting.



Genomics, risk, science and acceptability

The second day of the GE³LS Symposium was devoted to genomics, risk, science and public acceptance of new technology. The day's presentations touched on issues such as the

idea of risk, the perception of risk and the use of that perception by different stakeholders, as well as the labeling of genetically modified foods as an issue for risk management.

Dr. Margaret Lock, Marjorie Bronfman Professor in Social Studies in Medicine at McGill University, addressed public understanding (and misunderstanding) of complex scientific issues. She is convinced that the media and scientists alike have the responsibility to communicate in an accurate and effective manner, not just about potential benefits of genomics technologies, but also about complexity, uncertainty and risk.

"Estimates of relative risk for complex diseases such as breast cancer have tended to go down as more knowledge is amassed," she said. "The difficulty, of course, is that so often the media do not want to deal with such complexity — it does not make for a neat story. Moreover, the knowledge is continually changing and needs to be updated all the time. In order to deal with this problem, I would like to see working groups set up by Genome Canada and by the CIHR Institute of Genetics, whose mandates would be to build up a cadre of interested scientists and media people, to learn how to communicate effectively with each other."

Dr. Guy Cardineau addressed issues of genomics, risk and acceptability from the science perspective. Coming out of the agriculture and biotechnology sector, Dr. Cardineau has held senior positions with Dow AgroSciences and other American firms, and is the inventor of over 30 issued and pending patent applications in the plant sciences. He is currently Research Professor at Arizona State University, and is co-founder of proVACS.

"At proVACS, we are looking at growing vaccines in plants," said Dr. Cardineau. "Humans are presented with thousands of antigens on a daily basis. We have a lot of commensal bacteria in our digestive system all the time, and they help us digest food. We

don't make antibodies against those bacteria, because they are non-pathogenic... By eating a plant-vaccine, such as a banana, our immune system would tolerate the antigen and could become adjusted to seeing that antigen and therefore not produce antibodies. With vaccination, you develop cells with memory, which can develop antibodies to the virus." He noted though, that one risk issue with such transgenic plants could be overfeeding.

According to Dr. Cardineau, risk is not just a matter of what could happen if a technology is used, but also what could happen if the technology is *not* used. "Polio has been cleared in the Americas in the last ten years and in many areas of Europe," he said. "But in sub-Saharan Africa, polio is endemic in about thirty countries, and there are another one hundred countries where it is not yet certified. In many countries, there are issues of sterility, cold chain (from the day it is produced to the day it is delivered), wastage and patient compliance." The objective of Dr. Cardineau's team at proVACS is to help reduce the prevalence of such diseases, using plant vaccines that are easier to develop, transport, store and administer than vaccines currently available.

Dr. David Castle, Assistant Professor of Philosophy at the University of Guelph and principal investigator on two GE³LS projects, approached the risk of using vs. risk of not using technologies from a different perspective. "My view is that people should be able to exercise choice in their food preferences," he said, "but it is important that they make meaningful choices. Some may view genetically modified foods as risky. I think there are equal risks associated with not adopting some technologies."

Ultimately, for Dr. Castle, the issue of risk should be addressed by providing people



with appropriate information that is balanced and enables them to make an informed decision. "If people are to be able to distinguish between these different cases," he said, "they need reliable information that they can understand. I've been endorsing a position in which foods are indexed as novel or not novel, where individual products are given a reference number so that consumers can find out more about them. We are conducting research here at the University of Guelph on how one might label novel foods so that consumers are neither encouraged nor discouraged by the label — important research, because labels ought not to be the final arbiter in food choices, but should be a point of entry for informed decision making."

One way to address the challenges of genomics, science, risk and acceptability is to integrate the research work of scientists and the GE³LS community. "As technologies develop, there is a need for the public to have a conversation about them," said Richard Isnor, director of Biotechnology Horizontal Initiatives and Interdepartmental Relations, and coordinator of National Research Council of Canada's Genomics and Health Initiative. "There should be a way for some of the scientists to be involved and the GE³LS community and the public. Just polling the public is not citizenship engagement. We need more than that... There are probably a lot of scientists thinking about GE³LS issues. They may be following their nose, but they are not naïve about GE³LS. You don't want to have two separate communities; you need to integrate the two, so GE³LS is more relevant." NRC was a co-sponsor of the first GE³LS Symposium, held in Montreal. ▀