

GE³LS Symposium Gives Voice to the Unheard

It came up again and again. The thorny question of just what to call members of “civil society”, whose conspicuous absence in the genomics debate provided the impetus behind the 2004 GE³LS Symposium theme: “Genomics in an Open Society”.

Should they be called the “public”, or is “publics” more precise? The “4th helix” or “4th strand”? What about “stakeholders”, “consumers” or “citizens”? While no consensus was forthcoming, nor, for that matter, was one expected or even desired, many attendees seemed to agree about the pressing need to find ways of bringing these “unheard” or “missing” voices into public policy debates surrounding genomics and its associated biotechnologies.

Held from February 5th to 7th in Vancouver, BC, the symposium brought together academics, scientists, government representatives, industry leaders and members of civil society from Canada, US, Europe and Africa for an open dialogue to “probe the relationship between genomics and civil society from the perspectives of those beyond the GE³LS community”.

“GE³LS research is dominated by people who do a kind of bioethics work and tend to be from



David Castle, Chair, 2004 GE³LS Symposium

medicine, law, and philosophy,” explained the symposium’s chair, David Castle, who is an assistant professor with the University of Guelph’s Philosophy department and principal investigator on two large-scale GE³LS research

programs. “But there are many aspects about genomics, genetics, and biotechnology that could be covered from other academic perspectives. The non-academic may also have something to say that’s unique.”

“So the idea of the ‘open society’ was not only to bring together academics not traditionally represented in GE³LS research,” he added, “but also people from what we might call ‘civil society’ to come and share their perspectives on how genomics and associated biotechnology will impact Canadian Society.”

Why a symposium and not a conference? According to Castle, the symposium format was deliberately chosen by the organizing committee to ensure attendees would remain together in the same room and hear the entire program, rather than having to pick and choose between concurrent sessions. It was critical to organizers that attendees follow the program’s carefully planned “trajectory”.

The trajectory began with an exploration of what is meant by the triple helix model — the collaboration between academic, government and industry research much discussed in the sociology of science literature — and whether the model adequately represents how the science innovation system operates in Canada. That part of the program was kicked-off by the National Cancer Institute’s Dr. John Milner, who

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Attitudes on Biotech: First Canada-US Comparison Finds Key Differences

According to public opinion research presented at the 2004 GE³LS Symposium, both Canadians and Americans apply a “nuanced” risk-benefit analysis to express approval levels for biotech applications, but the US is more supportive overall.

Just how risky do Canadians and Americans rate biotechnology products?

According to public opinion research sponsored by Canada’s federal government, Canadians ranked genetically modified food far down a list of possible dicey situations, below nuclear waste, violent crime, serious car accidents, air pollution and pesticides. But they gave it a higher risk potential than severe weather and tap water.

Canadians seem slightly less perturbed with bio-engineered pharmaceuticals — drugs that contain genetically modified material to treat diseases like cancer — which ranked last on the list of nine perceived threats.

Deemed North America’s largest and most comprehensive look at people’s attitudes towards biotechnology, the bi-annual surveys are carried out by the Canadian Biotechnology Strategy Secretariat to gauge awareness and

opinions about biotech’s “processes, products and applications”, and also zero-in on specific ‘hot-button’ issues, like GMO foods, animal cloning and gene mapping.

For the first time since research began in 1999, the latest survey included US respondents, not only to establish US trend-lines, but also to compare Canadian and American attitudes.

Turns out Americans are somewhat less concerned than Canadians about the perceived risks of GM food and bio-engineered pharmaceuticals, which placed second last and last, respectively, on the list of possible threats. However, both populations still rated the biotechnologies as “high” risks to health and the environment.

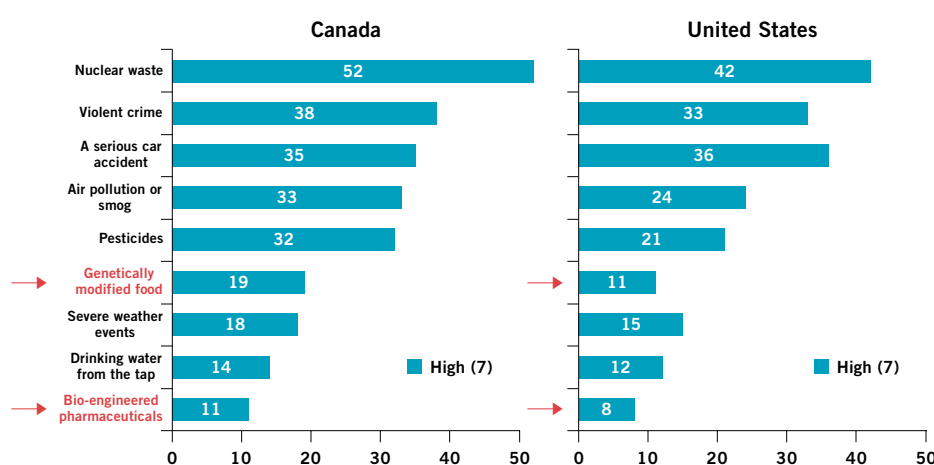
So, how do Canadians and Americans compare on other biotech issues? For the most part, Canadian opinion mirrors that of the US, but some key differences do exist.

Americans are more supportive of biotech overall. While support for biotech is growing in Canada (63% in support and 25% against) and strong opposition has shrunk to its lowest level since research began in 1990, current

findings show that Americans are more generally supportive (71% in support and 19% against), and between 5 and 10% more

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Risks in Society



Source: Canadian Biotechnology Strategy Secretariat

GE³LS Websites to watch

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

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From the Editor

This issue of the GE³LS Newsletter is devoted to Canada's second national GE³LS Symposium, held in Vancouver in early February 2004. The Symposium was entirely dedicated to the "unheard voices", what some call the fourth strand of the helix. Many of the advances in genomics and biotechnology are the results of the coordination between governments, universities and industries, which have been likened to intertwined strands of a triple helix. How the configuration and dynamics of this triple helix are to be understood is a subject of intense social and scientific debate. The second national GE³LS Symposium investigated the emergence and functioning of the triple helix, as well as the need for civil society and its

unheard voices to be integrated and legitimised as the fourth strand in the helix.

In order to report on almost every aspect of this fascinating three-day symposium, we have hired a fantastic freelance journalist: Elizabeth Morse.

Elizabeth has been a writer and editor for over twelve years. She was a regular contributor to *BCBusiness's* FasTrak section for three years, covering the dot-com bubble and bust and profiling companies such as Oracle and Electronic Arts. Her writing has appeared in diverse publications, including *Mining Magazine*, *Computer Dealer News*, *Control Engineering*



and *Northwest Palate*. Elizabeth brings to this newsletter her amazing talent of making complex issues easy-to-understand.

As Canada's GE³LS community grows, reaching out to researchers and diverse public audiences in Canada and other countries, we believe that Elizabeth's articles and interviews will make your reading both instructive and enjoyable.

Enjoy!

Anie Perrault
Vice-President, Communications
Genome Canada

GE³LS Symposium Gives Voice to the Unheard

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gave a talk on "nutrigenomics", the study of how genes and nutrients interact (see story on page 007).

Attendees then turned their attention to the "missing" voices in genomics: to hear whether or not the innovation system is addressing their needs. Viewpoints emerged from representatives of disability and environmental movements, non-governmental organizations,

encourage unmediated voices. Did the experiment work? Castle believes it did.

"We heard a wide range of disparate views. What pleased me is that real differences in point of view persisted, as they should. The symposium didn't turn into some kind of 'consensus-building love-in.'"

"It was a civilized discussion," Castle continued, "but it was pretty obvious that there were major points of disagreement. Differences between,

GM foods and labeling surfaced more trust issues — specifically the public's trust in having their voices heard. The issue was arguably the symposium's most commonly cited example of how the public's voice is either ignored in Canadian and American policy-making, or heeded, as in the UK example of the "GM Nation" debates.

Significant representation from the European Union also provided a measure of where Canada stands against other parts of the world. In the EU, explained Castle, "they've been wrestling with the question of public involvement in setting the science agenda, partic-

said at the symposium, but describe what they learned and how they've integrated that back into their own understanding of how innovation in genomics and biotech is proceeding.

"In the big scheme of things," Castle summed up, "it's probably going to take some time for a lot of this to grind through the backs of people's minds, and for them to answer whether Canadian science and technology innovation is less than ideally democratic, and whether or not they, in particular, have grounds for thinking they've been cut out of the steps leading to a formulation of the Canadian science and technology agenda." ❖

"Genomics: How does it function as an innovation system? Who are the players? Who gets left out? What do they have to say about it? How do we include them?"

David Castle, Symposium Chair, during his opening remarks.

"Isn't it the role of government to represent the interests of civil society?"

Ron Doering, partner, Regulatory Affairs Group of Gowling Lafleur Henderson LLP, former government regulator during his talk representing a government perspective.

religious communities, first nations, women's groups, and developing nations (see page 003 for a profile of disability activist Catherine Frazee). The general public's voice was also heard, albeit indirectly, in presentations about the latest public opinion research on biotech (see page 001 for a Canada-US comparison of public opinion on biotech).

The trajectory's arc ended with a look forward: issues of how to handle dissent, the role of

say, an ethical perspective and a religious perspective. Or in the roles that NGOs ought to play. Not all views are reconcilable in the short term, and maybe not even in the long term."

Among many themes to emerge was the issue of trust — trust in the purveyors of science-based information and trust in the authorities making decisions around genomics. For instance, it became clear that some organizations within government are enabling innova-

ularly with respect to GM foods, for a few years now. We were able to learn from them, because they have different insights into the problem, which might help us assess whether or not we're doing things right in the Canadian context."

Ultimately, not all questions were provided with easy answers. Rather, the symposium served more of an "educative function", as Castle put it, for people to network and make new connections between disparate areas.

Although they sometimes craved more discussion time and smaller breakout groups, philosophy graduate students Bill Hannah and Rana Ahmad, who work on GE³LS-related projects, found the symposium format helped them to network with colleagues and introduced them to topics outside of their areas of interest.

"It's hard as a graduate student to learn about others in the GE³LS community," said Hannah. "It was a good opportunity to get them all into one room. I also found out about new areas, like agriculture, and introduced others to my areas of interest."

Ahmad echoed those sentiments, adding, "If it had been a regular conference, I would have gone to presentations that I already knew something about or had an interest in, and would have skipped the other ones. I ended up having some major epiphanies."

Through the symposium, Castle argued, Canada has provided "leadership" on the topic of genomics in an open society, and started to lay down a foundation for thinking about how to address some of the inherent problems. He envisions attendees being in a better position to organize smaller workshops on topics such as public engagement and food safety, or the relationship between genomic innovation and aboriginal issues.

He also plans to help create an "enduring document" from the symposium, to serve as a kind of "benchmark" and a "reference point". Presenters would not simply repeat what they

[...] some organizations within government are enabling innovation, while also maintaining responsibility for regulating the fruits of the innovation. "The implication of government in both of those roles, even if it involves different parts of government, means that they become an interested party. [...] One has to ask some rather pointed questions: 'Is there a problem with our regulatory system?' 'If they enable innovation *and* regulate, are politicians and regulators able to do both parts of the job that we've entrusted them to do?'"

the media as science educators (see page 005 for a look at science coverage in the media), and alternative models of governance and regulation. A performance of the play *Sarah's Daughters*, which explores the ethics of testing for cancer genes, marked the event's conclusion (to read a review, see page 004).

In what was later deemed an "experiment" by Castle, symposium presenters were not given explicit directions, but simply asked to speak on a broad topic. Again, this was a conscious effort on the part of the organizing committee to

tion, while also maintaining responsibility for regulating the fruits of the innovation.

"The implication of government in both of those roles, even if it involves different parts of government," said Castle, "means that they become an interested party. That's a real issue for the regulation of areas such as IP and food safety. One has to ask some rather pointed questions: 'Is there a problem with our regulatory system?' 'If they enable innovation *and* regulate, are politicians and regulators able to do both parts of the job that we've entrusted them to do?'"

INVITATION TO READERS

Do you find this Newsletter interesting? What is your perspective on ethical, environmental, economic, legal and social impacts of genomics and proteomics? Would you like to receive more copies and distribute it to colleagues and friends?

Drop us a line c/o Genome Canada.

GE³LS

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“Fugitive from the Laws of Genetic Science”

Disability Activist Questions Genomics' Assumptions

Odds are that if Catherine Frazee was conceived today, she likely wouldn't survive past the amniocentesis. And Canada would have lost one of its foremost disability and human rights activists.

Born with a significant genetically-based disability, the self-described “fugitive from the laws of genetic science” was Chief Commissioner of the Ontario Human Rights Commission from 1989 to 1992, and is now a professor at Ryerson's Disability Studies program. She also co-directs Ryerson's Institute of Disability Studies Research and Education, and maintains a private practice in human rights mediation.

Presenting at the 2004 GE³LS Symposium as part of a panel session entitled “Genomics in the Public Interest — Unheard Voices”, Frazee's talk challenged several of genomics' chief assumptions, including the notion of reducing harm and suffering, and the concept of what should be considered normal health.

“According to genetic science, I am ‘genetically atypical’, ‘disrupted’, ‘mutated’,” she said during her symposium presentation. “When I read between the lines of genomics, I see an uncritical promotion of healthy futures that don't look the least bit like me. My problem is not that I cannot walk in that ‘quaint bipedal’ sort of way, it's that I'm living in a society that is premised on the fact that everyone should walk

through a variety of lenses — history, politics, economics, sociology, and others.

Disability scholarship questions so many of the presumptions that are invisible and embedded in our able-ist society, which presumes that people who have particular psychological and physical characteristics are ‘normal’ and that a group of individuals who don't match these ‘benchmarks’ are not normal.

In your opinion, does genomics carry particular assumptions?

Any research that seeks to eradicate disability or conditions of disability in an unqualified way needs more examination and reflection. Genomics proceeds from a fundamental assumption that something that *could* be prevented, like a particular disability, *should* be prevented.

What about extreme cases of genetic diseases — would eliminating them not diminish pain and suffering?

Policy decisions should not be based on extreme cases. My sense is that it's extremely difficult to draw a line and determine what constitutes discomfort, even suffering. We have to stand back from our own fears and subjectivity. Often accounts of suffering reflect the losses of third parties, rather than the direct experience of the disabled person. Suffering is



Catherine Frazee

You use the term “eugenic” to describe aspects of genomics — that's a strong word.

tion of life-threatening diseases such as cancer. But *I do* have a very fundamental concern about the way health-side genomics research constructs health as a state of being that excludes disability.

What do you say to future parents who want to be given more reproductive choices?

For valid and important policy reasons, we do not permit parents to choose, for example, the sex of their offspring; to do otherwise would entrench and perpetuate gender privilege. If we allow parents to choose their children's physical and intellectual characteristics, we entrench and perpetuate disability disad-

“We've all learned a lesson for the next wave of scientific innovation, which some say is nanotechnology — people might get upset if you encourage broad public debate early on, but in the long run it's the only thing to do. Not only is it the only ethical thing to do, but if you don't make opportunities for people to debate the issues early enough, then you guarantee that you're going to lose some of the trust and goodwill that are associated with support for that kind of research.”

Susanna Hornig Priest, *public opinion expert and professor at Texas A&M University*, during an interview after her presentation, “Genomics and Civil Society”.

That certain kinds of dependence, on things like wheelchairs or on personal care attendants, are structured to constitute disability, while certain other dependencies, such as on vehicles and hydro-electric power, are not.”

Frazee credits her own survival to “a combination of family, race, class, nationality, intellect, and access to urban amenities”. Not to mention a rare talent for turning widely-held beliefs and unexamined assumptions about disability neatly onto their heads.

“The prevention of human suffering is one of the ‘no-brainers’ of genomics,” she argued. “But when you start to think about them, these

complex; there are negatives and positives. Take Stephen Hawking's experience with ALS. He's quite clear that he would not have fully developed as a scientist had he not had that experience. ALS ultimately defined the direction of Hawking's life and career.

Was there a particular issue that galvanized you?

By the early nineties, I had moved into semi-retirement and was leading a more reflective life — not so engaged in the front lines of disability activism. But in 1993, we first learned of the killing of Tracy Latimer. I was deeply alarmed by her death, and even more so by the public

The term ‘eugenic’ often evokes the same response as words like ‘racist’ or ‘sexist’. But in the domain of disability studies, it's an accurate word to describe the impulse behind a society wishing to eliminate disability by intervening in reproductive processes. Eugenics has a long history with many extreme examples. Today we may be more subtle, but we still have the same tendency to intervene in human reproductive processes in order to eradicate certain populations.

To justify any implementation of genomic technology simply because disability is prevented or eliminated is a eugenic proposition. It harms not only the potential person, but also harms the community of persons who have, for exam-

vantage. As a matter of social policy, we must draw back from any inclination to commodify children.

Along with the majority of disability advocates, I support women's right to choose. But the choice is whether to bear a child or not. This is fundamentally different from choosing whether to have a particular kind of child. If we permit parents to choose not to bear a disabled child, what then is our expectation of a parent if and when a nondisabled child becomes disabled as a result of an accident?

How do you think genomics should deal with some of the ethical issues you raise?

At a minimum, we need to support more robust funding streams for research that is ethically based: social science research, instead of just medical research. We should shape ethical protocols that are more consistent with a disability perspective by actively seeking out the perspectives of disabled people.

Are you optimistic that this can be accomplished?

I'm cautiously optimistic. The concerns of disabled people often mirror those of the broader public, and I do think we're at a critical turning point where civil society is starting to ask searching questions that could change the direction of genomics.

If you look at aviation history, and at the Concorde in particular, you can draw some parallels. The Concorde was a state-of-the-art technology only available to a small number of elites. There was a tragedy and a number of casualties, which was very regrettable. Ultimately, as exciting as the technology was, the public didn't want it. Its demise marked the end of an era of aviation history.

If the public becomes more informed and engaged, it may become impossible to promote eugenic uses of genomics. They may go the way of the Concorde. ❖

“Policy decisions should not be based on extreme cases. My sense is that it's extremely difficult to draw a line and determine what constitutes discomfort, even suffering. We have to stand back from our own fears and subjectivity. Often accounts of suffering reflect the losses of third parties, rather than the direct experience of the disabled person. Suffering is complex; there are negatives and positives. Take Stephen Hawking's experience with ALS. He's quite clear that he would not have fully developed as a scientist had he not had that experience.”

no-brainers suddenly become very complicated and problematic. Eighty percent of fetuses found to carry Down's Syndrome are aborted, for example, yet Down's Syndrome doesn't meet the criteria — there's no inherent suffering. Accounts of suffering are usually made by third parties, not by disabled people themselves.” She graciously agreed to speak to a *GE³LS Newsletter* reporter at the symposium and later from her home in Hamilton, Ontario.

What are disability studies all about?

It's a social science discipline that looks at disability not through the lens of medicine, but

outpouring of sympathy for the man who took her life.

[Ed. Note: *Tracy Latimer was killed by her father, who claimed he could not bear to watch her suffer from a severe form of cerebral palsy. He was later convicted of second-degree murder and sentenced to life in prison.*]

Many disabled Canadians moved into activist positions as a result of these developments. We had failed to appreciate that the gains we had made — the gradual removal of barriers and having our voices heard — were more precarious than we could ever have imagined.

ple, Down's Syndrome. The whole community is devalued if your measure for success is to eliminate Down's Syndrome from the human family.

Are you implying that all genomics research is about preventing disabilities, and therefore follows a eugenic impulse? Is some research worth preserving?

My focus is strictly on health-side genomics, for starters. I would support genomics research that genuinely offers to improve the health and well-being of all persons — including disabled persons — by improving the effectiveness and availability of medical treatments and preven-

The Science of Drama: *Play Probes Ethics of Testing for Cancer Genes*

"She lives with the knowledge it will happen to her."

And with that soulful, poetic opening line, so begins *Sarah's Daughters*, a one-woman play that explores the ethical issues of testing for breast cancer gene mutations. Written by London, Ontario physician and playwright Jeff Nisker, the play is about the anguish of a young woman, "Joanne", whose mother and grandmother died at a young age from breast cancer. It explores her fear: for herself, and for her daughters.

The workshop production, followed by an audience discussion, was staged at Robson Square Theatre in downtown Vancouver on two evenings — one for attendees of the 2004 GE³LS Symposium, the other for the general public.

Directed by Dora Award-winner Liza Balkan, and performed by Martha Zimmerman and cellist Alyssa Wright, the play surfaces ethical issues inherent to testing for breast cancer gene mutations ('BRCA'), but its concerns apply to many adult-onset inherited conditions.

"Sarah" is Joanne's grandmother, who died at an early age from breast cancer, as did Joanne's mother. They were the only other women in her post-Holocaust family. As the opening lines

"Some provinces fund the counseling, some don't," he added. "Some have huge waiting lists, some don't have any. We're supposed to be a uni-tiered healthcare system, but it's not working that way. Wealthy people, no matter where they live in Canada, can just go to the United States, have the test and even get the counseling in some places. Genetic counseling and testing should be available to all Canadians at high risk of carrying gene mutations."

It was Nisker's experience as co-chairperson of Health Canada's advisory committee on reproductive and genetic technologies that initially galvanized his belief that the public should be more involved in policy-making.

"I became convinced that the public has very little input into policy decisions and that particularly in the area of genomics, they *must* be involved."

For Nisker, the stage was a natural tool for fostering more public participation. It wasn't such a huge leap: While in medical school, Nisker wrote and directed musical comedies for a theatre arts summer camp. As an ethics educator, he's written numerous short stories and plays to highlight the complex ethical issues healthcare professionals and students routinely confront. His work came to national attention in



Credit: Brian Hawkes Photographie

Actress Martha Zimmerman, accompanied by cellist Alyssa Wright



Credit: Brian Hawkes Photographie

1999 on the CBC when he was chosen one of Peter Gzowski's "Best Minds of Our Time."

Along with his experience in the medical field, Nisker credits Brazilian theatre director Augusto Boal for inspiring his provocative plays, of which *Sarah's Daughters* is the sixth. Boal's 'Theatre of the Oppressed' methodology was developed in the 60s to educate the public towards democracy.

Nisker's particular innovation is his proposed use of theatre to capture and analyze audience perceptions about genomics. He hopes one day to be able to use the data to help the public participate in policy development.

Sarah's Daughters represents a pilot project in

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"The 'unheard voices' in the UK are people from industry, people who don't care, and non-organic farmers." (...) "To what extent should the interests and values of one stakeholder group be allowed to constrain the options available to others?" (...) "You have to assess what kind of conflict you are dealing with. If it's ideologically based, public engagement doesn't work — it's big and expensive and only offers opportunities for special interest groups to gain new recruits."

Joyce Tait, *Innogen Centre, University of Edinburgh*, during her presentation "What Counts as Democratic Engagement?"

mournfully reveal, for Joanne, it's not so much 'if' she will contract the disease, as 'when': "She lives with the knowledge it would happen to her. That what happened to her grandmother, that what happened to her mother, would happen to her. She only wondered when it would happen."

A newly available genetic test could alleviate or confirm her fears, but her family's medical history, silenced as it was by the Holocaust, ironically doesn't offer up the necessary number of women with breast cancer for her to be considered an appropriate research candidate. Joanne later learns that she could go to the US for testing, but can't afford it.

Nisker's set design serves as a metaphor for the intersection between this stark, genetic information and Joanne's lived experience. Joanne speaks to us mostly from centre stage, a stage literally divided. On one side, representing the domestic sphere, is an overstuffed chair flanked by an end-table, floor lamp, and large potted plant — the stage equivalent of a favourite reading spot. The other side is a highly clinical, depersonalized counseling office, occupied when Joanne learns the results of her genetic test — contained in a menacing brown envelope, or, as Joanne calls it, "the death raft that could drown me".

A professor of obstetrics, gynecology and oncology, and coordinator of bioethics in the Faculty of Medicine and Dentistry at the University of Western Ontario, Nisker deftly weaves detailed, scientific information into a vivid narrative that never seems overwrought. On a much deeper level, Nisker uses the play to raise serious issues about access to genetic testing.

"My intent is not to suggest that genetic testing is the solution, but rather that counseling should be made available for all women at high risk of pre-menopausal breast cancer," commented Nisker. "Although genetic counseling in Canada is as good as anywhere in the world, the tragedy is that rapid access to counseling for women at high risk of carrying BRCA gene mutations lags behind other countries."

NEW WAYS TO ENGAGE CIVIL SOCIETY

Heading to the Pub? Don't forget your deck of "DEMOCS" cards.

The Society Religion and Technology Project (SRTP) was set up in 1970 by the Church of Scotland to examine the implications of new and emerging technologies. The group works with people from industry and technology, policy makers and those expressing opposition. As part of the UK-wide GM Nation debate in 2003, SRTP promoted a card game, called DEMOCS, to encourage lay people to discuss the issues. Devised by the New Economics Foundation (NEF), DEMOCS stands for DELiberative Meetings Organised by CitizenS and was designed as a way for informal groups of people to discuss critical issues in their own homes or work-places, but also feed their opinions into policy making. It was used as part of a recent government consultation on genetic testing kits in the UK.

www.srtp.org.uk/edingmpr.htm

And Your Final Answer Is...

On Saturday, July 20, 2002, 6,000 people from New York and area came together to shape the future of Lower Manhattan. This historic gathering — called "Listening to the City" — gave participants an opportunity to help shape the redevelopment of Lower Manhattan and the creation of a permanent memorial to the victims of 9/11. During the event, facilitated by *AmericaSpeaks*, participants sat in small groups and used state-of-the-art technology to voice their opinions on critical issues and vote on options brought before the entire group.

www.listeningtothecity.org/

Looking for African Lion Park Safari? You Must Have Taken a Wrong Turn.

Since the 1960s, Akwesasne, which has been occupied by Mohawks for many thousands of years, has borne the brunt of pollution and contamination from industries along the St. Lawrence River. Sure, researchers came and took samples to examine the effects of the pollution on area residents, but the results rarely flowed back into the community. Such individuals became known as "safari" researchers by Akwesasne residents. A result of increasing outrage on the part of Mohawks, the Akwesasne Task Force on the Environment (ATFE) was founded in 1987 as a community-based organization dedicated to addressing the environmental problems faced by the Akwesasne Mohawk Nation. ATFE works to promote environmental restoration and protection based on traditional teachings about the obligation to honor the sacred web of life and guard it for future generations. To establish more control over research data and funding allocation, ATFE became incorporated in 1995 and is now overseen by a Board of Directors. Since its founding, the ATFE has secured stricter environmental regulations, superfund clean-ups, and scientific studies. Now, as enshrined in its research process, the community owns all research data generated from studies in its geographical area.

<http://environment.harvard.edu/religion/religion/indigenous/projects/akwesasne.html>

Science Stories “*First to be Dumped*” During War, Elections

Without question, science holds an enduring fascination for most of us, a fact that has not gone unnoticed by the mass media. Just look at the popularity of shows like *CSI* and *Law and Order*, and their seemingly limitless spin-offs, which offer viewers an unprecedented and highly detailed look at the science of criminal investigation and prosecution.

The public also seems to have an unquenchable thirst for science-related news. Last year, according to a survey of newspaper editors and broadcasters conducted by the Canadian Press and Broadcast News, the top news story in Canada was not the war in Iraq or the Liberal leadership race, but SARS. Mad Cow, another science-related story, earned the fourth spot, after gay marriage and BC’s forest fires.

According to Véronique Morin, a freelance journalist and President of the Canadian Science Writers’ Association (CSWA) who gave a presentation at the 2004 GE³LS Symposium, it’s “undisputable” that the media plays a key role in educating people about science. The media not only acts as a watchdog for issues of potential public concern, she stated, but it’s also the general public’s main source of information on science after they leave school.

But even while media outlets are responding

a very poor job at covering the science angles — the ‘how?’ as opposed to the ‘how much?’ — of any story.”

Morin thinks one reason journalists do a “poor job” covering science is that few have specialized training in science journalism. Unlike other countries, such as the US and Britain, there are no programs entirely devoted to science journalism in Canada, and only two schools of journalism offer a science-journalism course as part of their overall curriculum. Coming from liberal arts backgrounds, many journalists don’t

understand or even like science, yet are assigned science stories.

“The trend in newsrooms is to give science stories to general journalists. But science journalism needs special training,” argued

lines that don’t accurately reflect their core content.

“Journalists will submit sensitive, balanced science stories to their editors, then hit a wall with editors who want to sell papers. The editors are the gatekeepers and often short-circuit the stories, turning them into sensationalistic events.”

Biotech-related stories seem particularly vulnerable to sensational treatments, with science taking a backseat to the embellished and even false claims of suspect sources, which go

were given more credibility and space in a newsroom, the coverage would have reflected the minimal amount of scientific content. However, broadcasters fell deeply into this story. In print, where science and medicine beats tend to have a stronger history, the reporting seemed to be more cautious. Nevertheless, the sheer amount of attention given to Raël, points to the ongoing need to train general news reporters at how science should be addressed.”

She also points the blame for poor coverage at a phenomenon known in academic circles as

Take the Raëlian cult’s announcement that they planned to be first to clone a human. In Morin’s opinion, if science reporting were given more credence in newsrooms, the story’s lack of a scientific basis would have been quickly uncovered, and it therefore wouldn’t have garnered the same level of attention.

unchallenged in the media. Take the Raëlian cult’s announcement that they planned to be first to clone a human. In Morin’s opinion, if science reporting were given more credence in newsrooms, the story’s lack of a scientific basis would have been quickly uncovered, and it

the “hoopla effect”, where the media becomes a key source of alarmist ‘risk’ stories. In simple terms, it’s a cycle that begins with the identification of a risk, say to health or the environment. Experts call for more scientific inquiry, but there’s no real reflection on the issues. As

“It’s impossible, but that’s no reason not to do it. Start by thinking about who you *don’t* want to hear from.”

Catherine Frazee, *Disability Activist*, responding after her presentation to a question about how to identify the ‘unheard voices’ in genomics policy-making.

“There has been no informed consent in the experiment of GM foods. Public opinion supports labeling — the consensus is clear. What more does the public have to do?”

Lucy Sharratt, *Polaris Institute*, during her presentation “The Public’s Voice”.

to the demand for science-related stories and coverage is increasing, Morin maintains that science stories still suffer from unfair press coverage, and unbalanced and inaccurate reporting. So, why the disconnect?

One problem stems from a belief held by many news editors that science stories are simply not newsworthy enough.

“Science-related stories were the first to be dumped during the Iraq war,” said Morin. “They’re also the first to go during an election.”

“One of the news business’ first rules of thumb for potentially interesting stories,” Morin explained in a recent President’s letter to the CSWA, “is that they have to be relevant to people in a not-so-distant future (i.e., something sooner than a million years from now). That’s why it may appear that science stories are a hard sell. Some academics even argue that there is very little — if any — actual news to be found in science.”

“I hold a totally opposite opinion,” she continued, “and therefore I work in a general news setting. I believe science is in fact a daily source of worthwhile news stories. Unfortunately we do

Morin. However, even if they take pains to write an accurate, well-balanced story, how it’s handled once it hits the editor’s desk is often beyond the journalist’s control. In a bid to sell more papers, said Morin, some stories are given “sensational” or “exaggerated” head-

therefore wouldn’t have garnered the same level of attention.

“You could say [the Raëlian human cloning story] was not a science story,” said Morin in her letter to CSWA. “But, if science reporting

the story progresses, organizations with a vested interest are given airtime. Arguments are presented, both for and against. But as the topic becomes more complex, media coverage starts to decline and so too does public interest.



Ultimately, the hoopla effect means the media is more effective at generating awareness of an issue, but less able to follow-through with meaningful, in-depth coverage. Yet, with the rapidly emerging field of genomics, and its accompanying ethical, legal and environmental questions, the public needs in-depth science coverage more than ever.

“Genomics is a dichotomy: It holds great promise, but also raises anxiety,” stated Morin. “The research is going so fast that even lawmakers can’t keep up. Imagine journalists, with our fast deadlines, trying to keep up.” All the more need, she argues, for specialized journalists who can convey complex issues in an accurate, balanced manner.

“The principles of fairness and accuracy are in the public’s best interest. The more specialized science becomes, the more specialized journalists need to be.” ❖

Play Probes Ethics of Testing for Cancer Genes

Continued from page 004

which Nisker investigated the ethical issues that arise when using theatre as a research tool. Nisker hopes to publish the results later in the year.

Applying what he learned during the *Sarah’s Daughters* research, Nisker will soon create a new theatrical production to be used as a research tool across Canada. Funded by the Canadian Institutes for Health Research (CIHR), *The Orchid’s Stem* will stimulate the public to think and talk about genomics, but this time

the data analysis will be presented to policy-makers.

If the discussion following *Sarah’s Daughters* public performance was any indication, the data from *The Orchid’s Stem* is sure to be frank, hard-hitting, and instructive for policy-makers. It’s one thing to see a play that, even if based on real-life situations, essentially remains a work of fiction. It’s quite another to hear what real people — some of whom are intimately familiar with Joanne’s fears — have to say.

After the floor was opened up for discussion, there was a long, anticipatory pause. Then a woman got up and slowly walked toward the microphone. “I am the character in your play”, she said, and then disclosed that, like Joanne, she too is a BRCA carrier.

After her, another woman. “You’ve just described my life,” she said. She had just tested positive, and so had her sister. Their mother had died of the disease at a young age. She had a question about how carrying the gene might affect her children, who are in their 30s and 40s. “I don’t know what it will do to their careers,” she said, launching a discussion into the privacy issues surrounding genetic information.

Other queries centered on the status of cancer gene testing and access to genetic counseling in BC. A student, who came to the play with a small group of genetic counselors-in-training, told the group she’d gained valuable, first-hand knowledge about the fears of women like Joanne. “It’s not just about lab results,” she now realized.

Despite the play’s heavy subject matter, by play’s end, Joanne’s fear is transformed by hope. Theatre that offers a chance for the audience to participate may offer a vehicle for people to share their fears, and hope, with policy-makers.

As Nisker wisely noted, “Lived experience is important data.” ❖

Attitudes on Biotech...

Continued from page 001

supportive on most specific issues. As for biotech applications — traditional types as well as cloning — Americans appear about 10% more supportive than Canadians. They show even higher support for agricultural applications.

However, each population expressed more “nuanced” opinions about biotech applications than earlier research suggested. Rather than paint all biotech applications with the same brush, they tend to differentiate between them by applying a risk-benefit analysis. The higher the risk to health and the environment, the lower the support. For example, both show high support (63%) for cloned animals used for medical research, but low support (24%) for cloned animals used as a food source.

According to the report, “the more intrusive the application, the higher the life form it involves and the larger the degree to which the application crosses boundaries separating plants, animals and humans, the larger the perceived risk.”

Perhaps not surprisingly, Canadians tend to be more cautious, expressing more concerns about biotech’s associated risks, particularly its possible long-term effects on health. Canadians show less trust in their regulatory regimes, believing them to be less rigorous than Americans consider theirs to be.

On one key issue both populations share near agreement: GM food. Americans tend to be

slightly more comfortable with GM food overall: about 42% of Americans expressed some level of discomfort, versus 52% of Canadians. But, overwhelmingly, both nations favour mandatory food labeling.

To explain why Americans are typically more supportive and less cautious about biotech than Canadians, survey researchers cite two key drivers more common in the US: “an unwavering belief in science and technology as pro-

viders of improved quality of life and standard of living”, and “a very strong belief in the power of entrepreneurialism, and a belief that biotechnology represents the new wave of entrepreneurial achievement for the United States.”

According to Canadian Biotechnology Strategy Secretariat’s John Olsthoorn, who presented the data at the 2004 GE³LS Symposium and was later interviewed by a *GE³LS Newsletter* reporter, focus groups were used to test the trend towards increasing support for biotech. “We wanted to rattle the cage to see how solid the support for biotech would remain.”

Researchers uncovered growing worries about

medical intrusiveness and human gene modification, concerns based chiefly on perceived risks to health and to a lesser degree on moral grounds, with the exception of cloning, where moral objections are paramount.

They were also surprised to find that both countries’ populations tend to underestimate their familiarity with biotech. US survey respondents were slightly more familiar with the issues than Canadians, but, said Olsthoorn, both groups are “more familiar than they think they are, and more familiar than we think they are. Even if they don’t have a lot of scientific information, they can still form a reasonable opinion.”

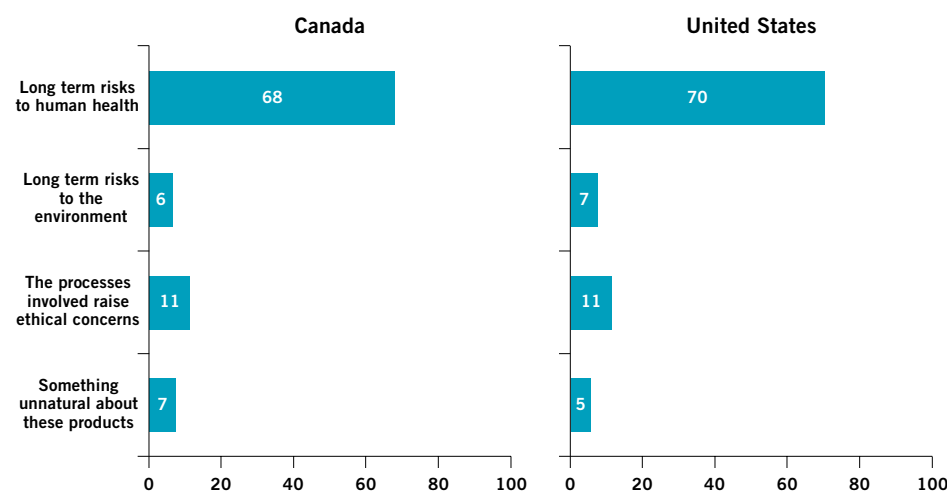
Overall, both nations share the same driving concern about biotech — perceived long-term risk to human health — which far exceeded risk to the environment, ethical concerns or worries that there’s something ‘unnatural’ about products.

Yet, remarkably, two thirds of people in both countries believe that science has the power to reverse biotech’s potential negative effects.

A complete report can be viewed at www.biotech.gc.ca. Results of the second Canada-US research wave will be released in June 2004. ♦

Considered a world leader in public opinion research, Canada conducts North America’s largest and most comprehensive investigations into attitudes about biotechnology and public policy. The publicly funded research data are available for study and analysis upon request at www.biotech.gc.ca.

Biotech Driving Concern: Risks to Human Health



Source: Canadian Biotechnology Strategy Secretariat

“There are implications behind increasing our lifespan. What kind of future are we getting ourselves into?”

Donald Bruce, *Society, Religion and Technology Project, Church of Scotland*, responding to a talk on nutrigenomics’ potential to diminish disease risk and prolong life.

“Whenever we do anything, we think about how it will affect the next seven generations.”

Maxine Cole, *Akwesasne Task Force on the Environment*, during her talk about how members of the Mohawk Nation have developed a community-based approach to research participation.

PASSING THE ‘TALKING STICK’

Public Opinion Research and Isolated Populations

Having your voice heard through public opinion research depends on three essential ingredients: having a phone, speaking the same language as whoever is posing survey questions, and, for focus group participants, living in an urban setting. True, the majority of Canadians take these things for granted. But what if you live in such a remote area it can only be reached by floatplane, and your only communication device is a two-way radio? Or, what if you do have a phone, but can’t understand the caller? How will your opinion be counted?

After attending the GE³LS Winter Symposium, John Olsthoorn began asking himself those very same questions. A communications and public outreach strategist with the Canadian Biotechnology Strategy (CBS) Secretariat — which commissions bi-annual focus groups and surveys on biotech — he decided to put his concerns to the delegates of a conference on public opinion research that he helped plan and organize.

Held March 24th and 25th in Ottawa and sponsored by the federal government through the CBS Secretariat, the conference largely focused on how to integrate worldwide public opinion research on biotechnology. Inspired by the GE³LS symposium, Olsthoorn also included a lunchtime session on the topic of reaching isolated populations, inviting Concordia communications professor Lorna Roth and *AmericaSpeaks*’ Carolyn Lukensmeyer to share their know-how with public opinion experts from across North America and Europe.

“Do we live with these limitations,” Olsthoorn asked, “or are there ways we can hear those ‘unheard voices’, those of people who are also impacted by advances in biotech?”

Roth, the author of *Something New in the Air: A History of First Peoples Television in Canada*, described some of the challenges involved in accessing isolated aboriginal populations for research purposes. Such peoples are not only isolated geographically, she said, but also linguistically and culturally.

Many aboriginal communities use ‘talking circles’ to discuss critical issues, Roth explained, passing a ‘talking stick’ to those wanting to express an opinion. Yet, what might seem an obvious method for eliciting first nations’ opinions is more complicated than many researchers realize. Some communities use talking sticks, others pass a feather or a rock. Other communities, like the Dene, have no such tradition. Roth used these examples to illustrate that first nations communities are not homogeneous, and that researchers can’t simply “add-on” a single aboriginal group to make a survey representative.

Historically, some researchers were also disrespectful of aboriginal groups — not sharing research results, for example — so those communities tend to be suspicious of research

enterprises. In fact, according to Roth, many Northern populations now require researchers to be licensed before they’re allowed access. She advised potential researchers to take the time to build trust with first nation councils, which are often charged with deciding whether or not research will take place.

Roth was quick to point out that marginalized groups do not always live in geographic isolation. She used the Hasidic Jews of Montreal as an example of a population that, while living in an urban setting, voluntarily isolates itself from mainstream society, and likely would not be included in public opinion research.

“Who is the ‘public’ in public opinion research?”, Roth wondered.

Even before attempting to contact marginalized groups, Carolyn Lukensmeyer added, much work should be done within the research organization itself. As president and founder of *AmericaSpeaks*, Lukensmeyer has devoted herself to planning large-scale public forums, including “Americans Discuss Social Security”, and “Listening to the City”, which brought together 6000 diverse citizens — including Muslims and illegal aliens — to discuss the redevelopment of the World Trade Center site in New York.

First, you have to determine “who needs to be in the room”, Lukensmeyer explained.

The next step is identifying barriers that might prevent those groups from participating. For example, a traditional Muslim woman may not want to express an opinion in front of a traditional Muslim man, so they may need to be separated during focus group discussions. Doing this “pre-work” with communities goes a long way towards understanding their cultural customs.

Lukensmeyer recommended researchers ask themselves a fundamental question before formulating their research: “What are the cues marginalized individuals look for to see if they’re being respected?”

One thing is clear: policy-makers are increasingly relying on survey and focus group results to influence their decisions. Meanwhile, as a conference delegate pointed out, biotechnology companies are increasingly targeting isolated populations because their genetic homogeneity is attractive to developers of databases such as gene banks. It’s therefore critical that researchers count the opinions held by isolated populations.

As Roth asked, “Can we be content with the absence of marginalized people in public opinion research? What is the cost of not knowing?”

Food and Genes: Nutrition's New Frontier?

"They're happy because they eat lard". Or so proclaims a 1940s advertisement from the Lard Information Council in the United Kingdom. And it's true: the trim family of three featured in the poster look positively cheery standing in their retro swimsuits, with mum beaming on as dad hoists their cherubic toddler onto his hip.

Ahh... the business of eating used to be so simple. Of course, we all know lard isn't the universal remedy it was purported to be. We know it's a saturated fat whose over-consumption can lead to heart disease and obesity. But even as our knowledge about dietary issues increases, so too does our confusion, skepticism, even downright paranoia about food.

Maybe it's because we're all getting conflicting information. Take margarine — for years it was touted for its positive health benefits, then suddenly we're told it's a trans-fat that makes butter seem almost wholesome. And now eggs are back in the nutritional good books, after being avoided for several decades over worries about cholesterol.

But according to Dr. John Milner, Chief of the Nutritional Science Research Group at the Rockville, Maryland-based National Cancer Institute (NCI) — whose presentation at the 2004 GE³LS Symposium included the humorous lard-promoting slide — such sweeping and often contradictory dietary advice may soon be a thing of the past.

in response is the genetics of the people consuming the foods."

That realization — the fact that genetic variations can cause people to respond differently to nutrients — may account for why dietary guidelines don't work for everyone, and why two people can eat the same foods and yet have vastly different health outcomes. It's also helped usher in a whole new set of "omic" buzzwords, including "proteomics" and "metabolomics".

"We believe that genes set the tone for what's absorbed from foods, what's utilized, what makes it to a site of action where it can change the expression of the DNA and lead to a new protein being formed — what we call 'proteomics' — and how that protein influences small cell components, what we call 'metabolomics', and what those two things have to do with your overall phenotype," explained Milner.

So, ultimately, it's your unique phenotype that may determine how you respond to certain food components. It may influence how you metabolize foreign compounds, for instance, or increase your susceptibility to cancer-causing agents.

Milner uses the example of a bronchodilator, a drug commonly given via 'puffer' to treat conditions like asthma. This drug was found to be quite effective in one group of individuals, but far less in another, likely due to differences in phenotype. The idea is to be able to identify

in the US, including the National Institutes of Health (NIH), will be increasing funding into nutrigenomic research "exponentially" over the next three to five years.

regulatory environment and the probabilistic strength of the test results", Milner concedes that concerns could arise. "Clearly, one has to be concerned about the



Credit: Brian Hawkes Photographic

John Milner giving the opening talk at the 2004 GE³LS Symposium

Despite its promise, nutrigenomics is not without detractors. In fact, many of the same ethical and legal questions that apply to genomics, also apply here.

possibility of information being used against you and maybe modifying what's available to you as far as health coverage," Milner admitted.

"In the developing world, we need an investment in science to help us develop a state-of-the-art infrastructure, not just a linear transfer of technologies."

John Mugabe, New Partnership for Africa's Development, on globalisation issues.

"The final model, of extended participation, involves a change in the form of governance. Implementing this is a great challenge of our time; for without it, 'the consent of the governed' in science-related policy issues will not be maintained."

Silvio Funtowitz, Institute for the Protection and Security of the Citizen, European Commission – Joint Research Centre, in absentia, as quoted by David Castle.

The burgeoning field of nutrigenomics — the study of how food components and genes interact — may be able to simplify dietary intervention strategies by tailoring nutritional advice to the individual.

Most people would agree that eating more fruits and vegetables promotes longevity and reduces our chance of disease. That's commonsense. In

those individuals who will benefit from the drug, "the responders", and find other strategies for those who don't, "the non-responders".

"The same holds true when we start dealing with dietary compounds," said Milner. "In my presentation, I made a comment about excess coffee consumption in people with a certain phenotype leading to bone loss. We won't

Professor Abdallah Daar, director of both the applied ethics and biotechnology program at the University of Toronto's Joint Centre for Bioethics and of genomics ethics and policy at U of T's McLaughlin Centre for Molecular Medicine — and one of nine members of an international panel that studied the ethical implications of nutrigenomics — believes that while nutrigenomics offers possibilities, the biggest issue right now is all the hype that surrounds the new field, when the science is not ready to deliver.

Daar also worries about how nutrigenomics testing would be offered to the public. "Direct marketing may be efficient, but I am not sure the public is ready for all types of genetic tests offered in this way, especially if not accompanied by proper counseling."

Another critical issue, he believes, is how to make nutrigenomics testing and nutritional supplements available to the developing world. "Our work at the University of Toronto Joint Centre for Bioethics is focused to a great extent on trying to ensure that the fruits of genomics and related biotechnologies also become available to people in developing countries," said Daar.

Because nutrigenomic information would have to be contained somewhere, privacy issues also become paramount. Issues, such as how information is collected and stored, who has access to it, and what happens when companies storing the information change ownership, would surface.

Those same issues might impinge on our health and life insurance coverage. Let's say we're found to have 'abnormal protein structures', or genes that metabolize a nutrient in a particular way, making us more vulnerable to a disease like diabetes or obesity. Could health and life insurance providers refuse coverage? And will we have to inform our closest relatives, whose insurability might also be adversely affected?

While Daar feels it's too early to answer these questions, and that "much will depend on the

"What we're trying to do is identify the responders who are going to get the maximum benefit," he added, "We're also interested in the non-responders, because we have to develop other strategies. It's not us versus them."

However, he does concede that individualized testing could be impractical and prohibitively costly to the healthcare system. To make testing and dietary advice more practical and less expensive, Milner envisions people being organized into "sub-groupings" of those with similar phenotypes. Above all, he cautions that we shouldn't overly focus on our "biomarkers".

"Genes are only one factor influencing our health," said Milner. "We have to look at the totality of factors, such as the environment that we live in. Do we use public transportation? Do we walk? We also have to look at our behaviour: things like exercise and caloric intake."

Ultimately, argues Milner, the goals of nutrigenomics mirror the National Cancer Institute's vision for reducing the pain and suffering caused by diseases like cancer.

"With nutrigenomics, we would like to minimize the pain and suffering that goes along with aging and disease states, and potentially expand and improve the quality of life in the later years." ♦

For more information on the US government's nutrigenomics strategy, see the NIH Roadmap for Medical Research, at <http://nihroadmap.nih.gov/>.

In what represents a new model for gaining public input before nutrigenomics technologies hit the market, a panel of international experts has been collecting input from interested parties, including professional groups, civic organizations and individuals at www.geneticethics.net.

The panel's consultation paper, which was presented at the 2nd International Nutrigenomics Conference held November 2003 in Amsterdam, can be previewed online at www.ge3ls.ca/ngx.

fact, five of the 10 leading causes of death worldwide are related to dietary habits. Yet, according to Milner, the same diet can influence health in remarkably different ways, which up to now puzzled researchers.

"When we look at dietary studies, not all studies give us the same answers," said Milner during an interview after his presentation. "One of the reasons we think there is so much variability

necessarily tell those people to stop their coffee consumption, but we'll develop strategies for them, like increasing calcium or vitamin D."

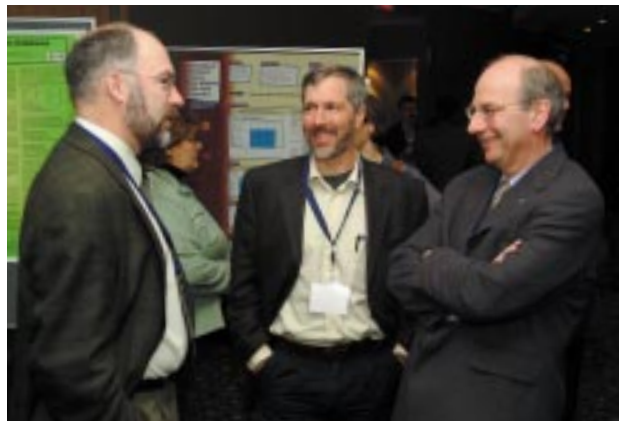
In the United States, money is being poured into this relatively new research area. The National Cancer Institute alone is spending \$175 million over the next several years to study nutrition as it relates to cancer prevention. According to Milner, other health institutes



Credit: Brian Hawkes Photographic



Credit: Brian Hawkes Photographic



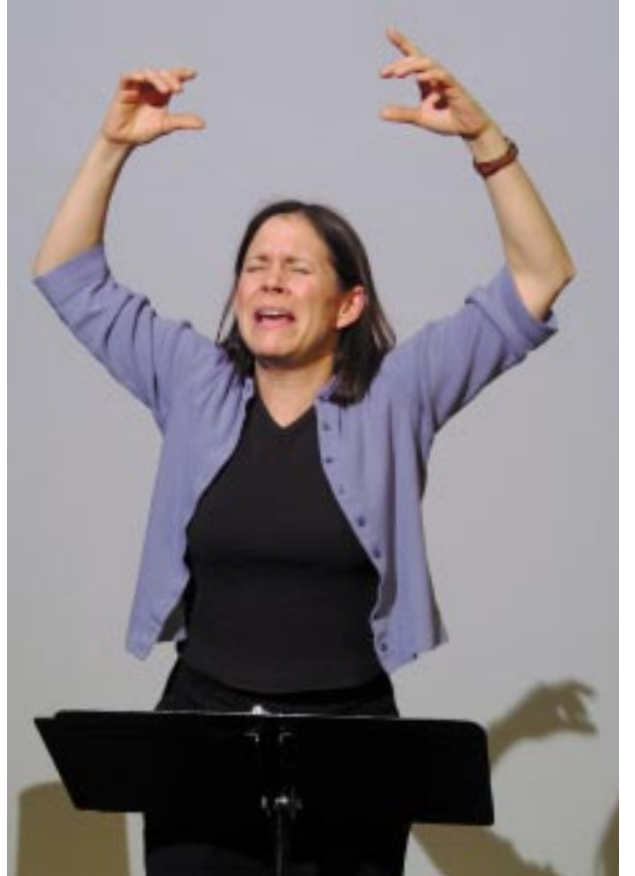
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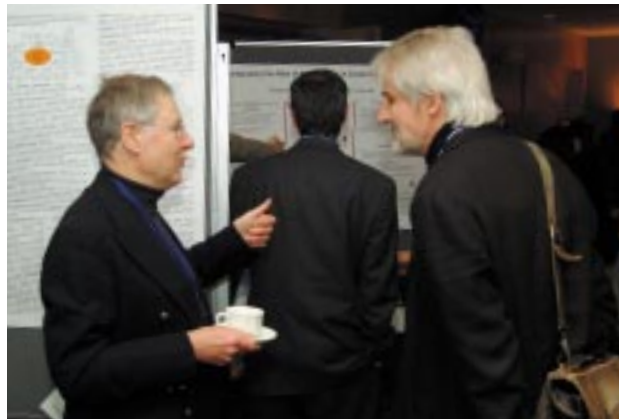
2004 GE³LS Symposium at a Glance...



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