

Fighting Genetic Discrimination in Canada

A new coalition takes up the cause

BY JO ANNE WATTON

While the United States, U.K. and many European countries have passed laws prohibiting genetic discrimination, Canada lags behind. Because Canada has a universal health care system, access to life, disability and critical care insurance - rather than health insurance - are the biggest issues at stake.

For example, 27-year-old Katie Lingard was recently told by a major insurance provider that she would have to prove that she didn't carry the gene for Huntington disease, a disease that runs in her family, in order to qualify for the life and long-term disability insurance she needed to set up a chiropractic practice.

The evidence of genetic discrimination in Canada isn't simply anecdotal, however. A 2006 survey of Canadians at risk for Huntington disease found that 39.9% had experienced discrimination. Conducted in genetic clinics and movement disorder clinics across the country, it was the first large-scale, empirical study of the nature and prevalence of genetic discrimination among people who are currently healthy but predicted to develop a genetic disease, based on genetic testing or family history.

Life and disability insurance companies were the main source of discrimination, with 29.2% of respondents reporting their applications for coverage were rejected, their premiums were increased, or they were forced to take a predictive test before they could obtain coverage. Just under 7% reported employment discrimination.

The vast majority of Canadians don't feel this is acceptable. In a 2003 poll on genetic privacy issues, 91% said that insurance companies should not be allowed access to their genetic information for an insurance assess-



ment, while 90% opposed employer access to the genetic information of their employees or job applicants.

In focus groups conducted as part of the survey, public opinion was clear. Although Canadians recognized that insurance is a private contract between an individual and a company, most believed that allowing insurers to screen out genetically high-risk individuals leaves those individuals unacceptably vulnerable.

The inadequacy of current legislation

Currently, Canada does have several laws protecting individuals from discrimination on the basis of disability. Article 15 of the Canadian Charter of Rights and Freedoms guarantees equality and grants each person the right to not be subjected to discrimination; the Canadian Human Rights Act protects individuals against discrimination based on disability; and the Personal Information Protection and Electronic Documents Act protects the personal information of individuals. However, none of this legislation addresses the concepts of future disability, perceived disability or imputed disability. Nor does it prevent discrimination from taking place; rather, it offers remedies after discrimination has occurred. This puts

the onus on the victim of discrimination to make the complaint and then seek appropriate legal action - a lengthy and expensive process.

Over the past two decades, various commissions and task forces have called for reform. In 1991, the Law Reform Commission of Canada suggested the insurance industry provide a "no questions asked" basic level of life insurance that would offer minimum coverage to anyone who wanted it, avoiding the issue of genetic discrimination. In 2001, the Ontario Provincial Advisory Committee on New Predictive Genetic Technologies called for a moratorium on the use of genetic information by insurance companies. Most recently, a 2003 task force of academics, industry representatives and consumer support groups - the Canadian Genetics and Life Insurance Task Force - called for a moratorium on the use of genetic test results and the creation of an independent advisory body.

To date, none of these recommendations have been implemented, and the Canadian insurance industry's position is that if an individual has undergone genetic testing, insurers can request access to the results. ,

The repercussions of poor protection

Genetic testing is often in the best interest of a person at risk. In some cases, the results can be used to prevent the onset of disease or ensure early detection and treatment. Someone carrying the BRAC2 gene, for example, can choose to have a preventive mastectomy to reduce the risk of breast cancer. In the case of diseases where genetics is one factor among many, gene carriers can lower their risk by making informed lifestyle choices. In cases of genetic diseases

for which no treatments currently exist, gene-positive individuals can use their test results to make informed reproductive decisions.

But in the face of potential discrimination from insurance companies and employers, many people feel the risks of genetic testing outweigh the benefits.

This is the unfortunate irony of genetic testing, according to a 2005 University of Toronto Faculty of Law report: “the promise of advances in genetics for improved health and health care may be compromised by the fear of discrimination ... Rather than a major medical breakthrough that may in time be able to prevent, treat or even help cure some of the genetic diseases, genetic information may be viewed as a personal, familial and societal disadvantage.” Important medical research also suffers because only a small pool of people are willing to incur the risk of discrimination in order to participate in genetic studies. In other situations, such as Katie Lingard's, insurance companies are forcing people at risk for certain genetic disorders to undergo testing, removing personal choice from a life-altering decision.

CCGF's seven-point plan

Now a new group is working to end genetic discrimination. Formed in 2009, the 15-member Canadian Coalition for Genetic Fairness (CCGF) brings together health advocacy organizations and research institutes including the ALS Society of Canada, the Huntington Society of Canada, Ovarian Cancer Canada, Muscular Dystrophy Canada and the Centre for Molecular Medicine at the University of British Columbia.

Ultimately, CCGF's goal is to protect the personal information of people with genetic diseases or disorders, allowing them to make the decision of whether to undergo genetic testing without repercussions from insurance companies or employers.

To achieve that, we have developed a seven-point action plan:

1. Put forward legislation within the federal jurisdiction to prevent insurers from receiving, collecting or requiring individuals to provide genetic information or the genetic information of a family member for eligibility, coverage, underwriting or premium-setting decisions.
2. Bring together provincial and territorial governments and the Canadian Council of Insurance Regulators to take corresponding measures to eliminate the use of genetic information within their spheres.
3. Have legislation enacted to prevent genetic information from being used in employment decisions that fall under federal jurisdiction.
4. Strengthen the Canadian Human Rights Act to protect citizens from discrimination based on the potential for future disability.
5. Strengthen the Personal Information Protection and Electronic Documents Act to limit access to genetic information for commercial purposes.
6. Regulate genetic tests to prescribe their purposes, ensure their health, safety and accuracy and ensure the appropriate use of the data they generate.
7. Amend the Canadian Labour Code to eliminate genetic discrimination in the workplace.

On October 6, 2009, we took our message to Parliament Hill in a highly successful “day of action.” We began with a press conference that earned national media attention, followed by a “lunch and learn” with leading researchers. We then met with more than 20 MPs from all parties to present the case for protection.

In parliament, the New Democrat Health Critic Judy Wasylycia-Leis introduced a motion calling on the government to implement protection against discrimination based on genetic information, including information gathered through genetic testing and family history.

Specifically, she called for effective enforcement mechanisms, along with a standing body mandated to doc-



ument cases, evaluate the effectiveness of anti-discrimination protections and make recommendations to the government about the uses of genetic information and direct-to-consumer testing. She also advocated a public awareness campaign to focus attention on the issue.

Representatives from all political parties have expressed support for the motion, and the Prime Minister's Office restated the ruling Conservative party's commitment to tackle discriminatory insurance practices.

Next steps

While we wait for Ms. Wasylycia-Leis's motion to go to a vote, we're continuing to build support among politicians, educate stakeholders and raise public awareness of the issue, as well as attract other concerned organizations to our coalition.

Our key message is that all individuals carry genes that make them susceptible to diseases, and thus all Canadian are vulnerable genetic discrimination. As the number of genetic tests available continues to grow, the need to address this both nationally and provincially becomes increasingly urgent.

No one among us has perfect genes - and no one should suffer discrimination as a result.

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