



## Canadian Coalition for Genetic Fairness/ Coalition Canadienne pour L'Équité Génétique

### **Proposal to Protect Canadians from Genetic Discrimination**

*Canada requires a genetic non-discrimination strategy to ensure that genetic test data is used properly without fear of repercussion. This strategy must prevent all businesses and services, including insurers and employers, from inducing applicants to take genetic tests and from receiving genetic information or family histories, for the purposes of assessing the liability of the applicant, based on imputed or perceived disability.*

**Action Needed Now:** The Canadian Coalition for Genetic Fairness (see Appendix) requests the Government of Canada explore all policy options and bring together stakeholder and government representatives with the aim of developing an effective strategy to eliminate Genetic Discrimination in Canada:

- Put forward legislation within federal jurisdiction to prohibit and prevent genetic discrimination by making it illegal to receive, collect or require individuals to provide genetic test information for the purpose of providing goods or services to that individual;
- Provide leadership and sponsor initiatives to bring together provincial and territorial governments and the Canadian Council of Insurance Regulators to take corresponding measures to eliminate the use of genetic test information within their spheres;
- Enact or amend legislation to prevent genetic test information from being used in employment decisions in areas of federal jurisdiction (e.g., Canadian Human Rights Act);
- Examine ways to strengthen the Canadian Human Rights Act to protect citizens from discrimination based on the potential for future disability;
- Regulate genetic testing to prescribe their purposes and to ensure health, safety, accuracy and use of data, e.g., Food and Drug Act, Criminal Code;
- Amend the Canadian Labour Code to eliminate genetic discrimination in the workplace.
- Support Bill S201-a Canadian Genetic Non-Discrimination Act

**Genetic Discrimination is Real** It is a well-established principal that individuals shall not be discriminated against based on their disability; yet outdated laws still enable insurance companies to discriminate based on perceived disability, or the prospect of future disability. Cases of genetic discrimination have been documented in Canada and they will continue to grow. It occurs when people are treated unfairly because of actual or perceived genetic differences, e.g., “bad genes”, “genetic underclass”. It may mean being rejected for employment, a lower level of employment or loss of access to insurance based on the notion that the individual may be disabled in future. Predictive, diagnostic information can be obtained through tests administered by trained medical personnel or through commercial tests available to the public or by asking for family histories.

**Extra Protection Required** UNESCO proclaims that “no one shall be subject to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing on human rights, fundamental freedoms and human dignity”. Genetic information is unique, personal and private information. It is much more than a standard medical test. It provides predictive information to help make vital life choices, and is not only about the individual, but also their parents, children, family members, and their ethnic background. Individuals have no control over their genetic makeup but must earn income and plan ahead for their own care and the care of their family.

**Faulty Assumptions** It is unfair to use genetic information to determine which individuals will be employed or insured, especially when the assumptions underlying the use of genetic information by insurers and employers are often faulty, misleading and speculative. Genetic information is often misunderstood. Human genetics are multifactorial with a complex relationship between genes, environment and lifestyle resulting in considerable variation in outcomes between individuals.

**No Transparency/Choice** Insurance law permits insurers to require health information and to use it without transparency to determine eligibility, set premiums and manage their risks. Insurers ask applicants to divulge personal health information, including genetic test data, and family histories and to consent to have this information verified. This puts consumers under duress as they are denied needed coverage if they fail to do so. Consumers must also agree to have their personal health

information, including genetic data, shared with other insurers through the Medical Information Bureau; effectively closing off an individual's insurance options and threatening privacy rights.

Failure to disclose this information can mean that the insurance policy will be deemed null and void or even fraudulent. For example, in a 1990 court case, the heirs of an asymptomatic individual, at the time of his application for life insurance, were denied benefits when the man died - even though the cause of death was not related to his genetic mutation.

**Provincial Leadership Essential** Leadership is required from the Government of Canada. In 2003, the Canadian Genetics and Life Insurance Task Force, was convened to find a solution to the genetics and life insurance controversy. The "moratorium approach" (not ask for genetic information) was favoured by the insurance industry and yet no action has taken place to date. In the future we will be able to predict most diseases to some degree.

**We Are All Victims** All people living in Canada are affected. Without intervention, tensions will continue to escalate as costs drop and the number of medical and commercial tests multiplies for common disorders. Access to genetic sequencing is cheaper and more readily available than ever. Science will enable medical professionals to predict disease to some degree and to prescribe medicine based on the individual's genetic makeup. Being denied insurance on the basis of one's genetic traits has serious consequences for individuals, families and society at large. What are these individuals to do? How do we expect them to provide for their families?

**Concerns are Widespread - Practices are Inconsistent with Public Opinion** About 91% of Canadians feel that insurance companies should not be allowed access to their genetic information for insurance underwriting. It is private, sensitive health information requiring a high degree of protection. It is also unethical to pressure individuals to take tests for these purposes. Fear of misuse is preventing people from undergoing genetic testing and participating in clinical trials, which are needed to eradicate disease. Genetic information must be used to prevent illness and save lives - and not be used against people.

**Canada is Lagging Behind** -Canadians require special protection. Other countries have taken steps to eliminate genetic discrimination, e.g. US, UK, EU. Federal and provincial privacy and human rights legislation is inadequate - it does not address the concept of "future disability", or prevent discrimination in the first place. Rather, it offers remedies after discrimination has occurred, which takes years, resources and a major effort, and the fear of discrimination prevents victims from stepping forward.

## **Current Members Canadian Coalition for Genetic Fairness**

ALS Society of Canada

NF Canada

Alzheimer Society of Canada

Osteoporosis Canada

Canadian Breast Cancer Association

Ovarian Cancer Canada

Canadian Congenital Heart Alliance

Parkinson Society of Canada

Canadian Cystic Fibrosis Foundation

Spina Bifida and Hydrocephalus Association of Canada

Canadian Organization of Rare Diseases

The Centre for Molecular Medicine and Therapeutics, UBC

Canadian PKU and Allied Disorders

The Foundation Fighting Blindness

Centre for Israel and Jewish Affairs

The Kidney Foundation of Canada

Huntington Society of Canada

Tourette Syndrome Foundation of Canada

Muscular Dystrophy Canada

Centre for Israel and Jewish Affairs