Dear Senator \_\_\_\_\_\_\_\_,

I am writing to you today regarding the real issue of genetic discrimination in Canada and the need for genetic non-discrimination legislation to protect the personal and private, genetic information, of all Canadians.

Canadians are increasingly concerned about the protection of personal information and improper access and use of personal data continues to be debated within the Canadian Parliament. However, as debate rages about the privacy of e-mail addresses, IP addresses, internet browsing history and other personal information that might be used for marketing or other more nefarious purposes, Canadian law allows and even encourages the use of one essential and basic piece of personal information — the contents of our DNA.

It is unfair to use genetic information to determine which individuals will be employed or insured, particularly when the assumptions underlying the use of genetic information by insurers and employers are often faulty, misleading and speculative. Genetic information is often misunderstood. The impact of human genetics on our health outcomes are one factor within a complex relationship between genes, environment and lifestyle.

Yet, insurance law permits insurers to acquire genetic 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 data, and family histories and to consent to have this information verified. This unfairly puts consumers under duress and they are denied needed coverage if they fail to fully disclose. 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.

As the only G-7 country without protection, I believe Canada urgently requires legislation to end genetic discrimination and to ensure that genetic data is used properly without fear of repercussion.

Other countries have taken steps to eliminate genetic discrimination, including the United States, the United Kingdom, and the European Union. Here in Canada, federal and provincial privacy and human rights legislation is inadequate – and does not address the concept of “future disability”, or prevent discrimination in the first place. Rather, it offers remedies, after discrimination has, occurred and unfortunately, for many, the fear of discrimination prevents victims from stepping forward.

Fear of genetic discrimination also presents a barrier to important health related diagnostic testing and clinical research participation, which are increasingly important components of the shift toward personalized health care. This barrier can negatively impact disease prevention efforts and treatments as well as participation rates in clinical research opportunities.

I am calling on you to support genetic non-discrimination legislation.

Genetic discrimination is real in Canada. Our outdated laws still enable insurance companies and employers to discriminate based on perceived disability, or the prospect of future disability. Cases of genetic discrimination have been documented in Canada and will continue to grow unless genetic discrimination is addressed.

Help put an end to genetic discrimination in Canada, please support genetic non-discrimination legislation.

Sincerely,