Dear Member of Provincial (or Territorial) Government,

Canadian media is often occupied with stories about the protection of personal information, and indeed the House of Commons is also engaged with issues in the same realm. However, as debate rages about the privacy of e-mail address, IP addresses, internet browsing history and other personal information that might be used for marketing or other more nefarious purposed, Canadian law allows and even encourages the use of one essential basic piece of personal information – our DNA.

It is unfair to use genetic information to determine which individual will be employed or insured, especially went 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 multi-factorial with a complex relationship between genes, environment and lifestyle resulting in considerable variations in outcomes.

Yet Canadian law permits insurers to acquire 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, because they are denied needed coverage if they fail to comply. 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 a genetic non-discrimination strategy to ensure that genetic data is used properly without fear of repercussion. This strategy must prevent insurers, employers, and other businesses from inducing applicants to take genetic tests and from asking for genetic information or family histories for the purposes of assessing the liability of the applicant, based on imputed or perceived disability or future disability.

I am calling on you, as my elected representative, to support the exploration of policy options and bring together stakeholders and government representatives with the aim of developing an effective strategy to eliminate Genetic Discrimination in Canada. Such a strategy should include:

* Legislation within Provincial and Territorial jurisdiction to prevent insurers from receiving, collecting or requiring individuals to provide genetic information, or the genetic information of family members, for eligibility, coverage, underwriting, or premium-setting decisions in the areas of life, mortgage, health, critical illness and disability insurance;
* Provide leadership and initiatives to bring together Federal, 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;
* Enact or amend legislation to prevent genetic information from being used in employment decisions in areas of Provincial and Territorial jurisdiction;
* Examine ways to strengthen Provincial and Territorial Human Rights Codes to protect everyone living in Canada from discrimination based on a potential future disability;
* Strengthen privacy legislation to deny access to genetic information with respect to business transactions;
* Regulate genetic testing and direct to consumer genetic testing options to ensure privacy, health, safety, and accuracy;
* Amend Provincial and Territorial Labour Relations Acts to eliminate genetic discrimination in the workplace.

Genetic Discrimination is real. It is a well-established principle that individuals cannot 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 the number of incidents will increase unless people like you take a leadership role in banning genetic discrimination.

Other countries have taken steps to eliminate genetic discrimination (e.g., United States, United Kingdom, and European Union). Federal and Provincial and Territorial 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 avenues of recourse after discrimination has occurred. This take years and a major effort, and the fear of discrimination prevents victims from stepping forward.

I would appreciate if your response to my letter outlines the steps you will personally take to end genetic discrimination in Canada.

Sincerely,