Dear Prime Minister and Ministers:

We are writing to you in our various capacities as genetic scientists, medical doctors, genetic counsellors and innovators building advanced genomics-based technology clusters across Canada, to thank you for your continued support of Bill S-201, the Genetic Non-Discrimination Act. This legislation has already passed the Senate and is currently under consideration by the House of Commons. **We urge that you ensure its prompt passage by the House of Commons, and that the final legislation retains all the key protections for Canadians in the bill passed by the Senate.** The strong protections afforded by this legislation are critical for improving Canadians’ health through the use of genetic testing.

Genetic testing is revolutionizing the practice of medicine and health care in Canada and the world over. At the October meeting of the American Society of Human Genetics in Vancouver, a group to which we all belong, we discussed with international delegates the ever-increasing use of genetic tests impacting all of First Nations people, children, adults, and new immigrant populations, burdened with common and rare diseases. The meeting affirmed how genetics is now being used as a clinical tool across Canada in the prevention, diagnosis, and treatment of disease.
However, many Canadians are fearful that undergoing genetic testing will lead to genetic discrimination, such as a life insurance company refusing to provide coverage because of an individual’s genetic make-up, or an employer taking disciplinary action against an employee wishing to keep their genetic test results private. Indeed, in the absence of any protections against genetic discrimination, there is evidence of such discrimination that demonstrates that these fears are well founded. The result is that many Canadians are declining to have genetic tests that could help them lead healthier lives.

We believe fears about genetic discrimination should not be a factor influencing a person’s decision whether or not to take a genetic test, particularly when their very lives could be at stake. Individuals should not be penalized for undergoing testing to improve their health. We therefore urge your government to support the passage of Bill S-201, the Genetic Non-Discrimination Act, and to make sure it retains the comprehensive consumer and employee protections in the Senate-passed bill.

Prompt passage of S-201 is critically important for ensuring that discoveries in research laboratories across Canada and other nations are translated into healthcare advances for Canadians. This legislation is critical for the health and well-being of your national constituency; to the optimal expenditure of health dollars; to the medical and research communities across the country; and to supporting the world class genomics innovation and technology sector that will advance precision medicine across Canada.

Canada now stands virtually alone among industrialized nations in failing to provide protections against genetic discrimination. Parliament’s failure to repair that deficiency will impede the progress of genetic medicine nationwide while it blossoms elsewhere.

Sincerely,

[signatures follow French]

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1 [http://www.parl.gc.ca/content/sen/committee/412/RIDR/11EV-51620-e.HTM](http://www.parl.gc.ca/content/sen/committee/412/RIDR/11EV-51620-e.HTM)

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18 novembre 2016

Monsieur le Premier ministre,
Monsieur le Ministre,
Mesdames les Ministres,

À titre de scientifiques spécialisés en génétique, de médecins, de conseillers en génétique et d’innovateurs qui établissent des grappes de technologies avancées fondées sur la génomique à travers le Canada, nous souhaitons vous remercier de votre appui indéfectible au projet de loi S 201, Loi sur la non-discrimination génétique. Cette mesure législative, déjà adoptée au Sénat, est actuellement à l’étude à la Chambre des communes. Nous vous prions de faire en sorte que la Chambre des communes l’adopte rapidement et conserve dans la version définitive toutes les protections essentielles qui sont proposées dans la version adoptée par le Sénat dans l’intérêt des Canadiens. Les importantes protections prévues dans ce projet de loi sont nécessaires pour améliorer la santé des Canadiens grâce aux tests génétiques.

Les tests génétiques sont en train de révolutionner la médecine et les soins de santé au Canada et partout dans le monde. Lors de la réunion tenue en octobre dernier à Vancouver par l’American Society of Human Genetics, groupe auquel nous appartenons tous, nous avons discuté avec des délégués étrangers du recours sans cesse croissant aux tests génétiques parmi les Premières Nations, les enfants, les adultes et les nouvelles populations d’immigrants aux prises avec des maladies courantes et rares. La réunion nous a confirmé à quel point la génétique sert maintenant d’outil clinique partout au Canada dans la prévention, le diagnostic et le traitement des maladies.
Or, de nombreux Canadiens craignent d’être victimes de discrimination s’ils subissent un test génétique. Ils craignent par exemple que leur compagnie d’assurance-vie refuse de les assurer en raison de leur constitution génétique ou que leur employeur prenne des mesures disciplinaires contre eux s’ils refusent de lui divulguer les résultats des tests. En effet, les faits montrent que, en l’absence de protections contre la discrimination génétique, cette discrimination est bien réelle et que les craintes des Canadiens sont fondées. Résultat : bon nombre de Canadiens refusent de subir des tests génétiques qui pourraient pourtant les aider à mener une vie plus saine.

À notre avis, la discrimination génétique ne devrait pas influer sur la décision de subir ou non un test génétique, particulièrement lorsque la vie pourrait être en jeu. Personne ne devrait être pénalisé pour avoir subi des tests dans le but d’améliorer sa santé. C’est pourquoi nous prions instamment votre gouvernement d’appuyer l’adoption du projet de loi S 201, Loi sur la non-discrimination génétique, et de faire en sorte qu’il conserve les protections complètes dans l’intérêt des consommateurs et des employés qui sont prévues dans le projet de loi adopté par le Sénat.

Il est absolument essentiel d’adopter rapidement le projet de loi S 201 pour faire en sorte que les découvertes des laboratoires de recherche du Canada et d’autres pays se traduisent par des avancées pour les Canadiens. Cette mesure législative est essentielle à la santé et au bien-être de l’électorat canadien, à l’optimisation des dépenses en santé, aux communautés médicales et de recherche au pays et au soutien du secteur de l’innovation et des technologies de génomique de calibre mondial qui se fera progresser la médecine de précision au Canada.

Le Canada est maintenant pratiquement le seul pays industrialisé à ne pas avoir établi de protections contre la discrimination génétique. L’inaction du Parlement nuira aux progrès de la génétique au pays alors que cette dernière se développe partout ailleurs.

Je vous prie d’agréer, Monsieur le Premier ministre, Monsieur le Ministre, Mesdames les Ministres, l’expression de nos sentiments distingués.

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3 http://www.parl.gc.ca/content/sen/committee/412/RIDR/11EV-51620-f.HTM
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