

The Right Honourable Justin Trudeau, P.C., M.P.
Prime Minister of Canada
Langevin Block
Ottawa, Ontario
K1A 0A2

The Honourable Jane Philpott, P.C., M.P.
Minister of Health
House of Commons
Room 162, Confederation Building
Ottawa, ON K1A 0A6

The Honourable Navdeep Bains, P.C., M.P.
Minister of Innovation, Science and Economic Development
House of Commons
Room 356, Confederation Building
Ottawa, Ontario K1A 0A6

The Honourable Jody Wilson-Raybould, P.C., M.P.
Minister of Justice and Attorney General of Canada
House of Commons
Room 451-S, Centre Block
Ottawa, Ontario K1A 0A6

November 18, 2016

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 founded¹. The result is that many Canadians are declining to have genetic tests that could help them lead healthier lives².

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]

¹ <http://www.parl.gc.ca/content/sen/committee/412/RIDR/11EV-51620-e.HTM>

² http://www.parl.gc.ca/Content/SEN/Committee/421/ridr/02ev-52394-e.htm?Language=E&Parl=42&Ses=1&comm_id=77

Le très honorable Justin Trudeau, C.P., député
Premier ministre du Canada
Édifice Langevin
Ottawa (Ontario) K1A 0A2

L'honorable Jane Philpott, C.P., députée
Ministre de la Santé
Chambre des communes
Bureau 162, édifice de la Confédération
Ottawa (Ontario) K1A 0A6

L'honorable Navdeep Bains, C.P., député
Ministre de l'Innovation, des Sciences et du Développement économique
Chambre des communes
Bureau 356, édifice de la Confédération
Ottawa (Ontario) K1A 0A6

L'honorable Jody Wilson-Raybould, C.P., députée
Ministre de la Justice et procureure générale du Canada
Chambre des communes
Bureau 451-S, édifice du Centre
Ottawa (Ontario) K1A 0A6

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 fondées³. Résultat : bon nombre de Canadiens refusent de subir des tests génétiques qui pourraient pourtant les aider à mener une vie plus saine⁴.

À notre avis, la discrimination génétique ne devrait pas influencer 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.

Dr. Stephen W. Scherer, PhD
Director, The Centre for Applied Genomics and McLaughlin Centre
The Hospital for Sick Children and University of Toronto

Dr. Ronald Cohn
Professor and Chair, Department of Paediatrics, Paediatrician-in-Chief
The Hospital for Sick Children and University of Toronto

Dr. Yvonne Bombard, PhD
Scientist, Li Ka Shing Knowledge Institute
Assistant Professor, Institute of Health Policy, Management and Evaluation
St. Michael's Hospital and University of Toronto

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

⁴ http://www.parl.gc.ca/Content/SEN/Committee/421/ridr/02ev-52394-f.htm?Language=E&Parl=42&Ses=1&comm_id=77

Gail Graham
Chief, Department of Genetics
Children's Hospital of Eastern Ontario

Samantha Wilson
PhD Candidate
University of British Columbia

Jeremy Parker, PhD

Emma Leach, MSc, CGC
Genetic Counsellor

Philip Awadalla
Professor, Director
University of Toronto, Canadian Partnership for Tomorrow Project, Ontario Institute for Cancer Research

Erwin Schurr
Professor
McGill University

George S. Charames, PhD, FACMG

Manuel Belmadani
Bioinformatics Analyst
Michael Smith Labs, University of British Columbia

Artem Babaian
University of British Columbia

Ken Sin Lo
Montreal Heart Institute

A Micheil Innes MD FRCPC FCCMG
Associate Professor
Department of Medical Genetics, Cumming School of Medicine, University of Calgary

Giulia Del Gobbo
University of British Columbia

Angelika J. Dawson
Director, Genomics (Cytogenetic) Laboratory
Diagnostic Services Manitoba

Stella Lanni

Oana Caluseriu
Assistant Professor
University of Alberta

Veronique LeBlanc

Jeremy Grushcow, PhD, JD
Chief Business Officer
Sequence Bio

Ben Callaghan
UBC

Maria Acero

Lemuel Racacho, PhD

Elise Heon
Professor of Ophthalmology, Associate Surgeon in Chief (research)
Hospital for Sick Children

Geraldine Aubert, PhD
PostDoctoral Research Associate
BC Cancer Agency - Terry Fox Laboratory

Susan Walker
Laboratory Project Research Coordinator
Hospital for Sick Children

Christopher E. Pearson
Senior Scientist, Full Professor
The Hospital for Sick Children

Marjorie Locke PhD Student
University of Western Ontario

Ting-Huei Chen

Daniele Merico
Director of Molecular Diagnostics
Deep Genomics Inc.

Jan C. Frijters
Associate Professor
Brock University

Colin J. D. Ross
Assistant Professor
University of British Columbia

Carles Vilarino-Guell
Assistant Professor and Canada Research Chair
University of British Columbia

Samantha Peeters
Graduate Student
University of British Columbia

Lauren Erdman
Research Student
University of Toronto/Hospital for Sick Children

Svetlana Madjunkova, MD, PhD
Director of Preimplantation Genetics
Create Fertility Centre

David Ripsman
Research student
The Hospital for Sick Children

Yanwei Xi, PhD
Alberta Children's Hospital

Dr Frances Lock
BC Cancer Research Center

Heather Gibling
Ontario Institute for Cancer Research

Daiana D. Becker-Santos
PhD Candidate
University of British Columbia, BC Cancer Research Centre

Caitlin Slomp
Genetic Counsellor
University of British Columbia

Michael Wilson
The Hospital for Sick Children

Pingzhao Hu
Assistant Professor
University of Manitoba

Meghan Slean

Emil Gustavsson
University of British Columbia

Isabelle Thiffault
Assistant clinical director
Children's Mercy hospital and clinics, center for pediatric genomic medicine

Dennis Bulman Professor, Pediatrics
Children's Hospital of Eastern Ontario / University of Ottawa

Greg Stewart
Phd Candidate British Columbia Cancer Research Centre

Emma Titmuss

Aria Shokoohi

Claire Lepine

Adam Sage
Graduate Student
BC Cancer Research Centre

Francis Rossignol
MD, Medical Resident, PGY-4, Medical Genetics
CHU Sainte-Justine, Université de Montréal

Tony Rupar, PhD, FCCMG
Professor, Pathology and Laboratory Medicine
Western University

Penelope Witte Allderice
Professor Emerita
Genetics, Faculty of Medicine, Memorial Univ. of Newfoundland, St John's NL

Alexandra Scott
Résident in medical genetics
CHU Sainte-Justine

Allison Matthews, PhD
Post-doctoral Fellow
University of British Columbia

Andrew Shuen, MD, FRCPC
Medical Geneticist/PhD Candidate
The Hospital for Sick Children

Julian Little, PhD
Professor, Canada Research Chair in Human Genome Epidemiology
School of Epidemiology, Public Health and Preventive Medicine, University of Ottawa

Guillaume Lettre
Associate professor
Université de Montréal

Dr. Marina Turlakis
Quest University Canada

Guyllaine D'Amours, MD
CHU Ste-Justine

Mohsen Hosseini, MD, PhD
Genome Scientist
Hospital for Sick Children, Toronto, Canada

Melanie Lacia
Children's Hospital of Eastern Ontario

Dr. Bekim Sadikovic
Head, Molecular Genetics
London Health Sciences Centre

Zaccary Alperstein, MSc
University of British Columbia

Maria Penaherrera, PhD. (Medical Genetics)
University of British Columbia

Fadi Hamdan, PhD
CHU Sainte-Justine Research Center

Bettina Mucha-Le Ny, MD
CHU Ste Justine, Montreal

Joël Lavoie
Chef du service de biochimie médicale
Institut de cardiologie de Montréal

Chantal Bouffard
Professeure titulaire
Faculté de médecine et des sciences de la santé de l'Université de Sherbrooke

Cheryl Shuman
Director, Genetic Counselling, and Program Director, MSc Program in Genetic Counselling
SickKids and University of Toronto

Marie-Julie Favé
Postdoctoral fellow
University of Montreal

Jean-Christophe Bérubé PhD student
CRIUCPQ-UL

Erika Tavares
Lab Research Proj Coordinator
Sickkids

Kit Green Sanderson
Lab Technician
The Hospital For Sick Children

Rafael Correa

Hanna Faghfoury
Geneticist
Mount Sinai hospital

Hilary Edgington
Postdoctoral Fellow
Ontario Institute for Cancer Research

Lamaze F, Ph.D.
Ontario Institute for Cancer Research

Kathryn Vaillancourt
PhD Candidate
McGill University

Rima Rozen
Professor
McGill University

Anna Lehman
Assistant Professor
University of British Columbia

Kaalak Reddy, PhD
Postdoctoral Research Fellow
University of Florida

Johane Robitaille, MD
Dalhousie University

Kaarina Kowalec
Postdoctoral Researcher
University of British Columbia

Venuja Sriretnakumar
University of Toronto

Paige Davies
Research Trainee
Center of Addiction and Mental Health

Ian M MacDonald
Professor, Ophthalmology and Visual Science & Medical Genetics
Faculty of Medicine and Dentistry, U. Alberta

Karen Chiang
MSc candidate
The Hospital for Sick Children

Alisson Clemenceau
M.Sc Student
Université Laval

Katey Enfield
PhD Candidate
University of British Columbia

Elizabeth J Ives
Emeritus Professor
Memorial University of Newfoundland, St John's NL

Rachel Wevrick
Professor of Medical Genetics
University of Alberta

William T. Gibson, MD PhD
Senior Clinician Scientist
BC Children's Hospital and University of British Columbia

Angela Brooks-Wilson
Distinguished Scientist
Genome Sciences Centre, BC Cancer Agency

Brenda de Carvalho Minatel
Graduate Student
University of British Columbia

Cynthia Ye
Graduate Student
University of British Columbia

Randi George, BSc.
MD Candidate
University of British Columbia, NMP

Samarpita Das
MD Candidate 2019
University of British Columbia

Alexandre Dionne-Laporte
Bioinformatics Lead, Guy A. Rouleau's Lab
McGill University

Ousmane Diallo
Bioinformatics Analyst
MNI - McGill University

Edouard Henrion
Software Developer
Canadian Center for Computational Genomics - C3G

Michelle Axford, PhD
Clinical Genetics Fellow
The Hospital for Sick Children

Dan Spiegelman, M.Sc., M.A.
Research Assistant
McGill University

Lena Dolman, MSc
Manager, Clinical Working Group
Global Alliance for Genomics and Health

Diane Salema
Genetic Counsellor
Genome Sciences Centre, BC Cancer Agency

Chen Wan
Genome British Columbia

David Arenillas
Bioinformatics Software Developer
University of British Columbia

Cristiana Cruceanu, PhD

Sonja Rummell
MD candidate
University of British Columbia

Amélie Racette, Ph.D.
Neuropsychologist
CIUSSS-du-Centre-Sud-de-l'Île-de-Montréal

Francois Bernier
Head and Associate Professor, Medical Genetics
University of Calgary

Shivani Mysuria
BSc Candidate
University of British Columbia

Erin Marshall
Graduate Student
BC Cancer Research Centre

Michel Cameron, PhD
Biogeniq

Elisha Lypchuk
Administrative Support IV
Alberta Children's Hospital

Teresa Hunt
Genetic Counsellor
Alberta Children's Hospital

Brenda Gallagher
Program Coordinator
Alberta Health Services

R.Brian Lowry
Professor emeritus
Alberta Children's Hospital & Univ Calgary

Stephanie Desmarais
Certified Genetic Counsellor
Hereditary Cancer Clinic, Alberta Children's Hospital

Catherine Morrison, MSW
Patient Care Manager
Alberta Health Services

Leslie Colvin James, MSc
Genetic Counsellor
Alberta Children's Hospital, Calgary

P.Y. Billie Au
Clinical Assistant Professor
University of Calgary

Aneal Khan
Associate Professor of Medical Genetics and Pediatrics
University of Calgary, Alberta Children's Hospital

Gerald Pfeffer, MD, PhD
Assistant Professor, Clinical Neurosciences and Medical Genetics
University of Calgary

Cathy Huculak
Genetic Counsellor
Alberta Health Services

Julien Marcadier
Clinical Geneticist
Alberta Children's Hospital

Mary Ann Thomas, MD CM, FRCPC, FCCMG
Medical Geneticist, Associate Professor
Alberta Children's Hospital and Department of Medical Genetics, University of Calgary

Amanda Melin
Assistant Professor
University of Calgary

Judy Chernos
Associate Professor and Clinical Site Lead - Genetic Laboratory Services
University of Calgary and Alberta Health Services

Linda MacLaren
Genetic Counsellor
Clinical Genetics, Alberta Children's Hospital, Calgary, AB

Vaughn Neff

Julie Richer
Clinical Geneticist and Residency Program Director
Children's Hospital of Eastern Ontario

Desirea Turner
Human Rights Officer
Alberta Human Rights Commission

Kellie Davis
Medical Geneticist
Royal University Hospital, University of Saskatchewan

Brenda McInnes
Genetic Counsellor
Alberta Children's Hospital

Claire Goldsmith
Genetic Counsellor
Children's Hospital of Eastern Ontario

Barbara Sibbald
Genetic Counsellor
Alberta Children's Hospital

Roberto Mendoza-Londono
Clinical Geneticist/Interim Head, Division of Clinical and Metabolic Genetics
The Hospital for Sick Children and University of Toronto

Nasim Monfared
Genetic Counsellor
The Hospital for Sick Children

Lizabeth Mellin
Metabolic Fellow
Hospital for Sick Children

Nada Quercia
Genetic Counsellor
Hospital for Sick Children

Michal Inbar-Feigenberg, MD
The Hospital for Sick Children

Laura Zahavich
Genetic Counsellor
The Hospital for Sick Children

Ashish Marwaha, MD
Hospital for Sick Children

Cheryl Cytrynbaum
Genetic Counsellor
Hospital for Sick Children

Lucie Dupuis
Genetic Counsellor
Hospital for Sick Children

Heather MacDonald
Genetic Counsellor
The Hospital for Sick Children

Pierre Sinajon, MD
PGY - 5 Clinical and Metabolic Genetics
The Hospital For Sick Children

Marla Jurek
IT Professional & mother of daughter with Aniridia

Coulter Beeson
Bioinformatics Research Assistant
Centre for Molecular Medicine and Therapeutics

Saadet Mahmutoglu, MD, PhD
Associate Professor
Department of Pediatrics, University of Toronto

Christopher Gray
Genetic Counselling Student
The Hospital for Sick Children

Gregory Costain, MD, PhD
PGY2 (Medical Genetics Residency Training Program)
The Hospital for Sick Children and University of Toronto

Sarah Robart
Genetic Counsellor
The Hospital for Sick Children

Riyana Babul-Hirji
Genetic Counsellor
The Hospital for Sick Children

Seema Jamal, MSc, CGC, CCGC
Genetic Counsellor
The Hospital for Sick Children

Linda Vorano
Research Administrative Assistant
The Hospital for Sick Children

Anna Szuto
Genetic Counsellor
The Hospital for Sick Children

William Brook
University of Calgary

Ray Lewkonia
Professor Emeritus, Medicine and Medical Genetics
University of Calgary

Seema Jamal, MSc, CGC, CCGC
Genetic Counsellor
The Hospital for Sick Children

Shelina Jamal, MD
Clinical Assistant Professor
Alberta Children's Hospital

Stacy Hewson
Genetic Counsellor
The Hospital for Sick Children

Andreas Schulze, M.D. Ph.D.
Associate Professor of Pediatrics
The Hospital for Sick Children and University of Toronto

Sarah Al-Qattan
Resident of Clinical and Metabolic Genetics
The Hospital for Sick

Hannah Dreksler
UBC

Resham Ejaz, MD
PGY4 - Medical Genetics
The Hospital for Sick Children

Folefac Aminkeng
Geneticist and Research Fellow
The University of British Columbia

Renee Perrier
Clinical Assistant Professor
University of Calgary

Harvey Taphorn
Management and Leadership Specialist
Crestcom

Dawn Cordeiro
Registered Nurse
The Hospital for Sick Children

Amanda Carnevale
Genetic Counsellor
The Hospital for Sick Children

Sarah Herd
Registered Dietitian
The Hospital for Sick Children

Eriskay Liston
Genetic Counsellor
Hospital for Sick Children

Felicia Collura
Genetic Counsellor
Hospital for Sick Children

Sam Khalouei, MSc, PhD
Bioinformatician
Hospital for Sick Children

Inara Chacon, MD
PGY2 Medical Genetics
Hospital for Sick Children

Henry J Duff
Professor of Cardiovascular Science

Michelle Lane
Genetic Counsellor
IWK Health Centre

Michael Brudno
Director, Computational Medicine
Hospital for Sick Children

Bailey Gallinger
Genetic Counsellor
The Hospital for Sick Children

Ny Hoang
Genetic Counsellor
Hospital for Sick Children

Susan Beeson

Antoine Bégin
Business Development
BiogeniQ

Sarah Neil
Genetic Counselling Student
Hospital for Sick Children

Caitlin Chang, MD
PGY2 - Medical Genetics
Alberta Children's Hospital

Deb Taylor

Tasneem Ezzy
Research Student
The Hospital for Sick Children

Rozmin Vsiram
Hospital for Sick Children

Priyana Sharma
Genetic Counsellor
Alberta Health Services

June Carroll, MD
Professor
Sinai Health System, University of Toronto