



FOR IMMEDIATE RELEASE

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CANADIAN COALITION FOR GENETIC FAIRNESS STATEMENT ON THE QUEBEC COURT OF APPEAL DECISION REGARDING THE GENETIC NON-DISCRIMINATION ACT

(KITCHENER, ON) January 16, 2019 – The Canadian Coalition for Genetic Fairness (CCGF) was disappointed with the Quebec Court of Appeal view that the Genetic Non-Discrimination Act (GNA) does not constitute a valid exercise of Parliament's criminal law power. On May 4, 2017, the GNA became law making it a criminal offence for a service provider or anyone entering into a contract with a person to require that person to take or disclose the results of a genetic test or collect use or disclose a person's genetic test results without written consent.

"People living in Canada should be able to benefit from genetic testing to inform health and life decisions rather than live in fear that their DNA will be used against them by employers, insurers, schools and more," says Bev Heim-Myers, Chair for the Canadian Coalition for Genetic Fairness. "The Quebec opinion is a step backwards at a time when we should be increasing the protection of our genetic information at federal, provincial and territorial levels. Genetic discrimination is an important issue in Canada and a barrier to science, medicine and the health and well being of people living in Canada. The Genetic Non-Discrimination Act addresses this problem and protects the genetic test information for the benefit of all Canadians. It is important to note that the Quebec Court of Appeal just provided an advisory opinion on the specific questions referred to them, however, this opinion does put the Genetic Non-Discrimination Act at risk. The CCGF is exploring all options as we move forward with our lawyers."

This historic law, which passed 3rd reading in the House of Commons by a vote of 222 to 60 in May 2017, enabled all people living in Canada the opportunity to make informed life decisions regarding health and reproduction, without fear of genetic discrimination. This legislation also enabled Canada to remain as a leader in genomic research and has already helped to alleviate the fears of Canadians, encouraging participation in genomics research and clinical trials. All Canadians deserve the right to proactively manage their own health and advance medicine without the fear of genetic discrimination. The Genetic Non-Discrimination Act alleviated that fear and removed barriers, by protecting genetic test information.

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The **Canadian Coalition for Genetic Fairness (CCGF/CCEG)** is a coalition of organizations dedicated to preventing genetic discrimination for all Canadians. The Coalition is deeply concerned about discrimination against individuals based on their genetic make-up. We are united to educate Canadians about genetic discrimination and to influence governments both federal and provincial, and other relevant organizations to create change. CCGF/CCEG currently represents 18 hereditary genetic diseases in Canada.

Members of CCGF/CCEG are:

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| ALS Society of Canada | Alzheimer Society of Canada |
| Canadian Cystic Fibrosis Foundation | CORD |
| The Foundation Fighting Blindness | Huntington Society of Canada |
| Kidney Foundation of Canada | Muscular Dystrophy Canada |
| Multiple Sclerosis Society of Canada | Osteoporosis Canada |
| Ovarian Cancer Canada | Parkinson Society of Canada |
| Tourette Syndrome Foundation of Canada | Centre for Molecular Medicine and Therapeutics |
| Canadian PKU & Allied Disorders | Spina Bifida & Hydrocephalus Association of Canada |
| The Centre for Israel and Jewish Affairs | Canadian Cancer Society |
| Canadian Congenital Heart Alliance | Individual Members |

The Genetic Non-Discrimination Act prohibits any person from requiring an individual to undergo a genetic test or disclose the results of a genetic test as a condition of providing goods or services to, entering into or continuing a contract or agreement with, or offering specific conditions in a contract or agreement with, the individual. Exceptions are provided for health care practitioners and researchers. The enactment provides individuals with other protections related to genetic testing and test results.

The act amends the Canada Labour Code to protect employees from being required to undergo or to disclose the results of a genetic test, and provides employees with other protections related to genetic testing and test results. It also amends the Canadian Human Rights Act to prohibit discrimination on the ground of genetic characteristics. (*Summary of Bill S-201 from openparliament.ca*).

For more information, please contact:

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