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## **American Society of Human Genetics Honours Senator James Cowan and Bev Heim-Myers, Chair of the Canadian Coalition for Genetic Fairness with 2016 Advocacy Award**

(Kitchener, ON) June 24, 2016 – The American Society of Human Genetics (ASHG) has named the Canadian Coalition for Genetic Fairness (CCGF) and Senator James Cowan, LLM, QC, as the 2016 recipients of its annual Advocacy Award. Senator Cowan and Bev Heim-Myers, Chair of the Canadian Coalition for Genetic Fairness and CEO of the Huntington Society of Canada will be honoured by the ASHG on Friday October 21, 2016.

This award honours individuals or groups who have exhibited excellence and achievement in applications of human genetics for the common good, in areas such as facilitating public awareness of genetics issues, promoting funding for biomedical research, and integrating genetics into health systems. ASHG will present the award, which will include a cash prize to the Canadian Coalition for Genetic Fairness and a plaque, on Friday, October 21, during the organization's 66<sup>th</sup> Annual Meeting in Vancouver, British Columbia.

For several years, Senator Cowan and Ms. Heim-Myers, as Chair of CCGF, have led efforts to pass a law preventing genetic discrimination in Canada. This year, Senator Cowan's bill was passed unanimously by the Senate of Canada. It is now before the House of Commons. First introduced in April 2013, Bill S-201 would enact a new Canadian Genetic Non-Discrimination Act that would protect individuals from being required to undergo a genetic test, or disclose the results of a test, as a condition of acquiring a good or service or entering into a contractual agreement. It would also prohibit employers from requiring employees to undergo genetic testing or disclose testing results, or taking discriminatory action against employees who refuse to undergo genetic testing or reveal testing results. Finally, it would amend the Canadian Human Rights Act to prohibit discrimination on the grounds of genetic characteristics.

Senator Cowan of Nova Scotia, who served as Senate Liberal Leader, has a history of advocating for public health policy. Prior to his time in Parliament, he was Vice Chair of the Metropolitan Mental Health Planning Board and Director of the Nova Scotia Division of the Canadian Cancer Society. In addition to Bill S-201, he has introduced legislation to address the criminal justice system's approach to people with mental illness.

"Senator Cowan first presented a Senate bill to end genetic discrimination in Canada three years ago," says Bev Heim-Myers. "He has been, and continues to be, a real champion and advocate for the protection of genetic test information leading to healthier lives for all people living in Canada through prevention, detection, targeted treatment, screening and management of potential disease without fear of genetic discrimination. It is an honour to receive this award jointly with Senator Cowan. The international community is watching Canada as our legislation finally catches up to the benefits of scientific advancements in better understanding the Human Genome."

"It is a tremendous honour to receive this award alongside Bev and the CCGF. The advances we have made on this issue would not have been possible without their continued advocacy and support," says Senator Cowan. "Each time I speak on this issue, I hear more and more heartrending stories from Canadians who have chosen not to have genetic testing for themselves or their children, for fear of genetic discrimination. We are working to change that."

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ASHG has long supported the establishment of strong protections against genetic discrimination, including advocating for the passage of the U.S. Genetic Information Non-discrimination Act in 2008, and recognizes a need for similar policies worldwide. Earlier this year, ASHG issued a statement of support for S-201. “Such protections are necessary to reassure members of the public that they can participate in genetic research or undergo a genetic test without fear that the results will be used to discriminate against them,” said Derek Scholes, PhD, ASHG Director of Science Policy.

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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. For a complete list of members visit <http://ccgf-cceg.ca/en/home>

#### **American Society of Human Genetics (ASHG)**

Founded in 1948, the American Society of Human Genetics is the primary professional membership organization for human genetics specialists worldwide. Its nearly 8,000 members include researchers, academicians, clinicians, laboratory practice professionals, genetic counselors, nurses, and others with an interest in human genetics. The Society serves scientists, health professionals, and the public by providing forums to: (1) share research results through the [ASHG Annual Meeting](#) and in [The American Journal of Human Genetics](#); (2) advance genetic research by advocating for research support; (3) educate current and future genetics professionals, health care providers, advocates, policymakers, educators, students, and the public about all aspects of human genetics; and (4) promote genetic services and support responsible social and scientific policies. For more information, visit: <http://www.ashg.org>.

**The Huntington Society of Canada** is the founding organization of the Canadian Coalition for Genetic Fairness (CCGF). CCGF is dedicated to preventing genetic discrimination for all Canadians. Canada is currently the only G7 country that does not protect its citizens against genetic discrimination.

#### **For more information, please contact:**

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