THE UNIVERSITY OF BRITISH COLUMBIA

Centre for Molecular Medicine and Therapeutics

CHILD & FAMILY RESEARCH INSTITUTE

UBC Public Affairs

310 – 6251 Cecil Green Park Rd.
Vancouver B.C. Canada V6T 1Z1

www.publicaffairs.ubc.ca

Tel: 604.822.3131
Fax: 604.822.2684
E-mail: public.affairs@ubc.ca

UBC News Line:
604.UBC.NEWS (822.6397)

Contacts:

Dr. Yvonne Bombard
Cell: 416.454.4900
yvonne.bombard@utoronto.ca

Dr. Michael Hayden
Cell: 604.338.3807
mrh@cmmt.ubc.ca

Sean Sullivan
UBC Public Affairs
Tel: 604.822.3213
Cell: 604.828.3867
sean.sullivan@ubc.ca

mr-09-069

MEDIA RELEASE |Embargoed until 5:01 p.m. PST, June 9

People at risk for Huntington's disease suffer genetic discrimination

[Editors: This story is under *British Medical Journal* embargo until 00:01 UK time Wednesday, June 10 -- or 5:01 p.m. Tuesday, June 9, Vancouver, Canada time.]

The first study of genetic discrimination in Canada shows that Canadians at risk of developing Huntington's disease frequently experience unfair treatment based on genetic information.

The study is published June 10 online in the *British Medical Journal at* *www.bmj.com* .

The research also found that discrimination is most often reported in insurance, family and social settings. It was conducted by Dr. Yvonne Bombard while a University of British Columbia doctoral candidate at the Centre for Molecular Medicine and Therapeutics (CMMT), in the lab of Huntington's disease researcher Dr. Michael Hayden, a principal author of the study.

In the study, 40 per cent of respondents to a national survey of individuals at risk of developing Huntington's disease – individuals with no symptoms – reported having experienced discrimination.

The study also found that family history of Huntington's disease, rather than the result of a genetic test, was the predominant reason given for discrimination. It is believed that the fear of genetic discrimination prevents individuals from undergoing testing.

The national survey of 233 people included 167 individuals who had been tested for the Huntington's disease mutation (83 had the genetic mutation and 84 did not), and 66 individuals who were at risk for the disease but had chosen not to have the predictive genetic test. Seven clinics across Canada collected survey data.

"Over the past two decades, the explosion of human genomic information has lead to more opportunities for genetic discrimination," said Dr. Paul Billings, Director and Chief Scientific Officer for the Genomic Medicine Institute at California's El Camino Hospital, and member of the Secretary's Advisory Committee on Genetics, Health and Society for the U.S. Department of Health and Human Services. "Dr. Bombard's study illustrates that we need continued research and improved public policy in order to create a safe society for knowing hereditary risks and acting on them appropriately."

"The study provides useful information that genetic professionals can tell people when they are counseling them on obtaining genetic testing," said Dr. Bombard, who is currently doing a post-doctorate fellowship in public health

THE UNIVERSITY OF BRITISH COLUMBIA

Centre for Molecular Medicine and Therapeutics

CHILD & FAMILY RESEARCH INSTITUTE

UBC Public Affairs

310 – 6251 Cecil Green Park Rd.
Vancouver B.C. Canada V6T 1Z1

www.publicaffairs.ubc.ca

Tel: 604.822.3131
Fax: 604.822.2684
E-mail: public.affairs@ubc.ca

UBC News Line:
604.UBC.NEWS (822.6397)

Contacts:

Dr. Yvonne Bombard
Cell: 416.454.4900
yvonne.bombard@utoronto.ca

Dr. Michael Hayden
Cell: 604.338.3807
mrh@cmmt.ubc.ca

Sean Sullivan
UBC Public Affairs
Tel: 604.822.3213
Cell: 604.828.3867
sean.sullivan@ubc.ca

mr-09-069

genomics and policy at the University of Toronto. "I would like to see society benefit from the effective translation of genomic discoveries while minimizing the risks such as the inappropriate use of these technologies or information."

The study participants reported discrimination most often in insurance (29.2 per cent), family (15.5 per cent) and social (12.4 per cent) settings. There were fewer reports of discrimination in employment (6.9 per cent), health care (8.6 per cent), or public sector settings (3.9 per cent).

"This research will help provide insights into approaches aimed at prohibiting discrimination on the basis of genetic information," said Dr. Hayden, CMMT Director, senior scientist at both CMMT and the Child and Family Research Institute (CFRI), and University Killam Professor in the Dept. of Medical Genetics at the University of British Columbia.

Information provided by genetic testing helps people plan for the future, make important decisions about their families and careers, and, in some cases, obtain preventative treatment, said Dr. Bombard.

Both Drs. Bombard and Hayden are members of the Canadian Coalition for Genetic Fairness, which promotes awareness and policy protections for genetic discrimination issues in Canada.

Huntington disease is an inherited neurodegenerative brain disorder affecting one in every 10,000 Canadians, according to the Huntington Society of Canada. There is no cure and some treatments are available for the symptoms, which are cognitive, emotional and physical. The children of a person with Huntington's disease have a 50 per cent chance of developing the disease.

For interviews Dr. Yvonne Bombard can be reached at 416.454.4900 (yvonne.bombard@utoronto.ca) and Dr. Michael Hayden can be reached at 604.338.3807 (mrh@cmmt.ubc.ca).

The study was supported by the Canadian Institutes of Health Research, National Institutes of Health, National Institute of Neurological Disorders and Stroke, Michael Smith Foundation for Health Research and the Child & Family Research Institute.

The Centre for Molecular Medicine and Therapeutics (CMMT) is a synergistic group of scientists and researchers who share a strong sense of commitment to solve the many genetic questions surrounding human illness and well being. Affiliated with the University of British Columbia and the Child & Family Research Institute, CMMT conducts discovery research and translates that research into effective clinical and therapeutic strategies to promote health. For more information, visit www.cmmt.ubc.ca.

The Child & Family Research Institute (CFRI) conducts discovery research, clinical investigation and applied health research to benefit the health of children and families. It is the largest research institute of its kind in Western Canada. CFRI works in close partnership with BC

THE UNIVERSITY OF BRITISH COLUMBIA

Centre for Molecular Medicine and Therapeutics

CHILD & FAMILY RESEARCH INSTITUTE

Children's Hospital and Sunny Hill Health Centre for Children, and BC Women's Hospital & Health Centre, agencies of the Provincial Health Services Authority; BC Children's Hospital Foundation; the University of British Columbia and Simon Fraser University. For more information, visit www.cfri.ca.

The University of British Columbia is one of Canada's largest public research and teaching institutions and consistently ranks among the top 40 institutes in the world. It offers a range of innovative undergraduate, graduate and professional programs in the arts, sciences, medicine, law, commerce and other faculties. UBC has particular strengths in biotechnology, and ranks in the top 10 universities in North America and number one in Canada for commercializing research, and for its patent activity in the life sciences.

- 30 -

UBC Public Affairs

310 – 6251 Cecil Green Park Rd.
Vancouver B.C. Canada V6T 1Z1

www.publicaffairs.ubc.ca

Tel: 604.822.3131
Fax: 604.822.2684
E-mail: public.affairs@ubc.ca

UBC News Line:
604.UBC.NEWS (822.6397)

Contacts:

Dr. Yvonne Bombard
Cell: 416.454.4900
yvonne.bombard@utoronto.ca

Dr. Michael Hayden
Cell: 604.338.3807
mrh@cmmt.ubc.ca

Sean Sullivan
UBC Public Affairs
Tel: 604.822.3213
Cell: 604.828.3867
sean.sullivan@ubc.ca

mr-09-069