

What is Huntington Disease?

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Huntington disease (HD) is an inherited brain disorder. HD causes cells in parts of the brain to die: specifically the caudate, the putamen and, as the disease progresses, the cerebral cortex. As the brain cells die, a person with Huntington's becomes less able to control movements, recall events, make decisions and control emotions. The disease leads to incapacitation and, eventually, death (generally due to other health complications).

Who gets it?

Huntington disease is a genetic disorder. The HD gene is dominant, which means that each child of a parent with HD has a 50% chance of inheriting the disease and is said to be "at-risk." Males and females have the same risk of inheriting the disease. Huntington's occurs in all races. Symptoms usually appear between the ages of 30 and 45, but the disease can appear in children or seniors.

What causes it?

It is not clear how the abnormal HD gene causes the disease. Since the discovery of the gene in 1993, scientists have been working hard to discover the biochemical processes that cause the brain cells to die.

So far, we have learned that the HD gene produces a protein called "huntingtin." In people with HD, this protein gets cut into one short piece and one longer piece. The shorter pieces stick together to form a protein ball.

Scientists are currently investigating whether it is the breakage of the protein, the formation of protein balls, or some other process that leads to cell death. They are also trying to understand why only certain brain cells die.

Are there treatments?

At the moment, there are no treatments that will slow down or stop the disease in humans. There are some drug treatments available that can reduce some of the symptoms of HD, such as depression, anxiety, and involuntary movements. These drugs can have side effects, so not everyone with Huntington's uses them.

On a more promising note, there are several advanced drug trials underway under the auspices of the Huntington Study Group, an international consortium focused on clinical research in Huntington disease.

Researchers are also looking at surgical treatments, such as stem cells, in the hope the cells will grow and take over the functions of the dead cells.

Researchers feel we are close to reliable treatments; the urgency lies in educating as many people as possible, including new outreach efforts in rural and culturally diverse communities.

The Huntington Society of Canada

Family is at the heart of our community. Our families and volunteers tell a powerful story of caring people who pull together to improve the quality of life for Canadians impacted by HD. We are a not-for-profit charitable organization which raises funds to deliver counselling services and other supports to individuals and families living with Huntington disease (HD). The Society works with health and social services professionals to enable them to better serve people living with HD. We also fund medical research leading to treatments that will delay or stop the progression of the disease.

Huntington Society of Canada

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What is genetic discrimination?

Genetic discrimination occurs when people are treated unfairly because of actual or perceived differences in their genetic information that may cause or increase the risk to develop a disorder or disease. For example, a health insurer might refuse to give coverage to a woman who has a genetic difference that raises her odds of getting breast cancer. Employers also could use genetic information to decide whether to hire, promote or fire workers. The fear of discrimination can discourage individuals from making decisions and choices that may be in their best interest. For example, a father may decide not to take a genetic test for fear of consequences to his career or the loss of insurance for his family, despite knowing that early therapy could improve his health and longevity.

Who needs protection?

All Canadians are affected by genetic discrimination. Every person has dozens of genetic differences that could increase or decrease his or her chance of getting a disease such as diabetes, heart disease, Parkinson's or Alzheimer's disease. Unless this genetic information is protected, it could be used to discriminate against people.

Why is genetic protection needed?

Genetic discrimination is real and growing: Cases of genetic discrimination have already been documented in Canada and are continuing to grow as more genetic information becomes available.

Genetic discrimination is unjust: It is unfair to use genetic information to determine which individuals will be employed or insured. To assume that someone's DNA will result in a disease or disorder is faulty, misleading and speculative.

Genetic discrimination concerns Canadians: Approximately 91% of Canadians feel that insurance companies should not be allowed access to their genetic information for an insurance assessment. Ninety percent of Canadians opposed the notion that employers should have access to the genetic information of workers or job applicants. (Government of Canada. Public opinion research on genetic information and privacy. Pollara Research, Earncliffe Research and Communications. 2003. Ottawa)

Fear of genetic discrimination prevents positive uses of genetic information. Fear is preventing people from participating in genetic testing and vital research, both of which are critical to understand and treat diseases. Genetic information must be used to prevent illness and save lives and not used against people.

What is the Canadian Coalition for Genetic Fairness?

The Canadian Coalition for Genetic Fairness/Coalition Canadienne Pour L'Équité Génétique is a group of 15 organizations dedicated to establishing and advocating for protections against genetic discrimination for all Canadians.

CCGF's mission: To educate Canadians about genetic discrimination and to influence provincial and federal governments, and other relevant organizations, to create positive change.

Canadian Coalition for
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