

What is Huntington Disease?

Huntington disease (HD) is a hereditary, neurodegenerative illness with physical, cognitive and emotional symptoms. Having HD is similar to having the symptoms of Alzheimer’s disease, Parkinson’s disease and ALS all at once.

HD is caused by a mutation in the gene that makes the protein called huntingtin. In people with HD, the CAG sequence is repeated too many times at the beginning of the gene. That causes cells to manufacture a harmful protein called mutant huntingtin. The mutant huntingtin protein causes certain parts of the brain to die - specifically the caudate, the putamen and, as the disease progresses, the cerebral cortex.

As the brain cells die, physical, cognitive and emotional symptoms will appear. To date, there are no drugs to slow or stop the progression of HD; however, there are specific drugs available to reduce some of the symptoms. Research is being conducted in Canada and globally to find promising treatments and approaches to treating the root causes of HD.

Who gets HD and What Are the Symptoms?

HD is a genetic disorder. The HD mutation is dominant, which means that each child of a parent with HD has a 50 per cent chance of inheriting the disease and is said to be “at-risk”. Males and females have the same risk of inheriting the disease. HD occurs in all races. Symptoms usually appear between the ages of 35 and 55, but the disease can appear in youth (under 20 years – Juvenile HD) or older adults (Late Onset HD).

Symptoms vary from person to person and at different stages of the disease. Physical symptoms include weight loss, involuntary movements (chorea), diminished coordination, and difficulty walking, talking and swallowing. Cognitive symptoms include difficulty with focus, planning, recall of information and making decisions as well as impaired insight. Depression, apathy, irritability, anxiety, and obsessive behaviour are some of the emotional symptoms that can be observed in a person with HD.

The Huntington Society of Canada

Founded by (the late) Ralph and Ariel Walker in 1973 the Huntington Society of Canada (HSC) is a not-for-profit charitable organization which is governed by a volunteer board of directors.

HSC is self-funded and dedicates those funds to family services and research efforts. HSC raises funds with the following objectives:

- Maximize the quality of life of people living with HD by delivering services to individuals and families, and by providing education to healthcare professionals
- Advance medical research to slow progression of the disease and to prevent HD
- Enable others to better understand the disease

HSC is Here to Help

HSC support is provided by our family services team across Canada. In addition, approximately 50 per cent of our mission spend goes to support world-class basic and clinical research. The ultimate goal is to prevent HD in future generations and treat and/or slowing the progression of the disease for individuals and families who are currently affected.

HSC is involved in national advocacy efforts to ensure that individuals’ rights are protected.

Our volunteer chapters across Canada also provide an excellent informal support network for people who are affected by this devastating disease, and it is these same amazing volunteers who raise a large portion of the funds to ensure we can support our mission.

What Kind of Help do We Offer?

- Family services team members offer direct assistance to individuals and families, information sessions, educational sessions (in-services) and support groups (in-person and virtual)
- Educational resources (e.g. booklets, factsheets, brochures, *Horizon* newsletter) are all available for individuals, families and healthcare professionals
- The HSC website (www.huntingtonsociety.ca) and electronic bulletins and emails can provide additional information
- Information about clinical trials and research

Family Services

HSC has a family services team composed of registered social workers and professionals who provide support to individuals and families affected by HD. Family services team members are located across Canada.

The family service team offers support and services to persons with HD, persons “at-risk” for HD, persons who have the genetic mutation or do not, caregivers and family members, community members, friends and neighbours. Some of the services offered include information and education, referrals to community resources and individual advocacy.

In addition, the family services team offers education and support to health, social service and community workers. The team also collaborates with other service providers to improve and expand existing services as well as increase awareness and understanding of HD and support for advocacy.

HSC Supports Clinical Trials and Critical Research

The universal goal for the international HD research focus is to find treatments that reverse, slow or prevent the progression of HD. Canada’s strategic research funding has helped to develop a critical mass of research in Canada. For more information on HSC research visit www.huntingtonsociety.ca/research.

Clinical trials depend on the participation of individuals and families affected by HD. HSC plays a key role in bridging the relationship between researchers and individuals by educating Canadians on the importance of the clinical trial process, how they can get involved, and why their participation is crucial. HSC will continue to build a strong foundation for clinical trials in Canada and work in partnership with our HD community to find answers.

National Advocacy Efforts

HSC has a mandate to advocate for systemic change to enhance the social, political and environmental conditions that contribute to the well-being of individuals and families affected by HD. HSC and the Canadian Coalition for Genetic Fairness (CCGF) worked very hard to advocate for legislation to protect genetic test information for all Canadians.

Support Networks

HSC has a network of volunteers who form chapters across Canada. Chapters participate in a wide variety of activities including fundraising, increasing public awareness, providing education, and supporting individuals and families who are a part of this community. Without the incredible passion and efforts of the chapter volunteers, the HSC couldn’t do the work that we do.

Find a Chapter near you to get involved in by visiting www.huntingtonsociety.ca/chapters-near-you.