

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 receives no government funding. As a self-funded organization, funds raised are directed to family services and research efforts with the following objectives:

- Maximize the quality of life of people living with Huntington disease (HD) by delivering services to individuals and families, and by providing education to healthcare professionals;
- Advance basic research to slow progression of the disease and to prevent HD; and
- Raise awareness to help others better understand the disease.

What Kind of Help do We Offer?

- [Family services team](#) members offer direct support 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 about HD, events, support, clinical trials and research.

Family Services

HSC's family services team is comprised of registered social workers and professionals who offer 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, guardians and friends. 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.

The [Youth and Young Adult Mentorship Program \(YMP\)](#) offers young people the opportunity to connect with a trained mentor who will be able to provide them with valuable support at critical points in their lives. As matches are virtual, mentors and mentees will be able to communicate by phone, text, email, FaceTime or social media.

HSC Supports Clinical Trials and Critical Research

The ultimate 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.

The HD Coalition for Patient Engagement (HD-COPE) is a unique and diverse international collaboration between the Huntington Society of Canada, the Huntington Disease Society of America (HDSA) and the European Huntington Association (EHA). HD-COPE was formed to replace the current ad hoc approach to incorporating the patient-voice in global therapeutic development efforts for HD. The group's role is to communicate the HD community's experiences and needs to regulators, industry and researchers.

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) successfully advocated for legislation that protects the genetic test information for all Canadians, through the Genetic Non-Discrimination Act.

Support Networks

While the family services team provides a variety of supports, information and advocacy to individuals and families affected by HD, there is another very important and large group of people who are critical to the success of HSC's mission. This group is the network of volunteers who form the 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.

What is Huntington Disease?

Huntington disease is a hereditary, neurodegenerative disease that affects primarily the brain with physical, cognitive and emotional symptoms. Although HD varies quite a bit from person to person, having HD can be similar to having the symptoms of Alzheimer's disease, Parkinson's disease and ALS all at once.

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 (over 60 years of age – late onset HD).

Symptoms vary from person to person and at different stages of the disease. Physical symptoms can 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 appreciation of the consequences of 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.

For more information on HD or HSC services, please visit www.huntingtonsociety.ca or call 1-800-998-7398.