

## 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 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 or prevent the progression of HD
- 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, and support groups (in-person and virtual)
- We provide [educational resources](#) (e.g., booklets, factsheets, brochures, *Horizon* newsletter) for individuals, families, and healthcare professionals
- [The HSC Website](#), electronic bulletins (e.g., *Strength & Knowledge*), and emails are excellent sources of additional information about HD, events, support, clinical trials, and research

## Family Services

HSC's Family Services Team is made up of registered social workers and professionals who offer support and services to anyone living with, at risk for, or impacted by HD in any way. This includes caregivers, family, community members, guardians, and friends. Some of the services offered include 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. Through collaboration with these service providers and health care workers, the HSC Family Services Team increases awareness and education in communities, resulting in improved services for families.

HSC's [Youth and Young Adult Mentorship Program \(YMP\)](#) offers young people the opportunity to connect with a trained mentor who is able to provide valuable support at critical life points. Matches between mentors and mentees are virtual, making communication through phone, text, email, and social media easy and accessible.

## HSC Supports Critical Research and Clinical Trials

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](http://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 and the Huntington Disease Society of America (HDSA). HD-COPE was formed to replace the 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

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**

