

# We are Here to Help!

## WHO is the Huntington Society of Canada

Founded by Ralph and Ariel Walker, the Society has been in existence since 1973 and is a registered charity in Canada. HSC is governed by a volunteer Board of Directors, which ensures the Society is accountable to our community, our clients and our donors. The Board of Directors is comprised of volunteers elected by the members at the Annual General Meeting. The Board is responsible for governing the Society, which includes: the Society's mission and strategic plan; policy development; stewardship of resources. The senior staff person, the Executive Director and CEO, reports directly to the Board. HSC subscribes to Imagine Canada's Philanthropic Ethical Fundraising and Financial Accountability Code.

## What the Huntington Society of Canada DOES

HSC works to increase awareness and understanding of HD by providing educational materials for health care professionals, caregivers, individuals living with HD, family members, the media, and the general public.

The Society produces a wide range of materials for families and professionals, including:

- Horizon newsletter
- Electronic bulletins and emails
- Booklets, brochures, fact sheets, articles and care manuals on many aspects of HD
- A comprehensive website ([www.huntingtonsociety.ca](http://www.huntingtonsociety.ca))

## 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 of Canadians impacted by HD. At the Huntington Society of Canada (HSC), we understand what you are going through, whether you have the disease yourself, are caring for someone with HD, are gene positive or are at-risk of inheriting HD.

We are a not-for-profit charitable organization which raises funds to deliver counselling and other support services to individuals and families living with Huntington disease (HD). We fund peer reviewed medical research leading to treatments and we work with health and social services professionals to enable them to better serve people living with HD.

## WHAT is Huntington Disease?

Huntington disease (HD) is an inherited brain disorder which is genetic in nature. About one in every 7,000 Canadians has HD, but 1 in every 1,000 are touched by HD, whether as a caregiver, family member or friend. It is like having the symptoms of Alzheimer's, Parkinson's and schizophrenia all in one disease.

## WHO Does HD Affect?

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 and HD occurs in all races. Primarily, HD affects adults. Symptoms usually appear between the ages of 30 and 50, but the disease can first appear in children as young as 5, or in adults in their 70s.

# What the Huntington Society of Canada Offers

## Services:

The HSC Family Services program provides support to individuals, families, and professionals as they face the many challenges encountered throughout the progressive course of Huntington disease (HD), as well as caregivers and those living at-risk. The Family Services Program strives to maximize quality of life and to assist with meeting urgent needs. Services are provided through a Director of Family Services, Resource Centre Directors, and Family Services Workers across the country.

The program includes:

- Direct support services
- Education and support
- Local community development
- Support to HSC's national advocacy efforts

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## Research:

HSC is dedicated to furthering research to slow and prevent HD. As well as attracting Canadian scientists to HD research, HSC is involved in all facets of the research spectrum. The Society works with other partners through various research programs to foster basic science about the underlying pathology of HD as well as to support clinical trials to test new treatments. Canadian researchers funded by HSC continue to play key roles in the international drug discovery process. The Society's Research Council, which comprises leading scientists, reviews grant applications and provides scientific direction.

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## Support Networks:

Across Canada, HSC has over 30 volunteer chapters and area representatives providing support to the many families affected by HD. These volunteers are active in a range of public awareness, educational, support and fundraising activities for families, health-care professionals and the general public. This enables the Society to reach out to those who are often isolated and alone. For more information about the Society and to read a copy of our annual report please go to [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca).

## The Huntington Society of Canada Strives to...

-  Maximize the quality of life of people living with HD by delivering services
-  Further research to slow and to prevent HD
-  Enable others to understand the disease

## Huntington Disease Facts

- HD is a fatal hereditary brain disorder
- A child born to a parent with HD has a 50% chance of sharing the same fate
- Approximately 1 in every 5,500 are at-risk of developing the disease
- One in every 1,000 Canadians is directly or indirectly impacted by HD
- Currently there is no known cure for HD