Huntington Society of Canada

We’re here to help

What is Huntington Disease?

Huntington disease (HD) is a hereditary brain disorder with devastating effects on both mind and body.

- One in every 1,000 Canadians is touched by HD — for example, as an affected individual, person at risk, friend, family member or caregiver.
- One in every 10,000 Canadians has Huntington disease.
- Every child of a person with HD has a 50% risk of inheriting the disease.

The symptoms of HD — including uncontrollable jerking movements and profound cognitive and emotional impairment — usually appear in the late 30s, although HD can occur in children as young as five, or in adults in their 70s.

Over its lengthy course, HD leads to incapacitation and death.

HD is a disease of families. No member is left untouched. Children, siblings, spouses and parents all face the difficult personal and financial decisions of caring for their loved ones.

There is still no cure for Huntington's, and there are no treatments which can prevent HD or slow it down. However, the accelerating pace of research is offering more hope than ever before that a solution will be discovered one day soon.

About HSC

At the Huntington Society of Canada, we understand what you're going through, whether you have the disease yourself, are caring for someone who does, or are at risk of inheriting HD.

The Huntington Society is a national network of volunteers and professionals united in the fight against HD since 1973. Our goal is to find new treatments and ultimately a cure for Huntington disease, and to improve the quality of life for people with HD and their families.

Our Goals

Service

To meet the urgent needs of the HD community now by linking people with HD, spouses, caregivers, persons at risk and other family members with appropriate services to meet their needs.

Research

To provide hope for the future by sponsoring basic and applied research which will enhance our understanding of Huntington disease, and advance the search for new treatments and a cure.

Education

To promote improved understanding and awareness of Huntington disease by providing educational materials for health care professionals, caregivers, individuals with HD, family members, the media, and the general public.

Our Structure

HSC Office

The staff at the Huntington Society of Canada's office can provide you with information about HD and put you in touch with your nearest chapter, area representative or social service staff person. We can also refer you to the closest clinic offering genetic counselling and testing.

Resource Centres

Our Resource Centres are staffed by trained social workers who can assist you in dealing with the many different needs and concerns associated with Huntington disease. Services may include information, counselling, referral, and discussion groups for family members.

Support Workers

A number of social workers are available on an on-call basis to provide support in several areas of the country that are not served by Resource Centres. These support workers are trained professionals who offer crisis counselling, referral, in-service presentations to health care providers, and leadership of family discussion groups.

Chapters and Area Representatives

Chapters and area representatives lead the fight against Huntington disease in communities across Canada. They pursue a broad range of fundraising and public awareness activities, and offer information and support to affected families, health care professionals and the public.

Our Services

Through our cross-Canada support network, we offer programmes and services to help all members of the HD family.

Day Programmes

In several cities across the country, HSC runs special programmes for individuals with Huntington disease. These provide unique and therapeutic social and recreational activities for the person with HD, as well as respite for the family.

Support/Discussion Groups

A number of support/discussion groups are held on a regular basis across Canada. They are facilitated by our social workers and provide an opportunity for families to share information and coping strategies, and to offer support to one another.

Summer Camps

The Society offers several summer camp programmes which allow people with HD to re-discover their abilities and talk about their frustrations and fears with others who share their feelings. The camps also offer invaluable respite for caregivers.

Outreach

Our Resource Centre Directors make outreach visits to other communities in their provinces. On these visits, they meet families and health professionals and provide information and support.

In-Service Seminars

Our Resource Centre Directors also provide in-service education seminars to professionals in health care facilities and community agencies.

Information and Counselling

The Huntington Society's social work staff provide counselling, crisis intervention, and referral to community services for individuals with HD and their families. They are also a key source of information about all aspects of the disease for families dealing with HD, and for health care professionals.

Housing

We can help identify long-term care facilities which have, or are willing to take, a special interest in HD. Our social workers assist with staff training to ensure that the unique needs of residents with HD are addressed. The Society also works with established housing agencies which are interested in supportive housing for persons with Huntington disease.

Annual Conference

Every October, representatives of our cross-Canada network gather at our Annual Conference to discuss and review the Society's governance and strategic priorities, to pursue volunteer training opportunities, and to learn more about recent developments in research.

Research

We believe that investing in research is crucial to finding a cure for Huntington disease. That's why we provide support for a wide range of initiatives through our NAVIGATOR programme, including:

- seed funding for scientific and clinical investigations of HD;
- training grants to outstanding young investigators;
- special awards to enhance international collaboration in HD research.

Our Research Council, composed of leading scientists and physicians, ensures that we have current, accurate information on research advances, and provides advice to our Board of Directors on HSC's research programme.

Education

HSC is committed to making accurate, up-to-date information available to families and professionals across Canada.

We produce a wide range of low-cost printed and audio/visual materials for families and professionals, including:

- our quarterly newsletter, *Horizon;*
- booklets, brochures, articles and care manuals on many aspects of HD;
- instructional videotapes.

Our local social service staff and chapters and area representatives also offer presentations and workshops of particular interest to professionals, and provide in-service programmes for health and community service workers and staff of long-term care facilities.

Public Awareness

The Huntington Society of Canada works to promote public awareness of Huntington disease by:

- producing public awareness materials, including posters, pamphlets, videos and public service announcements;
- coordinating “Huntington Disease Awareness Month” across Canada every May;
- providing speakers for service clubs, professional groups, church groups, etc.;
- maintaining a comprehensive Web site.

Accountability

We are a registered charity, governed by a volunteer Board of Directors which ensures we are accountable to our members, clients and donors.

The Huntington Society of Canada subscribes to the Canadian Centre for Philanthropy’s *Ethical Fundraising and Financial Accountability Code*.

Contact Us

To find out how we can help you, please contact us:

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