

HD Multi-Disciplinary Clinics in Canada

The Huntington Society of Canada (HSC) is committed to finding a reliable treatment for Huntington disease (HD). We work to accomplish this through supporting research, enabling others to understand the disease and by providing services. HD is a complex disease, impacting generations of families and there is a great deal of misunderstanding about the disease. HSC, through the Family Services Program, is committed to providing professional social work services to families, to help navigate through the evolution of this disease.

HSC Family Services is made up of a team of Resource Centre Directors (RCD) and Family Services Workers (FSW) who support individuals and families living with HD. These knowledgeable professionals advise those living with HD, and their families, about HD, community resources that are available, and act as resources to the community at large. Many of the RCDs participate in multi-disciplinary clinics, providing a vital link between clinical support, family and the community.

Huntington disease:

Huntington disease is an autosomal, dominant, inherited neurological disease, which gives rise to progressive motor, cognitive and behavioural symptoms. The symptoms of HD include: emotional turmoil, cognitive loss and physical deterioration.

Most people will be diagnosed between the ages of 30-50 and will live for approximately 15-20 years before finally succumbing to the disease. This rare disease affects one in every 7,000 Canadians and one in every 5,500 are living at-risk. A child born to a parent with

Huntington disease has a 50 percent risk of inheriting the disease as the HD-gene is dominant.

What is a HD Multi-Disciplinary Clinic?

A multi-disciplinary clinic is comprised of health care professionals who provide overall care for individuals living with this complex, devastating disease. Health care professionals can include, but are not limited to, a neurologist, psychiatrist, psychologist, social worker, physiotherapist, occupational therapist, dietician, registered nurse, etc.

One of the more effective ways to support individuals who are living with, or who are at-risk of, HD is through multi-disciplinary care. While there have been limited advances in treatments, either symptomatic or disease progression, multi-disciplinary care offers ongoing support from the time of diagnosis and throughout the disease process. International research shows that multi-disciplinary care plays a key role during the transitions of the disease, and in finding community based resources and supportive medical care. Many of these clinics are active in clinical and observational research with Canadian and international research groups.

Huntington Society of Canada 151 Frederick St., Suite 400, Kitchener ON N2H 2M2 1-800-998-7398 info@huntingtonsociety.ca www.huntingtonsociety.ca Charitable Registration Number 1 1896 5516 RR0001





Multi-Disciplinary Clinic Locations Across Canada

St John's, NFLD: The newest HD Clinic, at the Dr. Leonard A Miller Centre, is held four times a year and brings multi-disciplinary care (neurology, psychiatry, genetics, physiotherapy, nursing and social work) to people with HD from the province of Newfoundland and Labrador.

Halifax, NS: The HD Multi-disciplinary Clinic is located at the Halifax QEII Health Services Centre. It is a monthly, half-day clinic serving Nova Scotia, New Brunswick and Prince Edward Island. The clinic assists in coordinating health services for individuals with HD, monitoring the care they receive and providing follow-up appointments with appropriate health professionals (psychiatry, neurology, genetics and social work).

Sudbury, North Bay and Sturgeon Falls, ON:

The Centre for Movement Disorders brings specialist resources (neurologist, genetic nurse, social worker) closer to those living in northern Ontario. The clinics are conducted semi-annually, onsite in the Sturgeon Falls, North Bay and Sudbury areas with follow up via Telehealth videoconferencing services. Outreach and technology allow this innovative model to be possible.

Toronto, ON: The HD Clinic is located in North York General Hospital and operates twice a month. This clinic has developed strong links between genetics, neurology, neuropsychiatry, and HSC social workers; recognizing the importance for genetic testing as a significant step along the journey with HD.**

Ottawa, ON: Located at The Ottawa Hospital, Civic Campus, the Movement Disorders Clinic sees clients with HD on a regular basis. The clinic's professionals (including neurology and social work) link with psychiatry at the Royal Ottawa, genetics at the Children's Hospital of Eastern Ontario (CHEO), and the HSC Resource Centre Director to provide seamless support.

London, ON: The London Movement Disorders Centre holds monthly HD clinics. The HSC Family Services Worker works with the neurologist, psychiatrist and medical staff, to assist people on-site to provide them with information and link them to additional community based resources.

Winnipeg, MB: The Manitoba HD Resource Centre is integrated into the Movement Disorder Clinic in Winnipeg. The clinic offers quality individual patient care through a wide range of disciplines including neurology, speech language pathology, physiotherapy, occupational therapy, nursing, dietetics, genetic counselling and HSC social work.

Saskatoon, SK:

Individuals are seen at the Royal University Hospital. Clinics are held monthly and are offered to all Saskatchewan residents. Individuals and families can see the neurologist, psychiatrist and social worker all on the same day. This clinic uses Telehealth and videoconferencing to provide outreach to those unable to travel or to those living in remote areas.

Edmonton, AB: The Movement Disorder Clinic recently relocated to the Kaye Edmonton Clinic. It is a monthly clinic that provides separate appointments with medical specialists. The clinic serves northern Alberta, providing assessments, diagnosis and treatment for individuals with HD. Individuals and families are provided with ongoing support and are referred to the HSC Northern Alberta Resource Centre for assistance.**

Calgary, AB: The Calgary Movement Disorders Clinic is located at the Health Sciences Centre at Foothills Medical Centre. While the clinic is multi-disciplinary, some services are located at other local facilities such as the Presymptomatic Testing Clinic, which is located at the Alberta Children's Hospital. The HSC social worker provides support and follow up based on referrals from the clinic.

Vancouver, BC: The Centre for HD, located in UBC Hospital, serves the province by holding a weekly clinic. Individuals and families meet with the care team; in turn the team provides assistance to the family physician to ensure the best care possible. The clinic offers a wide range of disciplines including geneticist, genetic counsellor, psychiatry, neurology and HSC social workers. The clinic refers clients to the BC Neuromuscularskeletal outpatient team for speech language pathology, physiotherapy, occupational therapy, and dietician services.

**Note: The HSC Family Services team works closely and coordinates efforts with additional neurologists with an HD specialty located in Markham, Ontario, Ottawa, Ontario, and in Edmonton, Alberta (University of Alberta).