





VISION, MISSION & VALUES

Huntington Society of Canada (HSC) is a not-for-profit charitable organization that raises funds and supports individuals and families facing Huntington disease (HD).



VISION

**A world free from
Huntington disease**



MISSION

To improve the quality of life for those affected by Huntington disease. We will address our mission through:

- **Oversight and facilitation of excellent support services**
- **Providing access to the best and most up-to-date educational resources**
- **Increasing national and global awareness**
- **Advocacy**
- **Investing in promising research**

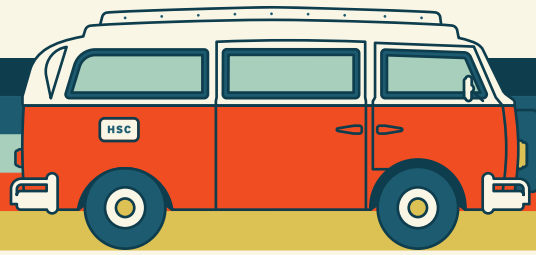


VALUES

**Compassion
Integrity
Accountability
Inclusiveness
Collaboration
Leadership
Empowerment**



GOAL: We're ready to head into the next 50 years with hope, innovation and results. The **ROUTE 50: Driving Hope Forward** campaign goal is \$3 million to meet our needs and goals in both research and support services. Let's make the journey together.



Shelly Redman
CEO, HSC

CEO NOTE

It is so very exciting to prepare for **HSC** turning 50 next year in 2023. The past 50 years have seen some incredible accomplishments in **HSC's** mission, which is to improve the quality of life for those affected by HD.

At the foundation of our mission are research and care. In spite of all of our strides in both areas, there is still so much more that we can do. The theme of our anniversary and this fundraising campaign is **ROUTE 50: Driving Hope Forward**, in honour of our co-founders Ralph and Ariel Walker and their cross-country camper van trips to connect with families, bringing with them information, vision and hope.

I hope you will join me in our **50th Anniversary** campaign as we continue to work toward a world free from Huntington disease.

CO-FOUNDER NOTE

It's hard to believe that **HSC** was once just Ralph and I working at our kitchen table after we had put the kids to bed.

Today, **HSC** is active in every province, with 20 highly skilled professionals from social work and psychotherapy backgrounds. Over 30 Chapters engage more than 10,000 fundraising and awareness volunteers each year. I have witnessed many firsts for the Society – Ralph being employee #1, the first office being established, national conferences evolving from our weekend workshops, Resource Centres getting off the ground, and research breakthroughs. I know there are many more meaningful firsts to come. So please, get involved. Surround yourself with the community. It will help and it truly inspires hope. Just remember the tagline for this campaign – **ROUTE 50: Driving Hope Forward**.



Ariel Walker
CO-FOUNDER, HSC

Here's to the future of this **Society** that has played such a large role in my life.



Our strategic partners support **HSC** in our achievements that reach into every community from coast to coast.

MEMORABLE MILESTONES INCLUDE:

RESEARCH

2015

A seminal study by the GeM-HD consortium identifies important genetic factors that modify the age of symptom onset in people with HD. This study helps us understand why some people with the same CAG number get the disease earlier or later in life.

2015

The very first patients are treated in a clinical trial with a drug targeting the root cause of HD. Tominersen, previously called HTRx and RG6042, was developed by Ionis and Roche with the aim of lowering levels of the harmful huntingtin protein.

2018

Scientists use cryo-electron microscopy to determine the structure of full-length human huntingtin protein, paving the way for an improved understanding of the diverse cellular functions and interactions of the protein.

2019

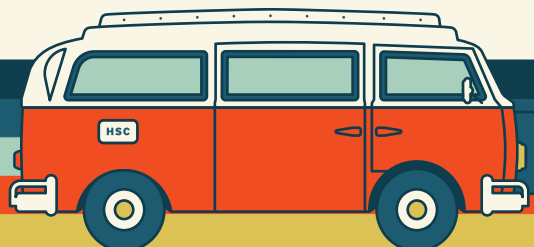
In the New England Journal of Medicine, the results of the tominersen trials are published. This showed for the first time that it is possible to lower the levels of the huntingtin protein in people.

2021

The development of a high-affinity ligand (selective small molecule) specific to the huntingtin protein serves as an important imaging biomarker for HD therapeutic development and disease progression.

2022

An international group of scientists unveils a new staging system for HD patients, based on the data obtained in large HD studies. This new system will improve recruitment of specific subsets of patients for clinical trials, as well as better comparison of data from many different trials.



FAMILY SERVICES

1975

HSC publishes their own 12-page brochure explaining HD in plain language.

1981

An HD Assessment + Referral Centre opens two afternoons a week in Sunnybrook Hospital in Toronto. The goal is to improve health care delivery to patients and families living with HD through referrals, diagnosis, treatment, counselling and support services in the home.

1982

The first family support group is offered by a social worker and member of the Southern Alberta Chapter. It is followed by the Metro Toronto Chapter's eight-session self-help support group in Jan. 1982, while support groups in Vancouver begin in Sept.

1985

A second Assessment + Referral Centre, now called a Resource Centre, opens in Shaughnessy Hospital in Vancouver. The Manitoba Resource Centre opens in Winnipeg in 1985, staffed by a full-time educator/counsellor who assists with requests for assistance and information from individuals and families facing HD, as well as health care professionals. These beginnings will grow 11 Huntington disease patient-centered multidisciplinary clinics in Canada.

2008

The first Canadian youth-specific Huntington disease support network, Young People Affected by Huntington Disease (YPAHD), is created. Organized by youth for youth between the ages of 14 to 35, YPAHD advocates for the rights and needs of young Canadians facing Huntington disease and aspires to a world free of HD.

2013

HSC develops the Youth and Young Adult Mentorship Program (YMP), offering young people the opportunity to connect with a trained mentor who is able to provide valuable support at critical life points.

2020

HSC launches the first national virtual support group, focusing on individuals at risk and gene positive for HD. It is followed by a virtual support group for carers in British Columbia B.C. and the Yukon, reaching more individuals and families than ever before in spite of geographical barriers.

ADVOCACY & INTERNATIONAL RELATIONSHIPS

2011

HSC partners with two other global HD organizations to help launch HDBuzz.net, a Huntington disease resource website run and maintained by globally recognized HD researchers and neurologists. Prominent work in HD research is peer-reviewed and then translated into everyday language, making research information accessible to the general public.

2014

Clinical Trials Consortium: 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.

2018

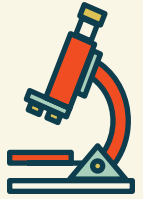
The HD Coalition for Patient Engagement (HD-COPE) is formed, a unique and diverse international collaboration between the Huntington Society of Canada and the Huntington Disease Society of America (HDSA). The group's role is to communicate the international HD community's experiences and needs to regulators, industry and researchers.

2020

HSC and the Canadian Coalition for Genetic Fairness (CCGF) successfully advocate for legislation protecting the genetic test information for all Canadians through the Genetic Non Discrimination Act in 2020. CCGF is a partnership of 16 health organizations dedicated to ensuring protection of the use of personal DNA information for all Canadians.

WHERE ARE WE GOING?

RESEARCH ROADMAP



Our research pipeline contains a variety of potential treatments and is full of hope.

Thanks to all of the brilliant researchers around the world, our fundamental knowledge about Huntington disease and the brain improves each year. Communication among the community and research collaborations has never been better.

Advancements continuously improve technology, allowing us to evolve research tools such as imaging, stem cells, biomarker detection and so much more. Currently, there are several ongoing observational studies, clinical trials, and many promising research studies. These provide hope that we will reach our goal – to treat the root cause of Huntington disease.

We are learning more each day and it is all thanks to you. The strength of the global HD community continues to provide inspiration. Will you help us continue to make progress in understanding Huntington disease and developing a treatment that will help those at risk or affected?



RESEARCH FUNDING OPPORTUNITIES

There are various research funding opportunities that would benefit greatly from your support. Make a difference by helping fund the following:

- Enhancing our Navigator Research Grant, offering more funding and for longer durations of study
- Investigating the root cause of HD
- Research into the impact of HD on people's lives

FAMILY SERVICES

Our number one goal is to expand support for all people in Canada affected by HD by enhancing social work services and support resources. There are many ways you can make it possible for HSC to offer support services to individuals and families affected by HD, in-person and virtually. Your donations enable us to offer a variety of support groups, making a difference in the daily lives of everyone impacted by HD. But we need your help.

As more individuals and families come forward, we will require more social work hours to support those seeking HSC services. It is also important to educate the medical and social services community to help them better understand HD and its impacts on the individual and families. Allow us to expand these front-line services in your community, supporting, educating, and advocating for folks within our communities. Will you help make sure that everyone, no matter where they live, has access to services and support during their HD journey?





Western
UNIVERSITY • CANADA



RESEARCH CHAIR

There is an amazing opportunity to make a difference in the future of HD by funding an endowed chair in Huntington disease research at Western University's Schulich School of Medicine & Dentistry.

Such a prestigious position will pave the way for accelerated advances in HD research, bringing those learnings from the laboratory to the community to make a significant difference in the lives of individuals and families facing the disease.

We need your support to make this groundbreaking opportunity an immediate reality – please donate to the **Huntington Society of Canada** Research Chair, held at Western University. Every dollar raised up to 2.5 million will be matched by our generous partners at Western University. We are incredibly grateful to everyone for these life-changing gifts.



CENTRES FOR HD CARE

We have a vision. An ambitious, heartfelt, important vision – to establish leading edge Centres for HD CARE (Clinical And Research Excellence) in Canada.

These clinical hubs will lead to addressing gaps in HD-related health care services across Canada, and specifically in hard-to-service segments of the Canadian population. They will expand access to HD-experienced clinical care, counselling and other community/health services. When a treatment for HD is found, they will be there, ready to accommodate individuals living with Huntington disease for the chance at a higher quality of life.



CAN YOU HELP MAKE OUR VISION COME TO LIFE?

HOW YOUR DONOR DOLLARS HAVE AN IMPACT:

Sharing educational materials and specialized HD consultation with a care facility

Providing an HSC youth mentor with training and support materials

Enhancing direct support services for someone with HD

Funding a community support group, providing help to families

HOW TO DONATE

Choose whatever method works best for you.

ONLINE

huntingtonsociety.ca/hsc50

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QUESTIONS

Rachel Thompson
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Scan to be taken to our online
donation page:





▲ **ORIGINAL BOARD OF DIRECTORS FOR HSC** Ralph Walker, Joan Wannamaker, Gord Hazzard, Joyce Grist, Jack Fish, Ellen Barrett



" For the past 50 years we have been putting the machinery in place and have spent a long time cultivating care and research. It has been wonderful to see the Family Services program develop and expand from coast to coast to coast. It has made such a difference for those living with **HD** in their lives. It's truly like night and day. We're an extended united family, and no longer do people deal with **HD** alone.

At the same time, we wish we were done with **HD** and that a meaningful treatment existed. Researchers have laid the groundwork and are pursuing a number of promising pathways to victory. We are hopeful and optimistic that their hard work will soon pay off. "

" I've spent a lot of my adult life involved with **HSC**, first with **YPAHD** and then with the **HSC** Board of Directors. The **HD** community is special and we are poised to do great things. I can feel the excitement as we celebrate our growth and successes over the past 50 years! I know we are all looking forward to the next 50, especially with our enhanced focus on research and care. "

Brynne Dalmao
HSC BOARD CHAIR



▲ **ARIEL WALKER'S TEAM** for the fundraising hoop-a-thon, 1995



▲ **HSC NATIONAL OFFICE STAFF & SOCIAL WORKERS (Red Blazers), 1997**



▼ **DIANE & JOHN KUZYSK**, original Northern Alberta (Edmonton) Chapter founders, 1983



▲ **NANCY JOHNSON**, Ralph's assistant and lifelong HSC supporter, & **JERRY WEBER**, Calgary, long-time donor and community builder

" It's amazing to be a part of the next era of **HSC**. I hope to help by instilling the strong sense of community and volunteerism that the founding members exhibited by involving youth, the leaders of tomorrow. "

Caleb Harding
PRESIDENT OF YPAHD

"I have long-standing ties to the Huntington Society of Canada, and was first invited to an HSC meeting by Ralph Walker in 1983. I became very close with Ralph. It was a joyful collaboration and a long-time commitment. The interaction with Canadian families with HD and the HSC sustains my ongoing passion and commitment to research. With many therapeutic initiatives underway, I have realistic hope, recognizing that no study or drug is certain of results in a clinical trial. However, I am optimistic for new approaches to treatment in the future and am inspired and grateful for the participation of so many Canadian families and HSC in these initiatives."

Dr. Michael Hayden
HD CLINICIAN & RESEARCHER, UBC



"Shortly after I opened my clinic in Markham in 1990, Ralph and Ariel Walker drove from Cambridge to visit. We had a chat that was transformational, with Ralph saying that he understood I was setting up my practice, and that he wanted me to focus on Huntington disease. Ralph told me that I needed to be involved – I had expertise and could support patients and families. I thought that visit and commitment was extraordinary. It shaped my entire career and focus on HD."

Dr. Mark Guttman
HD CLINICIAN

▼ **RESPIRE CAMPS AT FIVE OAKS**, just outside of Paris, ON, 1984



▲ **DR. MICHAEL HAYDEN**

Dr. Ray Truant
CLINICIAN PROFESSOR & RESEARCHER, MCMASTER

"My end goal in my career in HD research is to get something that's going to make a difference in the clinic. Half of my friends come from the HD community, making my work even more meaningful to me. I don't have any genetic motivation from my family's perspective. But I definitely have an emotional involvement."



▲ **GERRIT DOMMERHALT & RALPH WALKER** at a meeting of the International Huntington Association (IHA) in the Hague in Holland, 1999, Gerrit and Ralph were founding members of IHA



▲ **FIRST CAMPING TRIP OUT EAST**, meeting families with HD



► **MICHAEL WRIGHT**, Toronto, long-time donor and community builder





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