



# Donor Report

Huntington Society of Canada

Soci t  Huntington du Canada

*Do not follow where the path may lead.  
Go instead where there is no path and leave a trail.*

*Harold R. McAlindon*

*For four decades, the Huntington Society of Canada (HSC) has strived for excellence by providing practical help for families struggling with Huntington disease (HD) and investing in research to slow and prevent this disease that destroys both mind and body. Your leadership support of the Huntington Society of Canada is an integral component of that excellence and tells a powerful story: a story of a community of caring people who pull together and change the reality of families living with HD.*

## Research

Together we are carving a new path, a path that will bring us closer to a meaningful treatment for Huntington disease (HD). Our community has supported our efforts to ensure clinical trials of safe potential treatments proceed as quickly as possible. For the past two years the Huntington Society of Canada (HSC) has played 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 so crucial. On October 23, 2014, partnering with Canada's Research-Based Pharmaceutical Companies (Rx&D), the Society will host the Be Brave, Be Bold, Be Ready: Clinical Trial Preparation project to continue to build a national HD clinical trial strategy in Canada. This initiative is timely, as the first HD clinical trial is scheduled to begin in mid-2015.

We are pleased to share the details of this exciting initiative. A small pharmaceutical firm, Isis, has partnered with pharmaceutical giant Roche to launch Phase I clinical trials of a drug currently known as ISIS-HTTRx. By targeting the messenger RNA that holds instructions for making the faulty HD protein, ISIS-HTTRx attacks the root of the problem. Isis and Roche believe their gene-silencing approach could mean treatments for the thousands of Canadians diagnosed with Huntington disease and for the thousands more at-risk of developing it.

In 2012, Isis researchers reported that their approach not only delayed the progression of the disease in a mouse model of HD, it actually reversed the symptoms. Now they are ready to explore moving into human trials, ultimately aiming to see whether it can achieve similar results. In spring 2015, Isis and Roche will launch Phase I clinical trials in a few selected sites in Canada and Europe.

The launch of Phase I trials is an exciting step towards potential treatments for Huntington disease. However, what works in mice may not work in humans. Even if the drug does prove effective, it will take several years to get to market. The goal of a Phase I trial is simply to test the safety of a new drug. If ISIS-HTTRx proves safe, it then moves into Phase II and Phase III trials to assess how well it works. It is a time-consuming process.

HSC is very proud that those efforts have paid off and that Canadian sites may be selected for Phase I trials of ISIS-HTTRx. That means if this drug proves effective, Canadians will have access to it more quickly.

This has been a fortunate year as we have been in the unique position to fund all of the fundable research projects that were submitted through HSC's NAVIGATOR and NEW PATHWAYS granting programs. This was made possible because of our very generous donors and their commitment to research. We will be funding some new and exciting research this year and a project that is a continuation of the work we have funded previously.

We continue to fund excellent evidence-based research, thanks to the generosity of our donors. We are proud of the accomplishments that have been made to date and are looking forward to sharing the outcomes.

# Services

As the Huntington Society evolves and continues to grow, so does the Family Services program. Through a careful reallocation of savings and a small additional investment of donor dollars, it is with great pleasure that we announce the expansion of services in southwestern Ontario.

The new HD Resource Centre will be located in London, Ontario and led by Corey Janke. Corey, after over 20 years as a contract Family Services Worker, has joined the Family Services team as the Resource Centre Director, establishing a new Southwestern Ontario Resource Centre and expanding services to families in Kent, Lambton, Middlesex, Oxford, Norfolk, Haldimand, Perth, Huron, Grey and Bruce Counties! Corey's extensive social work experience in the rehabilitation sector as well as his many years supporting the HD community in the London area have positioned him well for this expanded role. We are thrilled to have Corey take on these additional duties and look forward to expanding our services in this region.

With the retirement of Sally Vincent, who served as the Northern Alberta HD Resource Centre Director for 12 years, we are pleased to announce that Bernadette Modrovsky has joined the Family Services Team. Bernadette joins us as the new Northern Alberta Resource Centre Director. With an extensive background in medical and community social work, Bernie is welcoming new challenges as she uses her well-honed social work skills in a new environment. In August, the office moved from St. Joseph's Hospital. We want to thank Parkinson's Alberta for accommodating the Northern Alberta HD Resource Centre within their Edmonton office.

In addition to Sally's retirement, Karl Lottes announced his retirement from the Resource Centre in Southern Alberta. Karl, who has served the area for five years, will retire from the HD Resource Centre in the fall and will help to train the new social worker for the area. We are thrilled with the significant advance notice so that we can ensure seamless transition for this community. Shannon MacKinnon joins us as Karl's replacement. She is excited to build upon her previous experiences and have the opportunity to provide services to families and to be in a community-based role.

In early 2015, Susan Tolley, HD Resource Centre Director in British Columbia, will move to part time. In order to provide B.C. with continued service, we are excited to announce the most recent addition to the Family Services Team, Olivier Couture. Olivier has accepted the Social Worker position in British Columbia and will join the team at the 2014 HSC National Conference in October. Both Susan and Olivier will work together full time until the end of the year, serving the HD Community in the province. This is an exciting time for the B.C. Resource Centre.

Heather Minthorn, a contract Family Services Worker, has found the demands of her full-time position to be growing and has made the difficult decision to resign. We will recruit for this 10 hour per month Thunder Bay area Family Services Worker position this fall. In the meantime, Angèle B nard, the Northern Ontario HSC Resource Centre Director, will provide services in northeastern Ontario.

**Changes are constantly occurring, primarily due to longstanding employees retiring, as always these translate into opportunities as well. We are fortunate to have a dedicated team of professionals who are enthusiastic about the opportunities on the horizon. We thank those who have recently left the Society and welcome those who are new.**



**Embracing our Strength**  
our future  
our vision  
our story

## Genetic Discrimination

We are thrilled to announce that, during the summer (July 10, 2014), the Office of the Privacy Commissioner of Canada (OPC) released a statement denouncing the use of genetic test results by life and health insurance companies. At this point in time they do not feel the use of genetic test results is demonstrably necessary for the insurance industry to achieve their objectives.

The hope is to have protection in place by this fall. The statement from the Office of the Privacy Commissioner of Canada will help inform the direction that the federal government may want to take.

As the leader of the Canadian Coalition for Genetic Fairness, the Society has been involved in every aspect of ensuring there is protection for all Canadians. We have been the experts at the table, educating government officials on why genetic fairness is critical and why it is so important to the Huntington community and all Canadians.

### *Summary of government action to date*

#### **October 2012**

A private member's bill (Bill C-445) was tabled in the House of Commons by Libby Davies, to add genetic characteristics to the Human Rights Act and protect individuals against genetic discrimination.

#### **April 17, 2013**

The Honourable James S. Cowan introduced Bill S-218, created to bring the necessary level of protection to Canadians. This bill aims to ensure that genetic information is used properly without fear of repercussions. This would ensure that genetic information is used for health and research purposes only.

#### **October 16, 2013**

The Speech from the Throne 2013, delivered by the Governor General, mentions the federal government's commitment to preventing employers and insurance companies from discriminating against Canadians on the basis of genetic testing.

#### **October 18, 2013**

The Honourable James S Cowan QC, Leader of the Opposition in the Senate, re-tabled the Genetic Non-Discrimination Bill as Bill S201; a comprehensive bill to end genetic discrimination in Canada. This proposed legislation will facilitate this very important work. Bill S201 made it through second reading to debate; earlier this year, it was moved to the Standing Committee on Human Rights and hearings are scheduled when the Senate sits in fall 2014.

#### **November 4, 2013**

Mike Colle, MPP for the riding of Eglinton-Lawrence, reintroduced a private member's bill, the Human Rights Code Amendment Act (Genetic Characteristics), 2013, that if passed would amend Ontario's Human Rights Code to include "genetic characteristics" as a prohibited grounds of discrimination.

#### **July 10, 2014**

The Office of the Privacy Commissioner of Canada (OPC) released their statement on the use of genetic test results by life and health insurance companies. They do not support the use of genetic information by life and health insurance companies at this point in time.

#### **September 2014**

The Senate Committee hearings are scheduled to begin.

# Youth Mentorship

With the first several mentor-mentee matches made, it is full steam ahead for HSC's Youth Mentorship Program. Early feedback has been very positive:

"I have a very open relationship with my child but I will never fully understand what my child is going through and their feelings."

"I am relieved my child can share their feelings with someone who truly understands. I feel so much better knowing my child has someone comfortable to talk to. I highly recommend parents look into this program."

The uniqueness of this program is what drives its success. Each mentor has undergone extensive training that is continued throughout the year by an HD Resource Centre Director.

Like any new initiative, growing the mentorship program will take time, but with the building blocks in place, this program is one to watch.

## YPAHD - Young People Affected by HD

We are very pleased to report, thanks to your support, that there has been a 10% increase in YPAHD members over the past year. This growth has been due to a concentrated social media outreach strategy utilizing both volunteers and staff. This team has proactively expanded the use of Twitter and Facebook to build awareness and provide support to young people facing Huntington disease (Twitter @YPAb\_HD; Facebook [www.facebook.com/YoungPeopleAffectedByHuntingtonsDisease](http://www.facebook.com/YoungPeopleAffectedByHuntingtonsDisease)).

These efforts, combined with the continuation of monthly meetings and an upgrade of the YPAHD website ([www.ypahd.ca](http://www.ypahd.ca)) are largely credited for the increase in members. Engaging and supporting youth is a strategic priority for the Society. YPAHD continues to work on engaging new members, supporting existing members, advocating, fundraising and supporting projects across Canada, including working closely with HSC on the Youth Mentorship Program.

We continue to tell a powerful story; a story of a community of caring people who pull together and change the reality for families living with Huntington disease. With your support we have good reason to be optimistic.

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## Thank You

On behalf of families living with HD, thank you for your continued partnership and generous support. Your donations make all the difference as we reach out to families who are not yet connected to HSC, continue to support and advocate for families from coast-to-coast, invest in world-class research, and play a leadership role in the international Huntington's community.

With your help, we are continuing to improve the quality of life for people with HD, cultivating strength and resilience in the Huntington's community and providing substantive reasons for hope by investing in globally recognized research leading to treatments that will slow or stop Huntington disease.