2016
2017

ANNUAL REPORT

Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada

WAVING THE HD FLAG

Bunny Clark

"Now we have hope — because of the awareness, because of the research, because of the clinical trials that they're doing."

Oshawa-native Bunny Clark ensured the Huntington Society of Canada (HSC) flag was flying high in Ajax, Whitby, Bowmanville, Oshawa and Pickering to mark Huntington Disease Awareness Month in May 2017. And if organizing five flag raisings wasn't enough, Bunny made sure she was at each one of those flag-raising ceremonies too.

When Bunny's first husband, Duncan, discovered the fatal brain disorder ran in his family, Huntington disease (HD) barely registered as a blip on the public radar, as medical professionals had little to offer. He watched several of his siblings slowly succumb to a disease that has been described as having Parkinson's, ALS and Alzheimer's combined. Rather than suffer the same fate, he took his own life in his late 30s.

Now, Bunny has lost a beloved nephew to Huntington disease, and her daughter and several other nieces and nephews have started developing symptoms. "It's tough," she says. "It's really hard to watch people have to give up things they've loved: their jobs, their hobbies, their families."

However, while a cure or meaningful treatment options have yet to be found, she draws strength from the progress that has been made since Duncan died. "He knew what was in store for him and couldn't see any hope in the future," she says. "Now we have hope — because of the awareness, because of the research, because of the clinical trials that they're doing."

Bunny has helped drive that shift. Since getting involved with the Huntington Society of Canada, she and local volunteers have established a local chapter in Durham Region and organized a series of events to raise awareness and money for the Huntington disease cause.

As well as five different flag-raising ceremonies, Bunny, with the help of Chapter volunteers, organized a fundraising concert featuring roots-rock band Eli & the Straw Man on April 2 and then on May 28th, she laced up her sneakers for the 4th Annual Durham "Walk to Cure Huntington Disease."

What keeps her motivated despite so much personal heartbreak? "I really, totally believe in my lifetime we will see a cure… and awareness is the only way that's going to happen," Bunny says.

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MISSION

The Huntington Society of Canada is a not-for-profit charitable organization which raises funds to deliver individual and group counselling services to support individuals and families living with Huntington disease (HD) and to fund medical research to delay or stop the progression of the disease. The Society also works with health and social services professionals to enable them to better serve people living with HD.

FROM THE CHAIR AND CEO

This year has been a very big year for the Huntington Society of Canada and the HD community.

Bev Heim-Myers
Chief Executive Officer

Susan Wright
Chair, Board of Directors

After six years of hard work it was very exciting to see genetic fairness become a reality in Canada. On May 4, 2017, Bill S201, now known as the Genetic Non-Discrimination Act, was passed into law. We should all be very proud as this would never have happened without our community and many champions coming together to do the right thing by protecting genetic test information for all people living in Canada.

Thanks to the extraordinary generosity of Wayne Atkinson and Margaret Steed, families in New Brunswick now have a much needed HD Resource Centre. HSC's long-time Family Services Worker in New Brunswick, Marthe Gautreau, stepped forward as our newly appointed Resource Centre Director. Marthe continues to apply her expertise and is making a tremendous difference for everyone she serves. The Centre is officially known as the New Brunswick HD Resource Centre – supported by the Mark Atkinson Family Fund.

Meanwhile, our network of chapters just got stronger. In late 2016, HSC's Board of Directors granted official chapter status to a passionate group of volunteers in Durham, Ontario, headed up by Bunny Clark. We knew from the moment we met Bunny and her team, that this group would achieve big things. Like other chapters across the country, they worked hard to make May Awareness 2017 a success. Each year, we continue to be impressed by how our community rallies to share their stories, organize events and raise hundreds of thousands of dollars. Thank you to every one of you who steps forward, to organize, to participate, to speak about your experience or to make a donation. Every single action has impact.

The year also saw an unprecedented event season with over 118 events executed across the country. It is the hard work and commitment of hundreds of volunteers that leads us to the success we experience. Our sincere appreciation goes out to the Halifax Chapter for their role in hosting one of the best National Conferences ever! With support from our Chapter Development team, 250 community members from across Canada came together to learn about the most current research and policy changes and just meet old friends in new places.

Our communications team truly influenced lighting up the world for HD awareness. This initiative, started by HSC, has grown significantly in a short period of time. Globally, 99 locations participated during May, Huntington Disease Awareness Month, to #Lightitup4HD. As far away as Australia, our global connections joined in to increase awareness for HD and JHD (Juvenile Huntington disease) by proudly displaying monuments in the HD and JHD colours.

We are at a very exciting time in HD research. This year Dr. Stephen Ferguson, Dr. Lynn Raymond and Dr. Matthew Parsons are the recipients of our 2017 Navigator Awards. Although research has come very far, we still need to better understand the underlying mechanisms of Huntington disease and this research will help increase our overall knowledge. We have also funded our second team as a result of the HSC-Brain Canada partnership. Dr. Blair Leavitt and his multi-disciplinary team have been awarded close to $1 million over the next three years for their work in exploring novel treatment delivery strategies for HD.

Our Believe Campaign has resulted in over $2 million in commitments for the next few years. From the launch of the Chloe Angus-designed, HSC Dragonfly Button Spirit Wrap, to the dedicated funds our esteemed Campaign Cabinet have secured, we are experiencing a very successful campaign.

As three stalwarts of the Society take a well-deserved retirement, we would like to thank them for all their outstanding contributions over their many years of service. Collectively, B.C. Resource Centre Director Susan Tolley, our National Office Administrator Shirley Barnes and our Family Services Worker in Brandon Manitoba, Meg McConkey, served the Huntington community for nearly 50 years. We are going to miss them in a big way and will always appreciate their contributions to make us the best that we can be.

Finally, we acknowledge our many volunteers, loyal donors and outstanding staff that work together to help make a difference. Without our shared belief in a future without Huntington disease, we could never achieve what we do. Thank you!

Susan Wright
Chair, Board of Directors

Bev Heim-Myers
Chief Executive Officer

GOVERNANCE

AT THE HUNTINGTON SOCIETY, STRATEGIC DIRECTION drives everything we do. Strategy starts with the Board of Directors. This team of dedicated volunteers come from across Canada to develop our strategic plans and policies, put proper risk management measures in place, and ensure we are stewarding our resources responsibly and providing clear accountability to members, donors and the public.

AT A GLANCE

Number of board members: 15

Term: Two years

Number of consecutive terms: Three

Attendance record: 80%

STRATEGIC PRIORITIES

Invest in world-class research to slow and prevent HD.

- Continue to build a critical mass of HD research in Canada that will lead to treatments for HD, while encouraging global collaborations and knowledge transfer
- Enhance clinical research in Canada
- Continue to forge strong connections to individuals and families living with HD to ensure a strong base for potential clinical trial participation

Increase awareness of HD and the Huntington Society of Canada.

- Create opportunities for interested parties to become involved in the Society
- Leverage and further develop grassroots relationships
- Effectively tell our story
- Continue our federal and provincial advocacy efforts to end genetic discrimination and create a safe environment for people to tell their story

Ensure financial and organizational stability, effectiveness and excellence.

- Achieve or exceed our revenue growth targets
- Enhance our financial and organizational processes to build efficiencies, manage risk and build capacity
- Improve our processes to meet internal and external financial reporting requirements
- Retain and nurture a high-performing team
- Be nimble enough to take informed, measured risks on mission-specific goals
- Have the courage to be innovative
- Ensure effective Board governance

Demonstrate leadership locally, nationally and globally.

- Increase global collaboration with HD service providers and organizations
- Inspire engagement and collaboration with internal and external stakeholders
- Influence a "Made in Canada" solution to end genetic discrimination
- Set the example for organizational stability, effectiveness and excellence
- Maximize attendance at events and build alliances for family support
- Investigate opportunities for joint projects with other service providers

Strengthen the focus on young people affected by HD and strengthen the services we provide to them.

- Build the numbers of youth affiliated with the Society
- Create a social media initiative for youth
- Build our leadership role in the emerging HD global youth movement
- Educate and advocate for youth-specific concerns and initiatives
- Build the fundraising capacity of YPAHD, the Society's youth chapter

Advocate for Canadians living with HD and enhance the services we provide to them.

- Maximize our connections with families and individuals living with HD
- Lead efforts to end genetic discrimination

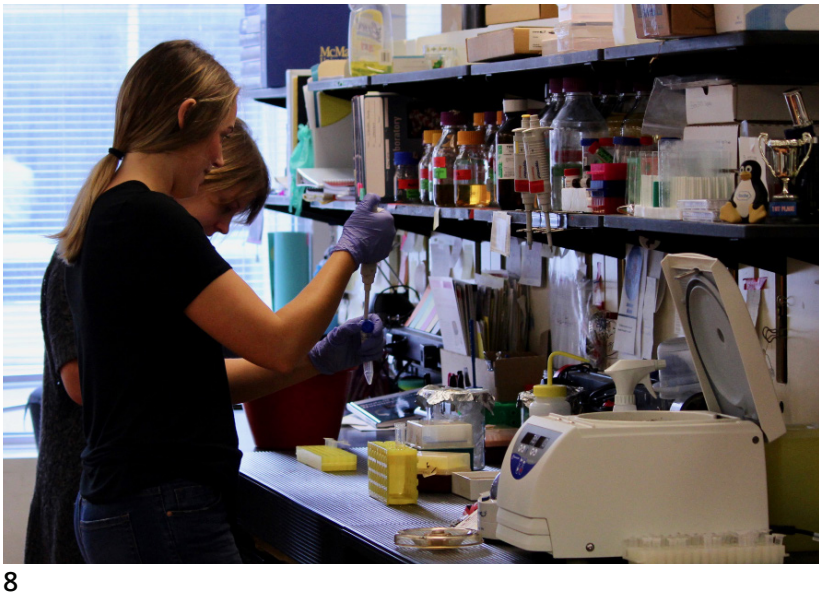
To see how the Society is achieving our strategic priorities, visit www.huntingtonsociety.ca/strategy.

RESEARCH

RESEARCH COUNCIL

Members of HSC's Research Council generously donate their time and expertise to review grant applications. They are established investigators and experienced scientists with one goal in mind - to invest your generous donations in the most promising and innovative research opportunities that lead to treatments to slow or stop HD.

For decades, HSC's strategic funding has helped to develop a critical mass of HD research in Canada. Canadian investigators are globally recognized as leaders in the field, and each year we receive more excellent research proposals than the year before. The Research Council selects the most promising and scientifically excellent proposals to fund, after a rigorous peer review process.



RESEARCH COUNCIL

Dr. Ray Truant – Chair
Dr. Jeff Carroll
Dr. Stephen Ferguson
Dr. Lesley Jones
Dr. Blair Leavitt
Dr. Marcy MacDonald
Dr. Lynn Raymond
Dr. Simonetta Sipione

2017 HSC NAVIGATOR RESEARCH AWARDS

Thanks to your generosity and vision, we were able to invest $375,000 in our Navigator research program this year.

The long standing Navigator Research Program supports HD researchers across Canada. This program supports basic scientific research of direct and immediate relevance to Huntington disease in Canada with the aim of providing a platform for the recruitment of outstanding investigators to HD research, to facilitate research collaboration nationally and to support research that is relevant to other neurodegenerative disorders. The competition is run once per year.

Recipients and Project Descriptions of the 2017 Navigator Research Awards

Dr. Stephen Ferguson, University of Ottawa

Targetting mGluR5 for the treatment of Huntington disease

Huntington disease (HD) is a devastating autosomal dominant inherited neurodegenerative disorder that is characterized by progressive motor, cognitive, and psychiatric impairments. A polyglutamine (CAG) expansion/ repeat at the amino-terminus of the huntingtin protein is the cause of HD, and the length of this repeat is inversely correlated with the age of disease onset and directly correlates with the severity of disease symptoms. However, the underlying mechanism(s) responsible for mutant huntingtin pathogenicity remain largely unknown. Glutamate is the primary excitatory neurotransmitter in the brain and is essential for a wide variety of physiological processes, such as integrative brain functions and neuronal cell development. We have preliminary data to show that antagonism of metabotropic glutamate receptor 5 (mGluR5) with a mGluR5-selective inhibitor significantly improves locomotor behaviour and reduces huntingtin aggregates in a zQ175 knock-in mouse model of HD. The present application focuses on validating the potential for repurposing mGluR5 antagonists to prevent the progression of Huntington disease symptoms in a pre-clinical mouse model of Huntington disease.

Dr. Lynn Raymond, University of British Columbia

Impaired corticostriatal synaptic plasticity in HD: Investigating a role for aberrant endocannabinoid signaling

Studies suggest that before abnormal movements and a diagnosis of Huntington disease, there are changes in the connections (synapses) between the brain areas that are most affected. Learning new motor skills, and performing well-learned motor skills accurately, depends on the ability to increase or decrease the strength of connections between neurons according to changing demands. This process is called synaptic plasticity and can be caused by production of natural brain chemicals called endocannabinoids that act at sensors or receptors on neurons that also respond to cannabis (marijuana). We have discovered that synapses in mice with the Huntington disease mutation cannot sufficiently produce an endocannabinoid involved in synaptic plasticity. Although the medical use of cannabis has not been proven to be effective in treating Huntington disease, a drug that modifies the production of endocannabinoids might address the synaptic dysfunction and thereby improve motor control and skill learning. Based on the results of these proposed studies, we will identify a drug that can restore synaptic plasticity, and test this drug to recover motor learning and coordination in mice with the Huntington disease mutation.

Dr. Matthew Parsons, Memorial University of Newfoundland

Probing Novel Therapeutic Targets for the Treatment of Cognitive Decline in HD

Our brain cells communicate with each other through synapses; those tiny spaces in which a chemical message is sent from one cell to influence the behavior of the next. When we learn something new, the connection between specific brain cells is strengthened by a process known as synaptic plasticity. In many neurodegenerative diseases, the brain's ability to undergo plastic changes in response to a variety of stimuli is impaired, and the desired strength of the connection between brain cells is not obtained. This forms the biological basis of cognitive impairments that are commonly associated with many different neurodegenerative diseases. Here, we aim to understand the mechanisms underlying the plasticity deficit in Huntington disease (HD), a devastating inherited neurodegenerative disease characterized by motor, psychiatric and cognitive decline.

Huntington Society of Canada-Brain Canada Multi-Investigator Research Initiative (MIRI), Accelerating Discoveries and Partnering with Brain Canada

Partnership with Brain Canada continues to provide HD Clinician to Scientist to Patient Virtual Networks

Two million dollars has gone a long way to move HD research discovery forward. Thanks to the generosity of an anonymous donor and a partnership with Brain Canada, the Huntington Society launched the $2 million Brain Canada-Huntington Society of Canada Clinician to Scientist to Patient Virtual Network Research Competition at the beginning of 2016.

Top thought leaders in HD research were invited by HSC to help establish a research competition that would not only be innovative, but also expedite research discovery to the HD community. The call for research proposals was answered by incredibly competent teams and globally recognized researchers from across Canada. HD research has evolved and is now at a point where researchers and clinicians can connect more closely with the HD community. Knowledge transfer from the basic scientist to the clinician to the HD population is critical and exactly what this competition aimed to achieve.

The first recipient of the HSC-Brain Canada Grant in 2016, was Dr. Simonetta Sipione from the University of Alberta. Dr. Sipione collaborated with other Alberta researchers and a colleague at the Université de Montréal to examine the link between HD and gangliosides — a group of molecules that are important for healthy brain function.

The second recipient, announced in early 2017, was Dr. Blair Leavitt from the University of British Columbia. Dr. Leavitt is collaborating with researchers from Canada and the US, and he is investigating two novel, non-invasive delivery platforms to enhance the current huntingtin lowering approaches for HD.

The funding for this research comes from a $2 million partnership between the Huntington Society of Canada and the Brain Canada Research Fund (a partnership between Brain Canada and Health Canada). The goal is to create multidisciplinary, multi-investigator networks that maximize the opportunity for discovery and expedite the translation of discoveries to effective treatments. To learn more, visit www.huntingtonsociety.ca/research

FAMILY SERVICES

WE'RE HERE FOR OUR FAMILIES.

NEW BRUNSWICK'S BIG BOOST: THE HSC RESOURCE CENTRE

Our strategic priority is to increase our services in new and remote areas. On January 16th, our newest HSC Resource Centre officially opened in Moncton, New Brunswick, thanks to funding provided by the Mark Atkinson Family Fund. Headed up by our long-time New Brunswick Family Services Worker, Marthe Gautreau, the new centre dramatically increases support for families across the province and enhances outreach to the community and care facilities.

Previously, Marthe worked a limited number of hours a month. Now, she has regular office hours, allowing her to accomplish far more. Already, she has launched efforts to establish a formal HSC Chapter and to create three support groups in a province that currently has none. She has also begun conversations to resurrect a dedicated HD clinic, so that New Brunswick residents can access specialized HD multidisciplinary care in the province.

RESPONSIVE BEHAVIOURS AND STRATEGIES FOR CAREGIVERS

This important topic was presented at the 2016 national conference and has been developed into a HSC Fact Sheet as well as a more detailed HD Educational Module. Responsive Behaviours and Strategies for Caregivers explains how responsive behaviours are not under a person's control and are simply a "response" to their environment and to the changes occurring within the brain due to cell death. This resource explains how responsive behaviours may appear as HD progresses, and as losses are experienced in the person's abilities and relationships. There are common responsive behaviours and possible strategies for caregivers such as trying to determine the meaning behind each responsive behaviour; using the technique 'accept, avoid, allow and acknowledge' and incorporating a consistent care team with ongoing communication that accounts for various personalities and preferences. This resource uses case scenarios to help illustrate a variety of strategies.

CONTINUING TO UPDATE AND CREATE MORE EDUCATIONAL RESOURCES FOR THE HD COMMUNITY

The Family Services Team continues to update and create more resources for individuals and families who are impacted by HD. This year the team, with assistance from the Huntington Disease Society of America (HDSA) and the original authors, updated and revised the publication Understanding Behaviour in Huntington Disease. This practical guide provides individuals, families and professionals hands-on practical assistance and examples of how to cope with HD. It has been well received by the HD community.

Additional resources that the team updated include fact sheets on topics such as End of Life Care in HD, Juvenile HD, Eating and Swallowing, HD and Feeding Tubes, Living At-Risk of HD, and Cognitive Changes in HD. All of these resources are available on the HSC website.

The Family Services Team continues to share the new HD Educational Modules across Canada, thanks to funding provided by the Beta Sigma Phi Sorority in Alberta, Canada. Educational Modules include topics such as: What is Huntington Disease?, Living with a Chronic Illness, Caregiver's Guide - overview, swallowing issues, emotions, movement, thinking, Law Enforcement, HD Clinical Trials, and Responsive Behaviours.

INCREASED SOCIAL WORK SUPPORT

In British Columbia, HSC hired a permanent part time social worker to complement the work and support offered by the HD Resource Centre Director in the BC Centre for Huntington disease.

In Northern Alberta, HSC formalized an agreement between the HD Northern Alberta Resource Centre and Dr. Suchowersky's clinic, at the University of Alberta, to enhance the coordination of services.

In Central Canada, the Centre for Movement Disorders has met more frequently with the three HD Resource Centre Directors from Central Ontario to further streamline services in the area and to coordinate the Family Services Team follow-up with individuals and families within their own community.

In Southwestern Ontario, HSC has formalized an agreement with the genetics clinic to include the HD Southwestern Ontario Resource Centre Director during the predictive testing process.

In addition, we have been able to increase services in the Kingston, Ontario area and are now able to offer a 'drop in' type of support group on a regular basis for individuals who are impacted by HD.

YOUTH MENTORSHIP

Our globally recognized Youth Mentorship program, funded in large part by the Mark Mercier Foundation, continues to support youth across the country who are impacted by HD. This year a new team member was added, a Youth Mentorship Coach, to help support the program. Corey Janke joined Erin Stephen, the Mentorship Coordinator.

The Society provided a HSC social worker and two youth mentors as part of the team of staff and volunteers that supported over 40 youth, including five Canadians, at the 2016 HDYO North American camp. During the three day gathering, youth were able to take advantage of traditional camp activities (swimming, paddleboarding, campfires, and archery) and also participated in various group discussions geared to those growing up in a home with HD. Dr. Jeff Carroll joined participants to talk about the newest research in Huntington disease.

INVESTING IN PROFESSIONAL DEVELOPMENT

HSC continues to place a high value on education for our Family Services Team. HD is a complicated disease, and it is critical that our Resource Centre Directors and Family Services Workers stay current in their support skills and resources knowledge. Members of the Family Services Team work independently across the country serving over 3,000 families and individuals.

Thanks to the support of the Charles Johnson Charitable Fund, the Huntington Society of Canada was able to bring the entire Family Services Team (14 Resource Centre Directors and 9 Family Services Workers) to the 2016 Huntington Society of Canada's National Conference in Halifax, Nova Scotia. As part of the conference, we integrate a full day of meetings for the Family Services Team the day before conference.

The funding enabled the entire team to meet and participate in group accredited training to address service delivery challenges. Our professional social workers must participate in two to five days (depending on province) of accredited training per year in order to maintain their designation. It was also an integral part of the training for the new HD Resource Centre Director from British Columbia.

The training focused on consent and capacity. The session was entitled: "Choice and Voice: The Importance of Human Rights in Promoting Wellbeing". The training highlighted how every person is guaranteed the right to legal capacity under international law. The role of family and friends in the support of the individual was also discussed. The trainers for this session were Dulcie McCallum and Steve Etsey.

This past spring, thanks again to the Charles Johnson Family Foundation, the team turned their professional development attention to a variety of topics which included: Therapeutic Touch (alternative therapy for individuals impacted by HD and their caregivers), Augmentative and Alternative Communications represented by a Speech Language Pathologist, Health Literacy, and Accessible Arts presented by Shannon MacKinnon, our southern Alberta HD Resource Centre Director, who shared her knowledge and provided strategies to offer arts for groups.

We welcomed some new faces to the Huntington Society this year. Antoine Coulombe officially assumed his position as the HD BC Resource Centre Director early in 2017, and in the spring, Rhonda Romolock joined the team as the Social Worker for the HD BC Resource Centre.

Finally, we said goodbye to three longstanding members of the team who contributed immensely to the community: Susan Tolley, our B.C. Resource Centre Director, Shirley Barnes from our national office, and Meg McConkey from Brandon, Manitoba. We wish them all much happiness in their retirement and new adventures ahead!

CCGF/CCEG

ADVOCACY

An epic year for genetic fairness in Canada. HSC's journey to protect genetic test information.

On May 4, 2017, Bill S-201 received Royal Assent and was passed into law. Known as the Genetic Non-Discrimination Act (GNA), this law protects the genetic test information of all people living in Canada.

In addition to the GNA, the Canadian Human Rights Act has been amended to add genetic characteristics, and amendments to the Canadian Labour Code will add an extra layer of protection for employees of federally-regulated industries.

The GNA's prohibitions apply to providers of goods and services and anyone entering into or continuing a contract with an individual. This would include (but is not limited to) employers, landlords, schools, insurers. In all situations, businesses are not allowed to require a person to take a genetic test or to disclose the results of a previous or future genetic test. The GNA also prohibits providers of goods and services, and anyone entering into or continuing a contract with a person, from collecting, using or disclosing the person's genetic test results without that person's written consent.

Canada stepping forward to protect genetic test information was a long awaited success story for all Canadians. Needless to say, it was disappointing when our Minister of Justice, Jody Wilson-Raybould, indicated that after the parliamentary process took place, she would ask Cabinet to refer this legislation to the Supreme Court of Canada. As of July 2017, that had not yet happened. The Quebec government, however, adopted the decree directing their Minister of Justice to file a reference before the Québec Court of Appeal. The reference has been filed and we have responded.

It has been a very long journey to protect genetic test information in Canada. The Huntington Society of Canada began this journey almost ten years ago and formed the Canadian Coalition for Genetic Fairness. Hours and hours of meetings with our decision makers, presentations to interested parties, participation on panel discussions, testifying at hearings, sharing the stories from our communities and working with many champions, has finally resulted in legislation to protect genetic test information everywhere in Canada. The voices of Canadians have been heard by the majority of our MPs, and they did the right thing by protecting our genetic test information. A huge barrier has been removed for medicine, research and individuals proactively managing their own health.

The insurance industry has aggressively pushed back on protecting genetic test information from day one. In the other G7 countries that protect genetic test information, the insurance industry thrives. The industry will also continue to thrive in Canada. It is important to note that the industry still has access to family medical history information, which has proven to be enough information for all other jurisdictions. It is disappointing and unfortunate that even after the best constitutional experts in Canada supported Bill S-201 and we witnessed democracy at its best with the passing of Bill S-201 into the Genetic Non-Discrimination Law (GNA), that Cabinet, the Quebec government and the insurance industry continue to fight this human rights issue.

For now we celebrate and thank all of the champions that helped pass legislation to protect our genetic test information in Canada. The GNA is law – your genetic test information is protected.

OUR CHAPTERS

This year, HSC Chapters and volunteers from coast-to-coast hosted an unprecedented 118 fundraising and awareness events attracting over 9,000 participants and raising almost $1.3 million for Huntington disease research and family services.

A hearty congratulations goes out to all 21 Chapters (including the newly recognized Durham Region Chapter), 11 active areas and over 150 leadership volunteers contributing to the planning and organizing of these events.

New events that were added to HSC's already busy calendar were the Eli and the Straw Man benefit concerts, Fish On Fishing Derby in London, Ontario, two Trivia Nights hosted in Niagara Falls and St. John's, the Victoria Run for a Cure, Work It Out for HD in West Coast Newfoundland, Edmonton Veterans Motorcycle Club Charity Ride, Vancouver Halloween Party and the New Brunswick Quilt Raffle.

118 EVENTS

9000 PARTICIPANTS

21 CHAPTERS

11 ACTIVE AREAS

150 LEADERSHIP VOLUNTEERS

1.3 MILLION DOLLARS RAISED

2016 HSC NATIONAL CONFERENCE
#HSCHalifax

Our 2016 National Conference hosted by the Halifax Chapter in Dartmouth, Nova Scotia, instilled a real sense of hope for those in attendance.

The sold out conference attracted many new families (40% of participants were first-time attendees). Youth were out in full force, both at the pre-conference YPAHD Day and at the conference itself, interacting and conferring with the many researchers and medical professionals who attended.

Keynote speakers included Dr. Terry Kelly who spoke of celebrating life and how life offers everyone gifts disguised as challenges. Jay Ingram cited the influence of Nancy Wexler, who is well-known in the HD community for her involvement with a study group in Venezuela that discovered the location of the gene that causes HD. Jay spoke about the significance one person can hold, through their 'powerful personage,' which can influence the course of science.

Dr. Ray Truant and Dr. Tamara Maiuri led conference delegates through an explanation of why the number 36 has such significance in HD research. In their talk, The Start of a New Era in HD Research, Truant and Maiuri explained that for years HD researchers have known that if someone has 36 or more CAG repeats, they will develop HD. They didn't, however, know why. In their presentation, Truant and Maiuri explained that they now know the answer to that question.

And back by popular demand, Dr. Ed Wild and Dr. Jeff Carroll brought energy and optimism to the conference. Using humour and the analogy of planting a tree, Dr. Jeff Carroll and Dr. Ed Wild used their interactive session to share what is new in the HD research world. Describing the root of a tree as the HD gene discovery, the trunk of a tree as connecting research to people, the branches as the trials and the fruit as the treatments, Carroll and Wild walked delegates through the current HD clinical trials and new HD lab discoveries. They explained the most promising research in HD today and how to interpret the latest science news stories.

While the conference addressed difficult topics including Cannabinoids in the Context of HD and Medical Assistance in Dying, the Halifax Chapter provided levity for attendees in traditional maritime fashion. The Chapter hosted an outstanding traditional lobster dinner complete with comedian Jimmy Flynn, a high-energy blend of side-splitting comedy and popular music, who welcomed delegates to Halifax as Canada's "Ambassador of Good Cheer."

99%
OF SURVEY RESPONDENTS RANKED THE 2016 CONFERENCE AS VERY GOOD OR EXCELLENT.

YOUNG PEOPLE AFFECTED BY HUNTINGTON DISEASE (YPAHD)

YPAHD is the virtual youth Chapter of the Huntington Society of Canada, connecting youth aged 14-35 who are affected by Huntington disease from across Canada. This year, we came together at the annual 1-day youth conference (YPAHD Day) in conjunction with the National Conference in Halifax.

YPAHD welcomed youth from across Canada at the fourth annual YPAHD Day event, hosting 40 youth (the most youth to ever attend YPAHD Day together to date) from across Canada in Halifax, Nova Scotia. Of the 40 participants attending, 50% were at-risk of developing HD. Survey results from YPAHD Day identified that the favourite session of the day was the Fundraising Dragon's Den. Groups presented their event ideas to a panel of Dragons including HSC's Chief Executive Officer, Bev Heim-Myers, HD researcher and scientist Dr. Ed Wild and HSC's Manager of Chapter Development, Annie Vanexem.

Survey results revealed that YPAHD delegates appreciated the one day youth event. The various sessions provided opportunities to further discuss and learn about HD related topics. Comments from those in attendance spoke to the value of meeting others in a similar situation, feeling less alone and the overall positive mood around a sometimes dark topic.

YPAHD members are also becoming more involved on a local level including several members taking leadership roles with their local Chapters (including several Presidents and Vice-Presidents). YPAHD members are also responsible for an incredible amount of fundraising activities this year including the Fish On Fishing Derby in London, Trivia Nights in Vancouver as well as St. John's, the first-ever Victoria Run, and the Exeter Hike of HD Heroes, an Eli and the Straw Man concert in Kitchener, the first-ever Windsor Walk, golf tournaments, yoga events, Facebook auctions, lemonade stands and bottle drives. Directly and indirectly, approximately $100,000 in revenue for the Huntington Society of Canada can be attributed to the work of YPAHD members.

BELIEVE

TRANSFORMING, TOMORROW, TOGETHER

Launched in 2016, the Huntington Society of Canada's new Believe Campaign is in full motion. This two-year campaign aims to bring new donors to the Huntington disease cause and raise $3 million for research and services to families, individuals and youth. The Honourary Chair of the passionate and enthusiastic advisory cabinet for the Believe Campaign is Julie Lawson Timmer, a 'Canadian-grown' and now Michigan-based author.

Successfully securing over $2.3 million dollars to date, the Campaign Cabinet aims to reach the $3 million goal by the end of 2018. A world free from the devastation of Huntington disease cannot come soon enough. The cabinet believes a brighter future is not only possible but palpable. "We are at a unique and exciting time in the history of Huntington disease," says HSC CEO Bev Heim-Myers. "The Believe Campaign will ensure we will have the funds to make a sustainable difference and together with our HD community, change the reality of Huntington disease. We are moving quickly to viable treatments. Now is the time to ensure we have the resources to fund the research that leads to those treatments and to prepare for clinical trials."

CAMPAIGN UPDATE

BELIEVE CAMPAIGN CONTRIBUTORS

BELIEVE: *TRANSFORMING, TOMORROW, TOGETHER* CAMPAIGN CABINET

The Huntington Society of Canada wishes to express their gratitude to the Campaign Cabinet for their hard work and dedication to this campaign.

Julie Lawson Timmer (Honourary Chair)
Jennifer McFadden
Vern Barrett
Dan Devlin
Jane Manning
Heather Heick
Brenda Wasylow

To those who have supported the Believe Campaign, we are thankful to the following donors for the tremendous impact they have made. Your efforts are deeply appreciated.

Anonymous (8)
Adobe Foundation
Margaret Andrews
Gus & Dana Angus
Wayne Atkinson & Margaret Steed
Ellen & Vern Barrett
Edward Bezeau & Angela Di Serio
Charles Borton
Anne & John Brace
Brenda Wasylow
David Briggs
Cambridge & North Dumfries Community Foundation
Chloë Angus Design
Terry & Danah Claridge
Diane Claridge
Ellen Cmolik
Fred & Diane Cranston
Dan & Jill Devlin
The Douglas Utting Foundation
Michael Drance
Mark Angus
Paul & Mary Fox
Kirk Gillespie
Doug & Wendy Goodbrand
The Gordon & Lorraine Gibson Family Foundation
The Halatsis Family Foundation
Lorraine Harrison
Heather M. Heick
William Hughes
Darrell & Shona Hurst
Lembit & Karen Janes
Marion Kennedy
Ellen Kennett
Dennis & Nancy Klassan
Ann Kowal
The Late John Kuzyk
Julie Lawson Timmer
Marlene J. Little
Juanita Manning
Paul & Jane Manning
In Memory of D. J. Manning
L. Maxine Mardell
The Mark Mercier Foundation
Todd & Wendy Mason
Elizabeth McKinlay
The McLean McCuaig Foundation
Joyce McNair
James & Carol Mitchell
Catherine Mosher
ASL Paving
RBC Foundation
Brad Smith
Shirley Smith
Mark & Gail Spurr
Tikkun 18 Foundation
Florence Wall
Stan & Dorota Weber
Arthur & Susan Willms
Winnipeg Executives Association Inc.
James Wiswell & Ellen Foster

WHAT IS HD? PSA CAMPAIGN

Our 2017 PSA Campaign, What is HD?, aims to spread the word about HD and JHD to the general public. During the month of May, we launched our TV and radio ads on several local outlets across the nation to raise awareness with the general public. Many of the ads are still airing. The ads were accompanied with testimonials from our community, including YPAHD President Jaclyn Skinner and Peterborough Chapter President Heath Sterling. We invite you to share these ads in your region so we can get every possible outlet engaged in HD awareness year-round!

RAISING AWARENESS

Every May, the Huntington Society of Canada (HSC) recognizes Huntington Disease Awareness Month and this year was no different. The Huntington disease (HD) community comes together to raise awareness, make connections, get support from their communities, and move forward with pride and dignity.

BARB'S RIBBONS OF HOPE

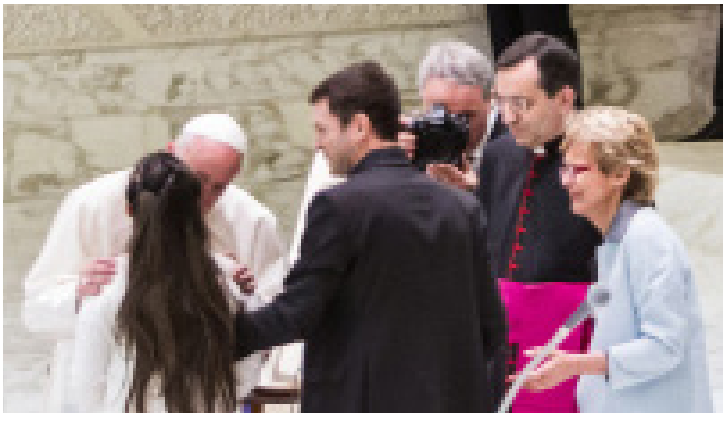
Started in 2016 by Barb Marshall, you may have seen these beautiful hand-crafted ribbons across social media or at other events. This year, these ribbons were available for fundraising at chapter events, and individuals could also request them. In 2017, Barb doubled her efforts making this year's donation almost $2000, with all proceeds going to the Huntington Society of Canada.

DRAGONFLY BUTTON WRAPS

On May 18th, another event new to HSC took place in Vancouver, BC. The Chloë Angus Design Studio partnered with HSC for an event where participants could design their own dragonfly wrap. These spirit wraps feature a beautiful dragonfly, created by Haida artist Clarence Mills, which is a symbol of both our Believe Campaign and a symbol of change, transformation and swiftness in Haida culture. Proceeds from the wraps go to HSC; HD has a special place in studio owner Chloë Angus' heart, as her mother was diagnosed two years ago.

#LIGHTITUP4HD

Inspired by a volunteer responsible for the CN Tower's involvement in 2015's LightItUp4HD activities, HSC volunteers raised the bar this year by creating and implementing a social media campaign called #LightItUp4HD. Volunteers from across Canada chose specific monuments to light up in blue and purple, for HD and JHD respectively. The idea caught on and HD organizations from around the world joined the initiative and requested sites to #LightItUp4HD. Throughout the month of May, volunteers lit up buildings and posted them on their social media accounts with the hashtag #LightItUp4HD. Buildings from coast-to-coast were lit up. This year additional countries joined the efforts including Ireland, Scotland, the UK, Spain, Australia, Cyprus and Germany to name a few.



HDDENNOMORE

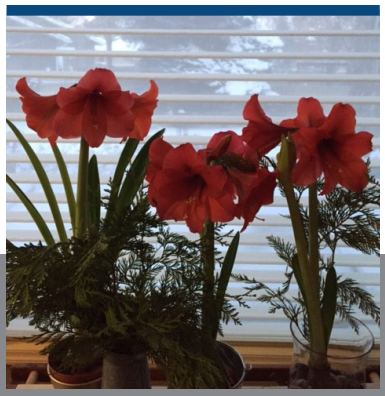
On May 18, 2017, in a historic meeting that was the first of its kind, Pope Francis met with and addressed families affected by Huntington disease in Vatican City. In doing so, he became the first world leader to recognize the devastating plight of those living with and affected by HD. Pope Francis was joined by families, researchers, foreign dignitaries and celebrities from across the world. The event was coined the 'HDdennomore' initiative (pronounced 'Hidden No More') to raise awareness of HD, bring HD families together, and generate action to end the stigma and shame around the disease that has persisted for generations.

PHOTOS COURTESY OF: PIER PAOLO LISARELLI PHOTOGRAPHY

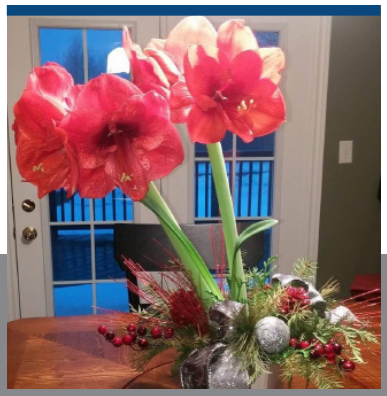
CONTINUING TO BLOOM
FROM COAST TO COAST

The Huntington Society of Canada's Amaryllis Campaign continues to inspire and capture the curiosity of all who chose to invest in growing this spectacular plant during the holiday season. Over 20,000 bulbs sold over the three month campaign ensures that the Huntington Society can continue to provide research and services to those who are impacted by Huntington disease across Canada.

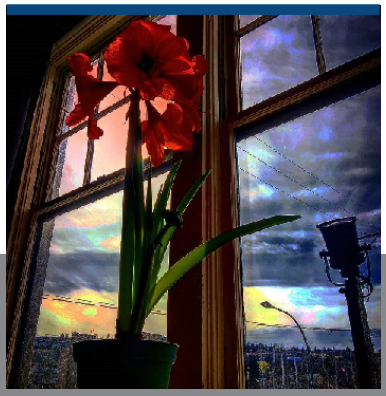
Thanks to our volunteers reaching out to others, the program welcomed a large number of new purchasers and sellers this year. The feedback regarding the quality of the bulb, the delivery time, the new packaging and the spectacular blooms was extremely positive. Our photo festival continues to be as strong and popular as ever.



"Everyone loves (and expects!) to receive their amaryllis bulbs for Christmas. I send them to New Brunswick, Nova Scotia and various places in Ontario. Gorgeous!"



"It is the dedication and commitment of our long-term supporters and our chapters that make all the difference," says Jeff Hoffman, who leads the campaign. "Without their support, we would not be able to reach as many people as we do through this program."



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With Gratitude

Our story is a powerful story: a story of hope, a story of a community of caring people who pull together to change the reality for families living with Huntington disease. With your support we have good reason to be optimistic. Thank you for believing in the work we do and for helping us transform tomorrow together. You make a difference each and every day in the lives of people affected by Huntington disease.

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To those who have supported the Amaryllis Campaign and have sold over sixty amaryllis kits this year, thank you. Your efforts are deeply appreciated.

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Thank you to the following donors who participate in our Summit Society and have included the Huntington Society of Canada in their estate planning.

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59%
INCREASE IN FACEBOOK REACH

74%
INCREASE IN HSCHAPPENINGS FACEBOOK REACH

WE REMEMBER

For those we have lost this year, we remember. Gifts made to the Huntington Society of Canada were made in honour of the following people.

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20%
INCREASE IN WEBSITE PAGEVIEWS

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Norbert Yurkoski

ESTATE GIFTS

To those who have remembered the Huntington Society of Canada during their lifetime, thank you. You will always be remembered.

Estate of Ivy Robbins Oakley
Estate of Jacob H. Adrian

OUT OF THE SHADOWS

Beka Pottery

"I believe that raising awareness will help towards finding a cure or some sort of help for Huntington disease patients."

It took Beka Pottery a while before she used the blood work requisition forms her doctor had given her. Understandably so, considering the stakes: the results of those tests would tell her whether she had inherited the gene for Huntington disease.

Beka remembers the day her dad was diagnosed with the fatal neurodegenerative disease. She was 17. Getting the news was a painful blow, but it also went a long way in explaining her dad's personality changes, violent outbursts and loss of balance.

In the decade that followed, his symptoms got progressively worse. Today, he's in a long-term care facility.

When Beka eventually chose to make use of those requisition forms, the results of the genetic testing confirmed her worst fear: she also carries the fatal gene and will one day develop Huntington disease.

"The hardest part is not knowing when that will happen," says the 27 year old.

Rather than sit around and wait for that day to come, Beka decided to do everything she could to make a difference. On a personal level, that translated to choosing a healthy diet, spending plenty of time at the gym and maintaining a positive outlook. "I'm very hopeful and optimistic that there will be a cure," she says. "There is a lot of research going on, and it seems quite promising."

But research requires funding, so Beka got busy spreading the word. Over the years, she has educated her large network of friends and family about HD. Now, she's going even further. In May, Beka took her passion to the streets of Victoria with a charity run she organized to support the Huntington Society of Canada and HD research.

"The more that people know about it, the more money that will be funnelled in for it," she says. "I believe that creating more awareness will help towards finding a cure or some sort of help for Huntington disease patients."

31%

INCREASE IN NUMBER OF EVENTS

23%

INCREASE IN EVENT ATTENDEES

FINANCIAL HEALTH
Treasurer's Report

There was much to be excited about during the past fiscal year as we move closer to a world free from Huntington disease.

It is my pleasure to report to the membership of the Huntington Society of Canada following the completion of the Society's fiscal year ended June 30, 2017.

The Society's revenue for 2017 was $4.375 million, an increase of close to 3% compared to the prior year. Maintaining revenue levels from all sources remains a continual challenge but one that our dedicated staff and volunteers continue to face with determination and creativity. Included in revenue for the first time was approximately $332,000 recognized from the $1 million funding received at the end of the prior year through a joint partnership with Brain Canada. The revenue from this restricted donation reflects the fact that the initial research grants have now been made representing incremental research efforts towards targeting Huntington disease.

The Society's surplus for 2017 was $223,000 compared to $56,000 in the prior year. The increase in the surplus is virtually all a result of the impact of the unrealized gain on the Society's investments relative to the prior year's unrealized loss. This was expected to occur due to the drop in the fair value of the investments at June 30, 2016 that was driven in part by the Brexit vote in late June. Our investment portfolio, which is held primarily for endowment purposes, recovered that unrealized loss, and more, in 2017.

Removing the impact of the unrealized gain/losses results in an intentionally modest surplus. This is consistent with the strategy of the Society to invest additional revenue into spending in family services, research or other strategic initiatives. As an example in the current year, additional funding was provided to support the opening of the New Brunswick HD Resource Centre. The direct investment to families increased slightly as a result, ending the year at close to $1.4 million. Total research spending remained in excess of $1.0 million.

The total assets held by the Society fell to $4.5 million from $4.8 million in the prior year primarily due to the Brain Canada funding that was received at the end of the prior year and is now being disbursed. The net assets at the end of the year were $3.75 million, of which over half is comprised of the endowment funds of the Society. The endowment fund continues to provide the Society with a stable position from which to operate.

There was much to be excited about during the past fiscal year as we move closer to a world free from Huntington disease. We continue to pursue our mission "to support individuals and families living with Huntington disease and to fund medical research to delay or stop the progression of the disease." With your help, I believe we can.

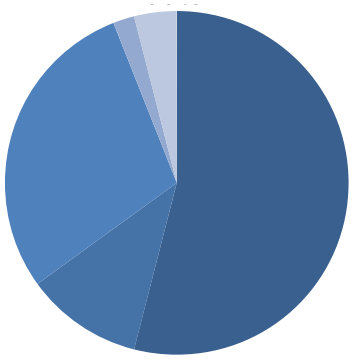
Glenda Rowein, CPA, CA
Treasurer

STATEMENT OF FINANCIAL POSITION

Year ended June 30, 2017.

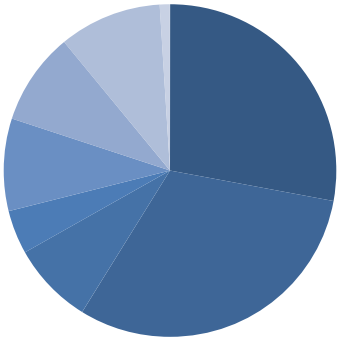
	2017	2016
ASSETS		
Current assets		
Cash	$1,562,952	$1,367,435
Investments	2,875,733	3,201,922
Accounts receivable	48,803	173,835
Prepaid expenses	79,255	71,054
	4,566,743	4,814,246
Capital assets	27,451	35,771
	$4,594,194	$4,850,017
LIABILITIES AND FUND BALANCES		
Liabilities		
Accounts payable and accrued liabilities	$147,333	$76,301
Deferred revenue	769,518	1,329,435
	916,851	1,405,736
Net assets		
General fund	834,635	661,978
Capital assets fund	27,451	35,771
Endowment fund	1,876,190	1,884,494
Laura's Hope fund	17,316	17,316
Ralph Walker Research fund	921,751	844,722
	3,677,343	3,444,281
	$4,594,194	$4,850,017

REVENUE



- Donations 54%
- Chapter and volunteer fundraising revenue 29%
- Grants 11%
- Other income and unrealized gain on investments 4%
- Investment and interest 2%

EXPENSES



- Family Services 33%
- Research 24%
- Administration 11%
- Public awareness and education 11%
- Development 9%
- Chapter and volunteer fundraising expenses 7%
- Chapter and volunteer support 4%
- Amortization 1%

STATEMENT OF OPERATIONS

Year ended June 30, 2017.

	General Fund	Capital Assets Fund	Endowment Fund	Laura's Hope Fund	Ralph Walker Research Fund	TOTAL 2017	TOTAL 2016
REVENUE							
Donations	$1,579,689	-	$15,670	-	$746,262	$2,341,621	$2,134,433
Grants	270,080	-	-		205,601	475,681	485,467
Chapter and volunteer fundraising revenue	1,264,103	-	-	-	6,364	1,270,467	1,573,314
Investment and interest income	71,662	-	-	-	33,724	105,386	140,687
Realized gain (loss) on sale of investments	5,211	-	-	-	2,452	7,663	(20,573)
Unrealized gain (loss) on investments	2,866	-	62,101	-	30,573	95,540	(75,229)
Other income	79,402	-	-	-	-	79,042	15,943
	3,272,653	-	77,771	-	1,024,976	4,375,400	4,254,042
EXPENSES							
Research	63,639	-	-	-	947,947	1,011,586	1,183,825
Family services	1,371,664	-	-	-	-	1,371,664	1,309,237
Public awareness and education	451,864	-	-	-	-	451,864	333,544
Chapter and volunteer support	169,994	-	-	-	-	169,994	159,512
Development	384,074	-	-	-	-	384,074	397,032
Chapter and volunteer fundraising expenses	292,715	-	-	-	-	292,715	361,776
Administration	443,381	-	-	-	-	443,381	432,148
Amortization	-	17,060	-	-	-	17,060	20,603
	3,177,331	17,060	77,771	-	947,947	4,142,338	4,197,677
EXCESS (DEFICIENCY) OF REVENUE OVER EXPENSES	$95,322	$(17,060)	$77,771	-	$77,029	$233,062	$56,365

A COMPLETE COPY OF THE SOCIETY'S AUDITED FINANCIAL STATEMENTS IS AVAILABLE AT WWW.HUNTINGTONSOCIETY.CA.

A ROCKY ROAD

Kathryn Jordan

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Kathryn Jordan thought she was prepared to get the results of her genetic test. She had done her homework on Huntington disease (HD). She knew she had a 50/50 chance of inheriting the fatal neurological disease. She had watched a documentary again and again about a young woman — like her — undergoing the testing process. Despite all that, she broke down when she learned she carried the HD gene — the same gene that killed her mother when Kathryn was just six years old.

Kathryn's memories of those early years are spotty. She remembers sitting in her mom's lap, being hugged and told stories. She recalls going go-kart racing to raise money for those impacted by Huntington disease.

She remembers the darker moments as well: her mom's moodiness and all the medications. The startling amount of time her mom spent in bed in the final months. After that, she had to deal with the grief and trauma of losing her mother, the rifts that were created within her family and her own fears of carrying the gene. "It's been a rocky road," she acknowledges. "A really rocky road."

Getting support from the Huntington Society of Canada helped Kathryn navigate that difficult terrain. "They were there when I needed them," she says. "When it felt like nobody was." Meanwhile, attending the Society's national conference introduced her to other youth affected by HD. Walking into a room full of people who shared her experiences shattered her sense of isolation. "It was amazing," she says. "We connected so deeply."

Now 26, Kathryn is making the most of life. She volunteers. She's carving out a career as a model. She has a loving boyfriend and dreams one day of having children — dreams buoyed by the hope that current advances in HD research will produce treatments before her own symptoms develop.

Kathryn is also raising awareness about HD. She knows that Huntington disease may one day take away her ability to speak. But until then, she's determined to use her voice to tell Canadians about the disease that has impacted her life so profoundly.

"AT LEAST, I TRIED. BUT I CAN'T KEEP MY PROMISE. EVEN IF I COULD GO BACK, NOT ONE OF THE WATER BUGS WOULD KNOW ME IN MY NEW BODY. I GUESS I'LL JUST HAVE TO WAIT UNTIL THEY BECOME DRAGONFLIES TOO. THEN THEY'LL UNDERSTAND WHAT HAS HAPPENED TO ME, AND WHERE I WENT."

AND THE DRAGONFLY WINGED OFF HAPPILY INTO ITS WONDERFUL NEW WORLD OF SUN AND AIR…

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