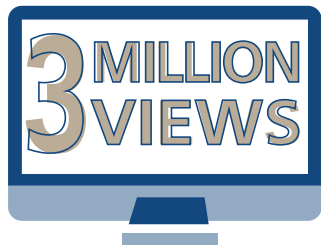


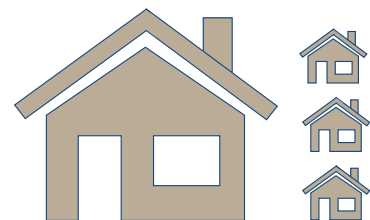
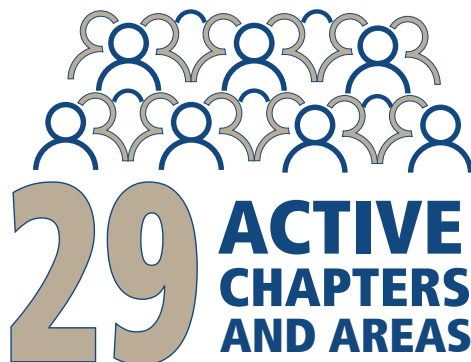


2017/2018 ANNUAL REPORT

2017/2018 AT A GLANCE



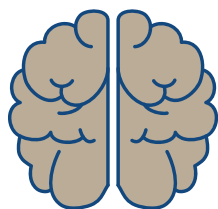
**ON SOCIAL
MEDIA**



14 RESOURCE
CENTRES

24 **SUPPORT
GROUPS**
MEET REGULARLY

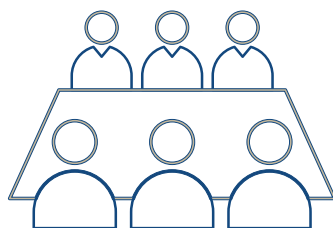
126



**CLINICAL TRIALS ADDRESSING
THE ROOT CAUSE OF HD**



20,508
AMARYLLIS SOLD



15 **BOARD
MEMBERS**



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ABOUT HSC

MISSION:

The Huntington Society of Canada is a not-for-profit charitable organization that 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.

VISION:

The Huntington Society of Canada aspires to a world free from Huntington disease.

The Society maximizes the quality of life of people living with HD by:

1

Delivering
services

2

Enabling
others to
understand
the disease

3

Furthering
research to
slow and
prevent the
disease



FROM THE CHAIR AND CEO

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

Thank you to our amazing donors, supporters and volunteer Chapters who are moving us toward our vision of a world free from HD. In the past year, our community has been given more and more reasons to maintain hope for the future of HD. Several research updates were provided this year with hopeful results in multiple studies. The Roche RG6042 clinical trial (formerly known as IONIS-HTT_{rx}) is getting ready for Phase III. Wave PRECISION HD-1 and HD-2 trials continue to move forward in Toronto as well. HSC donors have also funded some exciting research in this past year including the Navigator award, Brain Canada partnership and clinical fellowships. We also received promising updates from HSC funded research with Dr. Ferguson in Ottawa, Ontario and Dr. Truant in Hamilton, Ontario.

As new research continues to show promise, we are also maintaining our commitment to support families and individuals impacted by HD through our Family Services program. With your support, Family Services team members are piloting different ways to connect with families in rural areas, including teleconferencing. Our dedicated team of Resource Centre Directors and Family Services Workers are also organizing more social events throughout the year to give the community the much-needed opportunity to connect.

The community had a chance to meet with each other through our National Symposium and Regional YPAHD Days across the country. Thanks to our donors and volunteers, community members of all ages were able to connect and learn together. Symposium was attended by over 500 people from around the world either in person or virtually, while YPAHD Day continued to grow and welcomed 30% more attendees than in the past.

This year was a record breaking one for the HSC in many ways! Our National “Light It Up 4 HD” campaign for HD Awareness Month saw 123 sites participate worldwide – our highest number of participants to date. Our fan-favourite National Amaryllis campaign surpassed our goal of selling 20,000 bulbs with a 23% increase in sellers compared to the previous year, and our Believe Campaign has come to an end, surpassing its original goal of \$3 million.

Our dedication to supporting our community has also seen us continuing to advocate alongside the Canadian Coalition for Genetic Fairness (CCGF) for the Genetic Non-Discrimination Act (GNA) as it makes its way to the Quebec Court of Appeals in late 2018. Our goal is to ensure the genetic test information of all Canadians remains protected.

Without the hard work of our many volunteers across Canada that make up our 20 active Chapters and 9 active areas, or the generous support from donors like you, we could never achieve the things we do. Thank you for making a real difference in the lives of individuals impacted by HD.



Robin Markowitz

Robin Markowitz

Chief Executive Officer

Brenda Nowakowski

Brenda Nowakowski

Chair, Board of Directors





GOVERNANCE

BOARD OF DIRECTORS

BRENDA NOWAKOWSKI – CHAIR
MACK ERNO – VICE-CHAIR
SUSAN WRIGHT – PAST CHAIR
SEAN DEWART – SECRETARY
GLENDA ROWEIN – TREASURER
DR. RAY TRUANT – RESEARCH CHAIR
DR. BRYNNE STAINSBY – YPAHD REP
CHRISTIAN LEJEUNE – HSQ
BILLY ENGLISH
JONATHAN GENEST-JOURDAIN
ROBERT SCRIVEN
RICHARD TAYLOR
DORIS RAMPHOS
DR. MARK GUTTMAN
BRENDA MASON

AT A GLANCE

15
BOARD MEMBERS

2
YEAR TERMS

3
CONSECUTIVE TERMS

80%
ATTENDANCE RECORD

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

Strengthen the focus on young people affected by HD (YPAHD) 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

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

Increase awareness of HD and HSC

- 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 stories

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

Visit www.huntingtonsociety.ca/strategy to see how we are achieving these strategic priorities

RESEARCH



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

2018 HSC NAVIGATOR RESEARCH AWARD

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.



DR. CHERYL ARROWSMITH, UNIVERSITY OF TORONTO

Because of HSC donor support, we were able to award a two-year, \$150,000 NAVIGATOR grant to Dr. Cheryl Arrowsmith, a professor of medical biophysics at the University of Toronto and a chief scientist at the Structural Genomics Consortium, who is developing a detailed 3D model of the huntingtin protein. By figuring out its exact shape, right down to the level of atoms, she and post-doctoral researcher Rachel Harding can gain new insights into what the normal version of the protein does and what goes wrong in the mutant version.

It's challenging work. Because huntingtin is much bigger than most proteins in the human body, it forms a very complex three-dimensional shape. To examine it, they'll use cryo-electron microscopy, a revolutionary new technology for looking at large proteins. Once they've nailed down the bigger picture, they'll use high-resolution X-ray crystallography to zoom in on the details of key areas.

According to Dr. Arrowsmith, there's growing evidence that normal huntingtin might be involved in fixing the DNA damage that naturally occurs in our bodies over time. That's why she and Dr. Harding will also look at how huntingtin interacts with DNA and different repair molecules. "It will go a long way to try to help understand how this very elusive protein is behaving," she says.

What they learn, they'll share. Researchers typically don't reveal their data until they publish it in a scientific journal. However, Dr. Harding is taking the radical step of publishing all her experimental results in an online blog at www.labscribbles.com. As their research progresses, they'll make it available in a public database.

Research is a long, slow, painstaking process, but their "open science" approach and continued donor support will speed up the pace of discovery. "By sharing the information sooner, it should accelerate science," says Dr. Arrowsmith. "Anything we can do to make things move more quickly will help."



DR. RAY TRUANT, MCMASTER UNIVERSITY

A multi-institutional, international study was conducted in partnership with the Ray Truant lab of McMaster University, the Simonetta Sipione lab of the University of Alberta, the David Litchfield lab of Western University and the Christopher Ross Lab of Johns Hopkins University. They found that there is a unique type of signalling coming from damaged DNA, that signals huntingtin activity in DNA repair, and that this signalling is defective in Huntington disease.

“The concept was that if we applied the signalling molecule back in excess, even orally, this signalling could be restored in the Huntington disease mouse brain,” said Laura Bowie, a PhD student in the Department of Biochemistry and Biomedical Sciences at McMaster. “This resulted in the mutant huntingtin protein levels being restored to normal, leading to a correction of Huntington disease in mouse models.”

This discovery was made using a robotic microscope funded by HSC donors and drug screening by artificial intelligence, with state-of-the-art, super-resolution microscopy.



DR. STEPHEN FERGUSON, UNIVERSITY OF OTTAWA

Dr. Stephen Ferguson focuses on mGluR5, a receptor we know is disrupted by Huntington disease. His latest studies, funded by HSC donors through our NAVIGATOR grants, are the most promising yet. By using a drug called CTEP to block mGluR5, Dr. Ferguson and his team have produced dramatic improvements in mice with HD.

The investigators began by looking at motor symptoms. As mice with HD get older, they have more and more difficulty running across a horizontal ladder. They're slow, they pause frequently, and they make missteps. However, after being treated with CTEP, the mice navigated the rungs without hesitation. They also performed just as well as mice without HD on treadmill tests.

Even their cognitive symptoms improved. Typically, older mice with HD can't tell the difference between familiar objects and new ones. In contrast, the mice treated with CTEP easily identified new objects.

According to Dr. Ferguson, CTEP helps brain cells clear out the mutant huntingtin protein before it reaches toxic levels. When the researchers examined the mouse brains at the end of the study, they found far fewer clumps of mutant protein in the treated mice, and the clumps they did see were much smaller than in untreated mice. Most tellingly, there were fewer dead brain cells.

CLINICAL TRIALS

Clinical trials addressing the root cause of HD are here. Canada was the first clinical site to be approved for the WAVE precision trial. The first dose was given to a courageous trail blazer in Toronto. The Roche huntingtin lowering trial continues to move quickly. These promising trials are exciting and give us substantive hope that the solution is near, and our preparedness is all thanks to our dedicated donors.

ROCHE RG6042 (FORMERLY IONIS-HTTRX)

Ionis' 13-week Phase I/IIa trial has been completed. The study demonstrated that their drug was initially safe and that higher doses reduced huntingtin proteins by 40 to 60 per cent.

Phase III of the global study aims to answer several key questions: What are the effects of lowering huntingtin over a longer period of time? Do any unexpected safety concerns emerge? And does treatment slow or stop the progression of HD?

Roche is set to begin two upcoming clinical trials that will launch in late 2018/early 2019.

WAVE PRECISION HD-1 AND HD-2

In Toronto, Wave Life Science's PRECISION HD-1 and HD-2 trials continue to run smoothly at Dr. Guttman's clinic. "Things are going well," he says. "People are tolerating the medication. There are no problems that we've seen."

Like the Roche treatment, Wave's two drugs — WVE-120101 and WVE-120102 — are administered into the cerebral spinal fluid via lumbar puncture. Unlike Roche, they leave normal huntingtin protein unaffected, targeting just the mutant huntingtin by binding to specific bits of DNA that about two-thirds of gene-positive people carry. As a Phase Ib/IIa study, this trial is designed to test the safety and tolerability of the drugs in humans, not their therapeutic benefits.

Thanks to HSC donors, Canadians have more opportunities than ever to take part in clinical trials for potential HD treatments. Support from HSC donors has helped to lay the foundation for these trials to take place, and this will only prove more beneficial in the future as more trials become available.

HUNTINGTON SOCIETY OF CANADA AND BRAIN CANADA FUNDED RESEARCH



Brain health is one of the most pressing health challenges facing Canadians. Surpassing cancer and cardiovascular disease in their magnitude and impact, disorders of the brain account for 13% of the global disease burden.

This is why Brain Canada and the Huntington Society of Canada launched the Multi-Investigator Research Initiative (MIRI). This joint initiative supports two three-year MIRI research projects which connect clinicians, scientists, and the Huntington disease (HD) community.

Dr. Blair Leavitt from the University of British Columbia is continuing to advance his huntingtin-lowering research thanks to his three-year, \$950,000 grant.

“Funding from HSC donors and Brain Canada has allowed us to bring together researchers - both clinicians and basic scientists - with different areas of expertise to address the major rate-limiting steps and barriers to success of huntingtin-lowering therapies,” says Dr. Leavitt. “We have made significant progress in developing novel delivery modalities that will eliminate the need to inject antisense oligonucleotides (ASOs) directly into the spinal fluid and we are also making advances in the development of huntingtin-lowering biomarkers, the measures that tell us about the efficacy of the ASO treatments.”

Similarly, Dr. Simonetta Sipione is continuing to use her three-year, \$950,000 grant to examine the link between HD and gangliosides – a group of molecules that are important to brain function.

“Our work has shown that a brain lipid called GM1 is present at lower levels than normal in HD patients compared to healthy individuals,” says Dr. Sipione. “Thanks to the HSC-Brain Canada grant, our team of researchers and clinicians led by myself and Dr. Suchowersky are now investigating the mechanisms underlying the therapeutic effects of this molecule. We believe that the information we are gathering will be important to determine how GM1 works and whether it could be used in HD patients in the future.”



Because of you, the Family Services team offers support and services to persons with HD, persons at-risk, persons who have the genetic mutation or do not, caregivers and family members, community members, friends and neighbours. Some of the services offered include information and education, referrals to community resources and individual advocacy. In addition, the Family Services team offers education and support to health, social service and community workers. Your support allows the team to collaborate with other service providers to improve and expand existing services as well as increase awareness and understanding of Huntington disease and support for advocacy.

AT A GLANCE

6

FACT SHEETS UPDATED/CREATED

14

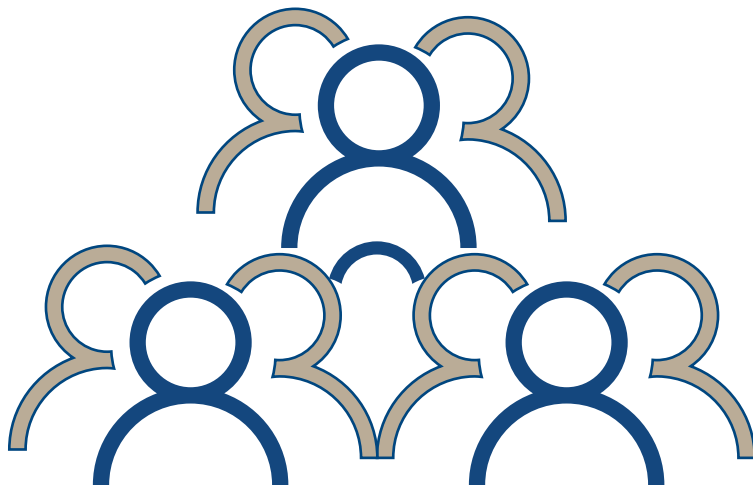
RESOURCE CENTRES

10%

INCREASE IN SUPPORT TO
FAMILIES IN CANADA

24

SUPPORT GROUPS
MEET REGULARLY



**FAMILY SERVICES WORKERS
CONTINUE TO SUPPORT OVER**
15,000
PEOPLE AFFECTED BY HD

YOUTH

Young people affected by HD are making an incredible impact in the HD community.

Through the youth mentorship program, youth are getting the chance to use their experience and knowledge to support their younger peers. When surveyed, 100 percent of the mentors, mentees and parents who responded told us the program fills a big need – all thanks to you!

An estimated 28% of all events in 2017/2018 were led by youth, with an estimated \$165,000 in revenue being attributed to young people. Of our 29 active Chapters and areas, 7 are led by youth.

Thank you for believing in our young people!

SOCIAL EVENTS

Across the country, our staff organize everything from potlucks and bowling nights to Christmas socials and meet-ups at local coffee shops with help from local volunteers and Chapter members.

Never underestimate the power of a hotdog and a bag of chips. Just ask the families who attended our Family Services BBQ in Vancouver last June. The event drew more than 30 members of the local HD community.

The BBQ is just one of many social events HSC's Family Services team offers throughout the year.

"Though informal, these events offer important therapeutic benefits." says Angèle Bénard, Director of Family Services.

SUPPORT GROUPS

It can be difficult for families with HD to get the support they need in remote regions in Canada. That's why a new piloted program of using teleconferencing for support groups has been introduced.

"For some people in Newfoundland, it can take them four to eight hours to travel to St. John's," says Elaine Smith, Newfoundland Resource Centre Director. "It just isn't feasible for families. But with teleconferencing, more people in rural areas are able to join. Since introducing teleconferencing, my caregiver support group has doubled!"

The teleconferencing program has been a success thus far. With your help, we plan to launch in more communities across Canada next year, providing additional support to those in rural areas.



HD-COPE

Families affected by HD now have the opportunity to help pharmaceutical companies understand the lived experience of HD when they're developing clinical trials, thanks to you. Last fall, the Huntington Disease Coalition for Patient Engagement (HD-COPE) was launched as a joint initiative between the Huntington Society of Canada (HSC), the Huntington Disease Society of America (HDSA) and the European Huntington Association (EHA).

The idea is that it is crucial to design clinical trials in a way that makes it less of a burden for volunteers to participate, to enable recruitment and ensure retention in clinical trials. To do that, they need to consult the experts: the people who face Huntington disease every day. That's why HD-COPE was established.

In February, HD-COPE's first official meeting was held in London, England. Twenty people from across Canada, the U.S. and Europe including caregivers, people with HD and individuals who are at-risk or carry the HD mutation attended. In the coming years, the coalition plans to include members from other countries around the world.

Bev Heim-Myers, former HSC CEO and Chair of Canadian Coalition for Genetic Fairness (CCGF), has been working closely with lawyers Bruce Ryder in Toronto and William Colish in Quebec, to move legal documents forward for the Genetic Non-Discrimination Act (GNA) and the Quebec reference to the Quebec Court of Appeals. Senator James Cowan and Barbara Kagedan, even though retired, continue to support and educate regarding the GNA.

In August 2017, CCGF was granted intervenor status in the matter of the Reference of the Government of Quebec concerning the constitutionality of the GNA. CCGF will support the GNA along with the Canadian Human Rights Commission. The Attorney General (AG) of Canada, AG of British Columbia and the Canadian Life and Health Insurance Association (CLHIA) have all been granted intervenor status as well, but they will challenge the GNA.

In April 2018, Doug Mitchell was appointed Amicus for GNA and he will support the legislation. Affidavits were also submitted to Quebec Court of Appeals. Dr. Yvonne Bombard and Bev Heim-Myers wrote a paper that was published in the Canadian Medical Association Journal about the GNA in May and in June, the CCGF Factum was submitted to Quebec Court of Appeals.

Moving forward, verbal arguments will be scheduled in December 2018 at the Quebec Court of Appeals in Montreal. It is important to remember that until further notice, the GNA is law in Canada, and the genetic test information of all Canadians is protected. CCGF is working with the provinces to influence the strengthening of provincial Human Rights Acts and Provincial Labour laws, to include the protection of genetic test information provincially. This is not mandatory given the robust GNA; however, it will offer options in the future for individuals who have been discriminated against.



FAST FACTS:

THE GNA
IS CURRENTLY LAW

WE ARE
PREVENTING GENETIC
DISCRIMINATION

THE QUEBEC
GOVERNMENT IS
CHALLENGING THE GNA

CCGF HAS
BEEN GIVEN
INTERVENOR STATUS

HSC
CONTINUES TO LEAD
THE CHARGE



OUR CHAPTERS

Chapters of the Huntington Society of Canada are comprised of local families and volunteers who provide each other with support and companionship. Your support allows Chapters to conduct regular meetings and plan community awareness and/or fundraising events all across the country. These events bring local families who are affected by HD together to build community, social networks, provide emotional support and create a sense of pride.

AT A GLANCE

126
EVENTS

9,500
PARTICIPANTS

20
ACTIVE CHAPTERS

9
ACTIVE AREAS

170
LEADERSHIP VOLUNTEERS

\$1.43
MILLION DOLLARS RAISED

2017 HSC NATIONAL SYMPOSIUM

Every other year medical professionals, community members and support professionals across Canada come together for a one-day HD educational event. Symposium was held on October 14th, 2017. Working with volunteers from across Canada, and donors like you, HSC hosted a variety of locations from coast-to-coast.

In October, 500 people attended one of the 18 locations across Canada, or chose to view from home with our virtual streaming option. Symposium saw a 155% increase in participation compared to 2015! Viewers joined us from all across Canada and as far as Dubai, New York and Florida.

Through a survey, we heard that participants “enjoyed being together with other HD families, felt a sense of community, formed bonds with other individuals and felt as if they were not alone.”





YOUNG PEOPLE AFFECTED BY HD (YPAHD)

Young People Affected by HD (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.

As part of our youth program, HSC holds YPAHD Day annually. In 2017, YPAHD Day was hosted on November 18th in Moncton, Toronto and Kelowna.

Over 70 youth attended this educational event, which is a 30% increase over the previous regional YPAHD Day. Youth received funding to attend, thanks to donor support, and 46% were first time attendees.

One YPAHD Day attendee, Jen, said, "This was a place that everyone felt like they belonged – a place where you could feel normal. In some families, like my own, the HD conversation is not an easy one to have. It's also something that some families tend to keep as a secret. YPAHD Day 'normalized' HD. People could mingle, share and ask questions with others. Connections and friends were made that day."

BELIEVE CAMPAIGN UPDATE

Throughout our Believe campaign, we've talked a lot about "transforming tomorrow together." As we surpass our \$3 million goal for research and services, it's exciting to think what that transformation might look like for the HD community.

For a teenager, it could mean getting the peer support she needs, thanks to more funding for our Youth Mentorship Program. For a couple living in a remote part of the country, it could result in more visits from a Family Services team member. And for researchers in the lab, a new grant could be the key to a treatment breakthrough. The recently opened Resource Centre in New Brunswick is a direct result of the Believe campaign, giving more families in the area access to the support they need.

The benefits of the campaign go beyond dollars and cents. Believe has allowed us to build new relationships with a number of first-time funders including corporations and foundations. We couldn't have come this far without our incredible campaign cabinet – volunteers who have come together from across the country to lend their expertise and open doors to prospective donors – and your support.

With their leadership, we've successfully surpassed our goal, helping to keep tomorrow looking brighter.



CAMPAIGN CABINET

HONORARY CHAIR:

JULIE LAWSON TIMMER

JENNIFER MCFADDEN

VERN BARRETT

DAN DEVLIN

JANE MANNING

HEATHER HEICK

BELIEVE CAMPAIGN DONORS

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

Anonymous (10)
1474297 Alberta Ltd.
Helen Adams
Patti Adams
Adobe Foundation
Margaret Andrews
Gus & Dana Angus
Tracy Arno
ASL Paving
Wayne Atkinson &
Margaret Steed
Ellen & Vern Barrett
Barteaux Durnford
BC Centre for Palliative
Care
Doug Beckman
Joe Berridge
Beta Sigma Phi, XI Epsilon
Phi Chapter
Jennifer Bettiol
Edward Bezeau &
Angela Di Serio
Charles Borton
Anne & John Brace
Brelín Holdings Ltd.
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Gilda Mahabir
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Dumfries Community
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Canada Foundation
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Ellen Cmolik
Elsie Cole Ford
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The Halatsis Family
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Ms. Catherine Hecimovich
Heather M. Heick
Ms. Bev Heim-Myers &
Mr. David Myers
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B.C. Rehab Centre
Lembit & Karen Janes
John Deere Foundation of
Canada
Larisa Kalist
Beata Karpati
Marion Kennedy
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Dennis & Nancy Klassan
John Knappett
Ann Kowal
The late John Kuzyk
Daniel Timmer & Julie
Lawson Timmer
LCBO
The Leflar Foundation
Marlene J. Little
Bernard & Dorothy Lukan



Maggi Thornhill Personal
 Real Estate Company
 Siegfried Maier
 Manitoba Community
 Services Council Inc.
 In Memory of D. J. Manning
 The Manning Family
 Fellowship
 Juanita Manning
 Paul and Jane Manning
 L. Maxine Mardell
 The Mark Mercier
 Foundation
 Todd & Wendy Mason
 Bryan McCrea
 Elizabeth McKinlay
 The McLean McCuaig
 Foundation
 Joyce McNair
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 Denise Morden
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Myrdal Inc.
 Robert Nowakowski
 Ottawa Community
 Foundation
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 The Pollard Family
 Foundation
 RBC Foundation
 Lynn & Iris Riese
 Kim Robinson
 Diane Robinson
 Douglas Ryhorchuk
 Shannon Ryhorchuk
 Scotia Wealth
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 Shared Inc.
 Arnie & Linda Shaw
 SickKids Foundation
 Sifton Family Foundation
 Brad Smith
 Debbie Smith
 Shirley Smith
 Mark & Gail Spurr
 Steed & Evans Holdings

Joseph Taylor
 Tikkun 18 Foundation
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 Victory Majors Investments
 Corporation
 Florence Wall
 Stan & Dorota Weber
 Katherine Whiting
 Arthur & Susan Willms
 The Windsor Foundation
 Winnipeg Executives
 Association Inc.
 The Winnipeg Foundation
 James Wiswell & Ellen
 Foster
 William & Mary Zant

**Thank you to all
 of our generous
 donors for your
 support. With your
 help, we surpassed
 our \$3 million goal!**

MAY IS HD AWARENESS MONTH



LIGHT IT UP 4 HD

Buildings, monuments and statues across Canada lit up in blue and purple during May to raise awareness for Juvenile HD (in purple), HD (in blue) and Huntington disease Awareness Month. Eight countries participated this year, with a total of 123 sites internationally – the highest number of sites to date! Fifty-two of these sites were right here in Canada, with at least one site lit up in every province across the country.

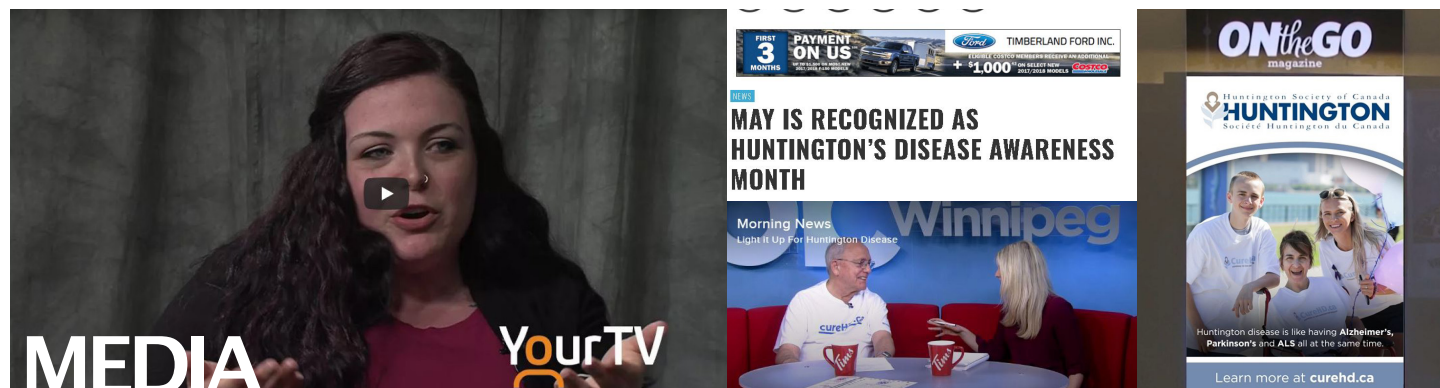


PROCLAMATIONS

Volunteers across Canada also strive to make HD Awareness Month official in their communities by having local government members proclaim May as HD Awareness Month.



As part of May Awareness, volunteers across Canada request that buildings in their community fly the Huntington Society of Canada flag for a period of time during the month of May. The flag raises awareness and honours those affected by the disease.



In an effort to gain national attention for HD Awareness Month, volunteers worked hard with us to participate in media interviews and segments across the country.



AT A

20,508
AMARYLLIS SOLD

23%
INCREASE IN SELLERS

GLANCE

The Amaryllis is the signature flower of HSC. Our Amaryllis volunteers sell bulb kits to raise vital funds for our programs in research, services and education. Last year, more than 20,000 amaryllis bulbs bloomed coast-to-coast, across Canada, inspiring hope for a world free of HD.

Thanks to our dedicated sellers, the 2017 Amaryllis Campaign was truly incredible. Together, volunteers raised well over \$120,000 to fund research and services for individuals and families affected by Huntington disease and spread awareness from coast-to-coast across Canada. Together we inspired hope for a world free from HD.

The campaign saw wide-spread involvement from across Canada – from our incredible long-time volunteers, Chapters, friends and families of the HD community, to private companies and corporations. There was fresh, renewed energy in the community as different avenues for Amaryllis sales were enthusiastically explored, and new leaders emerged to continue the incredible work as the baton was passed on. We are looking forward to what we can accomplish together for this year's campaign!

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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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Jack & Mary McMillan
Robert & Letitia McMurray
Carol McPherson
Dan & Marianne McQueen
Doug & Kim Meloche
Mrs. Joan Mercer
Betty Merchant
Thomas & Joann Meredith
Roy & Anna Metcalfe

Don & Faye Metz
Tom & Elsie Miehle
Joseph Mifsud
Helen M. Miller
Kristi-Jayne S. Miller
Mrs. Margaret Milliken
Geoffrey Milne
Bradley J. Milne
Richard & Lynn Miner
Bernice Minshull
Brett & Janet Mitchell
Helen Mitchell
Ken Moar
Tim & Arlene Moher
Laurie Moir
Mr. & Mrs. Mollerstedt
Holly Montgomery
Gailene K. Moore
Sally Morell
Norman & Maureen Morrison
Cyril & Sharon Moyse
Sara Mueller
Susan & Matthew Muller
June Murphy
William & Angela Myles
Valerie Nabb & Colin
Chesterman
Mike Naish
Brian & Beverley Nattress
Verna I. Neil
Valerie Nettleton
Ernest & Carole Neudoerffer
Tim & Darlene Neuman
June Nichol
Joyce & Greville Nifort
Lorraine M. Norwood
Joyce O'Brien
Elizabeth V. Oldford
Sean O'Sullivan
OPG Employees & Pensioners
Charity Trust

Outlook Donor's Choice
P. Racicot Sign Company
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Ann Pace
A. Padmaraj
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Lois Y. Pearce
Richard Pearson
W. B. Pearson
Joyce Peatfield
Ruth Pellmann
Brian Penner
Peter Penner and Clarice
Penner
Paul Perigord
Lyle & Gail Perkins
Frank Peters & Wendy Verbeek
G. R. and Elizabeth Peters
H. S. Petersen
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Mickey & Margaret Pikor
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Nicolai Popovici
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Frances Preston
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Earl & Nancie Quigley
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Steve and Doris Ramphos
Brenda Randall

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Ronald & Jane Reider
Demetrios & Penny Reklitis
Gisele M. Reklitis
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Franklin T. Richmond
Victor & Patricia Rivest
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Susan Robertson-Krezel
Mary-Lou Roder
Guy & Trudy Rogers
Burt Rollins
Wayne & Gail Roszl
Leander Roth
Glenda Rowein
The late Theresa Rueffer
Don & Anne Russell
Scott Barrows & Nicole E. Russell
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Scott J. Sampson
Maria Santos
Patricia Saull
Ron & Mary Saunders
Lindsey Saunders
Isabel E. Saunders
Margaret E. Savage
Robert Schellenberg
Philip & Diane Schiefer
Dr. & Mrs. David G. Schoales
Murray & Nettie Scott
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Walter & Eileen Shankman
Bernard Shannon &

Theresa Lawlor
D. Sheedy
Scott & Celina Shoji
Joe & Paula Silva
Bill & Michelle Silverberg
Nancy E. Simpson
Lorne Sinclair
Dianne Skikavich
The late M. Alene Skikavich
Bev & Elaine Skinner
Helen B. Skinner
Laurie & Ann Skinner
Janet M. Slade
William & Judith Slater
William R. Slater
Bonita B. Slimmon
Lyle & Ellie Smith
T. David & Lorraine Smith
Linda Smith
Joan Smyth
William Bates & Shirley Snow
Douglas E. Snow
Sandra Sorsdahl
Patricia & Kevin Sowers
Anne Spadoni
Gwenneth Squires
Mark & Kim Stainsby
John M. Stainsby
Barbara A. Stanley
Linda Starr
Herman & Joanne Steffens
Jim & Mary Sterling
Heath Sterling
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John Stewart
Patrick & Lenore Stillwell
Catharina J. Stoop-Sneek
Terry & Ruth Stortz
Leonard Sussman
Peter Sutherland
Jeannette Suzuki

Joan Swan
Camillia Switzer
Raymond & Rosilyn Switzer
Sam & Caroline Sych
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James & Deborah Talbert
Andrew Talbot
Antonietta Taverniti
John & Arlene Taylor
Richard Taylor
Wayne D. Carter & Amber Taylor
Mike Teed
Marlene Teske
Kevin Tessner
Susan Thack
Joyce Thibeault
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Mary Tierney
Mrs. Gordon Toms
Arthur Treloar
Michael & Susan Tremblay
James & Inge Trenton
William & Janet Trim
Nancy Trolley
J. Stephen Tweedle
Heather Urquhart
Ethel Urquhart
Algis J. Vaisnoras
Ginny Van Allen
Rhea Van Breda
Leendert & Maria van den Berg
Isla Vandelaar
Kristina Vandervoort
Garry Vann
Gerda Vennema
Lynn Voro
John & Judith Wakelin
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Blaine Wall

Ross Wallace
 Jean D. Wallace
 Barb Wallis
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 Mareile Walter
 Winnifred Walters
 Patrick & Ann Wannamaker
 John & Josie Watson
 Franz & Catherine Weber
 Roy & Ruth Weber
 Stan & Dorota Weber
 Linda Weber
 Harry & Annie Weersink
 Marjorie L. Welch
 Andrew & Kathy Wells
 The late Case Wessels
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 John & Lynne West
 Jim & Cherie Weston
 Christine Wheelhouse
 Patricia White
 Donna M. White
 Al & Beth Wickett
 Tracey & Bob Wickett
 Marvin & Maureen Williams
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 Robert & Faith Wood
 Helen Wood
 Susan Wood
 Doug & Faye Woodworth
 Susan Wright & John Sankey
 Andrew & Tory Wright
 J. Arthur Wynn
 Charles & Sheila Wyse
 S.A. Yetman
 David & Aleshia Zabok
 Roy & Gail Zabok
 Donna (Vibert) Zentner
 Louis & Patricia Zonta

SUMMIT SOCIETY

MEMBERS

**Those who have included
HSC in their Will.**

Anonymous (11)
 Christine Andrews
 Mr. Rex Ballard
 Ellen & Vern Barrett
 Jean Beakhouse
 William & Corinne Bees
 Terry Berngardts
 Kathleen Bissett
 Mr. and Mrs. Dave & Helen
 Bodnarchuk
 Larry & Louise Campbell
 Debi Campbell
 Ingeborg Dodds
 Shirley Eybel
 John & Sally Guggenheimer
 Colleen Huntley
 Stephen Hurst
 Cathy Johnson
 Tara Johnson-Ouellette
 Garry & Valarie Kinzie
 Jacqueline Lingard
 Janet Main
 Elizabeth McArthur
 Mr. & Mrs. Mollerstedt
 Norma Nevison
 Brenda S. Nowakowski
 Norma Stevens
 Terry J. Taylor-Topp
 Michael & Susan Tremblay
 Ariel Walker
 James Wiswell & Ellen Foster

WE REMEMBER

**Gifts have been made to
HSC in honour of those
we've lost this year.**

Claire Abbs
 Nicole Allen
 Chris Anderson
 Francis Anderson
 Heather M. Arthur
 Marjorie Atkinson
 Margaret Barr
 Bill Bates
 Mary G. Bell
 Antoinette Berridge
 George Berry
 John Blue
 Linda Bogart
 Irma Bogden
 Thomas R. Botter
 Joyce I. Brown
 Gordon Buttars
 Michael R. Callum
 Ross Cameron
 Giannoula Carayannis
 John D. Chester
 Brent Clark
 Scott J. Clark
 Grace L. Clement
 Martin Cleve
 Wesley Clow
 Nelson Coddington
 Courtney Comeau
 Gordon Cowdry
 Samuel Cox
 Andrew M. Crawford
 Donald Cummings
 Carol Cutter
 Sheila E. Delaney
 Jack Devine
 Felix Devlin
 Steven Dixon
 Wilfred Eisnor
 Judy Farynuk
 Jeff Fast
 Bruce Felker

Eric Fletcher
Robin W. Fraser
Lorraine Gallagher
Evelyn Gamache
Eleanor Gingras
Donald Glanville
Robert Glenney
Peter Gray
George G. Grills
Ken Ham
Hilda Hazel
Bastiaan Heemsbergen
Terence F. Heenan
James Henderson
Ms. Lilian Hewett
Robert W. Hiller
Lynne C. Hock
Jack Hopkins
Henry Horner
Terry Hrankowski
Regina Hudon
Alan Hughes
Bruce W. Hunter
Munroe Irvine
Philip Irwin
Joyce Kinzie
Lori Kirk
Anna Klein
Edna Klein
Roger Konopelky
Rene Laderoute
Lois LaFrance
Ben Lariviere
Stewart W. Law
José Leandres
Grace Lebold
Florence M. Lenz
Carolyn MacDonald
Barry MacNeil
Brenda Marshall
Gwen Martin

William Maxwell
Janice Mayowski
Twyla McAmmond
Gillian McCann
Cheryll McCracken
Verna McDowell
David McKeeman
John R. McKeeman
Joanne M. McLelland
Robert Mercer
Raymonde Meunier Jutras
Ted Middleton
John Mollard
Sarah E. Mulcahy
William P. Muller
Peter L. Neuman
James Newstead
Ada Nifort
Annie Noonan
Harmke Oosterlo
Annie Parko
Wilson Patterson
Christina Pearce
Shane Pearson
Betty Pickett
Norman Potechin
Eleanor J. Proctor
Garth W. Ramsay
William G. Reese
Allison Reid
Margaret Richardson
Alexandra M. Roche
John Roder
Theresa Rueffer
Julie Ryan
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Mary Savela
Joleen Saville
Lenita Schellenberg
Kyle Shorrock

M. Alene Skikavich
Donald Skuce
D. R. Smith
Bruce Speidel
Rosilyn Switzer
Pat Tallon
Angus G. Taylor
Kevin Tendler
Bill Thomson
Patricia L. Timms
Denis Tremblay
Alice Trieber
Jannetje Vanderstoel
Winnie Verbeek
Anne M. Watts
Rebecca Watts
Albert Weernink
Mareli Wells
Gerry A. Williams
Ann Williamson
Don Willis
Leonard Wilson
Sonia Zuidema

ESTATE GIFTS

**Those who have
remembered HSC during
their lifetime.**

Cheryl Kuzyk
John McKeeman
Kathleen Moon
Johann Penner

**Thank you to all of our
generous donors for
your support.**



"Bringing groups together to learn, bond and support each other really helps make HD feel less isolating."

For years, Joanne Kaattari has found lots of ways to get involved with the Huntington Society of Canada. She became a monthly donor, followed the Society on social media and kept updated on the latest HD news. But she still felt like she could be doing something more. That's when Joanne decided to organize the Barrie, Ontario area's first HD fundraising event.

Since Joanne had never planned an event before and didn't have a lot of volunteers, she decided that if she kept the event simple with only 20 attendees and created the event around something she was passionate about, then it would be a success.

And she was right! Joanne's Wildflower Walk in June was held at a local Barrie park where 25 people (most who hadn't heard of HD before) came to join her guided tour of the park's wildflowers.

"The awareness we raise is so important," says Joanne. "Of course raising money for family services and research is key too, but bringing groups together to learn, bond and support each other really helps make HD feel less isolating."

FINANCIAL HEALTH

TREASURER'S REPORT

I am pleased to present this report to the membership of the Huntington Society of Canada for the most recent fiscal year end. The Society's revenue for the year ending June 30, 2018 was \$4.286 million, representing the fifth straight year the Society has exceeded \$4 million in revenue. We simply cannot say thank you enough to all of our supporters, staff and volunteers who work tirelessly to make this happen and allow us to continue our work to support individuals and families living with Huntington disease.

The Society focuses on utilizing these dollars as effectively as possible to support a diverse range of needs of our community including direct services to families affected by Huntington disease, investing in critical research, preparing stakeholders for clinical trials, fighting for the rights of individuals impacted by Huntington disease and raising public awareness. The Society's spend on that mission and supporting roles totalled \$3.9 million resulting in surplus of almost \$350,000 for the fiscal year. Approximately \$100,000 of this surplus resulted from restricted gifts to our Research and Endowment Funds.

The Society has a strong financial position with the general fund and the research fund each topping \$1 million. The total assets of the Society exceed \$4.5 million. This is a strong financial position for the Society and it comes at a time of unprecedented change in the speed of research and clinical trials and increasing demands on our Family Services team. These funds will allow the Society to move forward with initiatives to enhance the programs and services to the HD community and continue to provide strategic investments in research and clinical trial support.

Within the Society, we continue to strive for efficiencies and improvements. One of the initiatives underway is the change of the fiscal year end to March 31st effective March 31, 2019. There are a number of advantages for the Society expected from this change, not the least of which is greater alignment of the budget cycle to the cash flow cycle. Historically, close to 40% of the Society's revenue is recognized in the final quarter of the fiscal year (i.e. the April to June time frame). By changing this to be the first quarter of the fiscal year, the Society will benefit from improved efficiencies for reporting to stakeholders and more accurate forecasting of both revenues and expenditures. In turn, the Society will be able to better utilize the resources available to it. We should expect that during the transition to the new year end, an operating deficit will be incurred in the initial 9-month period end as it will exclude the sizeable percentage of revenues generated in the April to June quarter. This will be a one-time event as we adapt to the new fiscal year, April to March.



Glenda Rowein, CPA, CA
Treasurer

STATEMENT OF FINANCIAL POSITION

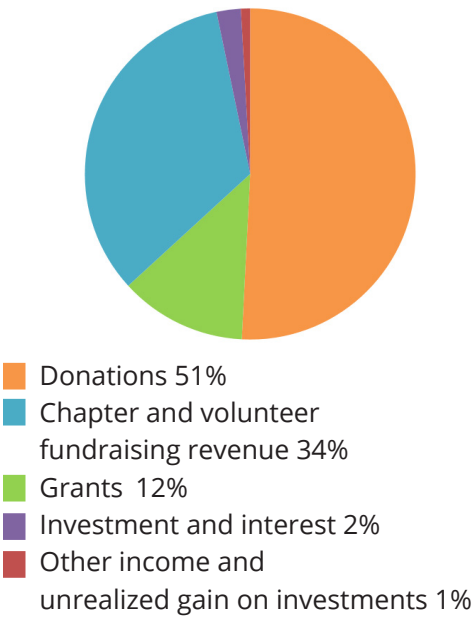
Year ended June 30, 2018.

ASSETS	2018	2017
Current assets		
Cash	\$1,287,995	\$1,562,952
Investments	3,084,049	2,875,733
Accounts receivable	49,360	48,803
Prepaid expenses	106,536	79,255
	<u>4,527,940</u>	<u>4,566,743</u>
Capital assets	17,509	27,451
	<u>\$4,545,449</u>	<u>\$4,594,194</u>

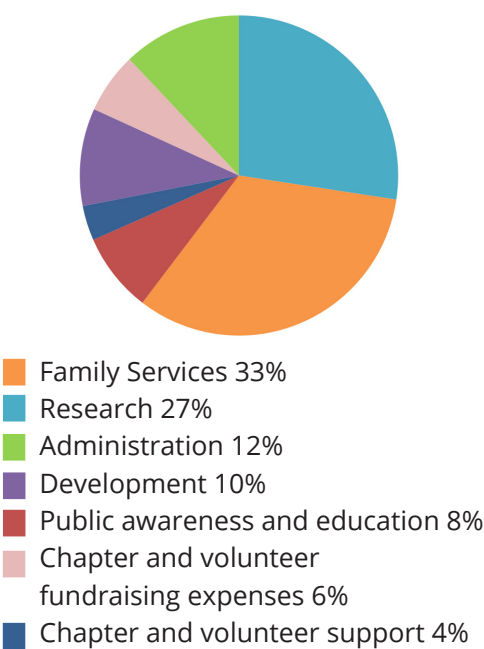
LIABILITIES AND FUND BALANCES

Liabilities		
Accounts payable and accrued liabilities	\$70,431	\$147,333
Deferred revenue	448,298	769,518
	<u>518,729</u>	<u>916,851</u>
Net assets		
General fund	1,103,053	834,635
Capital assets fund	17,509	27,451
Endowment fund	1,885,521	1,876,190
Laura's Hope fund	17,316	17,316
Ralph Walker Research fund	1,003,321	921,751
	<u>4,026,720</u>	<u>3,677,343</u>
	<u>\$4,545,449</u>	<u>\$4,594,194</u>

REVENUE



EXPENSES



STATEMENT OF OPERATIONS

Year ended June 30, 2018.

	General Fund	Capital Assets Fund	Endowment Fund	Ralph Walker Research Fund	TOTAL 2018	TOTAL 2017
REVENUE						
Donations	\$1,373,753	-	\$10,200	\$792,220	\$2,176,173	\$2,341,621
Grants	293,468	-	-	237,347	530,815	475,681
Chapter and volunteer fundraising revenue	1,432,564	-	-	4,160	1,436,724	1,270,467
Investment and interest income	69,956	-	-	32,921	102,877	105,386
Realized gain (loss) on sale of investments	(816)	-	-	(382)	(1,198)	7,663
Unrealized gain (loss) on investments	1,884	-	14,131	7,536	23,551	95,540
Other income	17,365	-	-	-	17,365	79,042
	<u>3,188,174</u>	<u>-</u>	<u>24,331</u>	<u>1,073,802</u>	<u>4,286,307</u>	<u>4,375,400</u>
EXPENSES						
Research	80,787	-	-	992,232	1,073,019	1,011,586
Family services	1,290,806	-	-	-	1,290,806	1,371,664
Public awareness and education	314,930	-	-	-	314,930	451,864
Chapter and volunteer support	138,553	-	-	-	138,553	169,994
Development	386,731	-	-	-	386,731	384,074
Chapter and volunteer fundraising expenses	241,428	-	-	-	241,428	292,715
Administration	481,521	-	-	-	481,521	443,381
Amortization	-	9,942	-	-	9,942	17,060
	<u>2,934,756</u>	<u>9,942</u>	<u>-</u>	<u>992,232</u>	<u>3,936,930</u>	<u>4,142,338</u>
EXCESS (DEFICIENCY) OF REVENUE OVER EXPENSES						
	\$253,418	\$(9,942)	\$24,331	\$81,570	\$349,377	\$233,062

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



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Toll Free: 800.998.7398
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www.huntingtonsociety.ca
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Huntington Society of Canada
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