

2012 - 2013

ANNUAL REPORT



Co-op's 14th Annual Charity Golf Tournament

Huntington Society of Canada
HUNTINGTON
Soci t  Huntington du Canada

40th
grassroots to mountaintops



Huntington Society of Canada

HUNTINGTON

Soci t  Huntington du Canada

Celebrating 40 years of achievement: Grassroots to Mountaintops Anniversary Campaign launched at the National Conference setting sights on \$5 million.

The message was simple and straight forward; we all have the power to influence the future, a chance to be a part of history.

Since 1973, HSC has recognized the importance of reaching out beyond borders. HSC is one of the four founding members of the International Huntington Association (IHA). The IHA is an organization that now consists of forty two member nations and works in close collaboration with the World Federation of Neurology Research Group on Huntington Disease. The Huntington Society is proud to remain a world leader in developing and delivering essential Huntington disease services and investing in the future of Huntington disease medicine.

The 40th Anniversary Campaign Objectives:

- Build upon research successes to date. Research results are cumulative. Canadians have made a significant impact on Huntington disease research. We strongly believe that a Canadian researcher will unlock the key to this devastating disease.
- Recruit people affected by HD and those at-risk to participate in clinical trials to test upcoming and promising new therapies. Canadians are quickly becoming the highest per capita participants in HD clinical trials around the world; however, we are not there yet.
- Continue to deliver and expand essential services. This includes reaching out to HD families who are currently not receiving critical support; building a network for youth affected by and at-risk of HD; providing caregivers the support they need; identifying and filling the gaps in order to reach the maximum number of Canadians who require these essential services each day.



This year, HSC has raised over \$1.3 million dollars towards our campaign goal. \$5 million in 5 years is possible. As Anne Brace, Chair of the Board of Directors, summarized at



the conclusion of the national conference:

“We each play a role and our success is rooted in our collective efforts. It takes every person, every volunteer hour, every event, and every contribution to make the Society successful. No matter what role you choose to take, big or small, I want you to know it matters! It matters each and every day!”

40 YEARS

History in Motion

1973 - 1975

On October 1st, volunteers Ralph & Ariel Walker begin a Canadian chapter of the American Committee to Combat Huntington's Disease by sending a newsletter to 29 families. Within days, the first public meeting in Canada on HD is organized, 150 people are in attendance. The Huntington Society of Canada is born.

Ralph Walker meets with representatives from Britain and the USA to form the International Huntington Association (IHA).

1978 - 1983

On behalf of HSC, Ralph Walker initiates the Canadian Neurological Coalition (CNC).

HSC awards its first post-doctoral fellowship in the amount of \$14,000 to further investigate HD-specific neurotransmitters in the brain.

HSC's first Huntington Disease Resource Centre opens in Toronto.

Co-op's 14th Annual Charity Golf Tournament

Canadian scientist, Dr. James Gusella, announces a marker linked to the HD gene, opening the door to a predictive test for HD.

1984 - 1992

Dr. Michael Hayden establishes an HD predictive testing centre in 1986. The second HSC HD Resource Centre opens in Vancouver.

The Huntington Society of Quebec (HSQ) is incorporated to facilitate fundraising, family support and public awareness in Quebec.

1993

The HD gene is discovered by Canadian, Dr. James Gusella and his team at the University of Massachusetts. Direct testing becomes available, providing those at-risk with a definitive answer as to whether they will develop HD, allowing families to plan and to arrange for future help.

1996

The first transgenic mouse for HD, the YAC mouse model, is created. This mouse perfectly replicates the HD symptoms and progression in humans. This mouse enables scientists to achieve more accurate results in HD experiments, testing new possible treatments.

1998 - 2007

Canadian researchers at the HSC funded Centre for Molecular Medicine and Therapeutics, in Vancouver, BC, stop the progression of HD in a mouse bringing us closer to finding a treatment.

The Huntington Society opens the Northern Ontario Multidisciplinary Clinic in North Bay.

2008 - 2010

HSC establishes the Canadian Coalition for Genetic Fairness to educate Canadians about genetic discrimination and to influence provincial and federal governments, and other relevant organizations, to create positive change.

Young People Affected by Huntington Disease (YPAHD) is established.

2011

HSC funds researcher Dr. Ray Truant of McMaster University. He discovers a common link between Alzheimer's and Huntington disease.

In partnership with three other lay organizations, HSC helps launch and support HDBuzz.net: research news, the first platform of its kind, in plain language.

2012

Dr. Simonetta Sipione, an HSC funded researcher from the University of Alberta, in collaboration with Dr. Ray Truant, of McMaster University, successfully reverses HD motor symptoms in a mouse model.

HSC works with Academy Award Winning director, John Zaritsky and award-winning producer, Kevin Eastwood, to help launch the Canadian documentary *Do You Really Want to Know?*. This film follows three families as they decide whether or not to be tested for the HD gene mutation.

HSC develops an innovative Youth Mentorship Project.

2013

The Huntington Society of Canada reaches its 40 year milestone. Together, we celebrate our journey from Grassroots to Mountaintops, a collective effort to educate and support Canadian families affected by Huntington disease; find meaningful treatments; and stop the progression of the disease.

MISSION

The Huntington Society of Canada's Mission and Guiding Principles

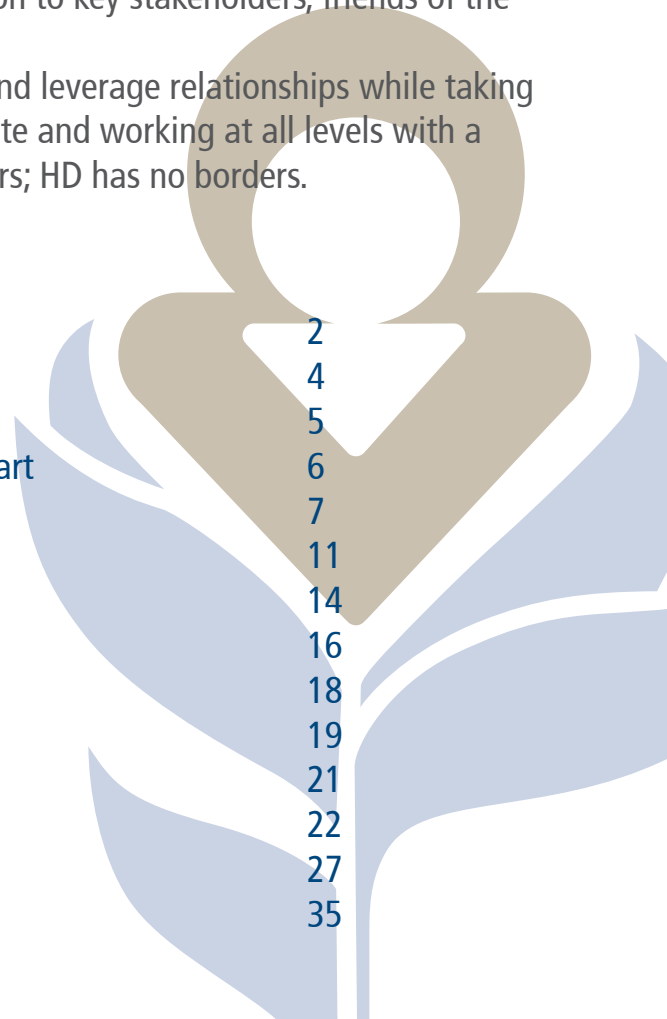
“The Huntington Society of Canada **aspires to a world free** from Huntington disease. The Society strives to: **maximize** the **quality of life** of people living with HD by delivering services; enabling others to understand the disease; **furthering research** to slow and to prevent HD.”

Guiding Principles

- HSC cannot accomplish what we need to do alone. We will enlist the broader community to develop networks of care and support.
- HSC will continue to educate and reach beyond the HD communities. We will identify and engage sustainable assets and resources on a local, regional, national and international level.
- HSC will continue to advocate for people living with HD and empower individuals and families to find their voice.
- HSC will continue to be an information broker by creating and disseminating reliable HD information to key stakeholders, friends of the Society and interested parties.
- HSC will continue to connect with and leverage relationships while taking on leadership roles where appropriate and working at all levels with a global HD community to find answers; HD has no borders.

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MESSAGE FROM THE CHAIR & CEO

For 40 years, the Huntington Society of Canada has been serving families across the country who live with Huntington disease. Dealing with a progressive, degenerative genetic illness puts stress on every member of affected families: the people diagnosed with HD, their spouses, the children who grow up with the knowledge that they have a 50 percent chance of developing the same devastating symptoms and friends.

In 1973, Ralph and Ariel Walker founded the Society to offer those families help and hope. Help, by breaking down the walls of isolation surrounding HD, offering accurate information and providing support. Hope, by funding research that would ultimately lead to treatments.

Today, HSC is a global leader in supporting families, promoting genetic fairness, addressing the special needs of youth, and catalyzing groundbreaking HD research. To the many, many donors who made those achievements possible, thank you.

While our 40th anniversary marked an opportunity to celebrate how far we have come, we also seize the chance to look forward. How can the Society reach out to families in remote areas and diverse communities? What can we do to ensure the clinical trials for potential treatments proceed as quickly as possible?

Last year, our Board and staff collaborated to create a strategic plan designed to guide our work over the coming years. It focuses on six key priorities:

1. Invest in world-class research that will lead to treatments
2. Advocate for families and enhance the services we provide to them
3. Increase awareness of HD and HSC
4. Demonstrate leadership locally, nationally and globally
5. Strengthen services for young people affected by HD
6. Ensure financial and organizational effectiveness

Our strategic plan also established indicators to track our performance and ensure we are using your dollars to the maximum advantage. As you will see in the pages that follow, we made substantial progress on every front in 2012/13.

Among our many achievements, we have created a new resource centre in East Central Ontario, added another Social Worker to our B.C. family services team and helped to establish a

new multidisciplinary clinic to serve families in Newfoundland. We have worked closely with Senator James Cowan to craft Bill S-218, the most comprehensive genetic fairness legislation proposed to date. We have expanded our services to youth with the launch of a new website for young Canadians affected by HD and the development of a youth mentorship program.

Our 2012 National Conference proved to be the most successful in HSC's history, while our new awareness campaign has resonated with Canadians more than ever. We continue to fund highly promising research that, according to an expert review we commissioned last year, provides an excellent return on investment. At the same time, we have continued to manage our expenses aggressively, create new efficiencies and leverage partnerships with like-minded organizations to increase our impact.

However, some of our most important achievements are not easily quantified. It is the handwritten note on a conference evaluation form telling us how connecting with other families has made a world of difference. It is the photo of participants at a therapeutic retreat beaming with joy and possibility. It is the tangible energy in the room when our youth leaders come together.

The strength, courage and resilience of the HD community inspire us on a daily basis and reinforce our commitment to fulfill Ralph and Ariel's original vision: to create a world free from HD.

Thank you for sharing that vision and for sustaining our work. In a fundraising environment that continues to prove challenging, your generosity means everything. This community of families, donors, volunteers, researchers, staff and healthcare professionals has achieved extraordinary things over the past four decades. Together, we will achieve even more in the years ahead.




Bev Heim-Myers
CEO and Executive
Director



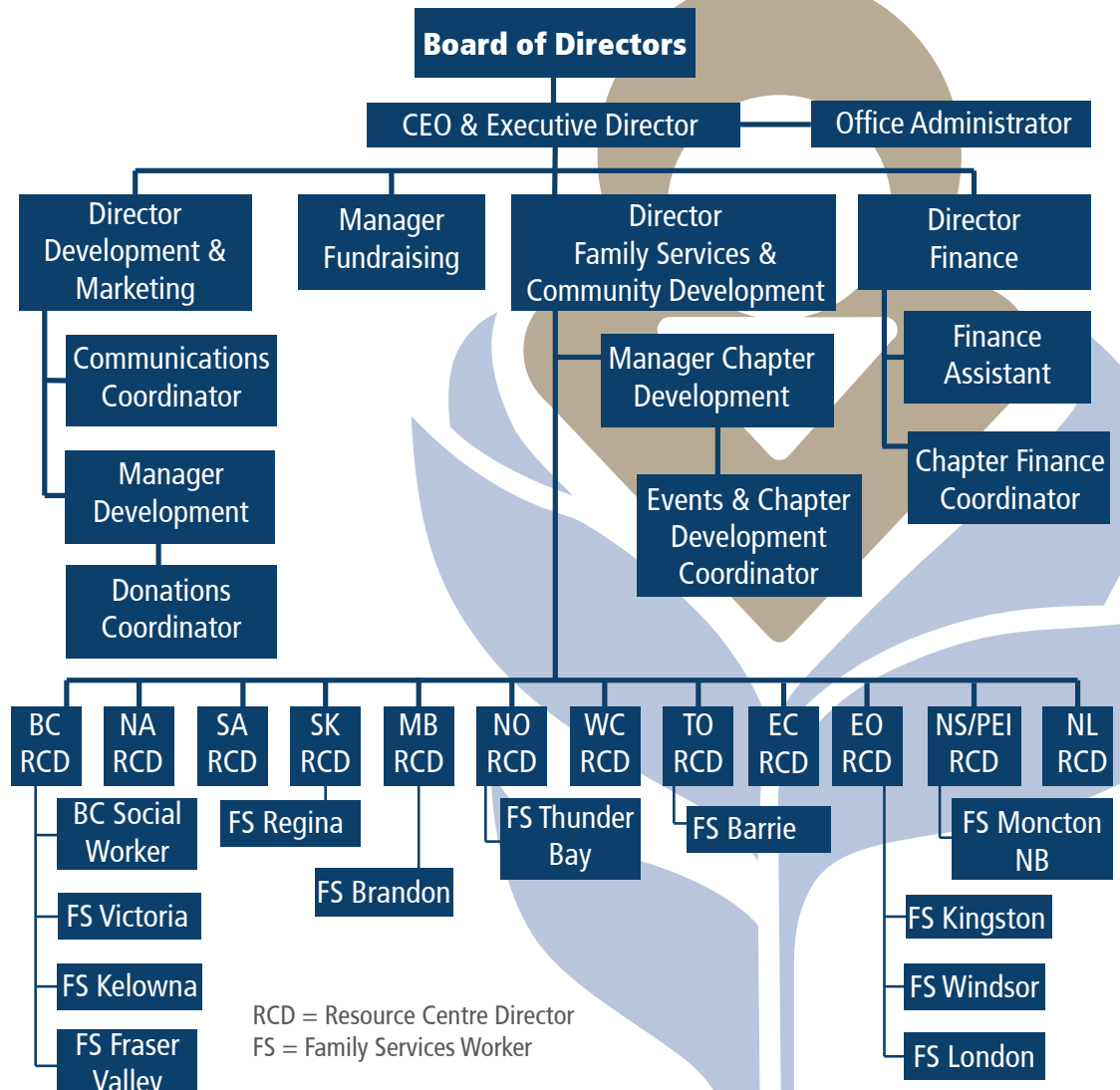

Anne Brace
Chair,
Board of Directors

The 2012-2013 Board of Directors

The Huntington Society of Canada (HSC) is a national network of volunteer Chapters and Area Representatives, governed by a volunteer Board of Directors that focuses on policy. HSC's team of full-time and contract staff manage the day-to-day operations, serving individuals and families affected by HD in communities across Canada.

Anne Brace Chair	Dr. Ray Truant Chair, Research	Ray Bailey Director	Dr. Sid Katz Director
Dan Devlin Vice-Chair	Bob Scriven Director YPAHD Rep.	Jim Godey Director	Mieke Wales Director
Sean Dewart Secretary	Christian Lejeune HSQ Rep.	Jacob Hendriks Director	Susan Wright Director
Glenda Rowein Treasurer		Stephen Hurst Director	Dr. Tom Dignan Director

The HSC team was described as: incredibly nimble when needed; **Helpful and quick.**

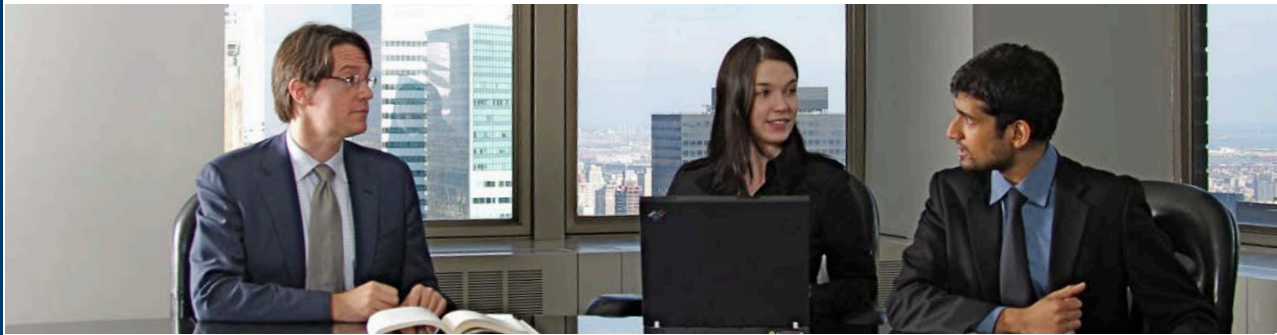


Board Directors

Hailing from all corners of Canada, the Board of Directors meets twice a year and is responsible for governing the Society. This includes the Society's mission and strategic planning; policy development; stewardship of resources; and accountability to members, donors, and the public.

One seat on the Board is reserved for a representative of the Huntington Society of Quebec, while another seat is reserved for a representative of Young People Affected by HD (YPAHD), our virtual youth chapter. Each Director is elected for a term of two years.

The election of the Board of Directors takes place at each Annual General Meeting of the members, with an emphasis on recruiting individuals that can bring specific expertise to the governance of HSC.



Board Committees

Executive/Finance Committee:

Board Chair, Vice-Chair, Secretary, Treasurer, CEO

Reviews the operating plan and budget prepared by the CEO; recommends whether to adopt the budget; reviews quarterly financial statements; reviews insurance coverage and risk protection.

Board Governance/Nominating Committee:

Past Board Chair, Chair, Vice-Chair, 2–3 other Board members

Evaluates the effectiveness of the Board; assesses the skills and competencies of the Board; recruits and orients new members; evaluates existing Board policies and develops new ones.

Investment Committee:

Board Chair, Vice-Chair, Treasurer, 2–3 other members appointed by the Board

Reviews the performance of the Society's investment portfolio; ensures the portfolio meets Board policies; reviews the appropriateness of the investment policy.

Audit Committee:

Treasurer, Board Chair, Vice-Chair, 1–2 other Board members

Reviews the audit plan; approves the audited financial statements; reviews internal controls; ensures proper financial stewardship.

Research Committee:

Board Research Representative, National and International HD researchers, CEO

Proposes research policy; works within the policy framework; advises the Board's strategy with regards to funding and promoting research. Reports to the Board of Directors.

Research Council

The Research Council is comprised of leading HD research scientists who generously volunteer their expertise in various areas of investigation. The Council assesses the applications HSC receives for the NAVIGATOR and NEW PATHWAYS research grants and recommends which projects to fund.

- Dr. Ray Truant (Chair), McMaster University – Hamilton, ON
- Dr. Patrik Brundin, Wallenberg Neuroscience Center – Sweden
- Dr. Eileen Denovan-Wright, Dalhousie University – Halifax, NS
- Dr. Stephen Ferguson, University of Western Ontario – London, ON
- Dr. Michael Hayden, University of British Columbia – Vancouver, BC
- Dr. Blair Leavitt, University of British Columbia – Vancouver, BC
- Dr. Marcy MacDonald, Harvard Medical School – Boston, MA, USA
- Dr. Lynn Raymond, University of British Columbia – Vancouver, BC

Huntington Society of Canada Staff

CEO & Executive Director

The CEO and Executive Director is the senior staff person and public face of the organization. The CEO reports directly to the Board, and meets with the Board Chair on a monthly basis.

- Bev Heim-Myers, CEO and Executive Director
- Shirley Barnes, Office Administrator

Management Team

Tasked with handling the day-to-day operations of the Society, the Management Team meets every other week and reports to the CEO & Executive Director.

- Maribeth Meijer, Director of Family Services and Community Development
- Cyndy Moffat Forsyth, Director of Development and Marketing
- Ean Robertson, Director of Finance
- Devin Bonner, Manager Chapter Development
- Danielle Havelka, Manager Fundraising
- Jim Martin, Manager Development

Development & Marketing Team

The Development and Marketing Team is responsible for the Society's marketing, communications and fundraising responsibilities. Their job is to ensure the Society has sufficient resources to help people affected by HD.

- Cyndy Moffat Forsyth, Director of Development and Marketing
- Jim Martin, Manager Development
- Sue Campbell, Donations Coordinator
- Christina Steinmann, Communications Coordinator

Finance Team

The Finance Team handles the Society's budget, financial reporting, payroll, accounts payable and receivable, and any other items related to the fiscal nuts and bolts of the organization.

- Ean Robertson, Director of Finance
- Sandra Peel, Finance Assistant
- June Sutherland, Chapter Finance Coordinator

Family Services & Chapter Development Team

The Society includes a network of professional Family Services staff across the country at 12 Huntington Disease Resource Centres. Twelve Family Services (FS) contract workers extend that network, serving families outside the geographic reach of our Resource Centres. Also, our Chapter Development staff support the work of our volunteer Chapters across Canada.

- Maribeth Meijer, Director of Family Services and Community Development
- Shirley Barnes, Office Administrator
- Devin Bonner, Manager, National Chapter Development
- Sally Litchfield, National Events and Chapter Development Coordinator
- Susan Tolley, British Columbia Resource Centre Director
- Renee Aeyelts, British Columbia Resource Centre Social Worker
- Randy Goossen, FS Worker, Fraser Valley
- Lynne Reeve, FS Worker, Victoria
- Tim Bayliss, FS Worker, Kelowna
- Sally Vincent, Northern Alberta Resource Centre Director
- Karl Lottes, Southern Alberta Resource Centre Director
- Erin Stephen, Saskatchewan Resource Centre Director
- Lisa Zaphe, FS Worker, Regina
- Sandra Funk, Manitoba Resource Centre Director
- Meg McConkey, FS Worker, Brandon
- Angéle Bènard, Northern Ontario Resource Centre Director
- Heather Minthorn, FS Worker, Thunder Bay
- Maike Zinabou, West Central Ontario Resource Centre Director
- Marilyn Mitchell, East Central Ontario Resource Centre Director
- Rozi Andrejas, Toronto and Area Resource Centre Director
- Deanne Graham, FS Worker, Barrie
- Paul Klodniski, Eastern Ontario Resource Centre Director
- Sherrie McKegney, FS Worker, Kingston
- Gioia Levesque, FS Worker, Windsor
- Corey Janke, FS Worker, London
- Barb Horner, Maritime Resource Centre Director
- Marthe Gautreau, FS Worker, Moncton
- Elaine Smith, Newfoundland Resource Centre Director

Chapters and Area Representatives

The backbone of the Society includes more than 30 Chapters and Area Representatives across Canada. Supported by the Family Services and Chapter Development team, these Chapters involve more than 10,000 volunteers in fundraising and awareness initiatives each year and provide support to families affected by HD.





Creating positive impact

Jaclyn and Leah Skinner

“You can’t change the fact that you’re at-risk, but you can make a difference and raise awareness and try to do all you can to help find a cure.”

Jaclyn Skinner

My mom is probably one of the strongest people I know. She’s a trooper. She found out that she had the gene when we were very young, but she didn’t tell us for a long time because she didn’t want it to hold us back, which was so selfless of her.

Even now, although she’s just lost her driver’s licence, she’s still so positive. “Don’t worry,” she says. “There’ll be a cure.” She just takes the burden away from you by convincing you not to worry about her.

Still, it dwells on everyone’s mind. Between me and my siblings, we’re home almost every other weekend to visit her because she changes so much now. It’s difficult.

Of course, we each have a 50 percent chance of carrying the gene. There are times when it gets me down, when I think “this isn’t fair.” Then there’s other times when you’ve got to be optimistic. You can’t change the fact that you’re at risk, but you can make a difference and raise awareness and try to do all you can to help find a cure.

That’s why I got involved in YPAHD a few years ago. It’s really fulfilling to be there for other people and make them feel like they’re not alone. Having a good support system makes all the difference in the world.

I’m optimistic they’ll find a cure for Huntington’s. They’re so close. But right now, it’s frustrating. Cancer you can beat — they’ve found ways to fix that. Huntington’s, there’s nothing.

Leah Skinner

When my parents told me that Mom has HD, I was in shock. I knew she was at-risk, but at the time, she didn’t have a lot of symptoms — I think that’s what made it so hard to believe.

It’s tough watching her get worse. It makes it even tougher knowing that one day, that could be your siblings or you. On the flip side, my mom has never let the disease get her down. She is probably the most optimistic and happy person that you’ve ever met.

I think for me, one of the biggest challenges is not knowing if I have the gene; the uncertainty of what the future holds. I think about Huntington’s every day and what it means to have it in your family.

Helping to found YPAHD has been so positive. It’s a way for young people affected by HD to raise money and awareness and also to help each other. You can chat with friends that aren’t affected and they try to be supportive, but they really don’t understand what you’re going through.

YPAHD also opens your eyes up to a lot of the promising research. I’m very hopeful that the research community will come through for us. There is so much positive energy and enthusiasm. It’s hard not to get caught up in that.

One of the biggest challenges is not knowing if I have the gene...

Operational Goals

The Society's operational goals are based on the strategic plan, outlined by the Board of Directors in 2012. It illustrates our plan for the future and articulates the objectives. The Society utilizes the operational goals to evaluate performance; which is based on the objectives set, the plan to achieve these objectives, and itemized accomplishments to date.

1. Invest in world-class research that will lead to treatments to slow and prevent Huntington disease

2012-2013 Priorities

- Assess the quality of publications resulting from the research that HSC funds
- Increase participation in the National Conference to increase interest in clinical trials
- Increase the number of medical sites participating in clinical trials
- Create and implement ways to connect clinical sites on a regular basis to share best practices



2012-2013 Accomplishments

- A review of the impact of HSC research funding was completed. Our external expert concluded that HSC has received an excellent return on our investment in HD research
- Attendance at HSC's 2012 National Conference increased by 35 per cent over the previous Conference
- Eight medical sites in Canada are now participating in clinical trials research
- HSC received a \$10,000 grant from Rx&D to host a clinical trial readiness roundtable with experts from across the country

Focus moving forward

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

2. Continue to advocate for families and individuals living with HD and enhance the services we provide them

2012-2013 Priorities

- Carry out a gap analysis to identify communities that are underserved or not yet served by HSC
- Reach out to communities to ensure that the greatest number of people possible can access HSC resources and services
- Continue to play a leadership role in the Canadian Coalition for Genetic Fairness (CCGF)

2012-2013 Accomplishments

- The BC Social Worker position was added at the BC HD Resource Centre in Vancouver to expand services to individuals with HD across the province
- HSC met with genetic fairness champion Senator James Cowan to discuss Bill S-218, the most comprehensive piece of genetic discrimination legislation proposed in Canada
- HSC opened the East Central Ontario Resource Centre in November 2012
- HSC met with the federal Privacy Commissioner, presented at the Privacy Commissioners Summit, and met with Alberta's Finance Minister and Justice Minister
- HSC attracted significant media coverage of genetic discrimination

Focus moving forward

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

3. Increase the awareness of HD and HSC

2012-2013 Priorities

- Develop a new communications strategy
- Increase the number of new volunteers

2012-2013 Accomplishments

- HSC completed a new communications strategy
- The new PSA campaign was launched, attracting considerable attention
- Resource gaps were identified and HSC developed a schedule to update and create new brochures and fact sheets
- Approximately 10,000 volunteers across Canada contributed to fundraising and awareness

Focus moving forward

- Effectively tell HSC's story
- Create more opportunities for stakeholders and interested parties to become involved in the Society

4. Demonstrate leadership locally, nationally and globally

2012-2013 Priorities

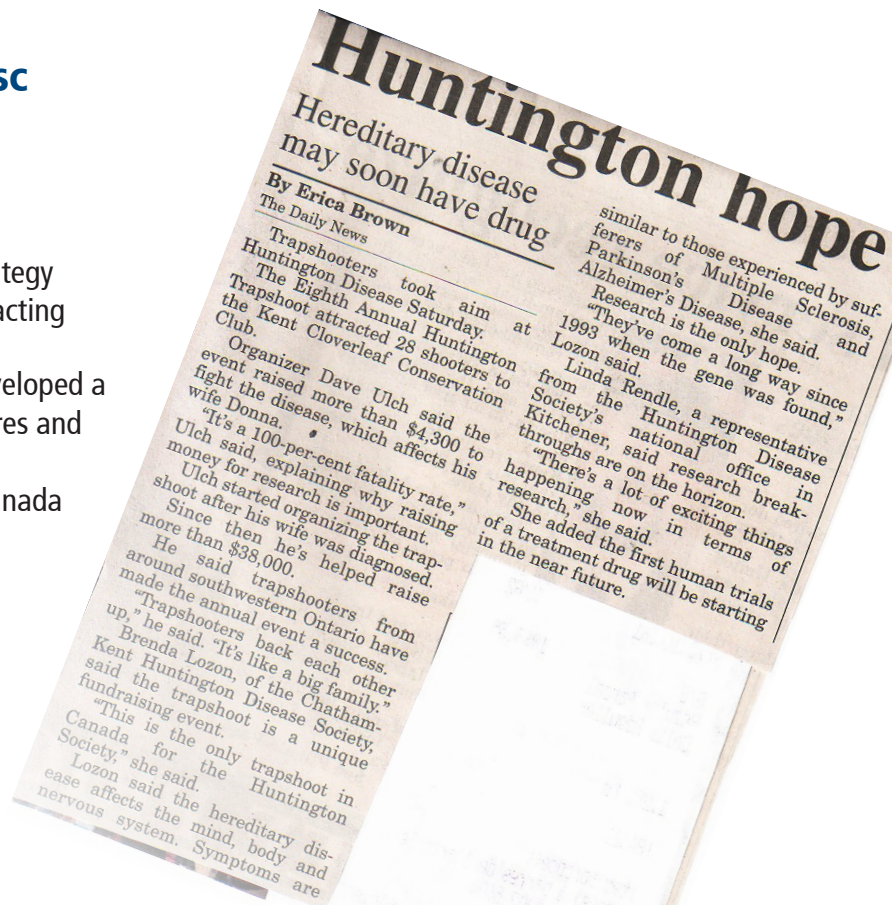
- Continue to play leadership roles and develop relationships with relevant coalitions, health organizations and like-minded charities

2012-2013 Accomplishments

- HSC's CEO continued to hold executive positions with the Canadian Coalition for Genetic Fairness, Health Charities Coalition of Canada and the International Huntington Association

Focus moving forward

- Increase global collaboration with HD service providers and organizations
- Explore opportunities for joint projects with other service providers (e.g., cultural organizations, First Nations, other neurological disease groups)



"Our Social Worker has watched over the kids since we learned of Bob's disease 6 years ago. He answers their questions, addresses their concerns and helps them manage the changes we see in Bob. I am so grateful to have the Huntington Society of Canada in our lives. The network of support they provide is invaluable. I could not imagine having to cope with HD without them." - Cheri DeLargie

5. Strengthen the focus on young people (pre-teens, teens, young adults) affected by HD and enhance the services we provide them

2012-2013 Priorities

- Ensure one member of Young People Affected by HD (YPAHD) is sitting as a decision-maker on each relevant international HD committee and the HSC Board
- Design and pilot a mentorship program for youth
- Enhance youth-specific support materials and website

2012-2013 Accomplishments

- HSC created a permanent position on the Board of Directors for a youth representative
- The YPAHD president sits on the Board of the Huntington's Disease Youth Organization (HDYO)
- The policy and procedure manual for our Youth Mentorship Program was developed and the recruitment of mentors began
- Our team worked with youth in the HD community to develop and launch a website that will serve as a hub for resources, events and community building

Focus moving forward

- Educate and advocate for youth-specific concerns and initiatives
- Train mentors and roll out the mentorship program
- Increase the number of youth affiliated with HSC

6. Ensure financial and organizational stability, effectiveness and excellence

2012-2013 Priorities

- Achieve financial revenue targets and manage expenses
- Continuously monitor and improve our policies and procedures
- Work towards charity accreditation opportunities to increase accountability and credibility
- Keep staff attrition at or below the industry standard

2012-2013 Accomplishments

- HSC met the expense management targets for 2012/13. The Society attracted four new major donors, experienced growth, and revenue from the grassroots fundraising events exceeded HSC's targets
- HSC enlisted the services of a Chartered Accountant consultant to identify operational weaknesses and help increase efficiencies
- HSC became a member of Imagine Canada in May 2013, a key step toward accreditation

Focus moving forward

- Achieve or exceed revenue growth targets
- Set the example for organizational stability, effectiveness and excellence
- Retain and nurture a high-performing team

***Overall the 2012
National Conference
was rated very highly***



Investing in Outstanding Research

Together, with your investments, HSC can take the next step and embrace promising new research such as gene silencing, advance pre-symptomatic treatments and develop promising new drugs to eventually reverse the effects of HD. This year the Huntington Society of Canada invested a significant amount of funds in research.

Each year, our Research Council members graciously donate their time and expertise to review grant applications from both established investigators and up-and-coming scientists. The HD Community works hard to raise that money, and we want to make sure that we continue to invest in quality and impactful research leading to answers as well as building research capacity.

Are we succeeding? In a word, yes. That is the conclusion of Dr. Harry Robertson, who reviewed the research we have funded over the past 15 years and the impact it has made.

“The quality and outcomes of the research supported by HSC is excellent,” reports the neurology and psychiatry professor from Dalhousie University.

Dr. Robertson bases his conclusion on several criteria. One is influence. HSC-funded researchers are getting published in prestigious, must-read science journals like *Nature* and *Proceedings of the National Academy of Sciences*.

“The quality and outcomes of the research supported by HSC is excellent.”

More importantly, other scientists are building on the research we fund. Take the example of Dr. Michael Hayden’s 2006 paper in *Cell*, describing how he and his team prevented HD from developing in a mouse model. While the average biomedical research paper is cited by 20 to 25 other researchers, Dr. Hayden’s paper earned 252 citations.

Most tellingly, Dr. Robertson could not find any examples of top-quality biomedical basic HD research in Canada that has not been funded by HSC. We have been successful in building a critical mass of excellent HD researchers in Canada. For that, we can thank HSC’s Research Council. The Research Council, along with other identified external experts, peer review each funding proposal we receive and select the most promising proposals leading to treatments that will slow or prevent the progression of HD.

The Research Council has also provided input to the HSC Board and helped us establish an effective funding strategy. Research is expensive and our grants are designed to support significant research. We are thankful for our partnership with the Canadian Institutes of Health Research who helps us to fund personnel awards and attract bright young investigators to the Huntington’s field.

As a result, our grants have helped to foster several centres of Huntington’s research across the country and encourage fruitful collaborations like the partnership between Dr. Simonetta Sipione and Dr. Ray Truant, who were able to completely reverse the motor symptoms of HD in mice using a drug called ganglioside GM1.

“In summary,” Dr. Robertson writes, “HSC has received an excellent return on their investment.”

According to Bev Heim-Myers, HSC’s CEO and Executive Director, that’s excellent news for the Huntington’s community. “Our donors can be very confident that their generous gifts are being used as effectively as possible to accelerate research, expediting the discovery of potential treatments to the HD population,” she says.

2012/2013 HSC Research Investments

NAVIGATOR:

Dr. Robert Cumming, Department of Biology, University of Western Ontario
Non-canonical activation of Nrf2 as a treatment for Huntington disease

We know that people living with HD have high levels of damaging “free radicals” in their brain cells. We also know that a protein called Nrf2 triggers the production of antioxidants that neutralize those radicals. Dr. Robert Cumming believes a drug called dimercaptopropanol (DMP) could enhance Nrf2 activity, reducing damage to brain cells. What makes this particularly exciting is the fact that, according to a report in 1955, DMP slowed the progress of HD in two individuals. Dr. Cumming will use his NAVIGATOR grant to determine how DMP activates Nrf2 and prevents brain cell death.



Dr. Robert Cumming

NEW PATHWAYS:

Dr. Jeff Carroll, Department of Psychology, Western Washington University
Mapping hepatic dysfunction in HD



Dr. Jeff Carroll

Huntington’s may be a brain disease, but it also affects the liver. Dr. Jeff Carroll wants to probe the connection between the two. He suspects that the changes HD causes in liver metabolism may reduce sugar levels in the blood, sugar that brain cells need in order to survive and function. Thanks to our New Pathways grant, Dr. Carroll will be able to investigate exactly how HD affects metabolism in liver cells in mice and identify key steps in the metabolic pathway that could serve as a target for drugs.



Maximizing Services

Due to the hereditary nature of Huntington disease, family is at the heart of the HSC community. In 1973, Ralph and Ariel Walker recognized that there was not only a need to connect with researchers, but also an overwhelming need to reach out to families affected by HD. The Huntington Society of Canada is a recognized global leader in the creation and advancements of Huntington disease family support programs.

The Huntington Society of Canada's Family Services program strives to maximize quality of life for those whose lives are impacted by Huntington disease. This program is the only comprehensive source of information, support and counselling within Canada. The complex and lengthy course of this illness, compounded by its genetic nature, means that Huntington's has a profound and often devastating impact on families. The HD community relies on HSC's essential services for guidance, resources, counselling and long-term care planning.

Reaching out – Providing Families and Healthcare Professionals with Needed Information

Families living with HD often describe how the disease isolates them. That is an even greater issue for families in remote communities and rural areas. For several years, HSC has used the Ontario Telemedicine Network to videoconference with families in Northern Ontario. This year, HSC negotiated a similar arrangement with the Saskatchewan provincial government. Using TeleHealth Saskatchewan, the Saskatchewan Resource Centre Director was able to connect with a family that is a five-hour drive from Saskatoon and advise staff in their local long-term care facility in a timely, efficient way. It's a delivery model the Society hopes to extend across the country.



Investing in Professional Development for Family Services Staff

Investing in the HSC staff ensures that the individuals the Society serves receive the best support possible. The day prior to the 2012 National Conference, HSC's team of Resource Centre Directors and Family Service Workers from across the country gathered for a **Family Services Update and Training Day**, honing their skills and gaining fresh perspectives into care, research and youth outreach. Meanwhile, attending the National Conference gave HSC's team the opportunity to connect with families, researchers and healthcare professionals from across the country. They returned home inspired, energized and better equipped as HD professionals.

Expanding Services

In keeping with our new Strategic Plan, two new staff members, each working 20 hours per week, have been hired to help boost the level of service in rural and remote areas. Last October, Renee Aeyelts joined the British Columbia HD Resource Centre in Vancouver as their **newest Social Worker**, focusing on supporting individuals with HD and planning the annual therapeutic retreat. Meanwhile, the opening of our **East Central Ontario HD Resource Centre**, last November, marked the Society's first new resource centre in more than five years. Director Marilyn Mitchell serves the fast-growing suburbs of Durham, the city of Peterborough, and the surrounding rural areas.

These positions expand HSC's services by more than five per cent, a big achievement in an environment where costs are rising and fundraising is challenging. Today, Canadians affected by HD can access a member of the family services team in every province from coast-to-coast except Prince Edward Island, which is served from the resource centre in Halifax.



Connecting, Inspiring, Informing 2012 HSC National Conference

The 2012 National Conference lived up to its title, connecting, inspiring and informing approximately 300 participants who gathered in Toronto in November. The biggest ever, the conference brought together families, researchers, volunteers, healthcare professionals and HSC staff to get the latest research updates and insights into care, as well as share their experiences and knowledge.

Ninety six per cent of participants rated the conference program **“excellent” or “very good,”**

Meanwhile, a new, award-winning Canadian documentary has drawn more attention than ever to the issues of genetic testing. The film, *Do You Really Want to Know?*, follows three families as they decide whether or not to be tested for the HD gene mutation. The film was screened at HSC’s National Conference in Toronto in November with rave reviews.

The Society also succeeded in reaching new people: for 58 per cent of participants, this was their first HSC National Conference. Perhaps most importantly, they told HSC that the conference left them with positive feelings about the future.

Advocating for Genetic Fairness

In December, The Globe and Mail helped raise the issue of genetic discrimination in Canada with an extensive and balanced series about Canada’s Personal Genome Project. It included an opinion piece by HSC’s CEO and Executive Director, Bev Heim-Myers that called for protection from genetic discrimination. It also told

the story of an individual who was denied mortgage insurance for the family farm because a family member was at-risk for HD. Bev also discussed the issue of genetic testing on an Ontario television station, TVO, in February before the screening of the award-winning documentary *Do You Really Want to Know?*.

The Society continues working closely with decision-makers in Ontario, Saskatchewan and Alberta to establish protection for Canadians against genetic discrimination. HSC has seen progress at the federal level. In June, the House of Commons Standing Committee on Health submitted a report on neurological disease in Canada. Among the committee’s excellent recommendations, they called on the Canadian government to protect the privacy of genetic test results.

In April 2013, the Honourable James S. Cowan QC, Leader of the Opposition in the Senate, introduced a very comprehensive genetic non-discrimination Bill in the Senate to end genetic discrimination in Canada.

Though other countries, including the United States, the United Kingdom, Germany and many other EU countries, have taken important steps towards eliminating genetic discrimination, Canada has fallen behind.

This Bill will help to bring the necessary level of protection to Canadians, aiming to ensure that genetic information is used properly without fear of repercussion. This would ensure that genetic information is used for health and research purposes only.

New Awareness Campaign Launched

In conjunction with the 2013 Huntington Disease Awareness Month, the Huntington Society of Canada launched a new Public Service Announcement (PSA) campaign called, "Do You Really Want to Know?". The campaign highlights Huntington disease and why the Huntington Society of Canada is leading the charge when it comes to genetic fairness in Canada.

Newspapers and television stations across Canada are generously donating their space and air time to run this campaign at no charge. This is the first time, thanks to the producers of the award-winning documentary *Do You Really Want to Know?*, the Society has been able to produce a commercial for television. It is being shown across Canada to raise awareness of HD and Genetic Fairness.

Researchers feel we are close to reliable treatments; the urgency lies in educating as many people as possible, including new outreach efforts in rural and cultural communities.

HUNTINGTON
SOCIETY OF CANADA

DO YOU REALLY WANT TO KNOW?

MY REALITY
I have a 50% CHANCE of inheriting Huntington disease. These results will tell my fate.
Huntington disease is a genetic brain disorder that DESTROYS LIVES. It is like having Alzheimer's, Parkinson's and Schizophrenia all in one disease.
AND WORSE YET IF I test positive, my children will have a 50% CHANCE of inheriting the disease too.
Currently, there is NO KNOWN CURE.

CANADA'S REALITY
Genetic testing is available to ALL CANADIANS.
WE ARE ALL AFRISK of our genetic information being used against us.
Employers and insurance companies can and do DISCRIMINATE based on our DNA information.
Canada is the only G8 country that DOES NOT PROTECT our genetic information.

The Huntington Society of Canada is actively working to end genetic discrimination in Canada.

www.huntingtonsociety.ca 1-800-998-7398

Scenes/Footage from the film, Do You Really Want To Know? www.Doyoureallywanttoknowfilms.com

Along with the Society's 40th anniversary campaign, HSC decided to update our publications and information with the new look and the most up-to-date and current information.

A major project that was completed was the new Canadian version of *A Physician's Guide to the Management of Huntington Disease*. This publication, aimed at helping physicians understand Huntington disease, was reviewed by the original authors and by many professionals from the Huntington's community to ensure the information accurately reflected Canadian content. Copies are now available and have been distributed across Canada.

Investing in our Youth

The Huntington Society of Canada's first ever Youth Day proved to be a huge success. Held immediately before last November's National Conference, the event brought together more than forty youth for peer-to-peer support and leadership development. The day featured many excellent sessions, but the biggest highlight was connecting with one another.

For many, it was their first experience with Young People Affected by Huntington Disease (YPAHD), HSC's national youth chapter, and their first opportunity to meet others their age from the Huntington's community. According to one participant, "This is the first time that I have hope."

Youth gathered from across Canada in Toronto, Ontario, to connect with each other, hear from experts in the HD field, and build a plan for youth collaboration for the coming years.

Attendees believe that YPAHD Day was a huge success!

The day included various sessions including a peer-lead HD 101 session, relationships and dating, international youth collaborations, and for the older attendees, discussions on genetic testing and pregenetic diagnosis & IVF.

The youth who attended left with a feeling of empowerment and focus. From seeds planted on November 8th, youth across Canada have hosted, or plan to host, information, support and fundraising events across Canada, and have assisted HSC in its development of the HD Youth Mentorship program. YPAHD has already started planning the schedule for the 2014 YPAHD Day.

Thanks to donors, HSC is piloting a new Youth Mentorship Program this year to help teens growing up in families affected by HD. Because HSC knows youth often feel more comfortable talking with other youth, the Society is recruiting volunteer mentors (in their twenties) who have lived through the same experiences. They will be trained to provide one-on-one support to their younger peers with assistance from the professional Family Services staff whenever they need it.

The HSC Youth Mentorship Program is designed to support young people across Canada face the everyday challenges of growing up in a family affected by Huntington disease. HSC is committed to offering a nationwide mentoring program that provides youth with one-on-one time and attention with a mentor who will receive ongoing support from the Social Workers within HSC.

The goal of the program is to offer young people the opportunity to connect with a volunteer mentor who will be able to provide them with valuable support at critical points in their lives. The volunteers involved in the program will also be from families affected by HD. Sharing this common experience may assist them in better understanding and connecting with the youth mentees. The mentors will be committed to supporting, guiding, and being a friend to the mentee. The mentors will listen and provide the youth with accurate and age appropriate information.

The Youth Mentorship Program strives to:

- Encourage and help prepare youth for the challenges they face
- Serve to help break down the sense of isolation many youth affected by HD experience
- Assist youth in making informed decisions about their life
- Provide youth with positive role models and support
- Connect youth to YPAHD, HSC and the HD community

An extra 10 years would be huge

The Patterson Family

“My only wish is for my dad to get better...When I was younger; I thought that if I wished on a star enough times, eventually my wish would come true. Now I know that the only way this wish will come true is with your help.”



Hank Patterson

When my mother was 41, she found out that her mother had died of HD. My father had already died of a heart attack, leaving her to raise four children in poverty. Now she had to deal with the news that her twitching, balance and memory problems were signs of a fatal disease, and that each of her children had a 50 per cent chance of inheriting it.

For the next two decades, my siblings and I watched HD take away her bodily functions, her memories, her personality and her dignity.

Not long after Sharanie and I got married, we decided that I should get tested. **Finding out I had the gene, as horrible as it was, at least allowed us to make the right decisions and plan for the future.**

When Sharanie got pregnant, we had Nicole tested in vitro. Finding out she didn't carry the gene was the happiest day of our lives. It was like winning the World Series. When I kiss my daughter goodnight, I can tell myself that she'll never have to deal with this disease.

She'll have to deal with me, of course. I would change that if I could. But at least she never has to look at me and think, "this is my future." She never has to worry about developing HD or passing it on to her future children. In my family, the disease ends with me.

Huntington's is a horrible, horrible disease. It affects your memory. It affects your personality. It takes away your dignity, and it destroys families. But I really do believe that in 10 or 15 years, researchers will find a way to delay the onset or stop it from progressing. They may even cure it, but just giving people an extra 10 years would be huge. **Investing in research gives families hope — and having that hope is just so, so important.**

Nicole Patterson

When my dad was no longer able to work, my parents decided to tell me about the disease. I was 11. It was the beginning of the worst year of my life.

The hardest thing to take was when they told me what would happen to my dad. I had seen what my grandmother was like, and honestly, it terrified me. The worst symptom for me was the memory loss. It wasn't so bad that my dad wouldn't remember little things, but mainly that one day he wouldn't remember who I am. He's been my best friend since I was a little kid.

My only wish is for my dad to get better and to be in my life for just a few extra years. When I was younger, I thought that if I wished on a star enough times, eventually my wish would come true. **Now I know that the only way this wish will come true is with your help.**

Is it too much to ask for? A few extra years with my dad?

TREASURER'S REPORT

2012 - 2013

I am pleased to report on the financial results of the Huntington Society of Canada (HSC) for the fiscal year ended June 30, 2013.

The financial statements for 2013 reflect the adoption of new accounting standards for not-for-profit entities as required by the Canadian Institute of Chartered Accountants. While the key accounting policies have remained the same, the new standards require that unrealized gains or losses on investments be included within the excess of revenue over expenses. This mandatory policy will create volatility in the financial results when the value of investments fluctuate. In addition, the contribution made by the Chapters is now presented on a gross basis, presenting revenue and expenses which provides greater transparency in financial reporting.

Revenues for 2013 exceeded \$3.9 million, increasing from the prior year by almost \$600,000. Donations and Chapter fundraising (on a gross basis) both improved over \$200,000 along with unrealized gains on investments relative to prior year unrealized losses. HSC is very dependent on the generosity of the community and Chapters who assist in fundraising efforts; the results have been outstanding. Chapter fundraising provided a net contribution exceeding \$1.3 million, compared to the prior year of approximately \$1 million.

The revenue growth contributed to an excess of revenue over expenditures of \$75,000 in the fiscal year, including a small surplus in the general fund which represents the activities not otherwise in a restricted fund. Expenses were held consistent with the prior year despite progress on initiatives including increased support to families and investment in youth programs. Our General Fund balance continues to exceed \$700,000 at June 30, 2013.

HSC is dependant on the generosity of the HD Community.

Spending within the two externally restricted funds, the Ralph Walker Research Fund and Laura's Hope Fund, was approximately \$380,000 supporting qualifying general research and pre-clinical/clinical research. Generally, the Society seeks to invest relatively equally in Family Services and research, however, we must also balance that priority with our Board policy regarding the maintenance of sufficient net assets in the Ralph Walker Research Fund to meet future research commitments. The Society remains committed to supporting high quality research in Canada. Total research spending in 2013 was \$760,638 which included \$378,648 of General Fund research expenditures.

The Statement of Financial Position reflects assets of approximately \$3 million, offset by liabilities of \$340,000. In order for the long term objectives of the Society to be achieved, opportunities to enhance revenue continue to be sought. The Board of Directors remains committed to appropriate stewardship of the Society's financial resources. The key financial roles of the Board are enhanced through both an audit committee and an investment committee. Our financial statements are subject to an annual audit by an independent auditor.

HSC continues to focus on supporting individuals and families affected by Huntington disease, building the foundation for clinical trials, investing in world-class research, and continuing our advocacy efforts to benefit the HD Community, including ending genetic discrimination in Canada. We wish to express our sincere gratitude to our funders, volunteers, and our staff for their continued support in finding answers for Huntington disease.



Glenda Rowein, Treasurer



HUNTINGTON SOCIETY OF CANADA

Statements of Financial Position

June 30, 2013, June 30, 2012 and July 1, 2011

	June 30, 2013	June 30, 2012	July 1, 2011
Assets			
Current assets			
Cash	\$ 274,225	\$ 148,842	\$ -
Investments	2,490,204	2,551,859	3,319,373
Accounts receivable	156,391	182,463	361,690
Prepaid expenses	45,171	56,658	45,047
	2,965,991	2,939,822	3,726,110
Capital assets	38,316	28,762	37,656
	\$ 3,004,307	\$ 2,968,584	\$ 3,763,766
Liabilities and Fund Balances			
Liabilities			
Bank indebtedness	\$ -	\$ -	\$ 425,242
Accounts payable and accrued liabilities	239,847	130,523	109,357
Deferred revenue	100,251	248,914	213,010
	340,098	379,437	747,609
Net assets			
General fund (note 1)	709,286	731,073	762,388
Capital assets fund	38,316	28,762	37,656
Endowment fund (note 2)	1,730,464	1,618,442	1,629,776
Laura's Hope fund (note 3)	3,049	68,312	176,894
Ralph Walker Research fund (note 4)	183,094	142,558	409,443
	2,664,209	2,589,147	3,016,157
	\$ 3,004,307	\$ 2,968,584	\$ 3,763,766

HUNTINGTON SOCIETY OF CANADA

Statements of Operations

Years ended June 30, 2013 and 2012

	General Fund	Capital Assets Fund	Endowment Fund	Laura's Hope Fund	Ralph Walker Research Fund	Total 2013	Total 2012
Revenue							
Donations	\$ 1,405,675	\$ -	\$ 13,535	\$ 17,842	\$ 199,997	\$ 1,637,049	\$ 1,319,915
Grants	63,376	-	-	-	100,250	163,626	375,510
Chapter and volunteer fundraising revenue (note 5)	1,813,951	-	2,800	-	22,274	1,839,025	1,608,097
Investment and interest income	74,468	-	-	715	1,830	77,013	84,922
Realized gain on sale of investments	35,423	-	-	-	1,964	37,387	25,727
Unrealized gain (loss) on investments	29,601	-	95,687	-	12,391	137,679	(50,681)
Other income	42,006	-	-	-	-	42,006	10,500
	3,464,500	-	112,022	18,557	338,706	3,933,785	3,373,990
Expenses							
Research (note 6)	378,648	-	-	83,820	298,170	760,638	820,485
Family services	1,191,255	-	-	-	-	1,191,255	1,078,131
Public awareness and education	391,828	-	-	-	-	391,828	262,599
Chapter and volunteer support	169,505	-	-	-	-	169,505	137,750
Development	375,832	-	-	-	-	375,832	479,369
Chapter and volunteer fundraising expenses (note 5)	472,254	-	-	-	-	472,254	547,259
Administration	479,664	-	-	-	-	479,664	459,091
Amortization	-	17,747	-	-	-	17,747	16,316
	3,458,986	17,747	-	83,820	298,170	3,858,723	3,801,000
Excess (deficiency) of revenue over expenses	\$ 5,514	\$ (17,747)	\$ 112,022	\$ (65,263)	\$ 40,536	\$ 75,062	\$ (427,010)

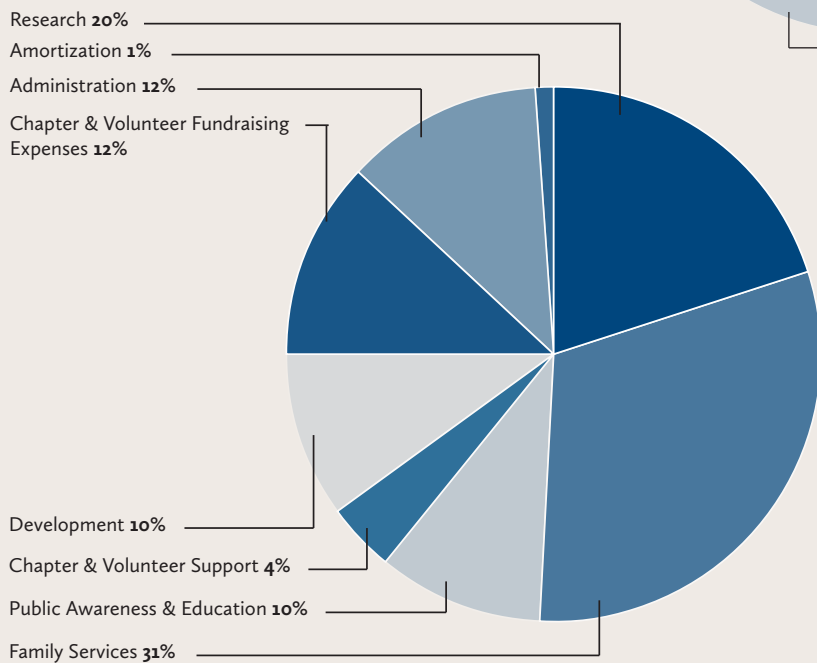
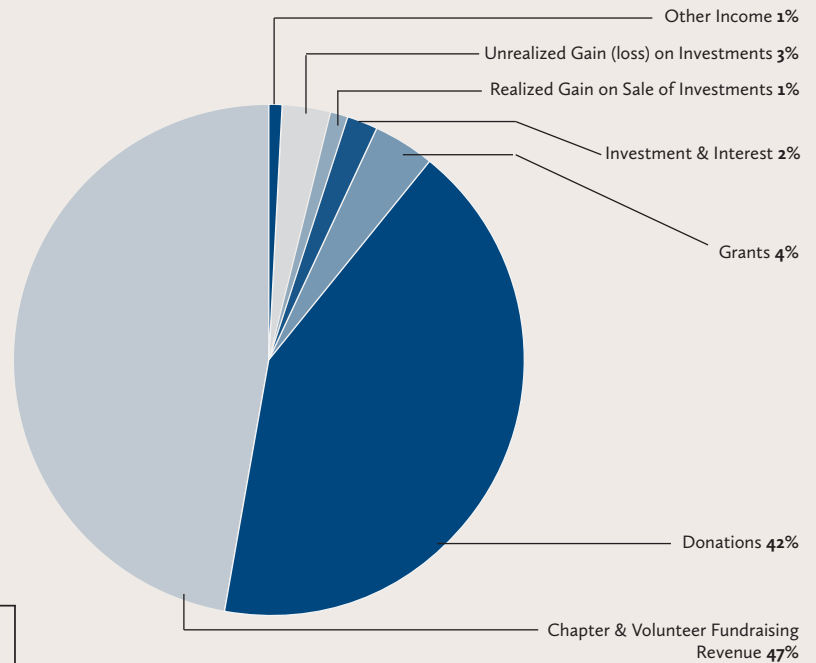
HUNTINGTON SOCIETY OF CANADA

Statements of Changes in Fund Balances

Years ended June 30, 2013 and 2012

	General Fund	Capital Assets Fund	Endowment Fund	Laura's Hope Fund	Ralph Walker Research Fund	Total 2013	Total 2012
Fund balances, beginning of year	\$ 731,073	\$ 28,762	\$ 1,618,442	\$ 68,312	\$ 142,558	\$ 2,589,147	\$3,016,157
Excess (deficiency) of revenue over expenses	5,514	(17,747)	112,022	(65,263)	40,536	75,062	(427,010)
Interfund transfers	(27,301)	27,301	-	-	-	-	-
Fund balances, end of year	\$ 709,286	\$ 38,316	\$ 1,730,464	\$ 3,049	\$ 183,094	\$2,664,209	\$2,589,147

Revenue



Expenditures

Notes to the Financial Statements

Years ended June 30, 2013 and 2012

1. The General fund is an unrestricted fund used at the discretion of the Board of Directors to fulfill the mission of the Society in all areas, including research, family services, public awareness and education, chapter and volunteer support, development, chapter and volunteer fundraising, and administration. All undesignated donations are recorded in this fund.
2. The Endowment fund is restricted and accounts for donations received which the donor has designated specifically for endowment purposes. In exceptional circumstances, and subject to approval of two-thirds of the Board of Directors of the Society, funds may be transferred from the capital of the Endowment fund to the General fund to finance special projects or unbudgeted annual deficits. Annual interest earned and realized gains (losses) on the sale of investments in the Endowment fund are used to fund operational expenditures in the General Fund. Unrealized gains (losses) on Endowment fund investments are retained in the Endowment fund until realized through the sale of investments.
3. The Laura's Hope fund is an externally restricted fund established in honour of Laura Evans by her parents in 2003. The purpose of this fund is to support pre-clinical and/or clinical research towards developing a treatment or a cure for Huntington disease, and revenues specifically designated by donors to this fund have been restricted for this purpose.
4. The Ralph Walker Research fund is a restricted fund established in 1983 to commemorate the 10th anniversary of the Huntington Society of Canada and to pay tribute to the Society's founder, Ralph Walker. Revenues specifically designated by donors to this fund have been restricted for research, along with any related expenses.
5. Chapter and volunteer fundraising revenue and expenses are reported at gross on the Statements of Operations in these financial statements. In prior years, chapter and volunteer activities were shown net on the Statements of Operations.
6. All research payments are expensed as payments are made.
7. The Society has adopted Canadian accounting standards for not-for-profit organizations in Part III of the Canadian Institute of Chartered Accountants' ("CICA") Handbook. These are the first financial statements for which the Society has applied these new accounting standards for not-for-profit organizations. In accordance with the transitional provisions in the not-for-profit accounting standards, the Society has adopted the changes retrospectively, subject to certain exemptions allowed under these standards. The transition date is July 1, 2011, and all comparative financial information provided has been presented by applying these standards.
8. There is no impact on opening fund balances as of July 1, 2011, as a result of the transition to Canadian accounting standards for not-for-profit organizations. The change in accounting standards does impact the reporting of deficiency of revenue over expenses, since the new standards require that unrealized gains and losses on investments, resulting from a change in fair value of investments, be reported directly on the Statement of Operations. Previously, unrealized gains and losses on investments were reported on the Statement of Changes in Fund Balances. Since investments continue to be recorded at fair value, there is no impact on investments or total net assets. As a result of the retrospective application of these standards, the Society recorded a transitional adjustment to increase the deficiency of revenue over expenses for the year ended June 30, 2012 from \$376,329 to \$427,010 due to an unrealized loss on investments in 2012 of \$50,681.

A complete copy of the Society's audited financial statements is available at www.huntingtonsociety.ca.

Breaking the Isolation

Brenda Wasylow

"I don't remember my mother ever being well. She had all sorts of odd behaviour; she had bad coordination; she staggered. We really didn't understand what it was. The kids in the neighbourhood assumed my mom was drinking, and they could be very cruel."

Brenda Wasylow

My mom was finally diagnosed with Huntington disease when I was 13, but even then we really didn't learn much. **We were told that there's a 50/50 chance you'll get it, and sorry, there's nothing we can do for you, there's no services in place, and there's really no one you can talk to about it.** We didn't have the internet back then, so there was nowhere to go for information.

At 13, you're starting to think about what life is going to look like. **My vision was that there was a loaded gun to my head.** I was a pretty bright kid, but my dad told me not to go to university because chances were, I wasn't going to need it. His attitude was, *"maybe you can find somebody that will marry you, but remember that you could get sick, and you shouldn't have children."*

I guess it's not surprising that I married the first guy that would have me. It didn't work out, but leaving him helped me turn the corner and decide to make the best of every day I had. I reached out after that and got the help I needed. At that point, there was an HSC chapter that had just formed in Saskatoon. It was good to

"As a young woman, you wonder if somebody is going to love you. You wonder whether someone will want to be your life partner, knowing what could happen to you. You wonder about having children."

connect with other people that were going through some of the same challenges and struggles.

I did go to university, and I eventually earned my CMA designation. Today, I'm a partner in a fabulous company. I also went for genetic testing and found out I do not have the HD gene. I'm doing OK. Now, it's about stepping up to the plate and helping other people who are affected.

I lost my mother to HD in 1992 and my sister in 2006. My brother is currently in a long-term care facility. Now it's my cousins and my cousins' children. **This disease touches people and families in such a profound way.**

As a young woman, you wonder if somebody is going to love you. You wonder whether someone will want to be your life partner, knowing what could happen to you. You wonder about having children. **We need resources in place so that young people can get information, feel safe asking questions and connect with other people who share their fears.**

We need support for people who test positive for the gene. How do they prepare? How do they deal with that emotionally? How can they make good choices?

And for people who have the disease, we need to provide resources such as communication devices and occupational therapy to improve their lives.

Our families are important. Our children are important. And that's why we need to reach out and help them live their best lives.

Thank you

On behalf of the Huntington Society of Canada, the Board of Directors, the Huntington's community and the families we serve, thank you for your generous donations. We have a unique opportunity in Canada to take a leadership role in building a strong Canadian Clinical Research network that will enable the translation of discoveries into meaningful treatments for patients. Many steps are needed to be successful in this endeavour and in our ongoing efforts to support families across Canada, your contributions help us begin to implement the necessary steps. Thanks to all of our generous supporters, for believing in the work that we do, you help us make a difference in the lives of people who have to face Huntington disease every day. You help us provide substantive hope.

Devlin Fund For Families (\$500,000.00 and above)

Dan & Jill Devlin

40th Anniversary Donors (All contributors)

Over the next two years HSC is celebrating their 40th Anniversary. Thank you to those who have committed to this historic campaign this year.

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Acrodex
Anne & John Brace
Vern & Ellen Barrett
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Dan & Jill Devlin
Stephen Gould
Maxim Power Corp
Ardis McArthur
Grant McArthur & Tamara Costa-McArthur
The Mark Mercier Foundation
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Bruce A. Saville
Jan M. Todd
Stan & Dorota Weber

Cornerstone Donors (\$250,000.00 +)

1214539 Ontario Ltd
Anne & John Brace
Co-Op Atlantic

Leadership Donors (\$100,000.00 +)

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Distinguished Donors (\$25,000.00 +)

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(\$1,000.00 +)

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Canadian Coalition for Genetic Fairness (CCGF): HSC chairs this alliance of 15 organizations dedicated to educating Canadians about genetic discrimination and advocating for positive change at the federal and provincial levels to ensure genetic fairness in Canada.

European Huntington's Disease Network (EHDN): A critical partner "across the pond," the EHDN provides a forum for working together and advancing clinical trials and research.

Health Charities Coalition of Canada (HCCC): As an executive member of the HCCC, HSC collaborates with more than two dozen other national charities to share best practices and advocate for better health policies in Canada.

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HDBuzz: HSC is proud to be a founding funder and ongoing supporter of this international initiative. The cost-effective and one-of-a-kind service delivers the latest HD research news in easy-to-understand language and is helping spark interest in upcoming clinical trials.

Huntington's Disease Society of America (HDSA): HSC shares a close relationship with counterparts south of the border. Whether collaborating through the International Huntington Association or through one-on-one projects like the *Physician's Guide*, the partnership continues to thrive.

Huntington Society of Quebec (HSQ): HSQ serves the distinct needs of Quebec while maintaining strong links with HSC. An HSQ representative sits on the Board of Directors, and partners with HSC to ensure all Canadians have access to the services they need.

Huntington's Disease Youth Organization (HDYO): HSC is a founding funder of this online community, which brings together young people affected by HD from around the world. By pooling resources with other HD organizations to support HDYO, HSC is able to give youth a voice and deliver age-appropriate information and resources.

International Huntington Association (IHA): HSC is a founding member and a current board member of this global forum dedicated to sharing best practices and resources with other HD organizations around the world.

Neurological Health Charities Coalition of Canada (NHCCC): By leveraging the collective strength of more than 20 organizations, including HSC, this coalition works to influence federal policy and improve the lives of people with neurological diseases and their caregivers.

HSC is playing a leadership role in the Canadian neurological community



Cheri DeLargie

A Part of Our Family

"I remember the first time I heard about the Huntington Society of Canada. It was September 1, 2006. Bob and I were sitting in a room at University Hospital in London, ON, getting the results from Bob's blood test. I didn't realize then how much our family would come to rely on HSC from that day forward."

Our Huntington Society of Canada Family Support Worker, Corey, has been a valuable part of our family. He was there for us just days after we decided it was time to tell our children. Katie was 10, Erik was 9 and Ty was just 4. They had an instant connection with him, and Ty even asked him to come over for Christmas dinner. **Corey has seen our ups and downs over these last six years and watched the kids as they grow and their questions and concerns change. We could not imagine having to cope with Huntington disease (HD) without him.**

For me, the support group meetings that Corey runs every month are invaluable. I have come to rely on our group for laughter, tears, support and friendship.

Our family's first introduction to the broader Huntington's community was in Toronto at the 2008 Casino Royale fundraising event. Katie was asked to be a guest speaker after my best friend Sarah sent the head office a copy of Katie's Grade 5 speech about her dad and HD. Later that year she was asked again to speak at the HSC Conference in Charlottetown and then the World Congress on Huntington's Disease in 2009. It has been great to see Katie develop through those experiences and contribute to the Huntington's cause.

Finally, the HSC Retreat in Ontario is just amazing. Not only does it do wonders for Bob, but it allows me and the kids, as caregivers, a much-needed break. Bob is able to go there, meet up with his HD friends and participate in supervised activities that would be difficult for him to do anywhere else. **He gains back some of his lost freedom in a safe, supervised, beautiful setting.** The kids and I are able to relax knowing that he is well taken care of and, most of all, he is enjoying himself. We can't thank the HSC enough for that small break for all of us.

Living with Huntington's isn't easy, but we try to stay positive, help each other, and do our part to raise money and awareness. And when we need support, we feel good knowing that HSC is there for us.

"Family life with HD is extremely difficult on many levels. It has its challenges, but ultimately we have to set our emotions aside and realize we need to make great memories to last a lifetime. The friendships and support we have found through HSC have helped make it possible for Bob and I and the kids to lead our best life with HD."

Volunteers are the backbone of HSC

Volunteers are instrumental in furthering HSC's mission through initiatives in fundraising, education and advocacy. Such a strong national network of individuals so passionately tied to this cause enables the Society to communicate their mission from coast-to-coast. The efforts of the volunteers enhance and multiply those of the HSC staff, allowing the Society to follow, the founder, Ralph Walker's motto, "When you dream, dream big". HSC's volunteers bring fresh perspectives, experiences and ideas to the table, moving the Society forward and contributing to the ultimate realization of the vision of HSC.

The Society thanks every volunteer for sharing the same vision and for sustaining HSC's work. The generosity of all the volunteers means everything to the Society. The HSC community of families, donors, volunteers, researchers, staff and healthcare professionals have achieved extraordinary things over the past four decades. Together, HSC and volunteers will achieve even more in the years ahead.

A special thank you to our Leadership Volunteers, your hours of dedication to the Society are truly valued.

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Co-op's 14th Annual Charity Golf Tournament

Co-op's 14th Annual Charity Golf Tournament

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