

2018 - 2019 ANNUAL REPORT

Stronger Together.



Mission

The Huntington Society of Canada (HSC) 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. HSC also works with health and social services professionals to enable them to better understand the needs of people living with HD.

Vision

HSC aspires to a world free from HD and works to maximize the quality of life of people living with HD by:

- Delivering services;
- Enabling others to understand the disease; and
- Furthering research to slow and prevent HD.

Family is at the heart of our community. Our families and volunteers tell a powerful story of caring people who pull together to improve the quality of life for Canadians impacted by HD. HD is a fatal hereditary brain disorder with devastating effects on both the mind and body. It is like having the symptoms of Alzheimer's disease, Parkinson's disease and Amyotrophic Lateral Sclerosis (ALS) all in one.

The good news is, with recent medical breakthroughs, many researchers and scientists believe that once we are successful in stopping the progression of HD we will also find the answers to many other neurological diseases. Your valued support is helping to bring us closer to this goal.

HD Facts:

- **Huntington disease is a fatal, hereditary brain disorder.**
- **A child born to a parent with HD has a 50 per cent chance of inheriting the gene mutation which causes HD.**
- **1 in every 1,000 Canadians is impacted by HD.**
- **Currently there is no known cure for HD.**





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Front and Back Cover Images: Southern Alberta Hope for a Cure Run/Walk, Calgary, AB.

Message from the CEO and Board Chair

For decades, the HD community has been powered by hope - a remarkably resilient force. Slowly but steadily, we have been carving a path toward meaningful treatments for HD. Now, we are closing in on our destination, with therapies currently in clinical trials that address the root cause of HD.

It is important to remember these are trials, not proven therapies and it is likely we are going to hit a few bumps in the road before treatments become commercially available. However, as more trials prepare to launch and more pharmaceutical companies enter the arena, we have never had more reason to believe there may soon be a treatment that will stop the progression of this disease.

HSC continues to invest in research and we have launched a clinical fellowship program to expand Canada's capacity to test and deliver potential treatments. The program is designed to attract young neurologists to the HD field and equip them with the expertise to run clinical trials. We are very excited to see what this initiative brings.

At the same time, HSC is seeing an increased need for our outreach services. In order to meet those demands, we continue to offer new types of support.

In August 2018, we opened a Resource Centre to serve Ontario's growing Halton/Peel region. We also established a new national social worker position to offer virtual ways to connect our community.

Over the last nine months, our Families Services team helped more than 3,000 Canadians affected by HD through various means such as support groups, one-on-one counselling, presentations and referrals. Meanwhile, 30 youth across the country received support from trained peers through HSC's world-leading Youth Mentorship Program.

As well, we continue to advocate for the HD community. The federal Genetic Non-Discrimination Act now protects Canadians — a landmark achievement — but it is being challenged. We extend our sincere appreciation to Bev Heim-Myers, who is working diligently to protect this legislation through the Canadian Coalition for Genetic Fairness (CCGF). You can read more about this on Page 7.

You will see from our financial statements, we are changing our fiscal year at HSC.

However, as explained in the Treasurer's Report beginning on Page 18, 40 per cent of our revenues come in between April and June, thanks, in part, to the highly successful HD Awareness Month in May. Shifting our year-end to March 31 means those revenues will arrive at the beginning of the fiscal year, making planning and budgeting much easier. This is our transition year, so when you review the 2018-19 financial statements, keep in mind you're looking at just nine months of numbers (July 1, 2018 to March 31, 2019).

Events continue to bring the HD community together. Our National Conference in Kelowna, BC last fall attracted more

participants than we have ever had before. The same was true for Young People Affected by HD - YPAHD Day. HSC's special youth conference and forum.

In fact, every event held serves to underline one key point: people are our strength.

We salute our 23 chapters and active areas, who do so much to support families, raise awareness and generate the funds that keep us moving forward. We are seeing more individuals step up to support HSC with new event ideas, ranging from car shows to comedy nights. Meanwhile, tried-and-true events are going strong across the country: walks and indys of course, but also volleyball tournaments, trapshoots and events like Calgary's "Night to Flourish", which celebrated its 30th anniversary in October.

Other volunteers are making equally important contributions. We are incredibly grateful to the clinical trial participants who are testing potential treatments on behalf of the entire HD community and to

everybody involved in the observational studies that are giving investigators important insights into this disease.

Kudos as well to the researchers, healthcare professionals and caregivers who work so tirelessly and to our HD-COPE volunteers, who are helping pharmaceutical companies to shape clinical trials. Thank you to our office and virtual volunteers, our Board of Directors and our Research Council members: HSC could not operate without you.

HSC is blessed with a strong staff of highly competent individuals who are each experts in their field and passionate about working on behalf of the HD community. We thank them, as well, for all they do, day in and day out.

Finally, we extend heartfelt gratitude to the hundreds of generous donors who continue to dig into their pockets to support families and put an end to HD.

Because of all of you, the future has never looked brighter.



Robin Markowitz

Robin Markowitz

Chief Executive Officer
Huntington Society of Canada



B. Nowakowski

Brenda Nowakowski

Chair
Huntington Society of Canada

2018-2019 Board of Directors

HSC Executive

Brenda Nowakowski
Chair

Sean Dewart
Secretary

Dr. Ray Truant
Research Council Chair

Mack Erno
Vice-Chair

George Halatsis
Treasurer

Catherine Price
YPAHD Representative

Christian Lejeune
Société Huntington du Québec

HSC Directors At-Large

Billy English

Dr. Mark Guttman

Brenda Mason

Doris Ramphos

Robert Scriven

Brynne Stainsby

Andrew Wright

Jonathan Genest-Jourdain

Canadian Coalition for Genetic Fairness

The Canadian Coalition for Genetic Fairness (CCGF), chaired by former HSC CEO Bev Heim-Myers, comprises a group of organizations dedicated to preventing genetic discrimination against individuals, based on their genetic make-up. CCGF is dedicated to advocacy within governments at the federal, provincial and territorial levels - to create positive changes for the HD community and all Canadians. HSC and the HD community have been strong supporters of this issue.

The Government du Québec (Québec government) is challenging the Genetic Non-Discrimination Act (GNDA), which came into effect in May 2017. Heim-Myers has been working closely with lawyers in both Toronto and Québec. On behalf of CCGF, Heim-Myers referred the Québec decision to the Supreme Court of Canada (SCC).

A hearing at the Cour d'appel du Québec (Court of Appeal of Québec) regarding the GNDA, took place on December 11 and 12, 2018. Arguments in support of the GNDA were presented by lawyers who represent both the CCGF and the Canadian Human Rights Commission (CHRC), stating that it is indeed a valid exercise of the Parliament of Canada's criminal law power. The court appointed an Amicus (an impartial adviser to a court of law), who also argued in favour of the GNDA.



Conversely, legal representation for the Québec Attorney General (AG) the Canadian Life and Health Insurance Association (CLHIA) and the AG of Canada argued against the GNDA being a valid exercise of the Parliament of Canada's criminal law power. British Columbia's AG also intervened against the GNDA, but did not verbally present arguments in court.

On December 21, 2018, the Court of Appeal of Québec unanimously took the disappointing, yet expected, view that the GNDA is not a valid exercise of the Parliament of Canada's criminal law power.

It is important to note, however, that the Court of Appeal of Québec did not express an opinion on the GNDA's ultimate validity or invalidity. That would have been beyond the scope, because courts do not issue declarations of invalidity in references; they simply provide advisory opinions on the questions referred to them. However, this opinion does threaten the GNDA.

The CCGF subsequently filed a notice of appeal, as the appellant (plaintiff), referring the decision of the Court of Appeal of Québec to the SCC. Accepted, as of right, in January 2019, this means that the CCGF will be the appellant as this case moves to the SCC.

The AGs of Canada, Québec, British Columbia and Saskatchewan each filed a notice of intervention (as is their right in such cases). The CLHIA, CHRC, Privacy Commissioner of Canada (PCC) and Canadian College of Medical Geneticists (CCMG) also applied for leave to intervene. Of these, the CHRC, PCC and CCMG all support the position taken by CCGF. The SCC granted all applicants intervener status.

Once granted intervener status, those interveners have the opportunity to file a factum (statement of fact) and each party has done so (the CCGF factum was also shared with the CCGF membership). CCGF Lawyers have responded to the factums submitted.

The SCC has appointed an Amicus to represent the GNDA. The hearing is scheduled for October 10, 2019.

It is important to remember that the GNDA is currently still law, but it is threatened. Please let our government decision makers know that a pan-Canada federal law to protect genetic test information is important to you and to the health and well-being of all Canadians.

Amaryllis Campaign

For over three decades, the Amaryllis has been the signature flower of the HSC. In particular, the robust and stunning Amaryllis Orange Sovereign (Hippeastrum) has become synonymous with the organization. Long-lasting, this well-proportioned blossom never fails to attract attention.

Each kit arrives packaged in a lovely gift box, which contains one high-quality Orange Sovereign bulb, growing instructions, soil, a planting pot, a plant stake and a saucer.

Our dedicated “Amaryllis Volunteers” across the country work hard each year to sell bulb kits to help raise vital funds for our HD research, and HSC services and programs. In short, each kit sold means we are a step closer to finding a treatment for HD.

During the 2018-2019 campaign, HSC supporters purchased 21,204 Amaryllis bulbs - eventually to bloom from coast to coast, helping to raise awareness and inspire hope for a world free from HD.

Since 1985, HSC’s dedicated Amaryllis volunteers have raised well over \$5.5 million in support of HD. We are looking forward to another successful campaign in 2019-2020.



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

AMARYLLIS CAMPAIGN

Throughout history, the amaryllis has been a symbol of success won after a struggle.

Today it has also come to symbolize pride and determination, especially for us at the Huntington Society of Canada (HSC) and within the Huntington disease (HD) community.

Every year, our volunteers sell over 20,000 Amaryllis kits across Canada to help raise funds and awareness for HD.

Each Amaryllis kit we sell brings us one step closer to finding a meaningful treatment for HD.

Individuals, groups, and corporations across Canada purchase or sell Amaryllis bulbs to give to family, friends, colleagues, and clients.

Kits are priced at only \$15 and come in a box with 12 kits. Each kit contains one orange sovereign bulb, instructions, soil, pot and saucer.

Amaryllis kits make a thoughtful, interactive gift that is cost effective and easy to manage.

For more information visit www.inspirehope.ca or contact amaryllis@huntingtonsociety.ca



Family Services

The HD journey is not an easy one. Whether an individual has tested positive (or negative) for the HD mutation, is at-risk or provides care for someone with HD, finding the right support is vital. HSC is committed to providing that help, be it through links to genetic or HD clinics, advice to help with daily living and independence in the early stages of HD, or legal and financial support for the difficult decisions taken as the disease progresses. At HSC it is a priority to develop resources that will make the road easier to navigate for our HD community.

15

Resource
Centre Directors

6

Family Service
Workers

90

Support Group
Sessions

Combined 238 Years of Experience

63

Information
Sessions

11

Drop-In
Opportunities

85

In-Services for 1250
Healthcare Staff

In the 2018-2019 year, the department grew, with the addition of an RCD in Halton/Peel, ON. This means a new resource centre was able to launch where previously there had been none. We also recruited a new FSW in Vancouver, and new RCDs in Calgary, AB and Southwestern Ontario.

As well, the new role of HSC National Social worker began much of the groundwork to develop virtual support systems for members of the community who may not have access to one-on-one physical meetings, due to their geographical location or life circumstances. This new capability is the dawn of a new era for the family services team in that the piloting of innovative ways to deliver services may well increase the support capabilities of the organization.

The family services team continues to listen to the HD community about the issues that can cause anxiety and concern. As such, five new and updated fact sheets were released over the nine-month fiscal year. These fact sheets were: *Tips When Working with Individuals Affected by HD*; *Caring for Carers and Families with HD*; *Helping Children Cope*; *Sexuality and HD*; and *Family Planning and HD*. In addition, the HSC booklet *A Carer's Guide for Huntington Disease* was also updated.

Going forward, the Family Services team will explore other service and support opportunities, as well as unique delivery methods that will better serve the HD community. HSC will continue to grow specialized HD support in Canada.



Chapter Development

HSC's 23 active chapters and areas are comprised of local families and volunteers who provide each other with support and companionship. Generous donor support to HSC allows its chapters to conduct regular meetings and plan community awareness and/or fundraising events all across the country. These events bring local families affected by HD together to build community, social networks, provide and receive emotional support, and create a sense of pride.

58
Events Held
Across Canada

4,700
Attendees

\$750K
Raised for HD Awareness,
Services and Research

Note: These statistics are for the nine month period ended March 31, 2019.

In particular, the YPAHD chapter continues to thrive and grow. In 2018, YPAHD Day was held in conjunction with the 2018 Conference (read more on Page 12). Over 70 youth registered for the event and HSC is pleased that almost 86 per cent of these youth attendees received funding from HSC's generous donors to attend the event. Feedback from YPAHD participants is always positive, with high energy, hope and enthusiasm. Anyone between the ages of 14 and 35 who is touched by HD is encouraged to become active in this chapter.



The HSC chapter development team also continues to engage through various other speaking engagements. In 2018-2019, staff attended and spoke at 24 events including three chapter holiday parties, seven chapter meetings, events or gatherings, seven fundraising events, the national conference and YPAHD day, four stops on the Jim Pollard tour, and an event management class at Conestoga College.

2018 HSC National Conference

Last year, HSC was fortunate to be able to hold our National Conference in beautiful Kelowna, BC – the heart of the Okanagan! Hosted by the dedicated volunteers of our Okanagan Chapter, the Delta Hotels by Marriott Grand Okanagan Resort was the only hotel in the region that could accommodate the record 313 attendees! What a treat it was to be in the middle of the downtown core and overlooking the water, and what a stellar job the hotel did at treating our delegates during their stay.

Volunteers worked tirelessly to make the Conference one to remember, with an incredible line up of keynote presentations and workshops.

Conference Highlights

Day One

- Icebreaker activities
- Breakout sessions for the YPAHD chapter of HSC

Day Two

- Peter Rosenberger, author/radio/host/caregiver and HD researcher Dr. Blair Leavitt of the University of British Columbia
- Dr. Lauren Boak, Global Development Team Leader for Roche
- Welcome dinner or YPAHD murder mystery

Day Three

- Registered nurse, author and radio/TV host, Yvonne Heath
- Dr. Jeff Carroll, HD researcher and co-founder of HD Buzz
- Interactive workshops
- Closing banquet/Awards gala

HSC sincerely thanks the Okanagan Chapter, our many volunteers, sponsors and speakers for making the 2018 National Conference such an impressive event. With 35 per cent new attendees, the feedback received has been extremely positive and many attendees have recounted that the event was inspiring to them - as well as informative.

We look forward to next year's event, when we will gather in the bustling town of Niagara Falls, ON, home of one of the Seven Wonders of the World. Please mark your calendars for November 12-14, 2020!



Young People Affected by HD

As a chapter of the HSC, Young People Affected by HD (YPAHD) aspires to a reliable treatment for Huntington disease. YPAHD helps youth think about and discuss topics such as genetic testing, family life and dating and supports them in their challenging journey. This group provides young people with peers they can relate to, talk to and lean on. The support system can be incredibly important during this stage in life.

YPAHD strives to:

- Provide a community and support network for young people affected by HD.
- Increase public awareness thereby enabling others to understand the disease.
- Raise funds to deliver services for those living with HD and to further research in order to slow and prevent HD.
- Listen to and advocate for the needs and goals of young people affected by HD through the communication mechanisms provided by the Huntington Society of Canada.

By all accounts, the 2018 YPAHD Day, held in conjunction with the 2018 HSC National Conference in Kelowna, BC was a resounding success. A staggering 72 participants — ranging in age from teenagers to the mid-30s — attended, with almost half being first-timers.

The agenda was full with informative workshops on topics such as hosting events, family planning and therapeutic recreation. The group also had the opportunity for a question-and-answer session with researchers Dr. Tam Mauri and Dr. Jeff Carroll.

“It was apparent that people left feeling invigorated and wanting to get more involved locally and nationally,” says YPAHD President, Doug Mallock. “And that was the goal. To inspire attendees to become active advocates for HD awareness. As the YPAHD

executive, we’re available to help facilitate that enthusiasm in any way we can.

“Although we’re reaching more people than ever, there’s always room to grow. I encourage anyone who is considering getting involved with YPAHD to reach out. Taking that first step can be hard. But, it can also lead to connections and friendships that last a lifetime.”

Thanks again to donor support, funding was available for participants to attend the 2018 YPAHD Day.



Research Dollars in Action

By deciphering the three-dimensional structure of disease-causing proteins, the Structural Genomics Consortium is paving the way for new disease-fighting drugs. And one of the proteins they're putting under the microscope is huntingtin.

In 2018, HSC awarded a two-year, \$150,000 NAVIGATOR grant to Dr. Cheryl Arrowsmith, chief scientist at the Consortium's Toronto lab, to further that work. Together with post-doctoral researcher Dr. Rachel Harding, she is comparing the structure of the normal version of the huntingtin protein with the mutant version that causes Huntington disease.

A year into the work, they've cleared the first big hurdle: producing large volumes of these proteins. For this research, the investigators need several milligrams of the protein they're studying. When you consider that a human cell weighs only a few millionths of a milligram, that's a tall order!

The basic approach is to put a bunch of cells in a test tube and convert them into protein factories. To do that, biochemists use the biological equivalent of a Trojan horse — typically a virus or a plasmid — to slip DNA instructions into the cells, hijacking their normal protein-making machinery.

It took a lot of experimentation, but Dr. Harding has found an effective way to package the DNA that codes for huntingtin protein, deliver it into cells and fire up those cellular factories. Now all systems are go for the next phase of the research.

First, they'll use a powerful technique called cryo-electron microscopy to understand the overall structure of each version of huntingtin. Then they'll take a detailed look at key parts of these proteins using high-resolution x-ray crystallography.

“We're trying to see if we can better understand how the [normal huntingtin] protein works and how the mutant proteins either fail to work or have some new, damaging activity,” Dr. Arrowsmith explains.

Those insights could help investigators design new treatments. But that's not the only payoff. Because Dr. Harding has shared her methods and materials with other labs, our investment is accelerating HD research across Canada and around the world.



Dr. Cheryl Arrowsmith (L) and Dr. Rachel Harding of the University of Toronto.

Clinical Trials

Today, four different drugs with the potential to slow or stop HD are being tested in Canada. This would not be possible without our generous donors, the volunteers who work so hard to raise funds, courageous clinical trial participants and many dedicated researchers and clinicians. Heartfelt thanks to all those who help make Canada a leader in this area and create hope for families around the world affected by HD.

Roche - Generation HD1

Roche's Generation HD1 is testing the effectiveness of RG6042, an antisense oligonucleotide (ASO) designed to stop cells from producing the huntingtin protein that causes HD. An earlier Phase I/IIa trial proved that RG6042 is safe and can successfully lower huntingtin levels. Now, with this Phase III trial, Roche aims to answer the big question: Can this drug slow the progression of HD?

Generation HD1 was launched in January 2019 but put on hold briefly in the Spring to restructure the trial, making the spinal injections less frequent. That's because results from the open label extension of the Phase I/IIa trial revealed that injecting RG6042 every two months was just as effective at reducing huntingtin levels as monthly injections.

Approximately half of the 105 world-wide Generation HD1 are now back up and running, including several Canadian sites. For up-to-date information in your region, refer to the clinics in your area.

Wave Life Sciences - Precision-HD1 and Precision-HD2

Roche's ASO lowers levels of both versions of the huntingtin protein: the normal version and the mutant version that causes HD. Meanwhile, Wave Life Sciences (Wave) is testing two different ASOs that target just the version responsible for HD. Precision-HD1 and HD2 are Phase I/IIa trials to determine the safety and efficacy of these drugs. As of March 31, 2019, the trials were running in Toronto and Montréal, as well as several sites in Europe. Wave expects to release initial results at the end of 2019.



Vaccinex - Signal

Vaccinex is taking a different approach to treating HD. They have developed an antibody called VX15/2503 which targets a key signalling protein in brain cells. This protein sets off a chain of events that leads to inflammation and, ultimately, cell death. By knocking out that signal, researchers believe they can stop the process before it begins, preventing damage to brain cells.

Vaccinex is testing their antibody in a Phase I/IIa trial called Signal that is currently running in Vancouver, Edmonton, Montréal and across the United States. The drug company hopes to have all testing completed by summer 2020.

Observational Studies

To judge the effectiveness of these potential treatments, researchers need to understand - in detail - how HD normally develops and progresses. That's where observational studies like ENROLL-HD, HDClarity and Roche's 15-month HD Natural History Study come in.

Volunteers at sites across Canada and around the world are helping researchers collect crucial data that will give us more insights into HD and help shape future clinical trials.

THANK YOU!



Quick Facts



58 Community Events Across Canada



15 Board Members



4,700 Event Participants



90 Support Group Sessions



23 Active Chapters



3,590 Open Individual Files



21,204 Amaryllis Bulbs Sold



238 Years of Combined Experience Across Family Services Team



313 Conference Participants. Our most ever!



14 HSC National Office Staff



15 HSC Resource Centres



3,306 Facebook Followers and 3243 Likes on Facebook



1 Fantastic, Engaged and Inspiring HD Community!

Treasurer's Report

It is my pleasure to report to the stakeholders of the HSC on its activities and financial results for the latest fiscal year ended March 31, 2019.

Before beginning, I must remind you that beginning this fiscal year 2018-2019, **HSC adopted a new fiscal year which ended on March 31 (instead of June 30, which was the case for previous fiscal years)**. This change was largely undertaken to improve on the predictability of HSC's annual forecasting.

Based on prior years' results, HSC's largest revenue-generating quarter each year is the period April 1 to June 30. In a typical year, approximately 40 per cent of the full year's revenues are realized in that quarter alone. By putting this quarter at the beginning rather than the end of a fiscal year, this enables HSC to better predict the coming year's total revenue and to adjust its plans and activities as necessary based on the actual outcome for that quarter. This should result in more predictable full-year results and more effective and efficient plan execution.

As a result of this change in year-end, this fiscal year 2018-2019 comprised only 9 months, running from the end of the previous fiscal year, which ended June 30, 2018, to the new year-end of March 31, 2019. From this point forward, each fiscal year will run a full 12 months from April 1 to March 31 of the following year.

Due to the shorter fiscal year and the resulting exclusion of its results for the April 1 - June 30, 2019 quarter, HSC's total revenue was \$2.5 million, a decline of \$1.8 million from the prior fiscal year, which included the full 12 month results, including the large April 1 - June 30, 2018 quarter.

However, I believe that in order to more accurately assess the performance of HSC over the past year, in terms of its Statement of Operations it is better to compare it against the results for the same 9-month period, July 1, 2017 - March 31, 2018, of the previous fiscal year. The table on the next page (19) contains that comparison.



Statement of Operations*

	AUDITED 9 Month Period Ended March 31, 2019	9 Month Period Ended March 31, 2018*	Quarter Ended June 30, 2018*	AUDITED Year Ended June 2018
Revenue:				
Donations	974,488	998,710	1,177,463	2,176,173
Grants	536,617	355,213	175,602	530,815
Chapter and volunteer fundraising revenue	753,164	838,262	598,462	1,436,724
Investment income	93,076	78,123	24,754	102,877
Change in fair value of investments	3,360	(14,044)	36,397	22,353
Other income	91,499	29,835	(12,470)	17,365
	2,452,204	2,286,099	2,000,208	46% 4,286,307
Expenses:				
Research	438,927	349,704	723,315	1,073,019
Family services	991,916	982,730	308,076	1,290,806
Public awareness and education	350,421	275,509	39,421	314,930
Chapter and volunteer support	122,843	97,961	40,592	138,553
Development	291,112	287,254	99,477	386,731
Chapter and volunteer fundraising expenses	245,044	170,559	70,869	241,428
Administration	412,418	337,841	143,680	481,521
Amortization	5,006	7,722	2,220	9,942
	2,857,687	2,509,280	1,427,650	3,936,930
Excess (deficiency) of revenue over expenses	(405,483)	(223,181)	572,558	349,377

*Note: These results are not audited and as a result have not been subjected to normal cut-off procedures.

Referring to the table above, at \$2.5 million, total revenues this past year were approximately \$0.2 million or 8 per cent higher versus that same period last year, with strong year-over-year increases recorded for each of donations and foundation grants. This is a testament to our donors, partners and advocates who support our mission and activities. Chapter and volunteer fundraising revenue was slightly off the pace of the prior year. This was primarily due to one-time events that took place in the previous fiscal year and not this recent fiscal year. Our team of committed, capable and tireless staff and volunteers continue to deliver solid revenues. A heartfelt thanks to all of you from our management and Board of Directors.

HSC is committed to effectively putting as much as possible of the funds it receives to work to deliver on its mission. The large support of our volunteer network, combined with a relatively small employee base coordinating and supporting this network is key to achieving this. Funds are spent on services to families impacted by HD, investing in critical, targeted research, engaging patients as participants in and preparing them for clinical trials, advocating on behalf of impacted families to relevant government and non-government bodies and raising overall public awareness and support.

Over this past 9-month period, HSC spent a total of \$2.9 million, an increase of approximately \$0.4 million or 14 per cent from the prior comparable period. Similar to last year's comparable 9-month period, this resulted in a relatively small operating deficit of \$0.4 million. This shortfall was funded from HSC's existing financial assets, which totalled over \$4.1 million at the end of the fiscal year.

A total of approximately \$1.0 million was spent on direct services to families affected by HD, comparable to the same 9-month period last year. The reach of our effort in this regard continues to grow as our services were extended with the opening of a new resource centre in Halton/Peel, ON.

In addition, a total of \$0.4 million was spent on supporting critical medical research - an increase of \$0.1 million from the same period last year. As of now, we expect that research spending will be somewhat lower this coming fiscal year as existing research projects (such as the Brain Canada joint-funding research program) are completed and new research projects have adequate alternative funding in place. However, we will continue to support important, promising new research efforts as they emerge and require our support.

HSC remains in a solid financial position. At the end of this fiscal year, total assets were \$4.2 million at March 31, 2019. Essentially all of which is in cash and marketable securities. Of this, \$3.1 million is in the General Fund and \$1.1 million is in the Research Fund. This positions HSC well to serve HD families, respond quickly to promising new research opportunities, and to build out its ability to respond to any new available therapies.

In closing, HSC had another solid year delivering on its mission. However, we know that so much more needs to be done. With the prospect of effective new therapies on the horizon, the organization is committed to growing its resources and capabilities to effectively and efficiently deepen and broaden its essential services.

George Halatsis
HSC Board Member and Treasurer



Statement of Financial Position*

March 31, 2019, with comparative information at June 30, 2018.

	2019	2018
Assets		
Current assets:		
Cash	\$ 1,007,463	\$ 1,287,995
Investments	3,037,917	3,084,049
Accounts receivable	30,111	49,360
Prepaid expenses	96,150	106,536
	<u>4,171,641</u>	<u>4,527,940</u>
Capital assets	19,600	17,509
	\$ 4,191,241	\$ 4,545,449
Liabilities and Fund Balances		
Current liabilities:		
Accounts payable and accrued liabilities	\$ 80,163	\$ 70,431
Deferred revenue	489,841	448,298
	<u>570,004</u>	<u>518,729</u>
Fund balances:		
General Fund	582,573	1,103,053
Capital Assets Fund	19,600	17,509
Endowment Fund	1,887,916	1,885,521
Laura's Hope Fund	17,847	17,316
Ralph Walker Research Fund	1,113,301	1,003,321
	<u>3,621,237</u>	<u>4,026,720</u>
	\$ 4,191,241	\$ 4,545,449

*These statements are extracted from the audited financial statements for the nine months period ended March 31, 2019. These statements have been audited by KPMG LLP. The full set of audited financial statements are available upon request.

Statement of Operations*

Nine month period ended March 31, 2019, with comparative information for the year ended June 30, 2018.

	General Fund	Capital Assets Fund	Endowment Fund	Laura's Hope Fund	Ralph Walker Research Fund	Total nine month period ended March 31, 2019	Total Year ended June 30, 2018
Revenue:							
Donations	\$ 901,717	\$ -	\$ -	\$ -	\$ 72,771	\$ 974,488	\$ 2,176,173
Grants	170,461	-	-	-	366,156	536,617	530,815
Chapter/volunteer fundraising revenue	753,024	-	-	-	140	753,164	1,436,724
Investment income	56,580	-	-	531	35,965	93,076	102,877
Change in fair value of investments	(139)	-	2,395	-	1,104	3,360	22,353
Other income	91,499	-	-	-	-	91,499	17,365
	1,973,142	-	2,395	531	476,136	2,452,204	4,286,307
Expenses:							
Research	72,771	-	-	-	366,156	438,927	1,073,019
Family services	991,916	-	-	-	-	991,916	1,290,806
Public awareness and education	350,421	-	-	-	-	350,421	314,930
Chapter and volunteer support	122,843	-	-	-	-	122,843	138,553
Development	291,112	-	-	-	-	291,112	386,731
Chapter/volunteer fundraising expenses	245,044	-	-	-	-	245,044	241,428
Administration	412,418	-	-	-	-	412,418	481,521
Amortization	-	5,006	-	-	-	5,006	9,942
	2,486,525	5,006	-	-	366,156	2,857,687	3,936,930
Excess (deficiency) of revenue over expenses	(\$ 513,383)	(\$ 5,006)	\$ 2,395	\$ 531	\$ 109,980	(\$ 405,483)	\$ 349,377

*These statements are extracted from the audited financial statements for the nine months period ended March 31, 2019. These statements have been audited by KPMG LLP. The full set of audited financial statements are available upon request.

The image features a textured, warm yellow background. In the center, the word "HOPE" is written in large, bold, black, sans-serif capital letters. Two dark silhouettes of hands are positioned on either side of the word, with their fingers gently holding the letters. The overall composition is simple and evocative, conveying a sense of care and optimism.

HOPE

