



2020/2021

ANNUAL REPORT



HOPE • BELIEVE • INSPIRE

The Huntington Society of Canada (HSC) is a not-for-profit charitable organization that raises funds and supports individuals and families facing Huntington disease (HD).

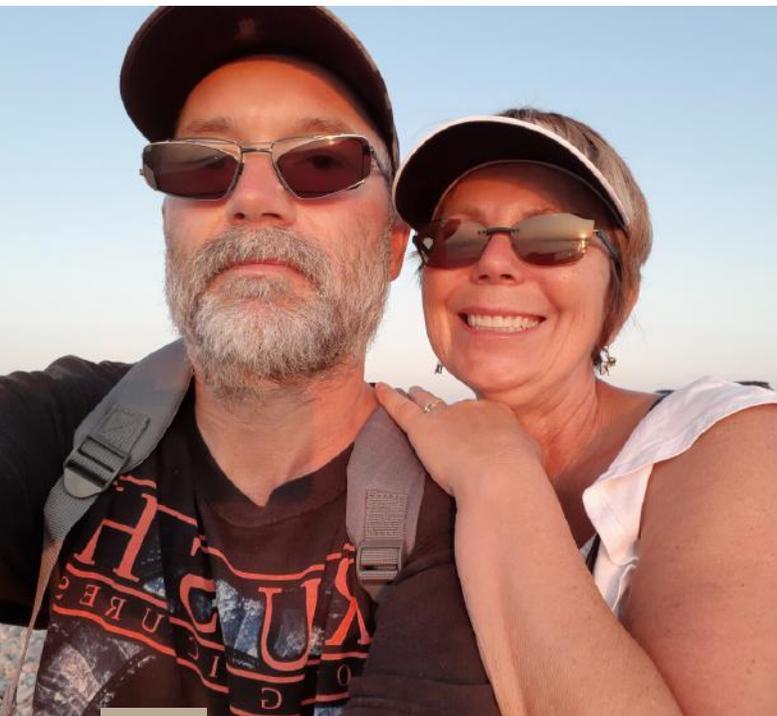


VISION: A world free from Huntington disease.

MISSION:

To improve the quality of life for those affected by Huntington disease.

We will address our mission through the oversight and facilitation of excellent support services, providing access to the best and most up-to-date educational resources, increasing national and global awareness, advocacy and investing in promising research.



VALUES:

COMPASSION

INTEGRITY

ACCOUNTABILITY

INCLUSIVENESS

COLLABORATION

LEADERSHIP

EMPOWERMENT



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2020/2021



MACK ERNO

BOARD CHAIR NOTE

Huntington Society of Canada (HSC) will long remember the fiscal year of April 2020 – March 2021 as a time of adapting to change – namely, Covid. During the pandemic, a time when our world was turned upside down, we welcomed a new CEO, Shelly Redman, as well as several team members. Many of these co-workers have never met in person, and the fact that this was their new normal tells you just how we’ve made the virtual world work to our advantage. In spite of everything, it was a year marked by tons of successes, which you will read more about in this report. We had record-breaking amaryllis sales and big

wins from our amazing volunteers. These community members found ways to raise awareness, hold online fundraisers, and work for the cause. Our dedicated donor base also really shone through, on every level, and that is truly remarkable in the midst of the uncertainty of a global pandemic. I’m so grateful for all of these efforts. I’m also thankful for a very engaged and dedicated Board over the past two years. We saw improved governance and committee work, and will really start to see the fruits of those labours now and into the future. It’s a great team, and I’m especially excited to welcome

new Board directors and a Chair. We’re moving forward under great new leadership, from our new Board Chair to our CEO, and I’m confident about the direction HSC is headed. Thank you for a wonderful time as Board Chair. The future is bright, and I know HSC and the community are in good hands.

Mack Erno
Chair
Huntington Society of Canada



**SHELLY
REDMAN**

LETTER FROM THE CEO

They say that adversity provides the breeding ground for new opportunities, and I agree completely. The past year was dominated by Covid. Yet, on a positive note, these restrictions forced all of us at HSC and the community to get creative and come up with new ideas. Change can be really hard. However, instead of the “but this is the way we’ve always done it” mindset, we embraced a can-do attitude, imagining and implementing powerful solutions. I like to think of it as “moving toward” and developing new ways of doing things that allow us to reap the rewards of being open to possibility. A perfect example of this innovation was the Virtual National Conference held in March. An in-person Conference had been set for November in Niagara Falls and seemed set to

sell out. When forced to cancel Conference, it was disappointing. But the virtual offering shattered all previous attendance records, with over 800 people signing up! In comparison, our 2018 Conference in Kelowna had 313 attendees. We brought the complete experience into the living rooms of people from around the world. People who previously couldn’t attend due to finances or travel barriers were now able to participate in the learning and connection opportunities Conference is famous for. While we are excited to be able to hold in-person Conferences again in the future, we will continue to offer virtual options to be more inclusive. My wish to meet people face-to-face goes beyond Conference. While it has been great to get to know donors, partners and community

members over phone and Zoom calls, I am so excited for travel to resume so that we can continue to develop those relationships. I know that we will hold on to the best solutions we developed during a challenging time even as we enjoy returning to some of our favourite in-person activities. Moving forward, I am filled with hope for the future and it is all because of this amazing organization and community. Thank you for a wild - and wildly successful year.

Shelly Redman
Chief Executive Officer
Huntington Society of Canada



GOVERNANCE

HSC Executive

- Mack Erno – Chair*
- Brynne Dalmao – Vice-Chair*
- Sean Dewart – Secretary*
- Anne Brace – Treasurer*

Hailing from all corners of Canada, the HSC board of directors currently meets four times a year and is responsible for governing the organization. This includes HSC’s mission and strategic planning; policy development; stewardship of resources; and accountability to members, donors and the public.

HSC Board Directors

- Cameron Barrett*
- Geneviève Bélanger*
- Dr. Mark Guttman*
- Brenda Mason*
- Ron Muller*
- Catherine Price*
- Patrick Thauberger*
- Dr. Ray Truant*
- Diane Tullson*
- Andrew Wright*

HSC board directors serve a two-year term and may stand for re-election for two further two-year terms. A few vacancies occur each year, since directors' terms are staggered. Nominations for these positions are recommended to the membership by the governance and nominating committee of the board.

One seat on the board is reserved for a representative of the Huntington Society of Québec, while another seat is reserved for a representative of Young People Affected by HD (YPAHD), our virtual youth chapter.

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.



FAMILY SERVICES

HSC's Family Services offerings are at the very core of our organization's mission - the Family Services team supports individuals and families affected by HD. Like all other functions, during 2020/21 Family Services had to drastically change service offerings because of Covid. Our priorities didn't change, but we had to use different methods.

We had challenges and we're proud to say that we also celebrated successes. Resource Centre Directors (RCDs) and Family Service Workers (FSWs) worked extremely hard to overcome access barriers and provide new services and content. Here are some numbers and notes to showcase what changed and how we were able to adapt.

43% decrease in HD Clinic and genetic appointments attended

- Covid limited access to medical staff and space in clinics and hospitals

10% decrease in total number of support group sessions

- Support groups moved to a virtual platform so that option was available to everyone who was interested
- Some group members preferred to wait for in-person meetings to start up again

34% increase in case conference meetings

- More direct one-on-one and group service work with families to ensure they were supported during the pandemic
- This led to increased connection among the community service providers supporting individuals and families affected by HD

58% increase in service development and collaboration activities

- Worked with other organizations to advocate for new services for families during the pandemic
- Developed new resource materials

What is Case Conferencing?

RCDs bring together the community and health service providers involved in supporting the individual and family affected by HD. They can do this by meeting in person in a conference room/office setting (non-Covid times) or via the online meeting portal TEAMS.

Having everyone at the table at the same time provides a connection and allows for conversation between the service providers. This makes the process of finalizing the plan of care for the individual and family more effective and efficient.

BY THE NUMBERS

HERE ARE SOME OTHER STATISTICS FOR THE YEAR 2020/2021:

3,384

SUPPORT MEETINGS VIA TELEPHONE



1923 VIRTUAL SESSIONS AND EMAILS FOR SUPPORT, RESOURCES AND EDUCATION

1

NEW "AT RISK/ GENE POSITIVE" NATIONAL VIRTUAL SUPPORT GROUP

1 HSC Youth Mentorship "Train the Trainer" series provided to 7 social workers at HDSA and HDYO. HSC youth mentorship is now available internationally!

2

VIRTUAL SUPPORT GROUPS FOR CARERS IN B.C.

9

COMMUNITY MEMBERS WHO JOINED THE INITIAL "AT RISK/ GENE POSITIVE" PILOT GROUP



183

ANONYMOUS REQUESTS VIA CALLS TO GENERAL NATIONAL OFFICE PHONE AND EMAILS TO INFO@HUNTINGTONSOCIETY.CA

323 **f**

MEMBERS IN THE CLOSED HSC NATIONAL FACEBOOK GROUP

Q&A: RECENT FAMILY SERVICES OFFERINGS



What is the closed HSC national Facebook Group?

The closed Facebook group was developed to be a private and secure forum, where families affected by HD can connect with others. Now with 323 members and counting, it is clear the group serves a very important purpose, offering the opportunity to connect 24/7 with other members.

How can people join the closed Facebook Group?

The group is intended for individuals and families affected by HD living in Canada. Potential members request to join, and, once granted access, can ask questions and comment on posts. The group is managed and moderated by Corey Janke, HSC's National Social Worker.

What are the benefits of the closed Facebook Group?

The benefits of the closed Facebook group really became apparent during the pandemic, when in-person support groups were put on hold. Members share stories, coping strategies, and solutions, like how to advocate for home care. It's a wonderfully supportive platform for people reaching out and also allows HSC to provide information and resources, such as articles, research updates and videos.

What is the At Risk/ Gene Positive National Virtual Support Group?

Many of HSC's support groups are for individuals with symptoms of HD or carers. This group takes a slightly different approach, providing

a safe space for individuals who are at risk or who have tested positive for the gene mutation to discuss issues like relationships, family planning and genetic testing.

How did the At Risk/ Gene Positive Group get started?

Covid provided the final push to launch this support group for people who are at risk or positive for the gene mutation for HD, which had been in the planning stages since 2019. Corey Janke ran the group nationally and the response was so positive the group split into Western and Eastern Canada segments in the spring of 2021.

Members have been very grateful for the forum and the support. It's another example of finding a silver lining in the cloud of Covid.

Q&A: RECENT FAMILY SERVICES OFFERINGS CONT'D...

What is the HSC Youth Mentorship program?

In this program, HSC-trained mentors (young adults from a family with HD) are paired with young people from across Canada facing the everyday challenges of HD and provide support and guidance.

What happened in the program during 2020/21?

The program matched five mentors with mentees, which is excellent considering the pandemic. This program also provided Train the Trainer sessions to HDYO and HDSA, and seven social workers from across the USA can now facilitate the HSC Youth Mentorship program in their regions. Plans include a roll out across Europe and Australia at a future date.



2020/21 Community Education Forums

Even in the midst of the pandemic, HSC's

commitment to education didn't stop. To meet the needs of the community, HSC offered three virtual Community Education Forums available as live broadcasts or to watch via video after the event took place. These videos remain available for viewing on HSC's YouTube channel. With the opportunity to join from the comfort of one's own home and the ability to ask questions, the CEFs provided a wonderful way to learn, connect and engage.

THE LINE-UP, RECORD-BREAKING ATTENDANCE NUMBERS, AND TESTIMONIALS INCLUDE:

May 2020 CEF Natalie Marnica: Self Care for Caregivers

107 registered
58 attended live

"She is a very personable presenter and the combination of educational material and practical strategies was excellent."

"Natalie's openness to share her own story is so helpful and the way she weaves her knowledge and strategies into her presentation gives people an excellent base on how to assess and implement change."

November 2020 CEF Prof. Ed Wild and Dr. Jeff Carroll: Research Update

277 registered
136 attended live

"Thank you for giving us MORE HOPE for a treatment for HD. Thank you again. Well explained and understood. You guys are amazing."

"The comprehensive and sometimes complicated HD information was presented in a casual, easy-to-understand, and informative method."

February 2021 CEF Clare Gibbons: Genetic Testing

222 registered
99 attended live

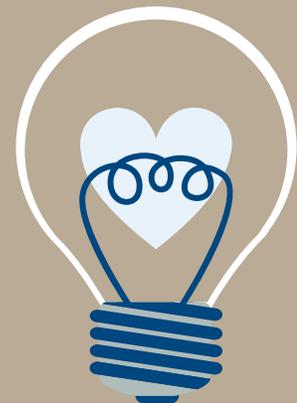
"Clare is such an excellent, experienced, and compassionate genetic counselor. I found her insights highly valuable."

"I had not understood previously that there were a range of genetic possibilities. I had thought HD was binary. I also gained a better understanding of the range of onset possibilities."

Thank you to our sponsors of these forums and to the speakers and attendees.

COMMUNITY EDUCATION FORUM

SEASONAL SERIES 2020-2021





RESEARCH DOLLARS IN ACTION

Clinical Fellowship Dr. Nguyen

Dr. Mark Guttman, Board director and physician with the Centre for Movement Disorders in Toronto, provides an update on the work of Winnipeg neurologist Dr. Dung Nguyen, HSC's latest clinical fellow. HSC started the clinical fellowship program in 2019 to attract promising young neurologists to the field of HD.

Dr. Guttman says:

"The objective for the Clinical Fellowship was to have training in clinical management of HD patients. Research training was not mandatory and was considered useful but not an expectation. Dr. Nguyen spent

four months with me in addition to his eight months training in Winnipeg. He had the opportunity to get involved with a number of trials including Enroll HD, HDClarity and Shield HD that continued throughout his time with us. Unfortunately, shortly after his arrival the Wave and Roche programs were altered and this dramatically changed his expected experience.

He learned about how clinical trials are run, the need for a team of dedicated professionals required to carry out the studies, the training required for each protocol, and how to administer HD specific rating scales. He learned how to perform research lumbar

punctures with ultrasound guidance as well. The most important aspect was observing the dedication of the patients and their families in participation in these studies and the huge effort that they all made to make the research happen."

Even though Dr. Nguyen's experience was not what was originally planned, he has supported patients and families facing HD and no doubt learned so much from them in return. Thank you, Dr. Nguyen for your interest in learning more about the clinical management of individuals affected by HD. Thank you to everyone who donates, making these funding and research opportunities possible.



**The Manning Family
and Beckman Family
University of British
Columbia (UBC)
Huntington Fellowship
Dr. Fabricio Pio**

Dr. Fabricio Pio holds the Manning Family and Beckman Family UBC Huntington Fellowship, a three-year commitment of \$100,000 in funds per year for clinical research at the Centre of Huntington Disease at UBC. He is supervised by Dr. Blair Leavitt and is learning how to conduct assessments on patients with HD. He is also gaining experience on how to run clinical trials, including: GEN-HD Phase III, Natural History study, Enroll-HD, Roche open label study (BN 40955), SIGNAL study,

CLARITY study, KINECTIC-HD, PROOF-HD, SHIELD-HD clinical trial, and Gut Microbiome in HD study. Dr. Pio also participates in Dr. Leavitt's HD clinic and lab meetings.

These skills, from performing neurological exams to collecting cerebrospinal fluid, will be much needed as more potential treatments for HD are developed.

WE ARE SO APPRECIATIVE OF DONORS FOR MAKING FELLOWSHIPS - TRUE LEARNING OPPORTUNITIES - POSSIBLE AND FOR MEDICAL TALENT LIKE DR. PIO FOR DEDICATING THEIR CAREERS TO RESEARCHING HD. YOU ALL TRULY MAKE A DIFFERENCE.

"Last year was a challenge for everyone. Covid has brought many changes to our daily routines and research was affected in many ways. Nevertheless, we managed to keep some of our studies ongoing.

I would like to thank you for the opportunity of being a fellow in Huntington disease at the University of British Columbia, supervised by Drs Blair Leavitt and Lynn Raymond. Your support has been crucial and highly appreciated."

- Dr. Fabricio Pio



CHAPTER DEVELOPMENT

Young People Affected by HD

Throughout 2020 YPAHD went virtual with Facebook Live sessions. They reached about 1500 people per session and covered topics including:

- How to cope when you test positive for the HD mutation
- Managing during the pandemic with loved ones affected by HD
- Event planning
- Family planning discussions including: adoption, IVF and PGD, and natural conception



2020/21: The Online Chapter

Due to the pandemic, Chapters were no longer able to meet in person throughout 2020/21.

Many chapters made the switch to meeting online seamlessly, working on virtual events, supporting each other, fundraising, and raising awareness for HD.

We thank all of our amazing volunteers who continued to support us throughout 2020/21.

November 2020: YPAHD Day found a home on Zoom! Youth connected virtually, playing games and celebrating YPAHD's 10-year anniversary.



AND COMMUNITY EVENTS

It was a year of firsts as we tried new things in the virtual event space with great success! The Winnipeg Walk and the Southern Alberta Hope Run were the first to transition, taking place in June 2020 – thank you for paving the way and showing us it was possible to run successful virtual events!

STANDOUT EVENTS IN 2020/21 INCLUDED:



Sophie's Keychains – Sophie Pollock (9 years old) of Weyburn, SK created and sold hundreds of keychains across Canada, raising over \$5000 for HSC.



Manny's Ride for a Cure - Manny biked over 100kms and raised \$3600 for HSC in April 2020.



The Niagara Chapter held their first annual Lake-to-Lake Challenge. Participants walked the parkway trail and together completed the entire 72kms of trail raising over \$7200 in its first year!

What fabulous creativity in fundraising – thank you everyone!



HUNTINGTON HEROES NATIONAL VIRTUAL WALK



NATIONAL VIRTUAL WALK



269
PARTICIPANTS

13+
EVENTS

1782
DONATIONS

OVER **\$176,000** RAISED

8 PROVINCES **1** STATE

107 CITIES ACROSS
CANADA & THE USA



2200 KMS WALKED
THAT'S LIKE WALKING FROM VANCOUVER TO
WINNIPEG!

1 IMPORTANT CAUSE
& COMMUNITY



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

CONTACT US!

EVENTS@HUNTINGTONSOCIETY.CA
1-800-998-7398
WWW.HUNTINGTONSOCIETY.CA



2020 National Virtual Walk



BECAUSE OF

continuing pandemic guidelines, over 13 community walks and events across the country moved from in person to virtual, taking place from September 1 – October 31, 2020



VOLUNTEERS TOOK

on the challenge and transitioned their walks and runs to allow us to come together as a community and raise money for HD – amazing teamwork!



AN ANONYMOUS

donor matched event donations up to a maximum of \$250,000 – thank you for your generosity

VIRTUAL National Conference

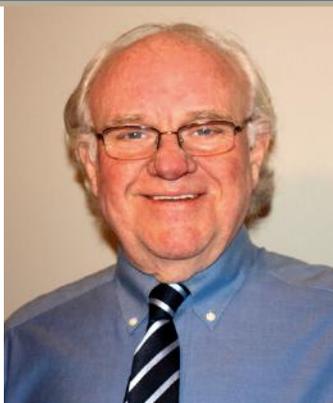
In March 2021, we held our first ever Virtual National Conference. We were set to host 350 attendees in Niagara Falls in November 2020, but due to the pandemic we had to cancel this much-loved event and move to online.

HERE'S THE UPSIDE - WE HAD MORE THAN 800 PEOPLE REGISTER FOR FREE, REACHING INDIVIDUALS ACROSS CANADA AND THE WORLD WHO MAY NOT HAVE HAD AN OPPORTUNITY TO PARTICIPATE OTHERWISE DUE TO FINANCIAL AND GEOGRAPHICAL BARRIERS.

We expanded our reach like never before. In fact, 49% were first-time attendees. One attendee said,

"I ENJOYED THAT MY MOM, WHO IS SYMPTOMATIC, COULD PARTICIPATE BECAUSE OF THE ONLINE PLATFORM. NORMALLY SHE STAYS AT HOME BECAUSE FLYING IS A BIG STRESS FOR HER."

Session topics included Medical Assistance in Dying (MAID), Genetic Fairness, Navigating Relationships, Research Updates and more. Breakout rooms allowed attendees to connect with others affected by HD across the country, a key aspect of our conference gatherings.



Individuals tuned in from over 28 countries including: USA, UK, Brazil, Germany, India, New Zealand. According to one participant:



I was translating the conference to Brazilian HD association; all the information acquired was shared with Brazilian HD community.

IT WAS ANOTHER BIG FIRST STEP FOR US INTO ONLINE EVENTS, AND WE REALLY APPRECIATE THE TURNOUT AND SUPPORT FROM ATTENDEES, PRESENTERS & SPONSORS.

Finally, one attendee's testimonial sums up the positive impact:

"The conference provided:

***Information** - knowledge is power; knowledge allows us to better navigate our future*

***Inspiration** - gives us the feeling that we are not alone and there is hope; encourages resilience and boosts our efforts to cope*

***Increased awareness** - helps to take away the mystery & uncertainty; the more we talk about it, the greater awareness of not only those affected but also society, in general"*

Virtual Gala

In another first for HSC this year, we tried out an online gala event for major donors. We presented a Q&A and video tour of Dr. Ray Truant's lab, where the team performs ground-breaking HD research. Next up was an informative and entertaining virtual wine tasting of three Peller Estates vintages, led by a sommelier from the winery. We would like to thank the anonymous donor for their generous donation of the wine. All in, the event raised \$7350 and showed that future gala events can be both online or in person.

HERE'S THE ENTIRE LIST OF PARTICIPATING COUNTRIES:

- | | | | | | |
|-------------|----------------|---------|-------------|--------------|----------------|
| Afghanistan | Czech Republic | Ireland | Morocco | Portugal | Turkey |
| Argentina | France | Israel | Netherlands | South Africa | United Kingdom |
| Bangladesh | Germany | Italy | New Zealand | Spain | United States |
| Brazil | India | Malta | Norway | Sweden | of America |
| Bulgaria | Iran | Mexico | Poland | Switzerland | |





AMARYLLIS FUNDRAISER

Once again Covid was no match for HSC staff and volunteers working on one of HSC's key fundraisers, the Amaryllis Campaign. With the pandemic complicating the usual sales opportunities, it would have been

understandable to have a down year. But the community rallied once again, finding ways to sell even when sports teams, community fairs, in-person workplaces, and other gatherings were non-existent.

In fact, amaryllis sales for 2020/21 were the most successful they have been in recent years. With funds going to HSC's programs in research, services and education, this was excellent news.



DID YOU KNOW: The average height of an amaryllis, in full bloom, is 27 inches. If you were to stack all of the amaryllis sold in 2020/21, they would stretch 47,952 feet – that's like 1.5 Mount Everests!



QUICK FACTS & FIGURES

21,312

AMARYLLIS
BULBS SOLD



**TOP SELLERS (CHAPTERS)
INCLUDED: SOUTHERN
ALBERTA & OTTAWA**

25,000

2021 CASES
ORDERED



One of the most remote locations ordering an amaryllis was a tiny island off the coast of Victoria accessible only by boat. Just imagine the voyage that gorgeous and resilient amaryllis took!



61

NUMBER
OF ENTRIES
IN PHOTO
CONTEST

AMOUNT RAISED SINCE 1985
VIA AMARYLLIS CAMPAIGN:

OVER \$5 MILLION

Entry subjects featured:

11 KIDS
1 DOG
1 CAT



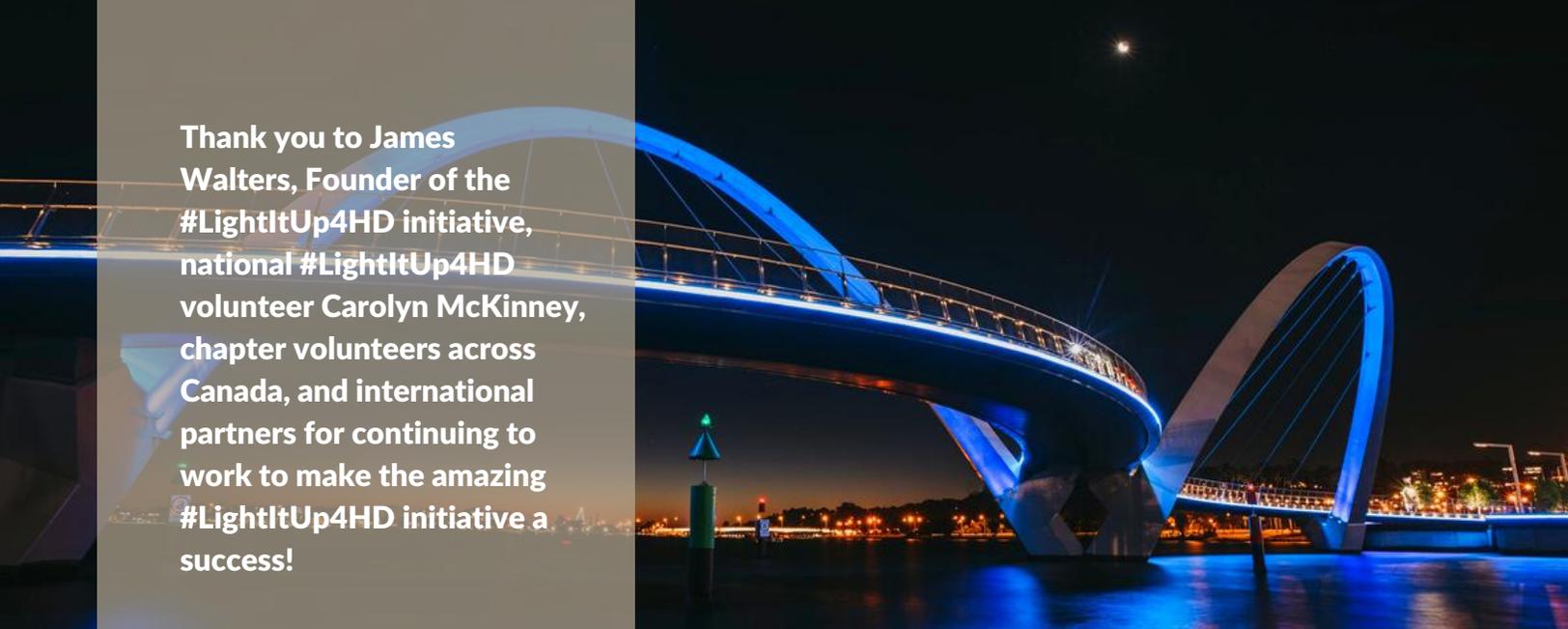
CASES WERE SHIPPED ALL ACROSS CANADA, TO
NEWFOUNDLAND, YUKON AND VANCOUVER ISLAND



2020 DONATIONS OVER AND BEYOND AMARYLLIS
SALES FROM DONATION SLIPS IN BOX: **\$13,445**



THERE ARE OVER 500
TYPES OF AMARYLLIS:
THE HSC AMARYLLIS
IS THE **ORANGE
SOVEREIGN**



Thank you to James Walters, Founder of the #LightItUp4HD initiative, national #LightItUp4HD volunteer Carolyn McKinney, chapter volunteers across Canada, and international partners for continuing to work to make the amazing #LightItUp4HD initiative a success!

AWARENESS MONTH

May Awareness Month 2020 was not the usual outpouring of in-person events and recognition because of the global Covid pandemic – it was a different year, for sure. But in spite of uncertainty & limitations, HSC and the HD community had an impact and raised awareness for HD, strengthening bonds and educating others.

DID YOU KNOW?

Since 2015, volunteers from across Canada have been working to illuminate various buildings, monuments and structures during the month of May to raise the visibility of HD & Juvenile HD. Thank you, volunteers, for all you do to shine a spotlight on HD.

Here are a few ways the community continued to make its mark:

#LightItUp4HD, in which buildings and monuments across Canada and the world light up in blue for HD & purple for Juvenile HD, continued in the face of Covid.

PARTICIPATING SITES INCLUDED:

- 23 locations worldwide, including Australia, Cyprus, Germany, Ireland, Spain and the USA
- 19 across Canada
- Through the determined efforts of local volunteers, Calgary, AB Mayor Naheed Nenshi also made a proclamation to declare May as HD Awareness Month in that city
- Guelph, Sudbury, and Chatham, all in Ontario, also raised flags in a safe manner or residentially

HSC got creative and asked people to deck out their homes with posters, chalk art, & lighting up their own trees and residences to highlight Awareness Month. This led to #ChalkItUp4HD and #StringItUp4HD – innovative solutions to help HD be seen and noticed during a pandemic that kept people at home.

TREASURER'S REPORT

Without a doubt, the 12 months covered by our fiscal year, April 1, 2020 to March 31, 2021, have been challenging times. As a community we have shared the difficulties of Covid and we have absorbed disappointing research news. However, I join with our CEO and Chair in pointing out some of the bright spots of the year also. Fiscal 2021 is a year where HSC, and our community as a whole, have demonstrated tremendous resilience. This is very evident in our financial results for the year. The Huntington Society of Canada is posting strong financial results, especially in the surplus in the General Fund. There are several reasons for this: we owe a tremendous debt of gratitude to our amazing Huntington disease community. Your support was unwavering. Even though we were not able to hold our walks, rides, indies and other Chapter events, our revenue in the General Fund, before government support, was about 78% of the prior year. This is a wonderful show of

strength in a very challenging year. Thank you to our community! We also need to recognize the results of our new management team. They were able to pivot remarkably to a virtual world of fundraising. These results are a testament to their hard work. And finally, we are grateful for the support of the federal government. The wage subsidy was critical to our results this year. You will notice a new focus on the differentiation of the Funds in this year's financial statements. For the first time, we have shown you the balance sheets of each fund, as well as their respective income statements (Statements of Fund Balances and Statements of Operations, respectively). Results in the General Fund indicate the relative financial successes of the operations of the Society. Results in the Endowment Fund will vary with unrealized changes in the market value of investments. Results in the Ralph Walker Fund can also vary, depending on the level of research investment made

in any one year. Research expenditures can vary, depending on the number and quality of grant applications that we receive. Aside from the impact of the Canada Emergency Wage Subsidy on our revenue, the other difference you may note in our financial results is the relative lack of research funding. These expenditures have been declining in recent years, not as a policy choice, but because we have not been receiving very many applications for our research funding. The organization and board of directors are working to understand the reasons for this, are developing a new research funding policy. We remain committed to funding research. Congratulations to the management team and our community at large. We have had a strong fiscal year in challenging times. We are looking forward to another strong year in Fiscal 2022.

Thank you for your support!



-Anne Brace, *Treasurer*

Statement of Financial Position *

March 31, 2021, with comparative information for 2020

	General Fund	Capital Assets Fund	Endowment Fund	Ralph Walker Research Fund	Total 2021	Total 2020
Assets						
Current assets:						
Cash	\$ 1,021,918	\$ -	\$ -	\$ -	\$ 1,021,918	\$ 870,424
Investments	-	-	1,736,024	1,250,508	2,986,532	2,642,350
Account receivable	259,832	-	-	-	259,832	134,130
Due to (from) other funds	(493,372)	-	193,067	300,305	-	-
Prepaid expenses	77,529	-	-	-	77,529	99,161
	865,907	-	1,929,091	1,550,813	4,345,811	3,746,065
Capital assets	-	67,673	-	-	67,673	77,032
	\$ 865,907	\$ 67,673	\$ 1,929,091	\$ 1,550,813	\$ 4,413,484	\$ 3,823,097
Liabilities and Fund Balances						
Current liabilities:						
Accounts payable and accrued liabilities	\$ 137,909	\$ -	\$ -	\$ -	\$ 137,909	\$ 160,818
Deferred revenue	153,686	-	-	-	153,686	309,305
	291,595	-	-	-	291,595	470,123
Deferred lease inducement	14,037	-	-	-	14,037	17,699
	305,632	-	-	-	305,632	487,822
Fund Balances:						
General Fund	560,275	-	-	-	560,275	298,552
Capital Assets Fund	-	67,673	-	-	67,673	77,032
Endowment Fund	-	-	1,929,091	-	1,929,091	1,755,311
Laura's Hope Fund	-	-	-	-	-	18,780
Ralph Walker Research Fund	-	-	-	1,550,813	1,550,813	1,185,600
	560,275	67,673	1,929,091	1,550,813	4,107,852	3,335,275
	\$ 865,907	\$ 67,673	\$ 1,929,091	\$ 1,550,813	\$ 4,413,484	\$ 3,823,097

*These statements are extracted from the audited financial statements for the year ended March 31, 2021. The full set of audited financial statements is available on our website.

Statement of Operations *

Year ended March 31, 2021, with comparative information for 2020

	General Fund	Capital Assets Fund	Endowment Fund	Ralph Walker Research Fund	Total 2021	Total 2020
Revenue:						
Donations	\$ 1,222,169	\$ -	\$ -	\$ 469,170	\$ 1,691,339	\$ 1,860,075
Grants	100,618	-	-	164,876	265,494	609,565
Chapter and volunteer fundraising revenue	741,811	-	-	1,510	743,321	1,277,055
Investment income	83,862	-	-	58,277	142,139	93,137
Change in fair value of investments	-	-	173,780	120,763	294,543	(147,319)
Other income	820,912	-	-	-	820,912	93,212
	2,969,372	-	173,780	814,596	3,957,748	3,785,725
Expenses:						
Research	52,080	-	-	528,163	580,243	915,092
Family services	1,187,710	-	-	-	1,187,710	1,343,180
Public awareness and education	235,914	-	-	-	235,914	321,007
Chapter and volunteer support	192,625	-	-	-	192,625	170,182
Development	301,186	-	-	-	301,186	388,691
Chapter and volunteer fundraising expenses	139,524	-	-	-	139,524	250,944
Administration	531,084	-	-	-	531,084	672,232
Amortization	-	16,885	-	-	16,885	10,359
	2,640,123	16,885	-	528,163	3,185,171	4,071,687
Excess (deficiency)						
of revenue over expenses	\$ 329,249	\$ (16,885)	\$ 173,780	\$ 286,433	\$ 772,577	\$ (285,962)

*These statements are extracted from the audited financial statements for the year ended March 31, 2021. The full set of audited financial statements is available on our website.



HD FACTS & FIGURES

HD IS A GENETIC BRAIN DISORDER WITH **PHYSICAL, MENTAL AND EMOTIONAL SYMPTOMS**



HD IS OFTEN DESCRIBED AS HAVING **ALS, PARKINSON'S AND ALZHEIMER'S ALL AT THE SAME TIME**



1 IN EVERY 7,000 CANADIANS HAS HD

1 IN EVERY 5,500 CANADIANS IS AT-RISK FOR HD

MANY MORE ARE TOUCHED BY HD AS A

CAREGIVER, FAMILY MEMBER OR FRIEND



A CHILD BORN TO A PARENT WITH HD HAS A **50 PER CENT** CHANCE OF HAVING THE GENE MUTATION THAT WILL LEAD TO THE PROGRESSION OF HUNTINGTON DISEASE

50%

CURRENTLY, THERE IS NO KNOWN CURE FOR HD.

COMMUNITY STORIES



Lesley Nantel, BC Chapter President

"I got involved with ENROLL HD and also HD Clarity, where I donated my cerebrospinal fluid.

I'll never know this, but what if, one day a researcher is looking at a petri dish and finds a cure using my spinal fluid?! For me, volunteering and getting involved in research makes me feel like I'm moving things forward, and also not letting HD define me."



John Hickson, Donor

"In 1971, we were shocked to learn that my wife Sylvia's mother had been diagnosed with HD. She died a few

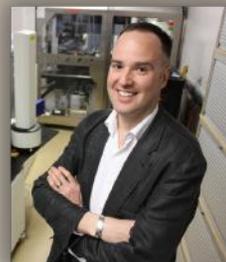
years later. At the time, there was very little information available about HD. Looking to connect with others facing HD, we put an ad in the newspaper and had a meeting in Calgary. This started the Alberta chapter of the HSC, aided by Ralph and Ariel Walker. As many of you know, they drove across Canada on vacation with their tent trailer in tow, visiting fledgling chapters and families who had come together to help fight this awful disease. These were the early days of HSC."



Brianna Voss, age 22

"My 17-year-old brother Connor has Juvenile HD. Last year Covid made visiting and getting him settled

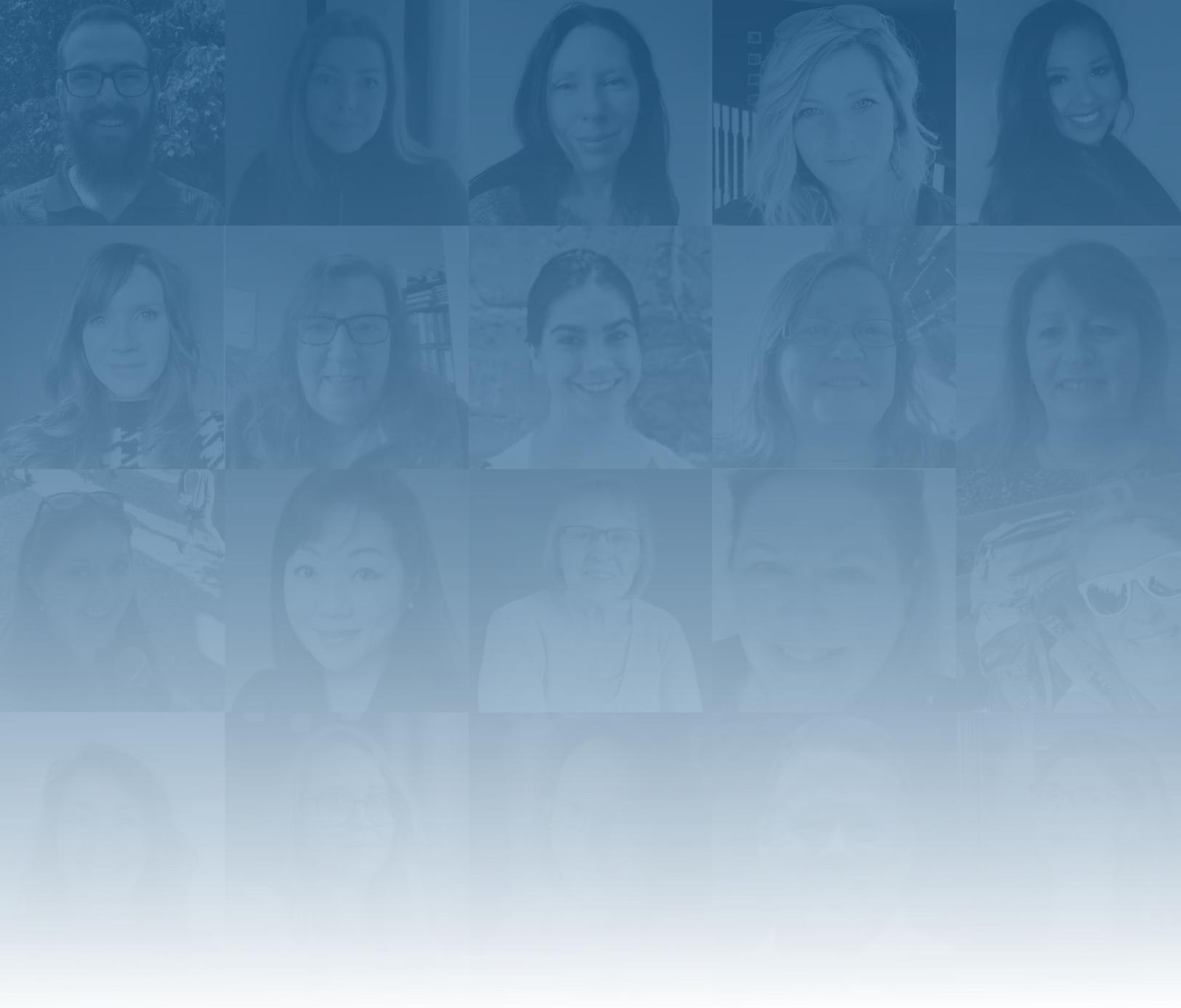
anywhere really hard. He ended up in a few different institutions, and I was stranded in Australia, where I had been working, unable to get a flight home due to Covid. When I finally got home, I was shocked by the change in my brother's condition. The last time I had seen him I was taking him to get a haircut. When I came back, I was only allowed a five minute visit, talking to Connor through a locked door in an institution. I decided to get genetic testing and I'm negative for the gene mutation that causes HD. But I'll never stop advocating, raising awareness, or fundraising."



Dr. Ray Truant, HD researcher with 20 years experience and HSC Research Council Chair

"My end goal in all of this - in my career - is to get something that's going to make a difference in the clinic."

TO VIEW OUR 2020-2021 DONOR LIST: [CLICK HERE](#)



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