



2021
2022

ANNUAL REPORT

HYDROCEPHALUS CANADA |

OUR MISSION

Hydrocephalus Canada's mission is to empower people impacted by hydrocephalus and spina bifida to experience their best life.

VISION

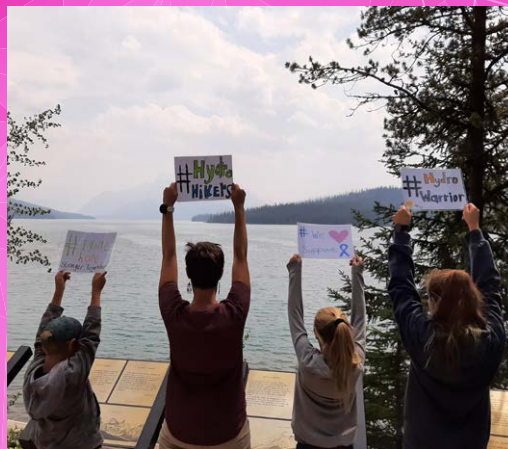
To establish a Canadian environment that protects, supports and enhances all individuals, families and caregivers impacted by the conditions by Bridging Research, Awareness and Innovation with Advocacy, Education and Support

PURPOSE

Hydrocephalus Canada (HC) is the trusted source for compassionate, progressive and innovative solutions that drive efforts to:

- Develop a Canadian strategy; to increase awareness about hydrocephalus and spina bifida
- Create solutions that support prevention, early and accurate diagnosis and access to appropriate treatment, advancement of new treatments and optimal outcomes
- Develop, establish, enhance and maintain education and awareness resources and encourage inclusive supportive hydrocephalus and spina bifida communities
- Fund impactful research

Hydrocephalus Canada has a devoted staff and a strong, diverse and innovative Board of Directors with legal, financial, scientific, media and not for profit experience. It is counselled by a Medical Advisory Board (MAB) comprised of experts who specialize in hydrocephalus and spina bifida, and who are known and respected internationally. As the authoritative voice of Canadians living with hydrocephalus and/or spina bifida, we help those impacted by these conditions to not only survive but thrive.



MESSAGE FROM THE CHAIR



The 2021-22 year was another eventful year for everyone, including our hydrocephalus and spina bifida community (the HSB community), filled with challenges, adjustment, evolution and growth.

For society at large, we continued to face the challenges of the pandemic – new waves and variants continued to affect our everyday lives. We collectively continued to adjust, slowly getting back to some of the important parts of our lives: spending time with our loved ones, connecting in person through school and work and taking care of our health.

Our HSB community faced unique challenges in the pandemic relating to securing the support they needed from the healthcare and social services systems. We were pleased to act as an intermediary between these two communities – helping our community members navigate a changing medical and social services landscape and providing feedback to these systems as they adjusted services through the pandemic.

Hydrocephalus Canada (HC), like all of our stakeholders, faced a number of hurdles as well, including the loss of key fundraising opportunities through our traditional events such as Spirit Wheel Walk Run events and an annual golf tournament. Loss of these fundraising events also resulted in less opportunity to connect with our HSB community in person.

In spite of these challenges, HC continued to evolve this year thanks to our amazing staff. There were a number of new and exciting ways that HC supported our community in 2021-2022:

- We reached out to our constituents to understand their needs – developing a needs survey to ask critical questions to determine how best to support them and to strengthen our organization (please see the details of the survey and results later on in the Annual Report).

- We expanded our support and programming geographically, welcoming new volunteer community contacts in Western Canada, Atlantic Canada and Ontario.
- We increased our methods of virtual support to constituents given the restrictions of the pandemic, offering monthly webinars on various topics for youth, adults, parents, caregivers and health professionals. We leveraged our Staying Connected electronic newsletter and social media to engage in virtual community building and volunteer recruitment.
- We also introduced our Healthy Living Series, a collection of webinars, classes and a social media campaign with tips, resources and links on key topics identified in our community needs survey. Stay tuned as we expand this series and publish our online Healthy Living Toolkit, a quick reference guide containing health and other resources to help support the needs of our community, right now.

In addition, we continued to bring new perspectives and skills to build for the future:

- We expanded our talented staff to improve and grow HC programs and services, welcoming the expertise of our new Director of Development and a Community Connections Ontario Coordinator.
- We built on our board expertise, welcoming Heather Cheeseman and Nikki Stone to our Board, who bring significant financial, marketing, advertising and business experience.
- We undertook strategic planning with our board and staff, to ensure that we keep taking the right steps to safeguard the longevity of the organization and continued support of our constituents.

Thank you to our staff, our talented board, skilled and dedicated medical teams throughout the country, corporate partners, foundations and most importantly, our fantastic HSB community of individuals, families, caregivers and donors. Together, we are connected in our cause and our momentum.

With YOUR support we can continue to transform and achieve our purpose: to champion those impacted by hydrocephalus and spina bifida to experience the best life possible. YOU make the difference!

GILLIAN AKAI

MESSAGE FROM THE DIRECTOR OF PROGRAMS & INFORMATION



Anything but business as usual." Those were some of the final words in my message for Hydrocephalus Canada's 2020-21 Annual Report. Last year, we came together to meet the chal-

lenges presented by COVID and a year later, two new words come to mind: DYNAMIC and CONNECTED. At a time in our world when we all felt uncertain, we looked inward for direction, for our collective future. I am happy to share that there is new energy in the hearts of those who make our mission possible. Confronting challenge has reinforced in us the knowledge that our community, partners, volunteers, supporters, board members and staff — they know best how to help us thrive in the face of adversity.

And thrive, we did! In September, supported by an Ontario Trillium Foundation (OTF) grant, Hydrocephalus Canada conducted a Community Needs survey. We asked your thoughts on our existing programs as well as new ones to be offered, now and in a post-pandemic future. We put your feedback to work, introducing a new Healthy Living Series with resources and activities to address the three topics most important to you: improving mental health, healthy living and financial security. We are so excited about the growth of this series, we thought we would give you a sneak peek into next year. Expect to see a new, online Healthy Living Series Toolkit chock full of resources and information, with subjects ranging from pressure wound management to diet and nutrition for the neurogenic bowel and bladder.

We went webinar crazy! Through the support of allied partners such as Association de spina bifida et d'hydrocéphalie du Québec, Sick Kids Foundation and Holland Bloorview Kids Rehabilitation Hospital,

we showcased professionals from inside and outside of our community. Together, we delivered 15 webinars on a multitude of topics, such as Pregnancy in Women with Spina Bifida and Job Search & Interview Preparation Strategies.

"I just wanted to thank you for an insightful webinar last week. Your efforts, passion and consistent hard work are clearly visible. As a family we value and appreciate your initiatives and support immensely."

Annette V., Cochrane, AB

We tried new things too, like dance classes.

"Being part of the BAMDance video... my best memory of 2021."

Angie M., Ottawa, ON

Although not all of the topics made the cut we definitely had fun along the way.

With full participation from our support group members, we launched a new, virtual support group meeting format. Each group created its own meeting ground rules and goals, as well as a list of topics to be discussed throughout the year. Members know that they can count on a caring, safe place to engage, connect and hear about the things that matter most.

"Great job. I love the support group meetings. It is great to know the topic ahead of time. It allows everyone equal chance to talk. It is so nice to have follow up emails and research done on the topics from HC."

Ashley M., Kanata, ON

In November of last year, HC hosted its first virtual volunteer orientation session. Our goal? Make it easy for people interested in volunteering to know about the ways to get involved. And get involved, they did, from coast to coast. From hosting our new Western Canada Hydrocephalus Facebook Support group, to signing up as volunteer editor of our Staying Connected Newsletter "Own Your Story" feature, to recent interviews for a community link volunteer in New Brunswick. Our volunteers are the heroes of our organization. You have been instrumental in helping to deliver on our mission. What you do — listen,

share, support, guide, raise funds, give voice to our stories, change outcomes and so much more — your work matters and is deeply appreciated.

As we look forward to great things in the future, Hydrocephalus Canada marks its 50th anniversary in 2023. Time for a gala? Let's hope for something fun, an event where we can all be together, to acknowledge what sets us apart: our people. Which leads me to my final word, when I reflect on the 2021-22 year at Hydrocephalus Canada...GRATEFUL.

SHAUNA BEAUDOIN

EXPANSION EFFORTS

With the generous support of new volunteers from the West coast, Hydrocephalus Canada was successful in expanding its virtual support to community members in Western Canada. Members from British Columbia, Alberta, Saskatchewan, Manitoba and the Yukon now have a virtual meeting place to hear and share tips, hints, suggestions, make friends, build a peer support network and find inspiration, especially for those who might be going through a tough time. Thank you to our support group admin Jeff Bourne and moderator Melody Rose for helping to build and grow this exciting new initiative!



JEFF BOURNE
WEST KELOWNA, BC



MELODY ROSE
CHILLIWACK, BC

TREASURER'S REPORT



The second full year for Hydrocephalus Canada of operating within the COVID restricted environment resulted in positive financial results.

Summary Financial Statements are included later in this Annual Report and I will supply some

explanatory commentary for these Summary or Condensed Financial Statements.

Our auditors, Cholkan & Stepczuk LLP, have again provided Hydrocephalus Canada with a positive opinion saying that our financial statements present fairly, in all material respects, the financial position of the organization as of February 28, 2022 and its financial performance for the 12-month period ending February 28, 2022.

As a matter of fact, the opinion offered this year was even stronger than the auditor's opinion provided last year and in previous years. As we have discussed before, auditors commonly provide a qualification to their opinion for non-profit or charitable organizations that receive funds that are not susceptible to normal audit tests and procedures. For our organization an example of these types of revenues that are not readily audited would be those collected by third parties during pledge walks and then the net proceeds are remitted to Hydrocephalus Canada. However, the auditors this year decided that these types of revenues were not signifi-

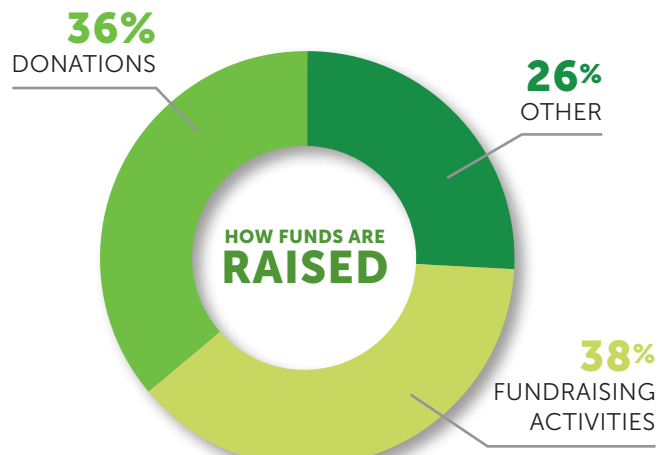
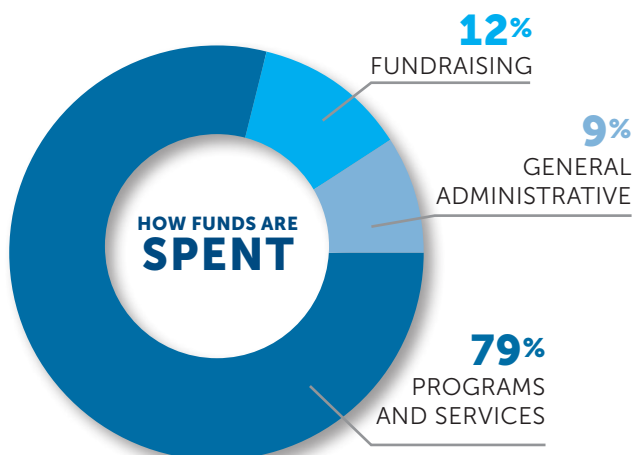
cant enough to warrant a qualification on the totality of our financial statements and have provided us with an unqualified opinion.

With respect to the Statement of Financial Position (formerly known as the Balance Sheet) our overall financial strength has increased and unrestricted deposits have grown to \$300,000 during the 12-month fiscal period ending February 28, 2022. Unrestricted deposits represent contingency funds for the organization should there be difficult financial or operational challenges in the future.

The reason Hydrocephalus Canada was able to strengthen its financial position is shown on the Statement of Operations (formerly known as the Income Statement). The Statement of Operations shows an excess of revenues over expenses for the 12-month period ending February 28, 2022 of approximately \$98,900. This was due to revenue factors such as an unrestricted one-time bequest of over \$71,000 and continuing revenues, in the first part of the year, from COVID-related government subsidy programs. Lower than expected expenses, largely due to an unanticipated delay in hiring additional staff, were also an important reason for the year end surplus.

This is the third fiscal year in a row that Hydrocephalus Canada has generated a financial surplus which places the organization in a solid position to expand programs and have a greater positive impact on the community we serve.

PAUL EGLI, CPA, CGA



SUMMARY ANNUAL FINANCIAL STATEMENTS

SUMMARY STATEMENT OF OPERATIONS

Year ended February 28, 2022

	2022	2021
Revenues		
Fundraising activities, net	\$180,208	\$179,467
Donations	168,678	95,087
Government grants and other	125,913	38,073
	474,799	312,627
Expenses		
Programs and services		
Awareness and education	156,647	117,200
Care and support	108,836	76,305
Advocacy, research and scholarships	28,842	26,109
General administrative	32,406	28,895
Fund development	46,221	11,398
Amortization of equipment	2,920	699
	375,872	260,606
Excess of revenues over expenses	\$98,927	\$52,021

SUMMARY STATEMENT OF FINANCIAL POSITION

February 28, 2022

	2022	2021
ASSETS		
Cash and short-term deposits	\$397,379	\$292,906
Other current assets	45,498	42,653
Total current assets	442,877	335,559
Endowment investments	221,446	221,092
Equipment	8,758	974
Total assets	\$673,081	\$557,625
LIABILITIES		
Accounts payable and accrued liabilities	\$13,772	\$20,517
Deferred contributions	36,234	12,960
	50,006	33,477
NET ASSETS		
Net assets restricted for scholarships and research	224,228	227,228
Unrestricted net assets	398,847	296,920
	623,075	524,148
Total liabilities and net assets	\$673,081	\$557,625

SUMMARY STATEMENT OF CHANGES IN NET ASSETS

Year ended February 28, 2022

			2022	2021
	Unrestricted	Restricted / other	Total	Total
Beginning of year	\$296,920	\$227,228	\$524,148	\$472,127
(Expenses over revenues) revenue over expenses	101,927	(3,000)	98,927	52,021
Internally restricted, transfers	-	-	-	-
End of year	\$398,847	\$224,228	\$623,075	\$524,148

Note to Summarized Financial Statements – Basis of the Summary Financial Statements

The criteria applied by management to prepare these summary financial statements are as follows:

- The information herein is in agreement with the related information in the audited financial statements.
- The summary statement of cash flows and financial statement notes have not been presented since that information can be obtained from the audited financial statements.
- The complete audited financial statements, with Auditors' Report dated July 5, 2022, may be obtained from the Organization office or viewed on its website.

REPORT OF THE INDEPENDENT AUDITORS ON THE SUMMARY FINANCIAL STATEMENTS

To the Members of Hydrocephalus Canada

Opinion

The summary financial statements, which comprise the summary statement of financial position as at February 28, 2022, the summary statement of operations and summary statement of changes in net assets for the year then ended, and related notes, are derived from the audited financial statements of Hydrocephalus Canada for the year ended February 28, 2022.

In our opinion, the accompanying summary financial statements are a fair summary of the audited financial statements, on the basis described in the note to the summary financial statements.

Summary Financial Statements

The summary financial statements do not contain all the disclosures required by generally accepted accounting principles for not-for-profit organizations. Reading the summary financial statements and the auditor's report thereon, therefore, is not a substitute for reading the audited financial statements and the auditor's report thereon. The summary financial statements do not reflect the effects of events that occurred subsequent to the date of our report on the audited financial statements.

The Audited Financial Statements and Our Report Thereon

We expressed an unmodified audit opinion on the audited financial statements in our report on July 5, 2022.

Management's Responsibility for the Summary Financial Statements

Management is responsible for the preparation of the summary financial statements on the basis described in the note to the summary financial statements.

Auditor's Responsibility

Our responsibility is to express an opinion on whether the summary financial statements are a fair summary of the audited financial statements based on our procedures, which were conducted in accordance with Canadian Auditing Standard 810, Engagements to Report on Summary Financial Statements.



Toronto, Ontario
July 5, 2022

Cholkan + Stepczuk LLP
Chartered Professional Accountants
Licensed Public Accountants

DONOR PROFILE

We so appreciate the support of Laura Gatensby, Hydrocephalus Canada Board member and volunteer hero! Hear what Laura has to say about how her involvement has led to empowerment, taking control of her life and making a difference.

When and why did you first get involved with Hydrocephalus Canada?

I picked up hydrocephalus as one of the parting gifts from a large, complicated, and thoroughly unexpected acoustic neuroma (brain tumour) in 2017 ([see Laura's full story on our website](#)). In the fall of 2020, I happened to see a posting for Hydrocephalus Canada Board members, and I was drawn to it immediately. In all my years in the non-profit world, as a professional fundraiser, on other Boards and as a grassroots volunteer, I had never had the experience of working with a charity whose mission impacts me so personally.

Why do you donate?

I feel like my donation is much more personal than ever before. The financial realities I've faced because of my health issues have been challenging to say the least, and have meant that I haven't been able to donate nearly as much as I would like. I began contributing monthly because it's a way to make a bigger difference than I could with a single gift, and because the organization can count on the funds on an ongoing basis. As much as I wish I could do more, I know that my gift is making a difference.

What do you wish people knew about hydrocephalus & spina bifida, and/or the organization?

There are thousands of people in Canada living with hydrocephalus and spina bifida who have no idea that Hydrocephalus Canada is there for them as a source of information, support and connection with others dealing with the same challenges. I want to find a way to build awareness of Hydrocephalus Canada's important work, so ALL the people who need us, know we're here for them!

What would you tell a prospective donor to the organization?

I would share the importance and impact of Hydrocephalus Canada's work to help those living with

the conditions. I would make sure that every prospective donor understands that the amount of the gift is secondary to just supporting – every donation makes a difference. It can also make you feel like you have just a little more control over the future of these conditions in Canada.

What is something you can share about yourself?

As much as the brain tumour was the BIG issue and the ongoing balance challenges are significant, the hardest thing in my health journey has been hydro-related – when the shunt enabled most of my eyesight to return, what I didn't get back was my peripheral vision; I see fine with glasses but my field of vision is much smaller than an average person's. This, according to the Ministry of Transportation, makes me legally blind and required the loss of my driver's license. While I feel very fortunate that I have people to rely on, having to rely on others for transportation has been the thing that most makes me feel like I'm not in control.

Something that would surprise people?

I'm working on re-applying for my license! It's the additional control I've felt because of my relationship with Hydrocephalus Canada, which has given me the confidence to make this application. Still in the early phases, but hopeful – wish me luck!

What is your dream for people living with hydrocephalus and spina bifida?

I want every one of the 120,000+ people living with hydrocephalus and spina bifida in Canada to feel empowered, not just existing with these conditions but taking control of them and their lives.

What is your hope for Hydrocephalus Canada in the next 5-10 years?

In addition to expanding the reach and awareness of its programs and services, I want to see Hydrocephalus Canada lead the way in funding medical research that has the potential to change the lives of our constituents.



ONTARIO TRILLIUM FOUNDATION GRANT SUPPORTS INSPIRATION & INVESTMENT IN OUR FUTURE



An agency of the Government of Ontario
Un organisme du gouvernement de l'Ontario

In June of 2021, HC was awarded an Ontario Trillium Foundation (OTF) Resilient Communities grant to help the organization rebuild and recover from the impacts of COVID-19. The purpose of the grant was to help HC re-imagine its programs and service delivery by developing online support and social, educational and health-focused initiatives for its members. The OTF grant provided inspiration, stability and an ability to invest in the future.

Through an online survey, the HSB community lent its voice to a very important conversation: how could HC best support their needs, now and in the post-pandemic future? For the full results and changes introduced as a result of the survey, read or download the [2021 Survey Report](#) or, see the Survey Results Infographic in the Annual Report.



GILDA K., FORMER ADULT
HYDROCEPHALUS
SUPPORT GROUP FACILITATOR

Funded by the OTF grant, HC hired a Community Connections Ontario Coordinator who initiated and built new programming based on the community needs survey conducted, resulting in a robust online programming series. New health-focused seminars by experts from within the medical and allied community expanded exponentially during the grant, offering one to two webinars per month. With virtual programming based on survey feedback, our community participated at levels not seen since the pandemic. They engaged, shared and discovered via our online education series.

Through virtual team building sessions, support group members helped to create a new meeting format. Members connected, laughed and learned and received and offered support to their peers throughout the year.

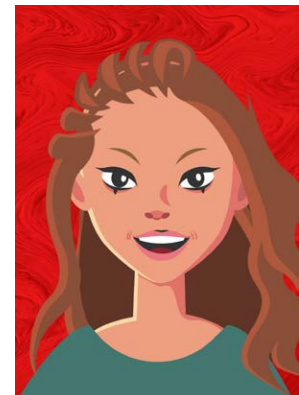
Also funded by the grant, HC hired a Director of Development. This position supported current fundraising initiatives, reviewed and updated fundraising policies and implemented e-fundraising campaigns. The Director of Development implemented new grant search software and a donor acquisition program, with a focus on expanding our donor community. As a result, new fundraising opportunities such as HC online auctions and text to donate will be considered for 2022-23.

The OTF grant also enabled HC to update infrastructure and communications via new technology, revamping our website and telephone system. Have you seen the [new website](#)? Check it out! The team at HC was so excited to deliver this and couldn't be more proud!

The OTF grant helped us to strategize and build organizational capacity through the development of new volunteer support for the community. HC grate-



ALEXIS NEEDS, COMMUNITY
LINK, GUELPH, ON



TIFFANY SMITH, PARENT
LINK, KITCHENER, ON

fully welcomed volunteers from across Canada in a variety of roles, including new Community Contacts and a Parent Link.

In the spirit of keeping the voice of those we serve front and centre, HC introduced a new Staying Connected Newsletter segment, “[Own Your Story](#)”. Featuring the lived experience of individuals impacted by hydrocephalus and spina bifida, the series began with the very moving story of [Lorri-Ann Champagne](#). Mary Dufton, an active member of the HC community, became the volunteer editor for this new segment.

Thank you to all of our volunteers.
Your dedication, especially during the pandemic, has helped us to connect and support the HC community and enrich the lives of many. We couldn't do what we do without you!

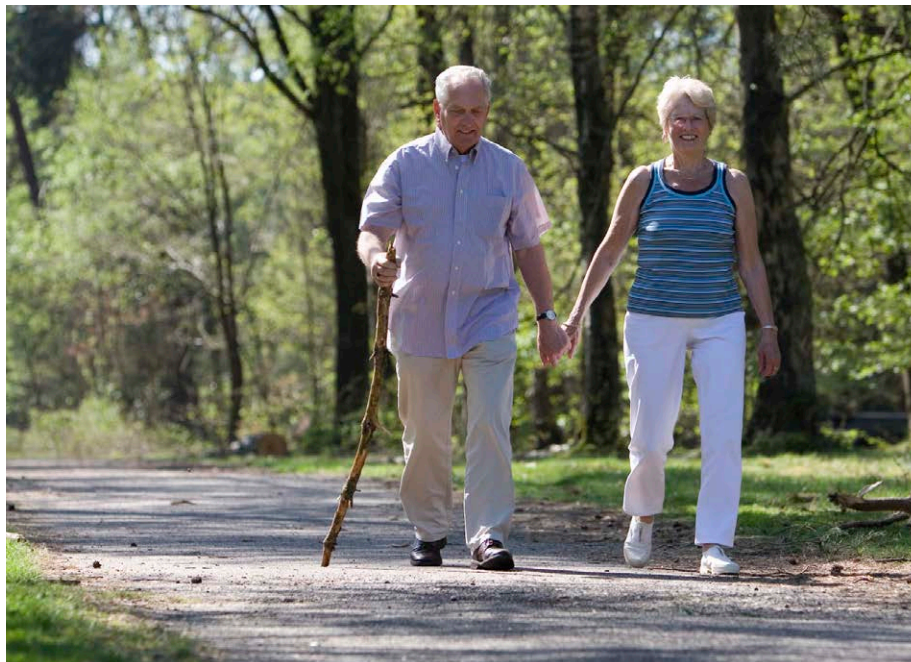


MARY DUFTON, VANIER, ON



LORRI-ANN CHAMPAGNE, BARRIE, ON

STAY CONNECTED – WITH HC AND WITH ONE ANOTHER



Connection is what keeps us healthy and strong. Join our mailing list and receive the HC Staying Connected newsletter. Contact our Board or staff, who are always interested in hearing from our constituents. Hearing from you helps us improve and evolve. Reach out to us at www.hydrocephalus.ca, on Facebook, Twitter and Instagram. Email us at info@hydrocephalus.ca or call toll-free 1-800-387-1575. We would love to hear from you!

HYDROCEPHALUS CANADA'S COMMUNITY NEEDS SURVEY REPORT

2021 HIGHLIGHTS

KEY SERVICES ACCESSED



WHO HAD THEIR SAY

of people who participated in the survey **206**

72% of the respondents are Ontario-based

AREA OF CONCERN
youth representation **2%**

PROGRAMS MOST LIKED



ENGAGEMENT POST-PANDEMIC

39% want mix of virtual and in-person

FEELINGS ON MENTAL & PHYSICAL HEALTH



AREA OF CONCERN

Some community members expressed feelings of poor to very poor feelings of mental and physical health

TOP RESEARCH AREAS TO EXPLORE



Hydrocephalus **58%**
Spina bifida **55%**
Mental health **42%**

MOST POPULAR SOCIAL MEDIA PLATFORMS



TOP 3 AREAS OF INTEREST FOR NEW PROGRAMMING

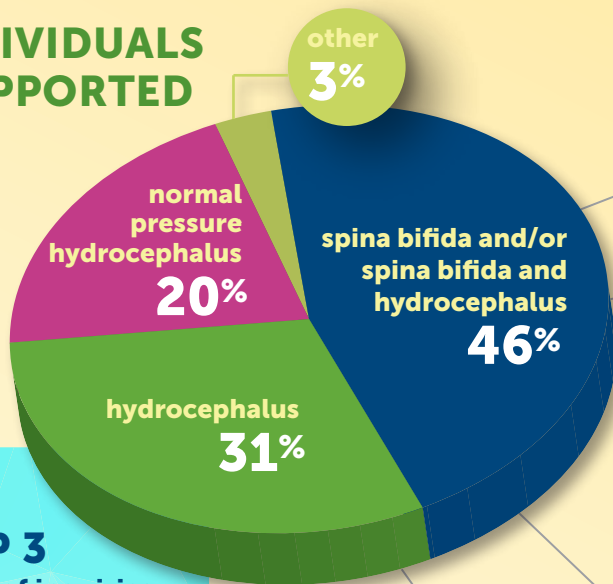
1 Mental health

2 Healthy living

3 Financial security

HYDROCEPHALUS CANADA 2021-2022 YEAR AT A GLANCE

INDIVIDUALS SUPPORTED



Community support links

Most common method of inquiry
email

Information requests evenly split
spina bifida and hydrocephalus & normal pressure hydrocephalus

Complimentary publications



AGM, WEBINARS & PRESENTATIONS

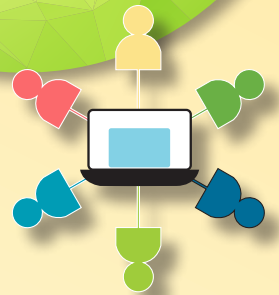
Educational webinars delivered:

15

Check out some of our events!

2021-22 AGM

News & Events –
Hydrocephalus Canada
Webinars & Presentations



TOP 3 types of inquiries

Doctor referrals

24%

Financial/equipment funding

11%

Bowel & bladder management

6%

SUPPORT GROUPS

Adult hydrocephalus on Facebook and virtually

Adult hydrocephalus Western Canada on Facebook

Adult sb on Facebook and virtually

Parent hydrocephalus on Facebook and virtually



FUNDRAISING EVENTS

In spite of the pandemic, our community pitched in more than ever!

13th Annual Jackson's Hope FORE Hydrocephalus

– started in 2009, over **\$33,000**

raised over \$4,500 in 2021

Thirty-One Gift fundraiser by Christine Iggulden. Raised **\$100**

Troy's Trail SWWR – raised over **\$3,400** in 2021

Team Layne SWWR – raised over **\$4,000** in 2021

Adam Barbour Memorial BBQ Fundraiser. Raised **\$550**

Many members of our community did Facebook fundraisers, commemorating birthdays, anniversaries and even their shunt or ETV anniversaries, while donating the proceeds to HC!

DONORS & PARTNERSHIPS



YOU ARE SIMPLY THE BEST!

To all of our donors and partners, you are the core of our organization. Without you, none of what we accomplished in this last year would have been possible. Your dedication and commitment allowed us to engage more deeply with our community and build connection in what continued to be a virtual world. Thank you for supporting Hydrocephalus Canada and the people that we serve.

PARTNERS

Association de spina bifida et d'hydrocéphalie du Québec

Holland Bloorview Kids Rehabilitation Hospital

Spina Bifida and Hydrocephalus Association of Northern Alberta

Teaching Awareness Through Puppetry (TAP)

SPONSORS

Coloplast Canada

OOS Medical/Amici Catheters

DONORS \$500+

YOU DESERVE A **BIG** THANK YOU!

Shirley Akai

Alice and Murray Maitland
Foundation

Janet & Gordon Baker

Heather & David Cheeseman

Claudio Cinapri

Scott D. Clark

Herman den Hollander

Paul Fair

Edwards Charitable Foundation

Estate of Alexander Peter Skinner

Gary Bluestein Charitable
Foundation

Gee's Tree Removal Service

Alan Hirsch

Suzanne Huggins

Larry's Small Engines Inc.

Sean McLane

Jane & Joseph McMahon

Guy & Suzanne Mongeon

Ontario Power Generation
Employees' & Pensioner's
Charity Trust

Ontario Trillium Foundation

Wade Partridge

Marni Przybylski

R.V. Anderson Associates

SickKids Foundation

Laura Smy

The Catherine and Maxwell Meighen
Foundation

The George Lunan Foundation

The Silvio Bot Charitable Foundation

United Way of Greater Toronto

WD-40 Company (Canada) Ltd.



Did you know that many employers have employee giving and matching gift programs? Companies like Bell Canada, Hydro One, RBC, BMO Financial Group, Travelers, LinkedIn and TD Bank have employee giving programs and may match your donation, dollar for dollar. Ask your employer today and sign up!

DONORS \$250-\$499

Nicole Albers
Darlene Andrew
Liz Breen
Michael Brolley
Laura College
Delta Marine
Shawna Henderson
Jess Herman
Lynden Lions Club
Joan MacArthur
Manor Tool & Die Inc.
Mafalda Ryan
Walter Ryan
John Torrey
Workplace Safety Compliance
Centre Inc.

MONTHLY DONORS

Thomas Armstrong
Sandi Beaudoin
Laura Booth
Shellyann Carroll
Bonnie Charbonneau
Rhiannon Davies
Brendan Fleming
Laura Gatensby
Priya Gnanabhaskar
Gunn Nuclear Inc.
Shirley Hess
Hayat Ibrahim
Ken Koffman
Jody Lachine
Heather Langridge
Hugh R. McKay
Joy Parr
Lisa & Rob Pieta
Althea Poulos
Wendy Reed
Alan D. Reeve
Elaine Wilson
Jim Zurbrigg

WHAT DOES IT MEAN TO BE A MONTHLY DONOR?

Monthly Giving Club Member gifts provide a constant source of funds that allow HC to plan ahead. Monthly giving is an affordable and effective way to make a difference in the lives of all individuals with hydrocephalus and/or spina bifida.

EVERY DAY, YOU HELP US HELP SOMEONE NEW... SOMEONE LIKE THIS PERSON, RECENTLY DIAGNOSED WITH NPH

"You really helped me and have given me hope. I know you'll probably say you are just doing your job, but you put your heart into your work and that can be felt even over the phone. I have so much to thank you for. Firstly, thank you for responding to my email. Thank you for calling me and listening to me. I felt understood for the first time in months. My anxiety has lessened considerably because i'm not on edge all the time wondering if or when the hydrocephalus clinic will call. Now I can put that unknown away for 3-6 months. Also having those handouts means i've got something i can give to my adult children, who have been very worried about me, to read and understand and also have hope. I can never thank you enough."

Individual diagnosed with NPH

RESEARCH

Hydrocephalus Canada supports research that will improve the quality of life for all individuals with hydrocephalus and/or spina bifida and their families. We work in partnership with hospitals, rehabilitation centres, universities and other research facilities. Hydrocephalus Canada chooses to play a role in facilitating research through a stronger presence in the research community and by influencing the creation of a research agenda (international and national) through increased collaboration with various stakeholders.

2021-22 was a particularly exciting year for Hydrocephalus Canada, with many opportunities for research participation, including:

- **Exploring the nature of disordered eating in adolescents with spina bifida and hydrocephalus.**

Led by Bloorview Research Institute with involvement from The Hospital for Sick Kids and Hydrocephalus Canada

- **Enhancing healthy, productive work for persons with disabilities.**

CIHR project, led by Dr. Sally Lindsay, Bloorview Research Institute (5-year study)

<https://hollandbloorview.ca/research-education/bloorview-research-institute/research-centres-labs/healthy-and-productive-paid>

- **What are the mental health and wellness needs of young adults with spina bifida and/or hydrocephalus?**

Led by Dr. Andrea Snider with Dr. Amy McPherson, Bloorview Research Institute

- **Discrimination, ableism, and racism hurt but inclusion can heal; listening to the intersectional living experiences of youth with disabilities and co-creating solutions.**

Led by Dr. Sally Lindsay, Bloorview Research Institute

- **Understanding the Sexuality of Youth with Physical Disabilities Using Art (SYDA).**

University of Toronto/Bloorview Research Institute study with Maddy Gilles and Dr. Fiona Moola

<https://www.sydstudy.com/>

- **Impact of COVID-19 on women and girls with disabilities in Canada: a life course perspective.**

Dr. Hilary Brown, University of Toronto, CIHR Project (Canadian Institutes of Health Research)

- **Maternal disability and child preventive healthcare: Supporting family-centred care.**

Dr. Hilary Brown, University of Toronto, CIHR Project (Canadian Institutes of Health Research)

- **Neurological Patient Perspectives on evaluation of residents in Competence by Design education.**

Led by Dr. Michael Cusimano, Unity Health Toronto St. Michael's Hospital Project

- **Child-Bright ReadyorNot™ Brain-Based Disabilities Trial – recruitment to test app.**

CanChild Centre for Childhood Disability Research
<https://www.child-bright.ca/readyornot>

- **Disability and Immigration Research-Women who have immigrated to Canada with a physical disability.**

Maryam Rezazadeh, PhD Candidate, McGill University



SCHOLARSHIPS & BURSARIES

This year the committee awarded the Dr. E. Bruce Hendrick Scholarship to three recipients and the Luciana Spring Mascarin Bursary to one recipient.

Dr. E. Bruce Hendrick Scholarship Recipients



Tino Balestrini

Rodney G. Walsh Award

Tino, from Maidstone, Ontario is working towards his Bachelor of Arts & Education at University of Windsor. An avid golfer, Tino enjoys dirt bike riding and watching hockey.



Kayla Latreille

Dr. Robin P. Humphreys Award

Kayla, from Windsor, Ontario is studying to become a Registered Practical Nurse at St. Clair College. Kayla enjoys yardwork, outdoor activities and physical activity.



Waffa Qurbani

Barton Family Award

Waffa, from Mississauga, Ontario, is working towards her Masters of Education at the University of Ottawa. Waffa's goal is to become an ESL instructor for adults.

Luciana Spring Mascarin Bursary Recipient



Nathan Wuerch

Nathan, from Windsor, Ontario is studying Community Integration through Cooperative Education at St. Clair College. Nathan cares about the hungry and homeless in his community and enjoys attending Windsor Spitfire hockey games.



HEAR HOW YOUR FUNDING MADE A DIFFERENCE FOR SCHOLARSHIP RECIPIENT WILL PIETA

"Being a past recipient of both the Dr. E. Bruce Hendrick Scholarship and Luciana Spring Mascarin Regional Bursary has possibly been the greatest way to learn about my fullest potential, despite my diagnosis of hydrocephalus. This opportunity has taught me that living with this condition does not have to define me, or be a hindrance on my success as a student, young professional, or human being. With the right support systems, anything can be possible. These opportunities have been integral to my graduation with my Honours Bachelor of Commerce degree in Digital Marketing."

Will Pieta

OUR PEOPLE

BOARD OF DIRECTORS

Gillian Akai, LL.B., M.B.A., Chair
Kristine Dorward, M.B.A., B.Sc., 1st Vice-Chair
Stephen Rex, BCom, CPHR, 2nd Vice-Chair
Justin Parappally, LL.B., M.B.A., Secretary
Paul Egli, C.P.A., C.G.A., Treasurer
Claudio Cinapri, Past Chair
Dr. Scott W. H. Barton, Ed.D, MBA
Laura Gatensby
Mark Hamilton, MDCM, FRCSC, FAANS
Abhaya V. Kulkarni, MD, PhD, FRCSC
Joshua Matthewman
Eric Smith
Heather Cheeseman, C.P.A., C.A.
Nicolena “Nikki” Stone, BB

STAFF

Shauna Beaudoin, Director of Programs & Information
Steve Kean, Communications Consultant
Jay Polczer, Support & Promotion Coordinator
Helen Sedej, Information Services Manager
Sheena Robert, Director of Development
Andrea Walters, Community Support Coordinator
Vicky Pastuch, Support & Promotion Coordinator
Catherine Laird, Support & Promotion Coordinator

MEDICAL ADVISORY BOARD

Abhaya V. Kulkarni, MD, PhD, FRCSC
Medical Advisory Board Chair
Jeffrey Atkinson, MD, FRCSC
Paige Terrien Church, MD
Michael Cusimano, MD, MHPE, FRCS, DABNS, PhD, FACS
Ruth Donnelly, PhD, C.Psych.
Khaled Effendi, MD, FRCSC(C)
Alfonso Fasano, MD, PhD
Mark Hamilton, MDCM, FRCSC FAANS
P. Daniel McNeely, MD, FRCSC
Kotoo Meguro, MD, CRCSC

Safraz Mohammed, MD MBBS
Andrea Neufeld, MScN, RN, APN
Andrew Parrent, MD, FRCSC
Adrianna Ranger, MD, FRCSC
Sandrine de Ribaupierre, MD, FRCSC
Jay Riva-Cambrin, MD, MSc, FRCSC(C)
Denis Sirhan, MD, FRCSC
Mandeep S. Tamber, MD, PhD, FRCSC(C)
David Tang-Wai, MD, CM, FRCPC
Alexander G. Weil, MD, FRCSC, FAANS, FACS



VOLUNTEER SUPPORT

VOLUNTEER HOURS – 3200

Our volunteers led fundraising events, supported individuals and families in need, helped to raise awareness through social media and other platforms, compiled critical data, led support groups, presentations and webinars, edited submissions from our community members who shared their stories, provided leadership and shared medical advice to those requesting assistance. Thank you to everyone who volunteered with us, for your time, effort, commitment, generosity and dedication to our cause. We are beyond grateful!

"As a volunteer writer for the *Own your story* column, my main objective in sharing these stories is to reach our community of individuals with spina bifida and or hydrocephalus to provide awareness, support and a sense of belonging. My hope is that this column will reach others with these conditions and that they will feel less alone by reading my column. They will realize that there are many people out there with these conditions who have experienced similar circumstances and have persevered."

Mary Dufton, Volunteer Editor



GET INVOLVED

If you haven't already, we invite you to join us!

- **BECOME a member**
- **SERVE on the Board**
- **VOLUNTEER**
- **DONATE**

Contact us today to find out more about volunteering and how YOU can make a difference.

HYDROCEPHALUS
CANADA | 



16 FOUR SEASONS PLACE, SUITE 111, TORONTO, ON M9B 6E5
P: 416-214-1056 OR 800-387-1575 • F: 416-214-1446
INFO@HYDROCEPHALUS.CA • WWW.HYDROCEPHALUS.CA

Charitable Registration #10799 9310 RR0001