



RECONNECTING WITH PURPOSE

2022-2023 ANNUAL REPORT

HYDROCEPHALUS CANADA

OUR MISSION

Connecting the spina bifida and hydrocephalus communities across Canada through services, support, education, awareness and research.

VISION

A future without spina bifida and hydrocephalus.

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 conditions to not only survive but thrive.



MESSAGE FROM THE CHAIR



Hello, everyone! I am Gillian Akai, Chair of the Board of Hydrocephalus Canada. Thank you for taking the time to read our 2022-23 Annual Report.

Hydrocephalus Canada has had an incredibly exciting year!

January 2023 marked the beginning of our 50th anniversary.

What a milestone for our organization – fifty years of dedication and support from our members, volunteers, donors, staff and directors. Happy Anniversary Hydrocephalus Canada!

Together we have witnessed the spina bifida and hydrocephalus communities flourish in Ontario and now, across Canada. Our celebrations will continue throughout the year!

Over the past year, we have continued to strengthen our organization to better support our constituents across Canada.

Our 2021 Community Needs Survey helped us to understand how and where we can best support our communities to ensure that we remain focused on the greatest areas of need.

Using that information, in 2022 our board of directors established our new strategic plan focused on four key pillars: SUPPORT, EDUCATION, AWARENESS AND RESEARCH.

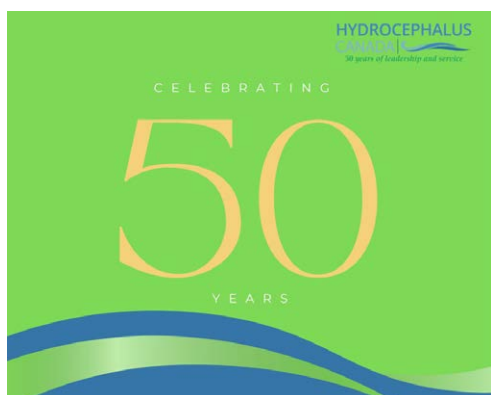
From there, we hired additional staff to help accelerate the achievement of our goals and implement that strategy into our day to day operations. This led to some important developments:

- ▶ Enhanced community connection and education initiatives through increased educational webinars, many delivered jointly with our Quebec partners, ASBHQ.
- ▶ Increased national presence and awareness through a variety of initiatives, including connecting across Canada with neurologists, neurosurgeons and other health professionals.

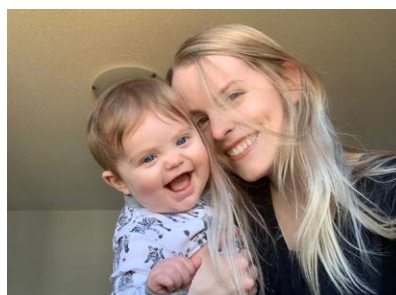
- ▶ With our Alberta colleagues we partnered to jointly pursue grants that will support our collective communities.
- ▶ We launched our new Allied Partner Network, beginning conversations across Canada with our peer organizations to increase awareness by strengthening our national voice.
- ▶ Hydrocephalus Canada was privileged to participate in and support research rooted in improving the lives of our constituents.
- ▶ This year, our CREMS Summer Program research project focused on the impact of pregnancy on bladder health in people with spinal cord injury;
- ▶ We welcomed 2nd year medical students from the University of Toronto who worked on updating sections of our hydrocephalus patient guide;
- ▶ We were partners in the ‘Discrimination, ableism and racism hurt but inclusion can heal’ project led by the DARE Research Alliance and
- ▶ We participated in the “We are Sexual Too” Project, led by Holland Bloorview Kids Rehabilitation Hospital.

Thank you to all of our donors, volunteers, directors and importantly, our fantastic staff. Together, they have furthered Hydrocephalus Canada’s mission to connect the spina bifida and hydrocephalus communities across Canada through services, support, education, awareness and research. I am so proud of the work we have done the past year and excited to build upon our already strong foundations in the coming year.

GILLIAN AKAI



Join us in celebrating 50 years of impact, 50 years of trust, 50 years of community and 50 years of hope! We have come a long way and are excited about what will come. We want to thank all of you for your unwavering support!

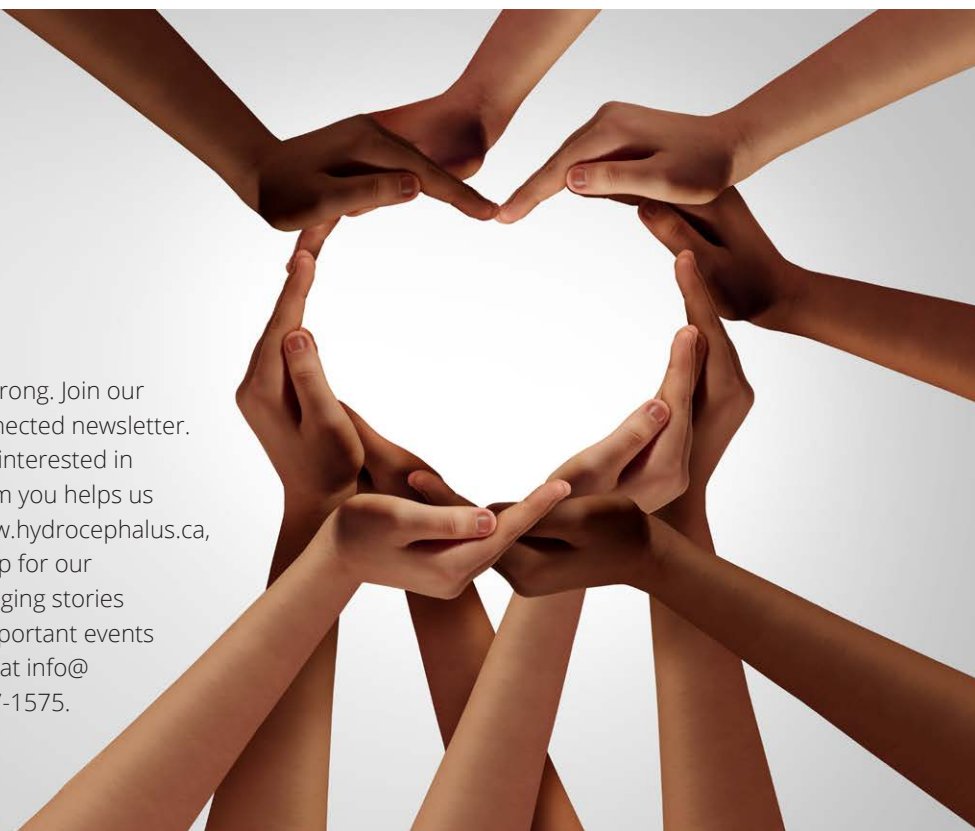


HUGS AND SMILES FROM THE SB&H COMMUNITY

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. Sign up for our Staying Connected Newsletter to read engaging stories about the members of your community, important events or research news and milestones. Email us at info@hydrocephalus.ca or call toll-free 1-800-387-1575. We would love to hear from you!



MESSAGE FROM THE DIRECTOR, PROGRAMS & INFORMATION



When our small but solid team sat down to reflect on our work over the past year, the theme for our 2022-23 Annual Report became apparent: “Reconnecting with Purpose”. One thing that stood out for us was how folks really wanted to come back together to support a good cause. We were thrilled that we SAW

people, IN PERSON! With the elimination of COVID restrictions, we were able to bring back the golf tournament, which was a huge success. Our valued volunteers led two Spirit Wheel Walk Run (SWWR) events, again, live and IN PERSON! Our community reconnecting with a shared purpose left us all feeling pumped and inspired. The team expressed gratitude for its new connections across Canada and

“It was a joy after the COVID years to restart our Annual Hydrocephalus Canada Golf Tournament and enjoy the game and the company of friends, colleagues and guests who attended the event.”

Paul Egli, Board Treasurer and golf tournament participant



friendships with our fellow provinces. We marvelled at the reciprocity and collaboration among our existing partners and the interest expressed by new organizations in joining our Allied Partner Network, a group led by Hydrocephalus Canada that supports individual organizations and increases awareness by strengthening our national voice.

We also saw new staff come on board and long-term staff retire. Tharani Rajan was hired as our new Fundraising & Events Manager and we were thrilled to have her join us! We were very fortunate to have Will Pieta, one of our summer students, continue to work with us part-time throughout the year as Program

Assistant. With the winding down of the Ontario Trillium Grant project, Andrea Walters, Community Support Coordinator remained with us part-time while

we said a fond farewell to Sheena Robert, Director of Development. In February, Steve Kean, Communications Consultant, announced his retirement. Steve worked faithfully for Hydrocephalus Canada for 28 years. He was a fixture, a friend and invested team member. He will be missed.

With our team of one-full time and four part-time staff, 2022-23 saw us back in business and working at full capacity, doing our best to answer everyone's calls, emails and provide individual support. With our new strategic plan in place, we continued to do our part to ensure our actions always synergized with the goals established by the Board and staff to help move us closer to our vision. Based on our Community Needs Survey feedback we continued to offer virtual educational opportunities for our community with an aim to have medical professionals



THARANI RAJAN



WILL PIETA



STEVE KEAN



NANCY DICKINSON, MEMBER OF
WESTERN CANADA HYDROCEPHALUS
FACEBOOK SUPPORT GROUP

guest speak at every opportunity. The community spoke, we listened and engagement in our educational webinars was its highest ever.

2022-23 was a year of change, growth, new direction and reconnection with purpose. As the Director of Programs & Information, I couldn't have been more proud of our team, grateful for the support of

our Board and thankful for the many volunteers and partners who help us achieve our mission.

SHAUNA BEAUDOIN

“Whenever the need arises, there is always someone here to lean on and to talk to so they do NOT have to face it alone. Our informal network of group support is available all year, but this one day brings us all together and keeps us connected. It gives us all a sense of belonging.”

Troy and Annette Chandler, Troy's Trail organizers



EDUCATIONAL
WEBINARS
DELIVERED: 13



INDIVIDUALS
SUPPORTED: 179



WEBINAR
PARTICIPANTS: 431



SUPPORT
GROUP
MEETINGS: 30



HOURS
OF DIRECT
SUPPORT: 93



YOGA
CLASSES
HOSTED: 18

TREASURER'S REPORT



The Financial Statements for the fiscal year ending February 28, 2023, show a continuation of positive financial trends for Hydrocephalus Canada.

Summary Financial Statements are included in this Annual Report and I will supply some explanatory commentary for these Summary or Condensed Financial Statements.

Our auditors, CS Chartered Professional Accountants 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, 2023 and its financial performance for the 12-month period ending February 28, 2023.

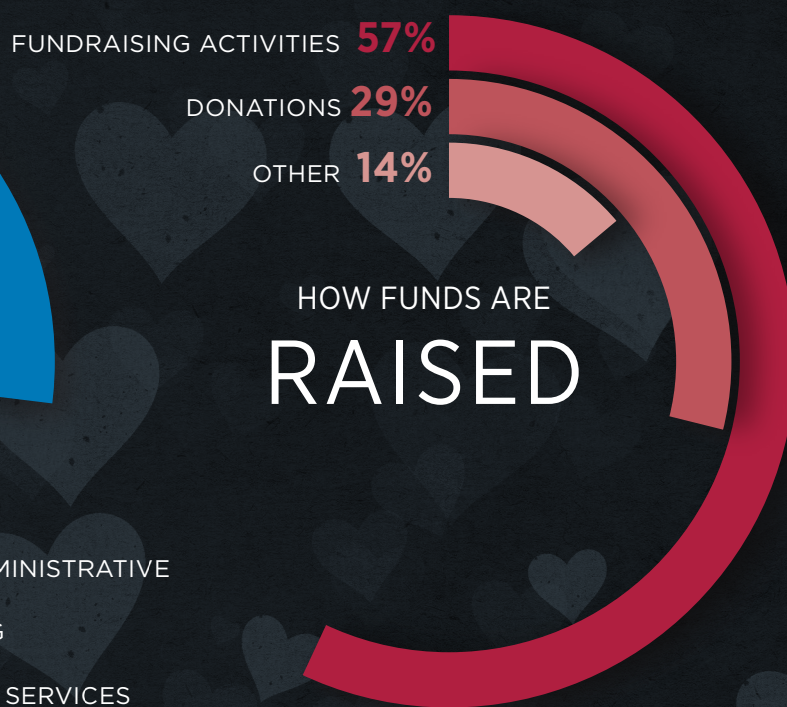
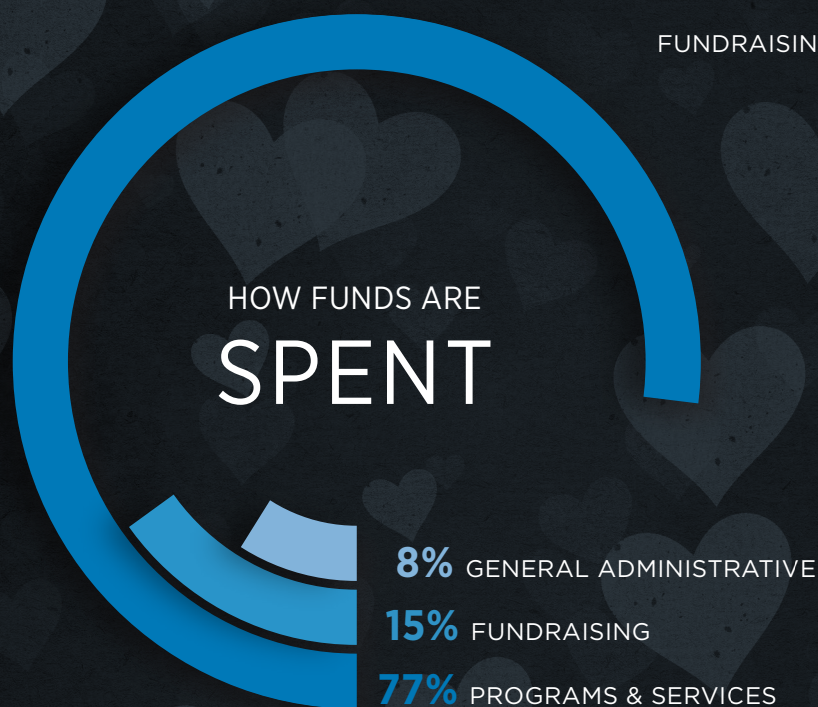
With respect to the Statement of Financial Position, our overall financial strength has increased and unrestricted financial assets have grown from

approximately \$398,000 to \$465,000 during the 12-month fiscal period ending February 28, 2023. Unrestricted financial assets can help an organization such as ours weather any unexpected future challenges or financial difficulties.

The reason Hydrocephalus Canada was able to strengthen its financial position is shown on the Statement of Operations. The Statement of Operations shows an excess of revenues over expenses for the twelve-month period ending February 28, 2023 of approximately \$66,000. This resulted to a large degree from a very significant increase in Bingo event revenues compared to prior years.

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

PAUL EGLI, CPA, CGA



SUMMARY ANNUAL FINANCIAL STATEMENTS

SUMMARY STATEMENT OF OPERATIONS

Year ended February 28, 2023

	2023	2022
Revenues		
Fundraising activities, net	\$266,343	\$180,208
Donations	135,918	168,678
Government grants and other	63,874	125,913
	466,135	474,799
Expenses		
Programs and services		
Awareness and education	170,760	156,647
Care and support	102,993	108,836
Advocacy, research and scholarships	30,720	28,842
Fund development	58,138	46,221
General administrative	34,310	32,406
Amortization of equipment	2,336	2,920
	399,257	375,872
Excess of revenues over expenses	66,878	\$98,927

SUMMARY STATEMENT OF FINANCIAL POSITION

February 28, 2023

	2023	2022
ASSETS		
Cash and short-term deposits	\$425,747	\$397,379
Other current assets	65,288	45,498
Total current assets	491,035	442,877
Endowment investments	222,961	221,446
Equipment	6,422	8,758
Total assets	\$720,418	\$673,081
LIABILITIES		
Accounts payable and accrued liabilities	\$13,203	\$13,772
Deferred contributions	17,212	36,234
	30,415	50,006
NET ASSETS		
Net assets restricted for scholarships and research	224,278	224,228
Unrestricted net assets	465,725	398,847
	690,003	623,075
Total liabilities and net assets	\$720,418	\$673,081

SUMMARY STATEMENT OF CHANGES IN NET ASSETS

Year ended February 28, 2023

			2023	2022
	Unrestricted	Restricted / other	Total	Total
Beginning of year	\$398,847	\$224,228	\$623,075	\$524,148
Revenue over expenses	66,878	50	66,928	98,027
Internally restricted, transfers	-	-	-	-
End of year	\$465,725	\$224,278	\$690,003	\$623,075

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 June 22, 2023, 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, 2023, 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, 2023.

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 June 22, 2023.

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.

CS Chartered Professional Accountants LLP

Toronto, Ontario
June 22, 2023

CS Chartered Professional Accountants LLP
Licensed Public Accountants

GIVING TUESDAY

DONOR PROFILE: GIVING BACK WITH GREATER IMPACT



Giving Tuesday is a global movement that harnesses the power of generosity and community to support causes that matter. It is a day dedicated to giving back. On this special day, individuals, organizations and communities come together to make a difference and create a positive impact in the world.

Our organization was lucky enough this year to make a greater impact with our very first matching donation from Hydrocephalus Canada Board Member **Heather Cheeseman**. Born with spina bifida, Heather feels fortunate it was repaired shortly thereafter and wants to give back to the spina bifida and hydrocephalus community through Board involvement.

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

I got involved as a director of Hydrocephalus Canada in the fall of 2021, as I was pregnant with my second child. I was born with spina bifida and was fortunate it was repaired shortly after birth. Having my own children brought it to the forefront of my life again as I navigated the complications in pregnancy and testing for our kids. I was feeling very fortunate and grateful and I wanted a way to give back to the community.

Why did you decide to become a donor and support?

As a director, I think it is important to support the organization in all ways you can. That includes sharing my experience and expertise as a professional accountant, as well as financially.

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

The organization is so incredibly committed to both the hydrocephalus and spina bifida communities. The resources available are excellent. And the people are truly trying to help in all ways they can. I wish we could reach more people.

What would you tell a prospective supporter/donor to the organization?

The people are truly the most caring you will meet. They work tirelessly to support and would love to hear your ideas for other ways we can keep doing what we do. The team counts on the support of our donors.

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

My hope is for us to continue expanding our reach and helping the sb and/or h community across Canada. There are so many ways we can do that - advocacy and research, education, resources, group and one-on-one support. My hope is that through us and our partners, we reach all those in the sb and/or h communities who want our help.

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

A world that is accessible to them and a medical system that provides the timely support they need.

There are many ways to get involved in an organization but giving the opportunity to allow someone's generosity to go that much further is a great way to make every dollar count!

FUNDRAISING & EVENTS HIGHLIGHTS

2022 brought us back to in person with our amazing volunteers and community involved in fundraising and social events. For full details on our Fundraising & Events highlights, please visit our [YEAR AT A GLANCE - Fundraising & Events 2022-23 webpage.](#)

- ▶ Charity Golf Event
- ▶ Emma's Empowering Strides: A Fun Walk for Hydrocephalus Awareness
- ▶ Donor Profile: Young Changemakers: Emma's Helping Spread the Message
- ▶ IA Financial Group Community Charity Contest
- ▶ Annual Giving Donor Profile: Janet and Gordon Baker



CHARITY GOLF EVENT

We are thrilled to present the overview of our highly successful annual Charity Golf Event in support of spina bifida and hydrocephalus programs, awareness and research activities. This event, held on September 12th, 2022 at Wyldewood Golf and Country Club in Milton, brought together golf enthusiasts, sponsors, and community members, all dedicated to making a lasting impact in the lives of individuals affected by spina bifida and hydrocephalus.

TROY'S TRAIL – CELEBRATING 11 YEARS OF SUPPORTING HYDROCEPHALUS AND SPINA BIFIDA IN SAULT STE. MARIE AND UNITING A COMMUNITY

In this donor profile, we proudly highlight the incredible journey of Troy's Trail, a remarkable initiative that

has been making a significant impact in supporting hydrocephalus and spina bifida in the Sault Ste. Marie community for the past 11 years. Let's delve into the inspiring story of Troy's Trail.

DONOR PROFILE: YOUNG CHANGEMAKERS: EMMA'S HELPING SPREAD THE MESSAGE

We are celebrating young changemakers who have become influential supporters of Hydrocephalus Canada. Despite their age, these remarkable individuals have demonstrated a deep commitment to making a positive difference in the world. Through their philanthropy and passion for social change, they have emerged as catalysts for progress, empowering their peers and inspiring others to join in their efforts. In this report, we shine a light on Emma St. Aubin and her commitment to making a difference in the sb and/or h community.

JUNE AWARENESS

June is recognized as Spina Bifida and Hydrocephalus Awareness Month in Canada. To highlight the conditions and celebrate those living with the conditions, HC and other spina bifida and hydrocephalus organizations across Canada have encouraged our communities to raise awareness through various activities and fundraising campaigns. Throughout the month, various initiatives and events were organized to raise awareness, educate the public, and support individuals living with the conditions. 2022 was all about encouraging people in the spina bifida and hydrocephalus communities to share their stories. We had photos of people submitted from across Canada share their powerful stories and show their incredible support. The winning photo of the contest is featured on the cover of our annual report.

CHECK OUT OUR:

- ▶ ANNUAL GENERAL MEETING
- ▶ NEWS & EVENTS
- ▶ WEBINARS AND PRESENTATIONS

WWW.HYDROCEPHALUS.CA

OTHER EVENTS

Through various SWWR's, third party fundraising and awareness activities both in-person and online, over \$30,000 was raised in 2022-2023 to support HC's programs and services. We thank our Spirit Wheel Walk Run organizers and participants across Canada for their support!

- ▶ Event in Tribute to Emmett Harrow
- ▶ Adam Barbour Annual Memorial BBQ fundraiser
- ▶ Judy's ETV Anniversary fundraiser
- ▶ Lerner's LLP Casual Day
- ▶ FaceBook birthday and special occasion fundraisers

ANNUAL
GENERAL MEETING,
SEPTEMBER 17;

65 ATTENDED



ABILITIES EXPO BOOTH -
INTERNATIONAL CENTRE -
MAY 13/14; 1 VOLUNTEER,

400 VISITORS



ZOOMER SHOW BOOTH -
OCTOBER 29 & 30;
3 VOLUNTEERS,

700 VISITORS

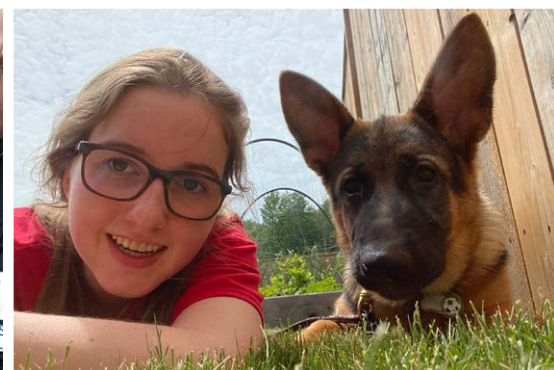


VOTE FOR HC

This year IA Financial Group is donating \$500,000 to charities that work with people with disabilities and their communities.

Support Hydrocephalus Canada and cast your vote for our Families Changing Lives Program.

Voting is Open Until November 24th



DONORS & PARTNERSHIPS

YOU MADE A HUGE DIFFERENCE!

Hydrocephalus Canada continues to be so fortunate to have the best partners, sponsors and donors! We are beyond grateful for the support you gave us in 2022-23. Your generosity allowed the spina bifida and hydrocephalus communities to reconnect again with purpose and engage more deeply than ever, strengthening the legacy that we have built over the past 50 years. Thank you for supporting Hydrocephalus Canada and the people that we serve.

PARTNER AND SPONSORS

Bingo World & Gaming Richmond Hill

Coloplast Canada

Delta Bingo Downsview

O.O.S. Medical/Amici Catheters

SickKids Foundation

Teaching Awareness Through Puppetry (TAP)

[Watch message from TAP](#)

Holland Bloorview Kids Rehabilitation Hospital

Association de spina-bifida et d'hydrocéphalie du Québec

Spina Bifida and Hydrocephalus Association of Northern Alberta

Spina Bifida and Hydrocephalus Association of Southern Alberta

GOLF SPONSORS

Baskin Wealth Management

Canoe Financial

Harvey Katz Professional Corp.

KPMG MSLP

Mackinnon and Bowes Ltd.

Scotiabank Scotia Capital Inc.

The MacLachlan Group-Scotia Wealth Management

A BIG THANK YOU FOR YOUR SUPPORT!

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 \$500+

Alice and Murray Maitland Foundation
Gordon & Janet Baker
Karen Boland
Heather & David Cheeseman
Scott D. Clark
Department of Canadian Heritage
Official Languages Support Programs
Edwards Charitable Foundation
Estate of Alexander Peter Skinner
Gary Bluestein Charitable Foundation
Gee's Tree Removal Service
Gladys Gascon
Alan Hirsch
Sylvia Langlois
Lerners LLP
Jane & Joseph McMahon
Ontario Trillium Foundation
Wade Partridge
Justin Parappally
Marni Przybylski
David Shields
Laura Smy
Gregory Michael Terry
The Catherine and Maxwell Meighen Foundation
The Silvio Bot Charitable Foundation

DONORS \$250-\$499

Darlene Andrew
Donald Belovich
Liz Breen
Andrea Boctor
Claudio Cinapri
Ryan French
Lisa Harper
Suzanne Huggins
Savvas Kotsopoulos
Jason Kroft
Joan MacArthur
Doug Meloche
Kevin Smyth
Carol Verity
Pavel Zeman

MATCHING GIFTS

Bell Canada
Stikeman Elliott LLP

MONTHLY DONORS

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

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.

“The connections and friendships made through our involvement with SBHAO (now Hydrocephalus Canada) will always remain in memory as a special time in our journey – an exceptional community of people brought together, working together, supporting each other and making a difference.”

Janet Baker

RESEARCH

Hydrocephalus Canada continues to support and fund impactful 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 strong presence in the research community and by influencing the creation of a research agenda (international and national) through increased collaboration with various stakeholders.

2022-23 was an incredibly exciting year for Hydrocephalus Canada, with an abundance of new opportunities for research participation, including:

The impact of pregnancy on bladder health in people with spinal cord injury

Led by Claire Mazzia, a second-year medical student at the Temerty Faculty of Medicine, University of Toronto, recipient of the 2021-2022 Hydrocephalus Canada Award. CREMS Summer Program 2022 research project; Project Supervisor Dr. Anne Berndt.

Bloorview Research Institute – CIHR-SSHRC grant – **Discrimination, ableism and racism hurt but inclusion can heal**. Listening to the intersectional lived experiences of youth with disabilities and co-creating solutions, Dr. Sally Lindsay, PhD, Senior Scientist, OT, HC takes part in webinars, workshops, providing insight, expertise and lived experience.

Bloorview Research Institute/ U of T/ SSHRC-CRSH/ Profile – **We are Sexual Too: A Partnership to Support the Intimate Citizenship of Disabled Youth Across Canada by Mobilizing Knowledge About Sexuality and Disability**

Dr. Amy McPherson, Senior Scientist, Partners – Hydrocephalus Canada, Alberta Health Services, Planned Parenthood Toronto/NL, Autism Nova Scotia, SIECCAN, Saskatoon Sexual Health and Youth Advisory Committee. Projects within study – Asset Mapping, Knowledge Network of Expertise in Disability and Sexuality, seminars, toolkits 3-year project.

Bloorview Research Institute & Engagement & Planning for Inclusive Communities **“Air transportation experiences of caregivers of children and youth with physical disabilities”**. HC is a recruitment partner for this study.

Bloorview Research Institute – Exploring the Nature of Disordered Eating in Adolescents with SBH

- Dr. Amy McPherson, Senior Scientist and study lead / Dr. Alene Toulany – Sick Kids, Dr. Fiona Moola – Holland Bloorview Kids Rehab, Lorry Chen, Dietician, HBKR, Marie Hooper – Family Leader, HBKR, Melissa Thorne, Youth Facilitator, HBKR, Dr. Paige Church and Hydrocephalus Canada Co-investigators. 3-year project.

Bloorview Research Institute – CIHR-SSHRC **Healthy & Productive work for youth with disabilities study**, Dr. Sally Lindsay, PhD, Senior Scientist, OT – 5-year project (2022 3rd year). Hydrocephalus Canada takes part in webinars, workshops, providing insight, expertise and lived experience.

Workplace disclosure topic <https://hollandbloorview.ca/stories-news-events/news/unraveling-complex-process-workplace-disclosure>

Brain Injury Association support letter – Accessibility Standards Canada Grant Application – Accessibility in Elections and Electoral Processes.

University of Toronto – CIHR Grant - **Disability & Reproductive Health during Covid-19 study** – Hydrocephalus Canada is on the Steering Advisory Committee. Program aimed at understanding the impact of the pandemic on reproductive health and health care for people with disabilities and learning from these impacts to build a more accessible and inclusive reproductive health care system as we look toward Covid-19 recovery. DAWN Canada is also a partner.

Neil Squire Society – Next Generation 911 focus group study – **understanding how new methods of communications (text, video calls) affect the ability of the disability community to communicate with 911 services**. HC is a recruitment partner for this study.

University of Toronto/Bloorview Research Institute – **Understanding the Sexuality of Youth with Physical Disabilities using Art**. HC is a recruitment partner for this study.

University of Toronto/Sick Kids – **Attitudes and perspectives of individuals with a genetic disability regarding reproductive decision making and the utility of genetic services**. Recruitment partner.

Association de spina-bifida et d'hydrocephalie du Quebec/Universite du Quebec a Trois Rivieres, Universite Laval and HC – **How to tame and live the transition to active and fulfilling aging for people with sbh and their caregivers;** co-development of a toolbox (Aging with SBH study) HC is on the Steering Committee, participated in recruitment and focus group activities.

CanChild Centre for Childhood Disability Research – **Child-Bright ReadyorNotTM Brain-Based Disabilities Trial.** HC is a recruitment partner for this study.

Spina Bifida Association of America – SBA Research Agenda – **Bowel Continence Group**, Dr. Maryellen Kelly, Duke University, HC participates in the steering group, workshops and dissemination of information. Partners – Cook Children's Hospital, CHOP, Nationwide Children's Hospital, CCHMC, KP, Children's National, OUHSC, UABMC, Texas Children's Hospital, Gillette Children's, Phoenix Children's, BCM, Lurie Children's, Cornell, Stanford, CDC, Kennedy Krieger.

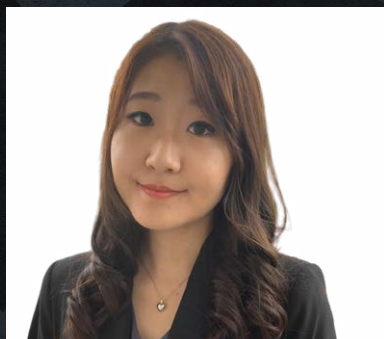
CanChild Centre for Childhood Disability Research – **Transition to Adulthood During Covid study.** HC is a recruitment partner for this study.

COMMUNITY-BASED SERVICE LEARNING (CBSL) STUDENT PLACEMENT, MD PROGRAM, UNIVERSITY OF TORONTO

Hydrocephalus Canada welcomed two 2nd year medical students from the University of Toronto to complete their CBSL placement. Soomin Lee and Ella deKemp participated in support groups, webinars and the Hydrocephalus Working Group meeting, created an informative hydrocephalus bookmark and worked on updating sections of our hydrocephalus patient guide. We wish them the best in their future endeavours!

“It was such a pleasure to work with you as well this year, we had an absolute blast! You were a phenomenal mentor, and we left with such amazing and unique experiences, I’m so grateful for you having us.”

Ella deKemp



“It was a pleasure and a joy to work with you and Hydrocephalus Canada. I have learned so much that I will take with me throughout the rest of my career. Thank you so much for the opportunities to participate and for your continued support.”

Soomin Lee

SCHOLARSHIPS & BURSARIES

Hydrocephalus Canada awards scholarships and bursaries to individuals with spina bifida and/or hydrocephalus who pursue post secondary education. Two programs, the Dr. E. Bruce Hendrick Scholarship and the Luciana Spring Mascarin Bursary are offered annually in January ([Visit our Scholarships & Bursaries website page for eligibility criteria and application details.](#))

The Hydrocephalus Canada Scholarship Selection Committee awarded the 2022 Dr. E Bruce Hendrick Scholarship to four recipients.



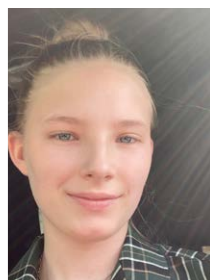
ALEXIS NEEDS

Sault Ste Marie, Ontario

Dr. Robin Humphreys Award

Pursuing her Bachelor of Science, Honours in Biology at Algoma University, Alexis intends to go to medical school and eventually become a neurosurgeon. She hopes one day to be able to treat individuals who have hydrocephalus.

Alexis enjoys outdoor activities, participating in social activism and volunteering.



NORA FITZPATRICK-

O'CONNELL

Toronto, Ontario

Michael Bailey Founders Award

Nora has been accepted by Concordia University working towards a Bachelor of Arts through a joint specialization program in English and History. She is considering

American Sign Language (ALS) interpretation as a profession. Nora has a love of learning/academics and among many other hobbies and interests, especially enjoys ballet, tap and playing the violin.

SOUGALE A. GOWRAH

Ottawa, Ontario

Barton Family Award

Working toward a diploma in Fitness and Health Promotion at College Boreal, Sougale's goal is to become a professional basketball coach. He will be leaving Ottawa for Sudbury to pursue his education, take advantage of student life and expand his network. Sougale enjoys cooking, baking, basketball, podcasts, travelling, walks and movies.

EMMA ST. AUBIN

Thorold, Ontario

Rodney G. Walsh Award

Hoping to have a career as a Child Life Specialist, Emma will be attending Brock University, studying to achieve a Bachelor of Child Health. Inspired by her own extremely positive experience with Child Life Specialists at McMaster Hospital she wants to create a comforting and reassuring environment for children while in hospital. Emma enjoys, playing soccer, training her dog, baking, gardening, volunteering, nature walks and spending time with family and friends.



“It can be intimidating knowing you have a condition that not everyone has, and it may feel like you are an outsider. I once felt that, but realized everyone has something that makes them unique and special. Hydrocephalus is one of the things that makes me unique and I am honoured... All in all, having hydrocephalus is definitely not a disadvantage. On the contrary, it is an advantage. It has enabled me to become stronger, more resilient and it has given me the opportunity to inspire others whether or not they have this condition. It is my superpower!”

Emma St Aubin

OUR PEOPLE

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We are so grateful for the support of Dr. Ruth Donnelly, esteemed member of our Medical Advisory Board, who announced her retirement in 2022. Thank you for sharing your skills and talents with the Board. We also wish Dr. Andrew Parrent a happy retirement from his practice. Thank you both for your work in the spina bifida and hydrocephalus community!



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

Connect with our online groups <https://www.facebook.com/HydrocephalusCanada/groups>
Sign up for our Zoom support group meetings info@hydrocephalus.ca

WE ARE HERE FOR YOU!

Hear from member [Judy Feeley](#) as she talks about discovering real support at Hydrocephalus Canada

SUPPORTING MORE PEOPLE THAN EVER!

Our **Adult Hydrocephalus Western Canada Facebook support group** has grown from 3 to 60 members in just over a year! A special shout out to our fantastic group admins, Jeff Bourne and Melody Rose for all their hard work and commitment to support more people than ever.

What makes the group important is the support of people who get what we're going through and knowing there's others like me/us out there. One thing everyone should know about the group is that we love it when you share your stories, comments, ask questions and connect with each other.

Melody Rose



I think this group is important for those of us in Western Canada to meet others with hydrocephalus and to share experiences and cheer each other on when we are having tough days. I hope to see an Eastern Canada hydrocephalus group, or even a Canadian hydrocephalus support group.

Jeff Bourne



VOLUNTEERING WITH HYDROCEPHALUS CANADA

VOLUNTEER HOURS – 3728

This year, 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. Our allied health professionals provided their expertise on a variety of subjects while other community members provided leadership and shared their lived experiences. Thank you to everyone who volunteered with us, for your time, effort, passion, commitment, generosity and dedication to our cause. We could not do this without you!

GET INVOLVED

HEAR FROM OUR VALUED VOLUNTEERS!

[Yu Xuan \(Amy\) HUANG](#) Expansion Project volunteer and event supporter

[Mary Dufton](#) "Own Your Story" editor, Taster's Club organizer and Ottawa Community Contact

[Tammy and Jackson Selkirk](#) Charity Golf Tournament organizers

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

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

Visit our website today to find out more about volunteering and how YOU can make a difference.



**HYDROCEPHALUS
CANADA**

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