

HYDROCEPHALUS
CANADA | 

CHAMPIONING THE SPINA BIFIDA
AND HYDROCEPHALUS COMMUNITY

COAST ^{TO} COAST



GROWING
TOGETHER



2024-2025 **ANNUAL REPORT**

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.

Equity, Diversity, Inclusion and Accessibility Statement:

At Hydrocephalus Canada, it is our mission to assist our unique population of all ages and walks of life to reach their greatest potential. We accomplish this by working in collaboration with our Board of Directors, volunteers and community partners to play our part in fostering an inclusive, diverse, accessible and equitable world, starting with our own organization.

For over 50 years, our core values have continually been based on building an inclusive, caring, respectful and responsible barrier-free Canada for all, with a strong commitment to those impacted by the complex life-long neurological conditions of hydrocephalus and/or spina bifida. We actively work to end discrimination daily and to provide an inclusive working environment where everyone feels respected, heard, valued and supported.

At Hydrocephalus Canada, we are more than an organization—we are a community. A community built on hope, strength, and unwavering support for individuals impacted by hydrocephalus and spina bifida.

With over 50 years of service behind us, we've evolved from a grassroots initiative into a national force—expanding our reach coast to coast and transforming how Canadians access care, support, and advocacy. Our expansion isn't just about geography—it's about impact. We're connecting more people, building stronger networks, and creating a truly inclusive, nationwide movement.

Inspired by voices like Shauna Beaudoin, our Director of Programs & Information—an advocate living with spina bifida—we work every day to break down barriers, challenge misconceptions, and create real opportunities for those living with these complex conditions.

Our mission is to empower, educate, and inspire, ensuring that no one walks this journey alone. Through support groups, awareness initiatives, and research advancements, we're building a future where every person living with hydrocephalus and spina bifida can thrive.

Together, we push for progress.
Together, we break barriers.



CHAMPIONING THE SPINA BIFIDA
AND HYDROCEPHALUS COMMUNITY

MESSAGE FROM THE CHAIR



As I reflect on my time as Chair of Hydrocephalus Canada, I am filled with deep gratitude for this incredible community. Serving in this role has been an honour, and I have been continually inspired by the strength, resilience, and dedication of the individuals and families we support.

Our mission is more than just programs and advocacy—it is

about building a national community where no one feels alone on their journey with hydrocephalus or spina bifida. Over the past year, we have made meaningful strides in awareness, research, and support, and one of our most significant accomplishments has been the successful expansion of our reach across Canada. From coast to coast, more individuals and families are accessing the resources and support they need—proof that our vision of

a truly national organization is becoming a reality.

This year is especially bittersweet as it marks my final one as Chair. While I step away from this role, my commitment to Hydrocephalus Canada remains as strong as ever. I leave knowing that the organization is in incredibly capable hands—with a dedicated board, tireless staff, and a passionate, growing community leading the way.

Thank you for allowing me to be part of this journey. Your continued support ensures that Hydrocephalus Canada can keep advocating, expanding, and providing life-changing services to those who need them most. Together, we are building a future filled with hope, connection, and possibility.

With gratitude,

GILLIAN AKAI

PAST CHAIR, BOARD OF DIRECTORS
HYDROCEPHALUS CANADA

“Glad to be part of the hydrocephalus community and give back for what it has provided me, my own voice and understanding of all the odd quirks that were always difficult to comprehend. It’s great to have an explanation for all things hydrocephalus. Almost everything.”

— ERSIN



MESSAGE FROM THE DIRECTOR, PROGRAMS & INFORMATION



This year has been one of both progress and perseverance for Hydrocephalus Canada. As we continue our mission to empower those impacted by hydrocephalus and spina bifida, we've seen a remarkable increase in community engagement, program participation, and awareness-building efforts across the country. Through advocacy, education, and partnerships, we've worked to reduce barriers to care, support families navigating complex health systems,

and push for research that will improve lives today and in the future. The strength and resilience of our community remain the driving force behind everything we do.

Looking ahead, we are focused on expanding our reach and impact. Our strategic priorities remain centered on equity in healthcare access, enhancing support services, and advocating for innovation in treatment and lifelong care. We are grateful to our donors, partners, volunteers, and staff for their unwavering commitment to our cause. Together, we are building a community where individuals living with hydrocephalus and spina bifida are seen, heard, and fully supported at every stage of life.

SHAUNA BEAUDOIN

Thank you to Paul Egli

With sincere gratitude, we thank Paul Egli for his years of dedicated service and expertise with Hydrocephalus Canada as Treasurer and for part of 2024/2025 as Chair. His commitment has helped shape our community and advance our mission, leaving a lasting impact on countless lives. Thank you, Paul, for all that you've given.



**“Congratulations!
An amazing feat to
pull off a great Annual
General meeting and
series of speakers.
Truly amazing, the
hydrocephalus and
spina bifida community
is lucky to have you
and your team!”**

**- DR. JAY RIVA-CAMBRIN
PROFESSOR AND PEDIATRIC NEUROSURGEON**

TREASURER'S REPORT



The Financial Statements for the fiscal year ending February 28, 2025, show Hydrocephalus Canada continues to be in a strong financial position.

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

Our auditors, CS Chartered Professional Accountants LLP, have provided

Hydrocephalus Canada with an unqualified opinion stating that our financial statements present fairly, in all material respects, the financial position of the organization as of February 28, 2025 and its financial performance for the year ended February 28, 2025.

The Statement of Operations for Hydrocephalus Canada indicates a small deficit of revenues over expenses of approximately \$20,000 for the year ended February 28, 2025. Steadily increasing revenue from Bingo events have been an important factor in our positive financial performance. However, given our accounting policy is to recognize bingo proceeds as revenue when the associated expenditures have been made, a portion of bingo funds received in the year have not yet been recorded as revenue. We have plans for using these funds in the future in accordance with the relevant requirements in the coming period.

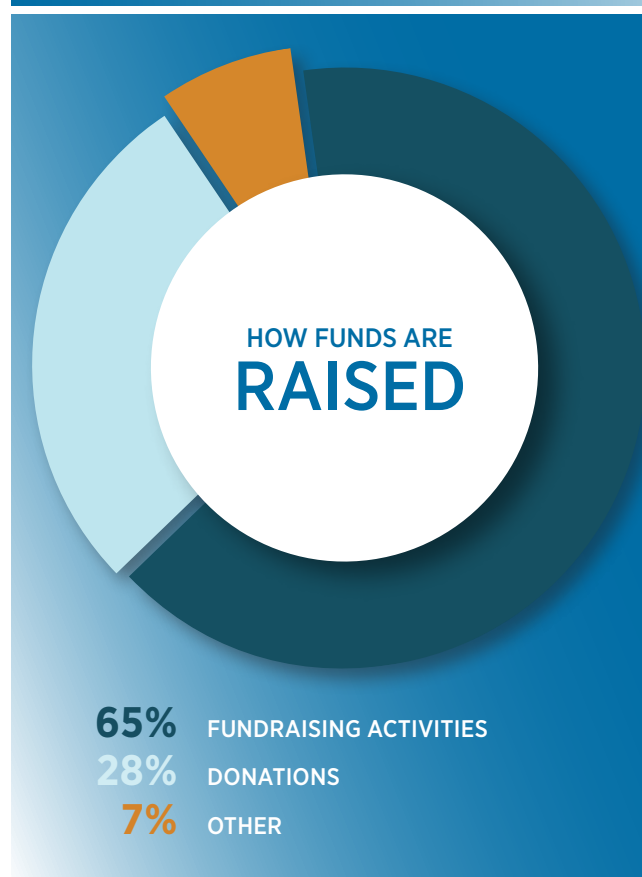
With respect to the Statement of Financial Position, our overall financial position continues to be strong and the statements show a modest increase in total assets during the year ended February 28, 2025, including an approximately \$6,000 increase in cash.

Our liquidity position is also strong, and Hydrocephalus Canada holds a significant amount in unrestricted financial assets which can help an organization such as ours weather any unexpected future challenges or direct funds toward an important priority in the future.

HEATHER CHEESEMAN

TREASURER,

HYDROCEPHALUS CANADA BOARD OF DIRECTORS



SUMMARY ANNUAL FINANCIAL STATEMENTS

SUMMARY STATEMENT OF OPERATIONS

YEAR ENDED FEBRUARY 28, 2025

	2025	2024
Revenues		
Fundraising activities, net	\$286,145	\$271,956
Donations	119,983	135,918
Grants, investment income and other	31,666	63,874
	437,794	389,197
Expenses		
Programs and services		
Awareness and education	206,881	195,476
Care and support	113,770	96,619
Advocacy, research and scholarships	55,483	33,995
Fund development	43,069	42,748
General administrative	35,163	32,786
Amortization of equipment	3,814	2,850
	458,180	404,474
Excess of revenues over expenses	(\$20,386)	(\$15,277)

SUMMARY STATEMENT OF FINANCIAL POSITION

FEBRUARY 28, 2025

	2025	2024
ASSETS		
Cash and short-term deposits	\$441,373	\$435,474
Other current assets	41,875	45,463
Total current assets	483,248	480,937
Endowment investments	219,132	218,516
Equipment	8,127	7,118
Total assets	\$710,507	\$706,571
LIABILITIES		
Accounts payable and accrued liabilities	\$14,064	\$13,863
Deferred contributions and bingo revenue	102,400	78,279
	116,464	92,142
NET ASSETS		
Net assets restricted for scholarships, research and expansion	277,622	271,278
Unrestricted net assets	316,421	343,151
	594,043	614,429
Total liabilities and net assets	\$710,507	\$706,571

SUMMARY STATEMENT OF CHANGES IN NET ASSETS

YEAR ENDED FEBRUARY 28, 2025

			2025	2024
	Unrestricted	Restricted / other	Total	Total
Beginning of year	\$343,151	\$271,278	\$614,429	\$629,706
Revenue over expenses	(11,730)	(8,656)	(20,386)	(15,277)
Internally restricted, transfers	(15,000)	15,000	-	-
End of year	\$316,421	\$277,622	\$594,043	\$614,429

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 August 11, 2025, 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, 2025, 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, 2025.

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 August 11, 2025.

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 as 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
August 11, 2025

CS Chartered Professional Accountants LLP
Licensed Public Accountants

DONOR & SPONSOR HIGHLIGHTS

FUELING NATIONAL IMPACT

In 2024, Hydrocephalus Canada was proud to partner with a diverse group of dedicated donors and sponsors whose generosity made it possible to expand programming, enhance national reach, and deliver meaningful impact to individuals and families across the country.

Featured Sponsor

O.O.S. Medical & Amici Catheters

Supporting Dignity, Access, and Awareness

Hydrocephalus Canada is proud to recognize O.O.S. Medical and Amici Catheters as trusted Canadian providers of urological, continence, and ostomy supplies for their meaningful support in 2024.

Thanks to their generosity this year Hydrocephalus Canada was able to expand access to important resources and national awareness efforts for the hydrocephalus and spina bifida community. Through their funding our outreach, information-sharing, education tools, and more became stronger across Canada. O.O.S. Medical and Amici Catheters have played an important role in our advocacy and community growth.



We are grateful for their ongoing partnership and dedication to building a more informed, connected, and empowered community across Canada.

Delta Bingo & Gaming and Bingo World & Gaming

Support from Delta Bingo & Gaming Downsview and Bingo World & Gaming Richmond Hill contributed directly to the development of impactful educational initiatives, including the Kidz & Youth Book Club and a wide range of resources for the community, caregivers, and healthcare professionals. Their continued investment

helps ensure that individuals impacted by hydrocephalus and spina bifida have access to the tools, information, and support they need to make informed decisions and feel empowered in their care journeys.



Post Media

Postmedia provided invaluable year-round national support across multiple awareness campaigns in 2024, helping Hydrocephalus Canada reach broader audiences and strengthen public understanding of hydrocephalus and spina bifida. Their most significant impact was seen through the Normal Pressure Hydrocephalus (NPH) awareness campaign, where national ad placements led to a marked increase in support calls and online engagement. Thanks to Postmedia's reach and commitment, more Canadians—especially older adults and healthcare professionals—are now better informed about the signs, diagnosis, and treatment options for NPH.



Featured Donor

The Rexall Care Network

The Rexall Care Network played a pivotal role in launching our six-week National Caregiver Workshop Series, delivered in collaboration with Recreational Respite. This interactive initiative offered caregivers an outlet to express what it means to be a caregiver, learn self-care tip and build tools for wellness, planning, and peer support. These workshops and the feedback from our participants resulted in the creation of a customized Caregiver Toolkit now available to caregivers across Canada at hydrocephalus.ca.



Partner and Sponsors

Bingo World & Gaming Richmond Hill
Delta Bingo Downsview
Holland Bloorview Kids Rehabilitation Hospital
SickKids Foundation
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
Teaching Awareness Through Puppetry (TAP)

Celebrate, Live, Dream, Walk Sponsors

Alba Medical Inc.
Coloplast Canada
Hollister Ltd.
O.O.S. Medical/Amici Catheters

Golf Sponsors

AgencyX Inc.
Baskin Wealth Management
Canoe Financial
Financial Planning Services Burlington
Harris Douglas Asset Management
Harvey Katz Law LLP
Hyundai of Oakville
KPMG MSLP
Mackinnon and Bowes Ltd.
Portl Media
Swing Lab Theory
The MacLachlan Group-Scotia Wealth Management
West Toronto Foot & Ankle Clinic



Donors \$500+

Alice and Murray Maitland Foundation
Brenda Andrews
Gordon & Janet Baker
Andrea Boctor
Michael Brolley
Heather Cheeseman Professional Accounting
Bruce Cowan
Integra Foundation
Scott D. Clark
Nancy Dickinson
Edwards Charitable Foundation
Gary & Maxie Bluestein Charitable Foundation
Gee's Tree Removal Service
Sylvia Langlois
Ann McAulay
Chris McKellar
Jane & Joseph McMahon
Suzanne Morrow
Ontario Charitable Gaming Association
Wade Partridge
Justin Parappally
Marni Przybylski
Paul Renaud
Rexall Care Network
R.V. Anderson Associates Limited
Laura Smy
TCM Produce
The Catherine and Maxwell Meighen Foundation
The George Lunan Foundation
University of Toronto Financial Services
Marcia Zosimadis

Matching Gifts

Bell Canada
Intact Insurance
Meridian Credit Union
Stikeman Elliott LLP

Donors \$250-\$499

David Bart
Tanja Bessey
Liz Breen
Kirk & Melissa Caldwell
Angela Cinapri
Peter Druxerman
Ryan Ffrench
Greg Haynes
Hiram St. Market
Joan MacArthur
Julie Matheson
Lawrence McGuire
Merrett's Pharmacy Ltd.
Onsight Inspection
Lucas Smith
Jacob Trenholm

Dream Circle Monthly Donors

Thomas Armstrong	Jody Lachine
Sandi Beaudoin	Heather Langridge
Laura Booth	Lucie Legault
Shellyann Carroll	Nona Mariotti
Bonnie Charbonneau	Hugh R. McKay
Patricia Ann Davidson	Joy Parr
Rhiannon Davies	Lisa & Rob Pieta
Judy Feeley	Althea Poulos
Lucinda Fry	Rodney Price
Brendan Fleming	Wendy Reed
Laura Gatensby	Alan D. Reeve
Gunn Nuclear Inc.	Serena Wang
Hayat Ibrahim	Elaine Wilson
Ken Koffman	Jim Zurbrigg

**A BIG
THANK YOU
FOR YOUR
SUPPORT!**



Join our Dream Circle Monthly Giving Program

Dream Circle Monthly Giving 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 impacted by hydrocephalus and/or spina bifida.

FUNDRAISING & EVENTS HIGHLIGHTS

Celebrate, Live, Dream, Walk, Roll & Run

The inaugural Celebrate, Live, Dream Walk marked a groundbreaking collaboration between Hydrocephalus Canada and the Dystonia Medical Research Foundation of Canada. This inspiring event brought together two neurological communities in a powerful display of unity, awareness, and shared purpose.

Held at Downsview Park, the walk welcomed people of all ages and abilities, many proudly wearing their Hydrocephalus Canada t-shirts in honor of loved ones. The atmosphere was festive and family-friendly, with face painting, temporary tattoos, a fun puppet character, and more creating joyful moments for attendees.

Adding to the excitement, cheer squads lined the walking route, encouraging participants every step of the way with energy and enthusiasm. Back at the event area, educational and resource stations offered opportunities to learn

more about hydrocephalus and dystonia, connect with organizations, and access valuable support materials.

The overwhelming positivity, community spirit, and meaningful connections made during the event have laid a strong foundation for June 2025. With growing momentum, we look forward to welcoming even more participants as the Celebrate, Live, Dream Walk continues to grow in impact and inspiration.

Golf

The Hydrocephalus Canada Annual Golf Tournament exceeded expectations with record attendance and a notable surge in first-time participants and corporate sponsors. Beyond successful fundraising, the day at Carlisle Golf and Country Club fostered meaningful connections as participants shared stories and experiences while enjoying friendly competition. The enthusiastic atmosphere and immediate interest in the upcoming 2025 tournament demonstrated how this signature event continues to build momentum and strengthen our community's commitment to supporting those impacted by hydrocephalus and spina bifida.



Troys Trail Spirit Wheel Walk Run

This heartfelt fundraising initiative united our communities in support of vital research and services, while raising substantial awareness about hydrocephalus and spina bifida through compelling personal stories and educational outreach. The partnership exemplified community commitment to cause-driven collaborations, demonstrating how strategic alignment with mission-focused organizations like Hydrocephalus Canada can create meaningful impact for families impacted by hydrocephalus and spina bifida while strengthening our community bonds.



Fundraising Extravaganza – Lemons fundraising official launch

Launched in summer 2024, our innovative “Lemons Across Canada” initiative has emerged as a powerful grassroots fundraising movement, empowering Canadians of all ages to support hydrocephalus and spina bifida awareness and research through community-based lemonade stands. The beauty of this initiative lies in its accessibility—families, schools, community groups, and even corporate teams can embrace the opportunity to host their own fundraisers, sharing personal stories of how hydrocephalus and spina bifida has touched their lives.



June Awareness

Hydrocephalus and Spina Bifida Awareness Month

June marked a powerful and inspiring time for Hydrocephalus Canada as we united communities across the country for Spina Bifida & Hydrocephalus Awareness Month. It was a month filled with action, visibility, and celebration—shining a light on the strength, courage, and dreams of those living with these complex conditions.

Our Celebrate, Live, Dream, Walk brought together individuals, families, and supporters in a meaningful show of unity and hope. More than just a walk, it served as a national moment to honour resilience, celebrate progress, and inspire a stronger community across Canada.

Our national reach and impact were strengthened through deepened partnerships with Association de spina-bifida et d'hydrocéphalie du Québec and the Spina Bifida & Hydrocephalus Associations of Northern and Southern Alberta. These collaborations expanded our collective awareness efforts, enabling us to reach more communities, amplify more voices, and increase visibility in powerful new ways.

Adding to the momentum, iconic Canadian landmarks, including Niagara Falls and the CN Tower, were illuminated in blue and green—offering a stunning visual tribute to our cause and honouring our SBH community.

Together, through every step taken, every cup poured, and every light that shone, we raised awareness and strengthened the national voice for those impacted by hydrocephalus and spina bifida.

Together, we Celebrated, Lived, Dreamed.





Hugs and Smiles

A Coast-to-Coast Celebration of Connection

This year, our Hugs & Smiles campaign brought joy, love, and togetherness to the forefront of our national community. What started as a simple idea, to collect and share moments of warmth and connection—quickly blossomed into a heartfelt celebration that spanned coast to coast.

We received touching submissions from individuals, families, and caregivers across Canada, each photo and message a powerful reminder of the strength and spirit of our community. Whether it was a child sharing a big milestone, a caregiver offering an embrace, or a family simply smiling together in solidarity, every hug and every smile told a story of resilience, hope, and love.

The campaign was more than a moment—it was a movement. It reminded us that even when we're apart, we are deeply connected. Through every image shared, we celebrated the everyday heroes living with hydrocephalus and spina bifida and the people who stand by them.

Hugs & Smiles reflected the very heart of Hydrocephalus Canada: a place where no one journeys alone, and where connection, no matter how simple, can change everything.

Giving Tuesday

Giving Tuesday continues to be a cornerstone of Hydrocephalus Canada's annual fundraising, uniting supporters across the country in a powerful wave of generosity. This global day of giving saw our community rally with unprecedented enthusiasm. Beyond the remarkable financial contributions, the campaign sparked meaningful engagement on social media, where supporters shared personal stories about their connections to hydrocephalus and spina bifida, extending our message to new audiences. Giving Tuesday beautifully demonstrates that when Canadians unite for a common cause, even for just one day, their collective action creates transformative support for those impacted by hydrocephalus and spina bifida.

Sponsors

Our strategic approach to sponsorship transformed our organizational landscape this year, establishing robust new partnerships while deepening existing relationships. Through targeted outreach and value-aligned collaborations, we expanded our sponsorship portfolio with several new corporate partners while strengthening our long-standing relationships. These partnerships have extended beyond financial support to include knowledge sharing, volunteer engagement, and collaborative initiatives that have significantly amplified our community impact while creating meaningful value for our corporate allies.

“A sincere thank you for sending all the SB material to me on such short notice. The SB day at school was a success for my student thanks to your help. They even added the *"Right Under Your Nose"* book to the library.”

- SHALIMA, TEACHER

KEY INITIATIVES HIGHLIGHTS

NPH National Awareness Campaign

Raising the Profile of NPH Nationwide

In 2024, Hydrocephalus Canada launched a national awareness campaign focused on Normal Pressure Hydrocephalus (NPH)—a frequently misunderstood and underdiagnosed condition affecting older adults. With generous support from Postmedia and Integra LifeSciences Foundation, the campaign featured national ad placements across print and digital platforms, dramatically expanding public awareness and reaching new audiences from coast to coast.

The impact was immediate: we experienced a notable increase in one-on-one support calls from individuals, caregivers, and healthcare providers seeking information about symptoms, diagnosis, and treatment options for NPH. This growing engagement reflects the urgent need for accessible, accurate information—something Hydrocephalus Canada proudly provides through downloadable resources and educational tools available at hydrocephalus.ca. Thanks to our partners, this campaign helped ensure that more Canadians receive timely support and life-changing answers.

WHAT IF
THE
DIAGNOSIS
WASN'T
DEMENTIA?



International Awareness Campaign

World Hydrocephalus Day was launched on September 20, 2023. Hydrocephalus Canada, along with Hydrocephalus Association (USA) and Harry's Hat Hydrocephalus Awareness Trust spearheaded the movement and launched a website in 2024 to highlight the awareness day. www.worldhydrocephalusday.org

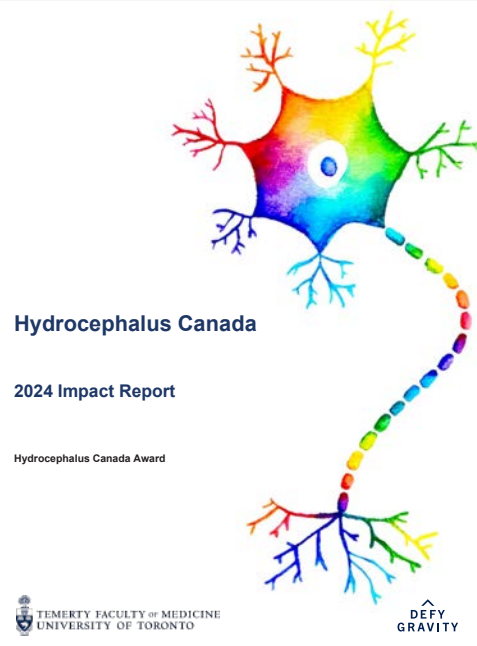


Research

Hydrocephalus Canada is committed to supporting and financing impactful research aimed at enhancing the quality of life for individuals impacted by hydrocephalus and/or spina bifida, as well as their families and caregivers. Our collaborative efforts extend across various institutions including hospitals, rehabilitation centers, universities and other esteemed research facilities. We actively engage with the research community, asserting our presence and influence to shape the research agenda at both international and national levels. Through heightened collaboration with diverse stakeholders, we endeavor to facilitate the advancement of research initiatives. The fiscal year 2024-2025 proved to be remarkably dynamic for Hydrocephalus Canada, marked by an array of promising opportunities for active involvement in research projects.

Hydrocephalus Canada Award - Comprehensive Research Experience for Medical Students (CREMS) Summer Research Program:

Hydrocephalus Canada supports this program, providing opportunities for medical students at the University of Toronto to engage in full-time summer research projects under faculty mentorship. The program focuses on advancing medical research related to hydrocephalus and spina bifida.



2024 Impact Report Hydrocephalus Canada Award

Negeen Halabian

MD Student, Temerty Faculty of Medicine,
University of Toronto



Negeen Halabian is currently a second-year medical student at the Temerty Faculty of Medicine, University of Toronto, as part of the Class of 2T7. She previously graduated from McMaster University with a BSc in 2017, and an MSc in Neuroscience in 2023. Her thesis was entitled "*Age and Sex Influence the Expression of Viral Host Factor Genes in the Human Brain*".

2024 CREMS Project Title: Novel classification models to enhance predictions of neurological outcomes in spinal cord injury

Principal Investigator: Michael Fehlings

Background: Traumatic and non-traumatic spinal cord injury (SCI), such as degenerative cervical myelopathy (DCM), cause a significant burden on the patient, their families, and the health care system. Predicting outcomes is not only important for setting the expectations of patients and their families, but also for clinical trial design. With emerging neuroprotective agents, it is essential to have prediction of outcomes based on this method: Our lab has access to the largest dataset on traumatic spinal cord injury from a culmination of previous international registries and clinical trials. The spine unit of the Toronto Western Hospital is a world-renowned center for pivotal trials in spine surgery, including landmark studies on the timing of surgery and application of neuroprotective and regenerative therapeutic options in SCI. Additionally, we have large clinical datasets for DCM; resulting from years of participation in major international trials as well as expert leadership in this field. We will be exploring machine learning (supervised and unsupervised learning), other AI analytic approaches, trajectory-based modeling, and advanced imaging to predict outcomes.

Significance: The student will have access to the data and resources to learn and practice conventional and machine learning statistical approaches to clinical data. The student will also learn about novel techniques in the evaluation and re-analysis of clinical trial designs through assessment of previous trial data. Lastly, the student will have opportunities to prepare a manuscript with emphasis on the use of robust statistical analysis, clear data visualization and sound scientific manuscript writing for subsequent submission to a peer-reviewed journal.

Research Collaborations

Exploring the Extent and Nature of Disordered Eating Among Canadian Adolescents and Young Adults with Spina Bifida and Hydrocephalus

Published in Wiley Child: Care, Health and Development, January 2025

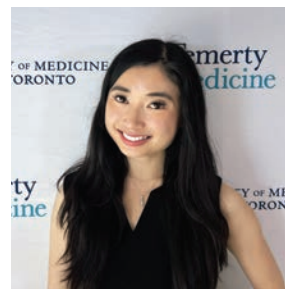
Community-Based Service Learning (CBSL) Student Placement, MD Program, University of Toronto

Hydrocephalus Canada has partnered with the Community-Based Service Learning (CBSL) program with the University of Toronto for several years. In 2024, we welcomed CBSL students Mariam Belghiti and Chloe Lau. CBSL enables community organizations to act as co-educators with faculty (family physicians and allied health professionals) in a continuous partnership. Mariam and Chloe were a delight to have with us this year, and we wish them all the best in their future academic pursuits.

Mariam Belghiti is a second-year medical student at the University of Toronto. Before medical school, she completed three years of an undergraduate degree at the University of Toronto Scarborough, in Human Biology and Psychology. Her past work in the community included founding the first epilepsy awareness student-group at U of T and working with Epilepsy Toronto. While working with Hydrocephalus Canada, Mariam made various info sheets regarding teaching self-advocacy to children and youth with hydrocephalus and spina bifida, supporting caregivers, health advocacy, and managing transitions. She also created an information database of other organizations and professionals around the world that support people with hydrocephalus and spina bifida. Finally, she found areas to update the adult section of the HC webpage to improve clarity and user-friendliness. Through her time with the team Mariam learned not only about the conditions themselves, but about the people who live with them who are the true experts. She also thanks HC staff and all the support group members that allowed her to sit in on their sessions and learn from them and their stories.



Chloe Lau is a second-year medical student at the University of Toronto, with a PhD in Clinical Psychology. She currently serves as a Postdoctoral Fellow at the Centre for Addiction and Mental Health and as an Adjunct Research Professor in the Department of Psychiatry at the University of Western Ontario. As part of her work with Hydrocephalus Canada, Chloe



contributed to the revision of the organization's Guide to Hydrocephalus booklet, applying a self-care and mental health-informed perspective to enhance its relevance for patients and caregivers. Through this work, she deepened her understanding of hydrocephalus and its treatment, and she is committed to integrating this knowledge into compassionate, evidence-based care as a future physician.

Advocacy Initiatives

Neurological Health Charities Canada (NHCC) continued to highlight the urgent need for a National Population-level Neurological Health Survey. Over 10 million Canadians live with neurological conditions that impact every aspect of life and contribute significantly to disability and healthcare costs. Since the landmark 2014 Mapping Connections study, the landscape of neurological health has evolved, with new challenges including a growing and aging population, diverse patient needs, and the lasting effects of the pandemic. An updated national survey is essential to fill critical knowledge gaps, improve prevention, diagnosis, and treatment, and support more efficient healthcare delivery across provinces and territories.

Hydrocephalus Canada, as a committed member of NHCC, has embraced this renewed focus and is actively involved in advocating for this vital initiative. Recognizing that elections provide a pivotal opportunity for change, NHCC partnered with Santis Health to launch a national campaign urging all political parties to commit to developing and funding this comprehensive neurological health study. The campaign aimed to elevate awareness, influence policy, and secure the resources needed to better support individuals, families, and healthcare providers impacted by and supporting those with neurological conditions.

Together, this collaborative effort will empower Canada's healthcare system with the data needed to prioritize resources effectively, reduce system pressures, and improve health outcomes for millions. By renewing focus on population-level data, NHCC and Hydrocephalus Canada seek to ensure that neurological health remains a national priority, benefiting individuals and caregivers for years to come.



Kidz & Youth Book Club Relaunch

Inspiring Young Minds

Hydrocephalus Canada proudly relaunched the Kidz & Youth Book Club, designed for children, youth and young adults aged 1 to 21 who are living with hydrocephalus and/or spina bifida. The program features a curated collection of age-appropriate books, including stories that reflect the lived experiences and unique journeys of those impacted by these conditions. By promoting reading, discussion, and personal connection, the book club encourages a love of literature while supporting cognitive development, self-expression, and social inclusion. This national initiative continues to grow as a meaningful space for young people to see themselves in stories—and share their own.



International Partnership

Expanding Beyond Borders: Building a Global Voice for Hydrocephalus

In 2024, Hydrocephalus Canada not only deepened its national impact—we also strengthened our role on the international stage. As awareness, advocacy, and collaboration remain at the core of our mission, we continued to grow meaningful relationships with hydrocephalus organizations around the world.

Through an ever-growing partnership with the Hydrocephalus Association (HA) in the United States and Harry's HAT (Hydrocephalus Awareness Trust) in the United Kingdom, we've joined forces to elevate global awareness, share knowledge, and advocate for the needs of those living with hydrocephalus across borders.

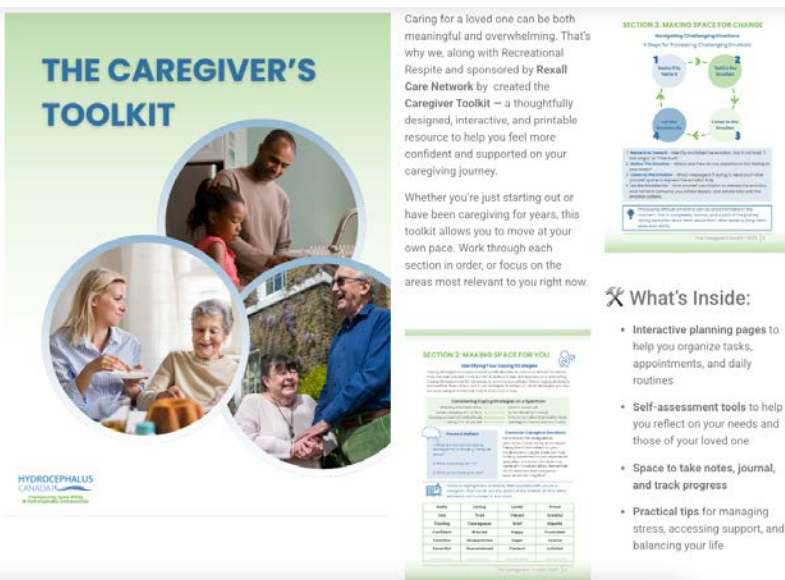
These collaborations, along with new connections in countries across Europe, Asia, and beyond, have played a central role in the success of World Hydrocephalus Day, held annually on September 20. What began as a spark of connection has grown into a global awareness movement—one that unites voices, shares stories, and highlights the need for research, education, and support on an international scale.

As we look ahead, Hydrocephalus Canada remains committed to being a strong Canadian voice in a growing global conversation—because hydrocephalus knows no borders, and neither does our determination to make a difference.

Empowering Through Education

New Resources on [Hydrocephalus.ca](https://hydrocephalus.ca)

Hydrocephalus Canada made significant strides in our commitment to education by launching a range of new and updated resources on [Hydrocephalus.ca](https://hydrocephalus.ca). These tools were thoughtfully developed to empower individuals, families, caregivers, and healthcare professionals with clear, accessible, and accurate information about hydrocephalus and spina bifida.



The expanded Education Hub now includes easy-to-navigate guides, downloadable toolkits, and real-life stories that speak to every stage of the journey—from diagnosis and treatment to day-to-day living and lifelong care. We've also added new sections to better support parents of children with hydrocephalus and spina bifida, youth transitioning to adult care, and adults navigating aging with these conditions.

These resources reflect the voices and experiences of our community, offering not only clinical insights but also practical, lived-in knowledge. With a fresh design and inclusive approach, the updated platform is helping users across Canada—and around the world—find the answers, guidance, and reassurance they need.

By investing in education, we are not only raising awareness but also building confidence, encouraging self-advocacy, and creating stronger connections between patients, families, and healthcare providers.

Strengthening Our Reach

A New Chapter for Staying Connected

In the past year, Hydrocephalus Canada redesigned and relaunched our Staying Connected digital newsletter to create a more accessible and inclusive platform for community engagement nationwide. The updated format included virtual support groups, webinars, and conversations featuring lived experiences, reaching people across Canada.

This new approach helped overcome geographic challenges and connect individuals, caregivers, and professionals from all provinces and territories. Through expert articles, community events, and the Own Your Story feature, more people were able to participate and engage.

The response was positive, with increased participation and engagement. Staying Connected has continued to grow into an important resource that supports and connects our national community.



“WHETHER IT IS ONCE A WEEK OR ONCE A MONTH, PARENTS NEED TO SET TIME ASIDE TO BE A COUPLE, EVEN IF IT'S JUST FOR A WALK OR DINNER OUT TOGETHER. TAKE CARE OF YOURSELF TO RECHARGE.”

READ MORE

SCHOLARSHIPS & BURSARIES

DR. E. BRUCE HENDRICK NATIONAL SCHOLARSHIP PROGRAM: EMPOWERING FUTURES ACROSS CANADA

The Dr. E. Bruce Hendrick National Scholarship Program continued to support Canadian students living with spina bifida and/or hydrocephalus in 2024. Open to applicants nationwide, the scholarship aims to assist students in pursuing higher education, thereby promoting independence and personal growth. By providing financial assistance, Hydrocephalus Canada helps remove barriers to education, enabling recipients to achieve their academic and career goals.

Luciana Spring Mascarin Regional Bursary Program: Named in memory of Luciana Spring Mascarin, this bursary supports students residing in the Windsor-Essex and Chatham-Kent areas of Ontario who are living with spina bifida and/or hydrocephalus.

The Dr. E. Bruce Hendrick Scholarship Selection Committee and the Luciana Spring Mascarin Bursary Selection Committee chose the following to receive awards:

Dr. E. Bruce Hendrick National Scholarship Program Award Recipients



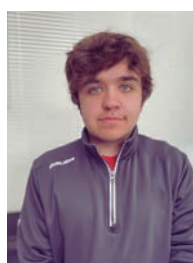
ANA-MARIA OPROESCU
British Columbia

Ana-Maria is pursuing her PhD in Biomedical Engineering at the University of Toronto and is very much involved in the community as a Youth Ambassador of Hydrocephalus Canada. Ana-Maria has also begun her career as an entrepreneur co-founding the STEM PASS Foundation. She hopes to start her own company based on Gene Therapy Technology. Ana-Maria was awarded the **Graham R.E. Gill Award**.



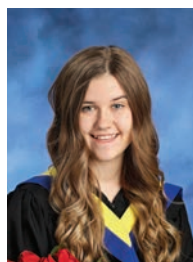
ANNE NITSCHKE
Beaverlodge, Alberta

Anne is working towards her Bachelor's Degree in Community Rehabilitation and Disability Studies at the University of Calgary. Her hobbies include reading, painting, building Lego, listening to music and traveling. She volunteers for the Spina Bifida & Hydrocephalus Association of Northern Alberta and acts as a mentor at a camp for wheelchair users. Anne was awarded the **Graham R.E. Gill Award**.



CONNOLLY GAMBLE
Wilcox, Saskatchewan

Connolly is attending the University of Regina hoping to complete a four-year Bachelor of Arts in Journalism, News Media & Communication degree. His passion is hockey and sports inspiring him to pursue a career in sports media. Connolly was awarded the **Michael Bailey Founders Award**.



KYLEIGH MORGAN
Havelock, Ontario

Kyleigh is working towards her Bachelor of Science in Nursing at St. Lawrence College. Over the long term she hopes to become a Nurse Practitioner specializing in pediatrics. Kyleigh plays three musical instruments and enjoys doing puzzles. Kyleigh was awarded the **Dr. Robin P. Humphreys Award**.



LILI MARIE ALDOM
Langley, British Columbia

Lili is following her passion for working with children by pursuing a Bachelor of Education at Trinity Western University in the hope of becoming an elementary school educator. Lili has volunteered at North Langley Community Church as a Child Ministry worker, leading and assisting various camps and programs. Lily was awarded the **Barton Family Award**.

LINDSAY DANIELS
Toronto, Ontario

Lindsay will be attending George Brown College to obtain a Social Service Worker Diploma. Her disability has motivated her to become a Psychotherapist, determined to help others with disabilities to overcome life's challenges and mental health issues. Lindsay was awarded the **Rodney G. Walsh Award**.



TROY KOPCZYK
Ottawa, Ontario

Troy is pursuing studies at Algonquin College in hopes of a career as a computer systems and networking technician. He enjoys volunteering at his church and in his community and is an avid video gamer and coder.

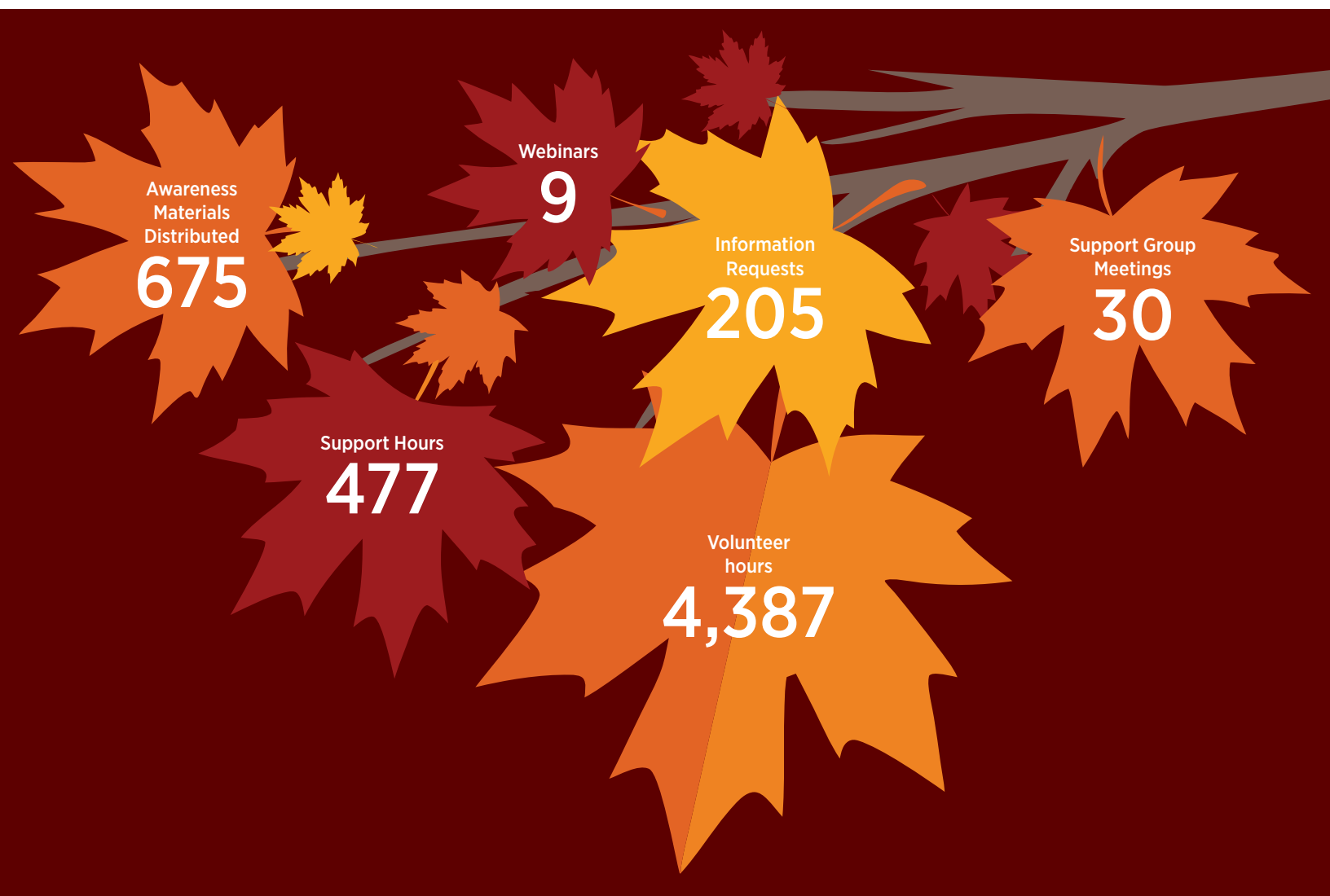
Dr. E. Bruce Hendrick Scholarship National Scholarship Award and the Luciana Spring Mascarin Bursary was awarded to:



EMILY GIOUGOVAZ
Bothwell, Ontario

Emily is pursuing a Bachelor of Music Honors at Wilfred Laurier University. A talented singer, along with her music education, Emily hopes to be a high school teacher and/or music therapist. Someday she hopes to

open her own private school to help motivate and support others. Emily loves music, songwriting, playing various instruments and performing.



HYDROCEPHALUS CANADA VOLUNTEERS

Our dedicated volunteers organized fundraisers, provided one on one support to individuals and families, raised awareness and helped facilitate support groups, attended information fairs and presented webinars. Our sincere appreciation and gratitude goes out to all who volunteered their time, expertise and dedication to make 2024 a memorable year! We recognize that our activities and achievements would not be possible without your invaluable contributions.

Mary Dufton & Claudio Cinapri

We are proud to congratulate our incredible volunteers, Mary Dufton, from Ottawa and Claudio Cinapri, Past Chair, from Wasaga Beach, on receiving the 2024 Ontario Volunteer Service Award! This prestigious honor, presented by the Ontario government, recognizes their continuous years of dedicated service and invaluable contributions to our organization. Mary and Claudio's commitment, generosity, and passion have made a meaningful difference in our community. We are truly grateful for their unwavering support and proud to see them celebrated alongside thousands of outstanding volunteers across the province. Congratulations, Mary and Claudio!

Hydrocephalus Canada also recognized Claudio Cinapri's long standing commitment to the organization and our community at our Annual General Meeting where he was presented with The Bonnie E. Charbonneau Award of Distinction. This award is given to honour those who have inspired in all of us Hope, Courage and the Strength to Persevere.



Claudio Cinapri, was elected to the Board of Directors in 2006. He held the position of 2nd Vice Chair for 5 years, 1st Vice Chair for 3 years and became the Chair of the Board in 2014. He led our organization through some challenging and inspirational times. He and his family participated in the annual golf event and you could also find him at a few of the Spirit Wheel Walk Run events throughout the years. His greatest achievement with the organization was leading the Board and staff through the transition from a provincial to a national voice for those impacted by spina bifida and hydrocephalus in 2016. Mr. Cinapri stepped down as Chair in 2020 but remained on the Board as Past Chair until 2023. He has spent countless hours leading our organization to ensure we continued to follow our mission and support those in the sbh community. HC is grateful for your dedication, hard work and time. Thank you for your commitment to our mission, your dedication and volunteer service of 20 years and your ongoing support.

OUR PEOPLE

2024-2025 Board of Directors:

Paul Egli, Chair

Gillian Akai, LL.B, M.B.A., Past Chair

Kristine Dorward, M.B.A., B.Sc., 1st Vice-Chair

Stephen Rex, BCom, CPHR, 2nd Vice-Chair

Heather Cheeseman, CPA, CA, Treasurer

Laura Gatensby, Secretary

Dr. Scott W.H. Barton, Ed.D, MBA, Director

Dr. Jay Riva-Cambrin, MD, MSc, FRCSC,
Director & Chair of the Medical Advisory Board

Natalie Clydesdale, Director

Dr. Mark Hamilton, MDCM, FRCSC, FAANS, Director

Dr. Abhaya V. Kulkarni, MD, PhD, FRCSC, Director

Ryan McGrade, Director

Amy St. Aubin, Director

Sam Sinjari, Director

Nicolena “Nikki” Stone, BB, Director

Staff

Shauna Beaudoin, Director, Programs & Information

Sharnette Beckett, Information & Services Coordinator

Tanja Bessey, Community Engagement Manager

Ingrid Exner, Community Support Coordinator

Chelsea Willis, Development & Fundraising Events Coordinator

Catherine Laird, Support & Promotion Coordinator

Vicky Pastuch, Support & Promotion Coordinator

Medical Advisory Board

Dr. Jay Riva-Cambrin, MD, MSc, FRCSC(C) – Medical Advisory Board Chair, Calgary

Dr. Abhaya V. Kulkarni, MD, PhD, FRCSC – Past Medical Advisory Board Chair, Toronto

Dr. Dominic Venne, MD, MSc, FRCSC, Montreal

Dr. Mark Hamilton, MDCM, FRCSC, FAANS, Calgary

Dr. Paige Terrien Church, MD, Boston

Dr. Jeffrey Atkinson, MD, FRCSC, Montreal

Dr. Michael Cusimano, MD, MHPE, FRCS, DABNS, PhD, FACS, Toronto

Dr. Khaled Effendi, MD, FRCSC(C), Sherbrooke

Dr. Alfonso Fasano, MD, PhD, Toronto

Dr. P. Daniel McNeely, MD, FRCSC, Halifax

Dr. Kotoo Meguro, MD, FRCSC, Saskatoon

Dr. Safraz Mohammed, MD, MBBS, Ottawa

Ms. Andrea Neufeld, Pediatric Nurse Practitioner, London

Dr. Andrew Parrent, MD, FRCSC, London

Dr. Adrianna Ranger, MD, FRCSC, London

Dr. Sandrine de Ribaupierre, MD, FRCSC, Montreal

Dr. Mandeep S. Tamber, MD, PhD, FRCSC(C), Vancouver

Dr. David Tang-Wai, MD, CM, FRCPC, Toronto

Dr. Alexander G. Weil, MD, FRCSC, FAANS, FACS, Montréal

Dr. Denis Sirhan, MD, FRCSC, Montréal

Welcome!

Join us in welcoming **Sharnette Beckett** to the Hydrocephalus team as our new Information & Services Coordinator! Sharnette brings a wealth of knowledge and a strong passion for helping others, and she will play a key role in connecting individuals and families with the information, support, and resources they need. We're excited to have her on board and look forward to the difference she will make in our community. Welcome, Sharnette!



We're thrilled to introduce **Chelsea Willis** as the new Development & Fundraising Events Coordinator on the Hydrocephalus Canada team! With her dynamic energy and experience in event planning and donor engagement, Chelsea will be instrumental in supporting our mission through impactful events and initiatives. We're excited for all she will bring to the role—welcome aboard, Chelsea!

SUPPORT GROUPS

WE ARE HERE FOR YOU!

You can connect with our online parent and adult groups at <https://www.facebook.com/HydrocephalusCanada/groups>

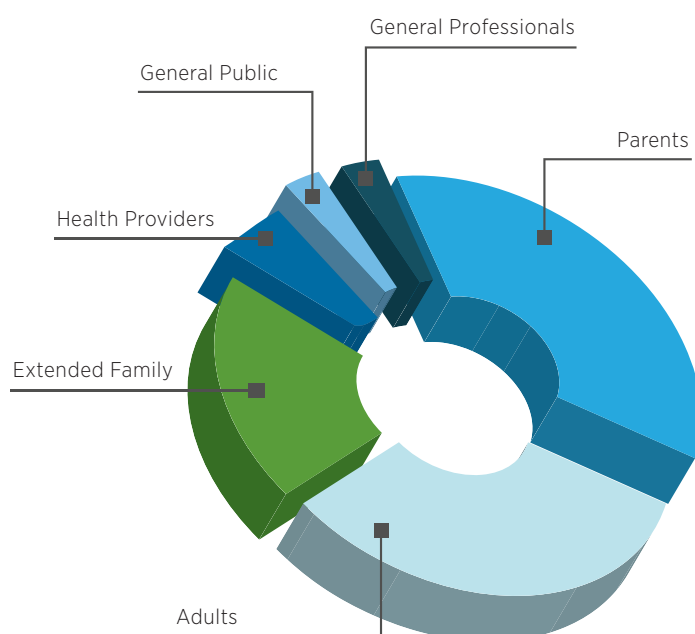
To sign up for our monthly Zoom parent, youth and adult support group meetings and yoga sessions, email Ingrid Exner, Community Support Coordinator at ixner@hydrocephalus.ca or visit our [website](https://www.hydrocephalus.ca) and click on News & Events for meeting dates.

“Thank you very much for hearing me out the other day, and for taking the time to send all the information, and doctor contacts. It is greatly appreciated. I am going to do my best to join the group for the next meeting, and thank you also for inviting me.”

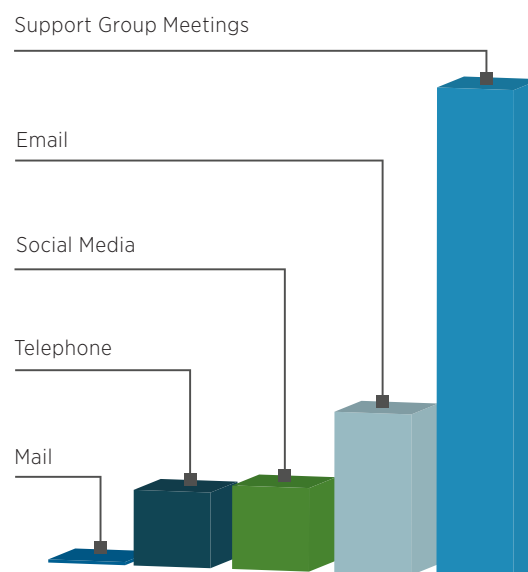
- SHANNON M.

DELIVERED SERVICE AND SUPPORT

SUPPORT HOURS BY GROUP SERVED



SUPPORT HOURS BY TYPE





GET INVOLVED

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 |

CHAMPIONING THE SPINA BIFIDA
AND HYDROCEPHALUS COMMUNITY

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P: 416-214-1056 or 800-387-1575 ▪ F: 416-214-1446

info@hydrocephalus.ca ▪ www.hydrocephalus.ca

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