

BRAINWAVES
HYDROCEPHALUS
CANADA | 

Bridging Research, Awareness and Innovation
With Advocacy Education & Support

RESEARCH

SUPPORT

RESILIENCE

CARE

AWARENESS

2020-2021 **ANNUAL REPORT**



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 (BRAINWAVES).

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



I joined Hydrocephalus Canada (HC) due to my close connection to its purpose – my husband was diagnosed at the age of ten with hydrocephalus, had a shunt inserted and had one revision during childhood. We were very grateful for what we understood to be a rare

situation - with no revisions or complications arising after that time. I heard stories of the exceptional support that my husband and his family received during that difficult time and was inspired to give back to a community that had served him so well. After sitting on the Board for a number of years, I had the honour and privilege of being appointed Chair of the Board of Hydrocephalus Canada in the Fall of 2019. I am excited to become even more involved and to lead the organization's mission and strategic goals.

I did not anticipate two life changing events occurring shortly thereafter, both of which had a significant impact on my role as Chair of the Board.

The first event was a malfunction of my husband's shunt. This resulted in a temporary, but dramatic and rapid physical and cognitive decline over a 24 hour period. While I was certainly educated about the condition and symptoms, I had never personally seen the effects on my husband. I cannot express my deep gratitude to those in our hydrocephalus and spina bifida network, who supported Justin and our family through a diagnosis, emergency shunt insertion, subsequent revision and ultimately a full recovery. The experience not only renewed my strong desire to give back to the organization, but also gave me the important experience of being a caregiver to a person impacted by hydrocephalus. This experience provided me with a better understanding of how my position as Chair can enhance our advocacy issues for the organization and all of our constituents, hydrocephalus and spina bifida alike.

The second life changing event, was COVID-19. It affected all of us and had a particularly challenging effect for our constituents in terms of their ability to secure support from their communities, HC, medical

resources and care from our heavily taxed medical and social services communities.

HC, like many other organizations, focused on an immediate response to the Covid-19 crisis - keeping our staff safe, while doing our utmost to continue to provide support and services, particularly those we considered most essential, in spite of lockdowns. We adjusted quickly and our fantastic staff went to extraordinary lengths to keep our programs and services available.

Once we managed through the initial stages of the crisis, it became clear that we had to think about re-imagining our operations to best serve the hydrocephalus and spina bifida (h/sb) communities during the longer term - knowing that COVID-19 was here to stay for some time. Despite all of these challenges, we were able to undertake a number of initiatives in support of our communities. Our Annual General Meeting and conference became a virtual event, which allowed participants from across the country and internationally to attend and have access to information on current research, shunts, parenting with a disability considerations and how to advocate for your needs in the age of Covid. Dr. Alfonso Fasano discussed the neurologist's view of NPH. This virtual experience, led HC to partner with the Association de spina-bifida et d'hydrocéphalie du Québec. We began working on hosting a series of bilingual educational webinars for all in the h/sb community. HC support groups went online and attendance increased. We launched a new support group for parents of individuals living with hydrocephalus and our Facebook support group participation doubled. HC's research and advocacy efforts continued throughout the pandemic and other highlights from the year are featured in this report.

2020 saw the expansion of our Medical Advisory Board to include members from across Canada. Many on the Board, also participated in the second meeting of the Canadian Working Group on Adult and Transitional Hydrocephalus meeting hosted by Integra LifeSciences and HC. A document from this meeting is being prepared for submission to the Canadian Medical Association Journal in 2021.

Throughout the pandemic, our Board and organization have strengthened our strategic focus to continue the important work of building for our future.



As the voice of Canadians living with hydrocephalus and spina bifida, we continue to pursue our purpose of empowering those impacted by these conditions to experience the best life possible through awareness, education, support and research.

During my term as Chair, working with the Board, staff and our constituents, I am hopeful that we are able to build on the amazing 47 years of work and accomplishments of the organization. We have made significant progress on this strategic work and intend to build on this momentum in the coming year:

Rejuvenating our organization

It is imperative that we welcome new directors, volunteers and members to bring new perspectives and skills to propel the organization forward and help to ensure longevity of Hydrocephalus Canada's important work for years to come. In 2020, we welcomed three new directors to our organization - all of whom are making meaningful contributions to the organization.

Expanding our reach and bringing together our communities

We continue to work on national expansion in an effort to connect with and better support stakeholders across Canada. In 2021, we will launch a needs survey and continue our partnership building with like-minded groups across the country. Our goal is to continue expanding our support and services and more importantly, help to connect our stakeholders, with each other in furtherance of all of our objectives. Simply put, we are stronger together!

Innovating our operations

With involvement from new directors, members, volunteers and community groups, we are considering new perspectives and ideas to improve and innovate in terms of our operations. Adjusting our programs and services, heightening our communications and outreach to best support the ever changing needs of our stakeholders is paramount. Implementing new fundraising ideas to sustain our important work is also key for building on our objectives.

I am so amazed and proud of the devotion and resiliency of our staff, our talented board, amazing medical teams throughout the country and most importantly, our fantastic spina bifida and hydrocephalus community of individuals, families and caregivers. We have come together during this exceptionally challenging time to help each other and work towards our collective mission. Thank you to each and every member of our community, including our donors, corporate partners and foundations, without whom, we could not do what we do.

I encourage everyone to stay connected with Hydrocephalus Canada and with one another. Join our mailing list and receive the HC Staying Connected newsletter. Our Board and staff are always interested in hearing from our constituents – sharing your experiences is how we can do better. You can always reach out to us at www.mybrainwaves.ca, on Facebook, Twitter or Instagram. Email us at info@hydrocephalus.ca or call toll-free 1-800-387-1575. We would love to hear from you!

The team at HC is looking forward to the day where we can spend time together in person to continue to build a better and stronger Hydrocephalus Canada for our hydrocephalus and spina bifida community.

Gillian Akai

Message from the Director of Programs & Information



This year, the 47th anniversary of Hydrocephalus Canada was one of the most challenging times in our history. As the world struggled to understand and cope with COVID-19, nothing was certain. What emerged very quickly was an incredible sense of community. Everyone pulled together! The HC Board acted quickly to ensure that the staff and other people working on HC's mission were safe. Staff and volunteers worked hard to move support groups to virtual formats. Just like everyone across the world, we all jumped in to learn how to use Zoom and other virtual platforms. It was wonderful to see the faces of those in our hydrocephalus and spina bifida community, some for the first time. We even took our normal pressure hydrocephalus awareness campaign online and presented to a group of seniors.

We expanded our support groups online through Facebook and held our first virtual meeting for parents of individuals with hydrocephalus.

Our community connections made it possible for us to access quantities of masks, wipes and hand sanitizer for distribution to people living with hydrocephalus and/or spina bifida.

Though it was anything but "business as usual", we met the challenges head on and continued to offer programs and services across Canada – together.

Shauna Beaudoin



Treasurer's Report

This past fiscal year for Hydrocephalus Canada, from March 1, 2020 to February 28, 2021 coincided with one of the most challenging periods in our country's history. However, for a number of reasons Hydrocephalus Canada was able to respond to the Covid 19 challenges and our financial results, while not as strong as the previous year, are still very positive.

Summary Financial Statements are included in this Annual Report and I will provide 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, 2021 and its financial performance for the 12 month period ending February 28, 2021.

The auditors, as in previous years, have qualified this opinion by saying that certain fundraising revenues received by Hydrocephalus Canada in the form of donations cannot be verified by standard audit methods. This is a very common qualification for charitable organizations in Canada, and it is my opinion that this qualification is not a problem with respect to the accuracy and completeness of the financial statements for Hydrocephalus Canada for the fiscal year ending February 28, 2021.

The Summary Statement of Financial Position (formerly known as the Balance Sheet), shows greater than a \$50,000 increase in Net Assets and Unrestricted Net Assets compared to the statements of the previous year. This means that our organization does have contingency funds to rely on in the event of any future difficult situations.

The reason Hydrocephalus Canada was able to strengthen its financial

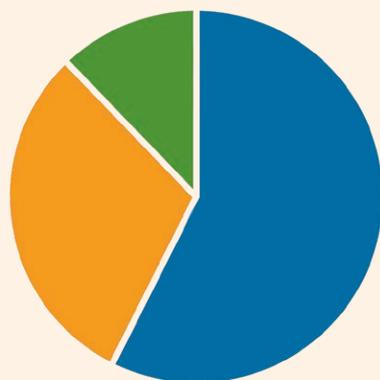
position is shown on the Summary Statement of Operations (formerly known as the Income Statement). The Summary Statement of Operations shows an excess of revenues over expenses for the last fiscal year of \$52,021. This was due to a number of factors including continuing strong performance of our break open lottery tickets (\$112,000), revenue from government subsidy programs (\$30,000) and the overall careful financial stewardship by our staff.

The positive financial results and the strengthening of our financial position come at a good time for our organization. We are all hopeful of a gradual improvement of the Covid 19 issue, but it may have lingering negative impacts on our financial performance and our ability to raise funds in the community.

Our solid financial position will help us to cope with any future uncertainties.

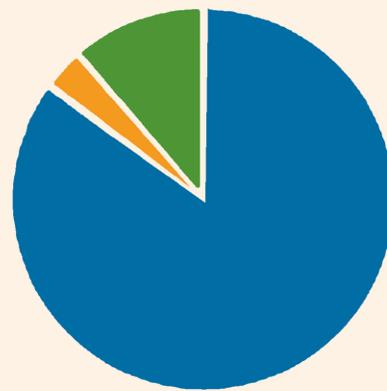
Paul Egli, HC Board of Directors

HOW FUNDS ARE RAISED



- 57% Fundraising Activities
- 30% Donations
- 12% Other

HOW FUNDS ARE SPENT



- 84% Programs and Services
- 4% Fundraising
- 11% General Administrative

Summary Annual Financial Statements

Summary Statement of Operations

Year ended February 28, 2021

	2021	2020
Revenues		
Fundraising activities, net	\$179,467	\$257,909
Donations	95,087	83,261
Other	38,073	7,376
	312,627	348,546
Expenses		
Programs and services		
Awareness and education	117,200	120,895
Care and support	76,305	63,429
Advocacy, research and scholarships	26,109	23,399
General administrative	28,895	26,776
Fund development	11,398	8,756
Amortization of equipment	699	699
	260,606	243,954
Excess of revenues over expenses	\$52,021	\$104,592

Summary Statement of Financial Position

February 28, 2021

	2021	2020
ASSETS		
Cash and short-term deposits	\$292,906	\$221,456
Other current assets	42,653	58,547
Total current assets	335,559	280,003
Endowment investments	221,092	219,604
Equipment	974	1,673
Total assets	\$557,625	\$501,280
LIABILITIES		
Accounts payable and accrued liabilities	\$20,517	\$13,456
Deferred contributions	12,960	15,697
	33,477	29,153
NET ASSETS		
Net assets restricted for scholarships and research	227,228	230,228
Unrestricted net assets	296,920	241,899
	524,148	472,127
Total liabilities and net assets	\$557,625	\$501,280

Summary Statement of Changes in Net Assets

Year ended February 28, 2021

			2021	2020
	Unrestricted	Restricted / other	Total	Total
Beginning of year	\$241,899	\$230,228	\$472,127	\$367,535
(Expenses over revenues) revenue over expenses	55,021	(3,000)	52,021	104,592
Internally restricted, transfers	-	-	-	-
End of year	\$296,920	\$227,228	\$524,148	\$472,127

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 17, 2021, may be obtained from the Association 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, 2021, 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, 2021. We expressed a qualified audit opinion on those financial statements in our report dated June 17, 2021.

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 Audited Financial Statements and Our Report Thereon

We expressed a qualified audit opinion on the audited financial statements in our report on June 17, 2021. The reason for our qualified audit opinion was that we were unable to obtain sufficient appropriate audit evidence about the completeness of cash donations and fundraising event and activity revenues since, due to their nature, they are not susceptible to satisfactory audit verification. This is common with many not-for-profit organizations. Consequently, we were unable to determine whether any adjustments to revenues, changes in net assets, assets and net assets were necessary.

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
June 17, 2021

Cholkan + Stepczuk LLP
Chartered Professional Accountants
Licensed Public Accountants

Donor Profile

Alan Hirsch

Alan Hirsch is a valued member of the HC family as a donor and supporter. We have enjoyed getting to know Alan over the last many years, and would love for you to get to know him as well.

Alan, can you tell us how you came to be involved with Hydrocephalus Canada?

In 1979, I was in desperate need of a talented typist to prepare the manuscript for a physics textbook I was writing. A friend introduced me to Lorna Wreford who turned out to be not only an excellent typist but also a fantastic editor. Lorna lived with spina bifida and hydrocephalus into her 80s. These conditions, however, limited her mobility. She was creative in adapting to various situations without complaint and was a great inspiration to me. Lorna introduced me to Hydrocephalus Canada (known at the time as the Spina Bifida & Hydrocephalus Association of Ontario) and its fundraising efforts. I was excited to participate in their lottery calendar awareness and fundraising campaign which featured Lorna's artwork on several occasions. I was honoured to support the calendar sales and, more importantly, the sale of original water colour paintings Lorna had created. Today, three of those paintings are on display at Hydrocephalus Canada's office in Etobicoke.

What was your first impression of HC?

My first impression of Hydrocephalus Canada was that the people I met were welcoming and intelligent, and they displayed a very positive attitude to life. More than forty years after first meeting Lorna, the people I have met recently have those same characteristics, and it is a pleasure to get to know them and support their efforts wholeheartedly.

What do you wish people knew about hydrocephalus and spina bifida?

Medical research has contributed enormously to help improve the lives of people who experience challenges, including those with Hydrocephalus or Spina Bifida. An important example is brain research that reveals how the brain's elasticity allows new brain pathways to take over (with training and practice) the responsibilities of pathways with reduced function. Knowing this, I think it is important for all of us to realize that we should continue to dream and hope, and not give up.



What would you like to share with prospective donors?

One of my favourite fundraising activities is the golf tournament (cancelled this year due to the Pandemic). You can enjoy a great round of golf with your friends followed by a banquet with live entertainment and a lively auction. For other donor suggestions, the office staff, including Shauna Beaudoin, are always happy to share their ideas.

What is something about yourself that might surprise people?

Being outdoors close to nature is among my favourite activities. I have been blessed in being able to observe and identify more than 2400 bird species, about 25% of the number of species in the entire world. What's amazing about this is that I'm short-sighted, and my ability to recognize bird species by sound is embarrassingly useless. But I've spent a lot of time looking for birds (through binoculars, of course!) wherever I've travelled, and I've taken numerous close-up photos of birds to help me identify them.

What is your hope for HC in the coming years?

My greatest hope for Hydrocephalus Canada for the near future is that the restrictions caused by Covid-19 will diminish enough in Canada so we can all begin meeting again. Contact with other people is so important, and if everyone who can get vaccinated does so, we will experience togetherness soon. In the distant future, I hope that the organization receives funding from wherever possible to be able to support its members to a high degree.

The Hydrocephalus Canada team wants to thank Alan for his decades of steadfast support. The work that the organization undertakes in support of our community could not be accomplished without the support of donors like Alan.

THANK YOU, ALAN – FOR EVERYTHING!

Programs & Services Overview

2020-2021 was a year unlike any other in the 47 year history of Hydrocephalus Canada. Covid-19 protocols meant that we had to completely reimagine how we offered our services and more importantly, how we connected with you. Keeping everyone safe mattered most of all. We leaned heavily on our website, social media channels and STAYING CONNECTED e-Newsletter to keep in touch with each other. Adapting our in-person support groups and Annual General Meeting and Conference to the popular ZOOM platform provided a new way to deliver information and programming to a wider audience. You adapted as well and engaged with us, and each other, in a way we could not have even imagined. THANK YOU!

In many ways, this fiscal year was incredibly successful and we couldn't have done it without the support of our hydrocephalus and spina bifida communities and donors across Canada! Thank you!

Awareness and Innovation

Everyone had to find new ways to stay connected through the pandemic. It was especially important to people living with hydrocephalus and/or spina bifida who may have already felt isolated and alone. We were so excited to see people embracing technology and not letting anything stand in the way of getting and giving support to each other. ZOOM, our website and social media became our primary modes of communication and service delivery. We were there for each other and the sense of community was so strong! Thank you! Here's a little of what our community accomplished this year:

TEACHING AWARENESS THROUGH PUPPETRY (TAP) PARTNERSHIP

Teaching Awareness through Puppetry (TAP) teaches sensitivity, awareness and understanding of disabilities and differences through lively and entertaining puppetry. Our goal is to provide an educational experience to help students accept differences in themselves and in others. Each performance is followed by a question and answer period between the puppets and the students. Questions are answered in an open and supportive way.

- 58 workshops to over 1000 students
- volunteer hours 1446
- launched new grade 4-6 mental wellness workshop



RESEARCH SUPPORT & RECRUITING

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.

Community-Based-Service-Learning MD Program, University of Toronto

We had three great students from the University of Toronto Medical School work with us through the academic year. They updated our brochures, revised power point presentations, and advocated to have more sbh information added to the U of T medical school curriculum. Initial response was positive. We will keep you posted.

Summer students-worked hard to support our awareness efforts with health care providers. Also assisted with virtual fundraising initiatives.

- "Reproductive and Pregnancy Outcomes in Women with Spina Bifida-Indications for Caesarean Sections in Women with Spina Bifida"- Hydrocephalus Canada Access to Excellence Award, Temerty of Faculty of Medicine, University of Toronto (CREMS)

- Brothers & Sisters involvement with health care Transition for youth with Brain-based Disabilities (BEST SIBS) Study



- Youth Healthcare Transition: Supporting Individualized Role and Responsibility Transitions, OCAD University Design for Health Masters program
- Neurosurgical Patient Perspectives on Evaluation of Residents in Competence by Design Education, St. Michael's Hospital, University of Toronto
- Ready or Not Brain-Based Disabilities Trial, Child Bright, McGill University, McMaster University, Strategy for Patient-Oriented Research (SPOR)
- Disability & Reproductive Life Plans Study, University of Toronto and CIHR-SSHRC

Holland Bloorview Research

- Exploring the extent and nature of disordered eating in youth and young adults with spina bifida and hydrocephalus across Canada, Bloorview Research Institute and Hospital for Sick Children
- Experiences of working, volunteering and unemployment during Covid-19 pandemic among youth and young adults, Bloorview Research Institute.
- Sexuality Workshop for Children and Youth with Disabilities, Bloorview Research Institute
- CIHR-SSHRC Partnership Project on Healthy & Productive Work for Youth and Young Adults with Disabilities
- What are the Mental Health & Wellness Needs of Young Adults with Spina Bifida? A Stakeholder Engagement Workshop
- Parent participation about Mental Health & Wellness in children and youth with Spina Bifida



"I am very grateful to Hydrocephalus Canada for their contribution to making this research project and experience a reality. "

Noroh Dakim

2020 University of Toronto CREMS Program grant recipient

WEBSITE

The HC website played a pivotal role in making sure that people who needed us could find information and access our programs & services throughout the isolation required by the Covid-19 pandemic.

- 13,125 users: 62% Ontario, 12% BC, 7.5% AB, 6.4% QC, 3.3% NS, 2.48% MB, 1.94% SK, 1.86% NB, 1.14% NL, 0.5% PEI
- 26,855 page views
- Sources: 61.9% Organic search, 33.6% Direct, 3.8% social, 0.7% referral
- Most referrals come from Facebook then LinkedIn and Twitter a distant third followed by Instagram

SOCIAL MEDIA

In the 2020-2021 fiscal year, social media allowed us to stay connected to people living with hydrocephalus and/or spina bifida across Canada.

- Facebook: 186 posts, 1600 fans, 1200 engagements, 287 shares.
- Twitter: 304 tweets; 700 followers; 273 engagements: 199 likes, 67 retweets, 7 replies; 523 clicks
- Instagram: 233 posts, 296 followers, 2100 engagements,

STAYING CONNECTED

Our E-Newsletter is an important way for us to share the stories of people living with hydrocephalus and/or spina bifida and information that can help us all live our best lives. Stories like Meaghan and her bulldog Louis who both have hydrocephalus. Its is our greatest hope that people read these stories and feel more connected and less alone.



HUGS AND SMILES PHOTO CAMPAIGN

This fun social media campaign drew some amazing entries! Connection was more important this year than perhaps at any other time. Whether it is a connection with your dog, sibling or parent. Thanks to everyone who submitted entries.



Support, Programs & Information

SUPPORT GROUPS

Our Adult Hydrocephalus and Spina Bifida group meetings were held online in order to keep everyone safe. This format also made it easier for people from across Canada to join us.

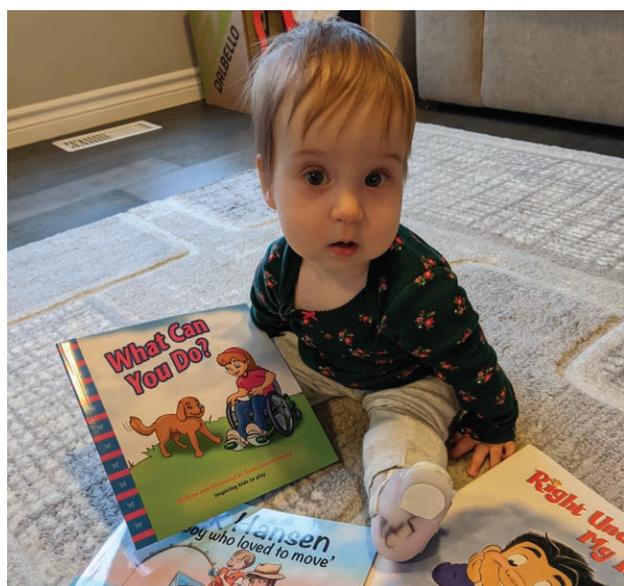
- **Adult Groups:** Adult support groups for those living with hydrocephalus and spina bifida provide a safe place to connect, gather information and socialize..
- **Facebook Groups:** made it possible for more people living with the challenges of spina bifida and/or hydrocephalus from across Canada to connect with each other.
- **Peer to Peer Support** – HC facilitated direct connections between people with similar concerns helping them to feel less isolated and alone.

UNITED WAY SUPPORT

HC applied for and received the United Way Emergency Community Support Fund Grant. This grant allowed us to distribute 1500 latex free masks and 4350 anti-bacterial hand wipes to those with hydrocephalus and spina bifida.

KIDZ & YOUTH BOOK CLUB

This HC program provides complimentary books to children and youth to educate them about spina bifida and hydrocephalus as they grow with these conditions.



NORMAL PRESSURE HYDROCEPHALUS (NPH) BRIDGING THE GAP AWARENESS INITIATIVE

The goal of this initiative is to educate the general public about this relatively unknown neurological condition. Outreach includes distribution of brochures to retirement and senior community hubs to increase knowledge of the condition. In 2020, we adapted our in-person outreach to include virtual info sessions to senior's groups like CARP.

- Supported 20 people newly diagnosed with hydrocephalus through our website, social media & toll-free support helpline
- 5 people were linked and were able to support each other through our Linking Program.
- Distribution of NPH resources were provided to neurosurgeons, neurologists and geriatric health professionals across Canada.

Advocacy

NEUROLOGICAL HEALTH CHARITIES CANADA (NHCC)

Neurological Health Charities Canada (NHCC) is a coalition of organizations that represent people with brain diseases, disorders and injuries in Canada. Hydrocephalus Canada is a proud member of NHCC and in 2020, was asked to join the Governing Council. Collectively, our 2020 advocacy work has been focused on promoting brain health to MPs, Senators and policy advisors to increase awareness, education and research. Our collaboration will improve diagnosis, treatment and supports that will benefit people impacted by conditions like hydrocephalus. Highlights from the year include:

- A partnership with the Canadian Brain Research Strategy to increase involvement of persons with lived experiences to contribute to the development of their research strategy.
- Participated in the Ontario Neurodegenerative Disease Research initiative scientific retreat, where an NHCC representative presented an overview of our work and to push for further research into brain health.
- NHCC was invited to participate on the advisory board of the Canadian Institutes of Health Research Institute of Neurosciences, Mental Health and Addictions which supports research to enhance mental health, neurological health, vision, hearing and cognitive functioning.

PROVINCIAL PARENT ASSOCIATION ADVOCACY COMMITTEE ON SPECIAL EDUCATION ADVISORY COMMITTEES (PAAC ON SEAC)

Hydrocephalus Canada is a member with a 20 plus year history with this collaborative group of Ontario parent associations that encourages valuable partnerships among trustees, educators, voluntary associations and parents. PAAC on SEAC has an extensive communication network with valuable resources for SEACs, the Ministry of Education, school board officials, service providers, parents and the community at large. The group also receives updates from the Ministry of education concerning changes in government policies and programs, to which PAAC on SEAC provides feedback about implications relating to SEAC members. In 2020, PAAC on SEAC focused on:

- Distribution of 3 surveys to SEACs across Ontario to determine what has changed and whether there are new issues or challenges in special education. These were divided into sections that outlined

SEAC Meaningful Participation, Engagement and Community, Recruitment, Orientation and Training and Awareness The information received provided key areas of responsibility and involvement and any needs for improvement such as enhanced training for all SEAC members.

Other contributions in 2020:

- HC endorsed an open letter from the ARCH Disability Law Centre for urgent changes to the Ontario Health's Clinical Triage Protocol for Major Surge in Covid-19 pandemic.
- Collaborated with Spinal Cord Injury and other organizations to create a position paper on recommendations to the Ontario Government for Intermittent Urinary Catheterization Supplies. This call to action is for the Ontario Government to review public coverage for intermittent urinary catheterization supplies in order to address important patient safety and potential liability risks associated with individuals having to reuse single-use catheters for financial reasons.

Medical Advisory Board (MAB)

In the last year, Hydrocephalus Canada's Medical Advisory Board has grown in leaps and bounds and now has representation from across Canada. New member Dr. Alfonso Fasano presented NPH- The Neurologist's View at our annual meeting and conference.

Integra LifeSciences and Hydrocephalus Canada co-hosted the second meeting of the Canadian Working Group on Adult and Transitional Hydrocephalus. Several members of our MAB are involved in this working group, led by Dr. Mark Hamilton. Progress to date includes:

A \$25,000 grant study on hydrocephalus is being undertaken to obtain information on shunt insertions, revisions, complications, infections, and costs across the country.

A consensus document highlighting the need for standardized pathways for transitional hydrocephalus and adult hydrocephalus is being drafted for submission to the Canadian Medical Association Journal.

Dr. Kulkarni's message at MAB meeting:

"We have worked hard to ensure a MAB that cuts across Canada and the many sub-disciplines of national hydrocephalus experts. I thank you all for agreeing to be part of this wonderful group."



Education & Networking

Mini-Conference

Once again, the speakers at the 2020 Conference delivered inspiration, information and support to those who attended our virtual event. Topics included:

Disability Disclosure Toolkit for Youth Seeking Employment

NPH-The Neurologist's View

Ten Ways to Advocate for Your Needs in the Age of Covid

Overview of the Codman Specialty Surgical Valve Portfolio

Reproductive Health, Sexual Health, and Pregnancy

Experiences of Women with Spina Bifida:

A Qualitative Study

Parenting with a disability; psychosocial considerations

Disability Tax Credit Planning for Seniors & Families

**All sessions were recorded and are available on our YouTube Channel.*



BRAINWAVES HYDROCEPHALUS CANADA | **NPH - The Neurologist's View**
Dr. Alfonso Fasano, MD PhD

Normal Pressure Hydrocephalus
a Movement Disorders Neurologist Perspective

Alfonso Fasano, MD, PhD

Chair in Neuromodulation and Multi-Disciplinary Care
Professor of Neurology - University of Toronto, Canada
Clinician Investigator - Krembil Research Centre
Co-director surgical program, Movement Disorders Centre
Toronto Western Hospital - UHN

Thanks to our sponsors:



BRAINWAVES HYDROCEPHALUS CANADA | **Thriving in the Era of COVID**
Tara Geraghty-Ellis, Clinical Social Worker, Disability Consulting & Coaching

About Tara Geraghty-Ellis

- Tara Geraghty-Ellis, @TaraGeraghty, is The Disability Empowerment Guru
- Author of *ViaBle and Empowered: Confronting Barriers and Creating Abundance*
- Creator of *ProsperAbility: The Universal Abundance Movement*
- She empowers people with disabilities to create the lives they want and control their circumstances

BRAINWAVES HYDROCEPHALUS CANADA | **EMPOWERING PEOPLE**
Impacted by Hydrocephalus and Spina Bifida. 10 Experiences the Best Life Possible

Reproductive Health, Sexual Health and Pregnancy Experiences of Women with Spina Bifida: A Qualitative Study

Dr. Anne Berndt, MD, PhD, M.Sc., Associate Scientist, Sunnybrook Research Institute and Aislinn Brennan, Senior Medical Student, University of Toronto



Scholarship & Bursary Awards

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

2020 DR. E. BRUCE HENDRICK SCHOLARSHIP RECIPIENTS



DIALLO O. N. BARROW

York, ON

Studying sign language at George Brown College

MICHAEL BAILEY FOUNDERS AWARD



WAFFA QURBANI

Mississauga, ON

Working towards her Masters of Education at the University of Ottawa

DR. ROBIN P. HUMPHREYS AWARD



SEJAL MANJREKAR

Mississauga, ON

Studying electronic music production at Metalworks Institution



MAILAWALANA ARACHCHIGE LISHAN THARINDA

Pickering, ON

Fourth year of undergraduate at the University of Toronto, Honor Bachelor of Arts in Public Policy

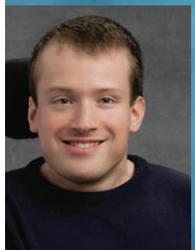
RODNEY G. WALSH AWARD

CONNOR MCGOWAN

Georgetown, ON

Studying radio broadcasting at Humber College

BARTON FAMILY AWARD



LUCIANA SPRING MASCARIN BURSARY

NATHAN WUERCH

Windsor, ON

Studying community integration through cooperative education at St. Clair College in Windsor. His goal is to own a business

“I wanted to send a heartfelt thanks to everyone for awarding me with the Luciana Spring Mascarin Bursary! I will work hard to complete my second year in the CICE program as I keep Luciana’s memory alive and well. I am determined to become a productive member of society despite all obstacles! Thank you for supporting and believing in me.

Nathan Wuerch

Donors & Partnerships

Thank You from the Bottom of Our Hearts!

This year, more than any other, we needed our partners, sponsors, donors and volunteers who raised funds through Spirit Wheel Walk Run virtual events and Facebook. COVID-19 made everyone's life and work so much more challenging. Yet, our dedicated donors and hsb community showed their boundless compassion and creativity to support the work of Hydrocephalus Canada.

- Our corporate partners Coloplast donated a quantity of hand sanitizer that was randomly distributed to the hsb community through a contest.
- HC member Christine Iggulden hosted a Thirty-one gifts fundraiser for the second year during June Awareness month.
- Jackson's Hope Fore Hydrocephalus Golf Tournament – Jackson and his family were able to host their annual Jackson's Hope Fore Hydrocephalus Golf Tournament in Orangeville in September raising over \$3,600 for HC.
- Tammy Tryon's Bald For a Cause virtual event raised over \$1,200 for HC as she bravely shaved her hair off live on Facebook.
- HC's Annual Golf Event was postponed due to the pandemic. The Lyte Clinic & Lyte Medical sponsored our **In the Spirit of Golf** virtual campaign. Board members shared giving pages with colleagues, friends and family and raised \$6,200.
- Members who annually participate in the HC Spirit Wheel Walk Run took the pandemic in stride and moved their events online to Facebook and Go Fund Me. OOS Medical/Amici Catheters continued their annual sponsorship of the campaign. Troy's Trail, Trek for Trev and Team Logan raised an amazing \$5,600 in support of HC programs and services. Again, THANK YOU!
- Generous and enterprising members of the hsb community organized Facebook fundraisers to celebrate special days in their lives to support HC. Combined they raised \$4,300.
- HC introduced the online HC Hope 50/50 raffle in November. Thank you to everyone who purchased tickets to support this endeavor and congratulations to our first Grand Prize winner Rita Batts, of St. Catharines who won \$2,185.



Donors \$500+

A big thank you to all of our donors, including those not listed!

Shirley Akai

Thomas R. Armstrong

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Sandi Beaudoin

Karen Boland

Kim Brough

Chabot Wealth Management

Scott D. Clark

Aranjit Daid

Estate of Joan Roddick

Frederick & Douglas Dickson
Memorial Foundation

Gary Bluestein Charitable
Foundation

Gee's Tree Removal Service

Government of Canada

Dr. Mark Hamilton

Alan Hirsch

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Maureen Vanderhoek

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Integra Life Sciences/Codman
Specialty Surgical

Lyte Clinic Medical Cannabis
& Lyte Medical

OOS Medical/Amici Catheters

Ryelle Strategy Group

snapp

Volunteer Support

■ Volunteer hours - 650

Hydrocephalus Canada values the time generously given to us by our team of volunteers. Our volunteers organized events against the backdrop of COVID-19, distributed learning materials, and shared their stories so people didn't feel so alone and much more!

Volunteers lead us, raised much needed funds, and have worked hard to increase awareness of the issues faced by people living with spina bifida and/or hydrocephalus.

Thank you to everyone who volunteered with us. ***We are more grateful to each and every one of you than you know!***

It is our pleasure to recognize and celebrate those individuals who have given of themselves and provided outstanding contributions to the success of Hydrocephalus Canada:

Joseph Sedej – Special recognition for his outstanding volunteer efforts at our annual golf event and his welcome assistance with administrative tasks in the office.

Amber Harnett – Special recognition for her dedication to helping those diagnosed with NPH in the London region by starting a support group.

Unsung Heroes

So many more people and organizations than we could possibly name were there for HC and people living with hydrocephalus and/or spina bifida over this most difficult and trying year. Thank you to everyone who provided a gift to Hydrocephalus Canada. Your contributions truly made a difference in our community!

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- ✓ SERVE on the Board
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- ✓ DONATE

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