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Announcing Our 2022 HA Scholarship Recipients!

We are proud to honor 13 young adults with scholarship awards.



MESSAGE FROM THE PRESIDENT AND CEO

Dear friends,

Once again it is that time of year when we gather around the table with our friends

and families and pause to reflect on that which we are thankful. High on the list of what I am thankful for is you, our Hydrocephalus Association (HA) community. It is an honor and a privilege to serve as HA's President and CEO and to work with the dedicated members of our board of directors, staff, and volunteers.

One of the biggest highlights of the year was HA CONNECT. What an amazing experience this year's conference was! This was the first in-person conference for HA in four years and the response was exceptional. Participants engaged in educational and interactive sessions with some of the nation's leading experts in the field. Patients and families were able to connect with others who face similar challenges, and physicians, scientists, and exhibitors were able to receive insight on the perspective of patients and caregivers regarding life with the condition. Our conference is truly special because it brings together everyone touched by hydrocephalus.

We listened as many of you gave us input on what research outcomes matter most to our community. After two years of collating countless survey responses from almost 900 representatives of the hydrocephalus community, and then bringing community members together for a virtual workshop earlier this year, we are delighted to share our new Top 20 Community Research Priorities. These priorities will significantly influence our research strategy moving forward, as well as our advocacy, education and awareness efforts. You can read more about these on page 11.

In June, Amanda Garzon and I traveled to the UK for the first ever Parliamentary Reception focused on hydrocephalus hosted by the Right Honorable Michael Gove MP, House of Commons. We were there to provide support and collaboration between HA and Harry's HAT, which helps children and families affected by hydrocephalus in the UK, and to help them launch their 'Get-a-Head' campaign.

As always, we continue to provide you with ways to connect with your peers online and in person through our Community Networks, which hold in-person and virtual events to help you meet and network with others in the hydrocephalus community. You can learn more about these events on page 19.

In October, we hosted an impactful research workshop in Houston, TX. With support from the Rudi Schulte Research Institute, we are now able to host a research workshop every year across a range of topics critical to moving the care and treatment of hydrocephalus forward. The focus of the meeting was *Improving Cognitive and Psychological Outcomes in Hydrocephalus*, and we honored the legacy of Dr. Michael Pollay, an incredible physician and scientist with 99 publications to his credit. Over 50 participants were in attendance, and we received so many positive comments and expressions of gratitude for bringing the scientific community together again for a hydrocephalus-focused workshop.

Please take a moment to read through this edition of Pathways to learn even more about everything we have been working on and the support we continue to provide to our community. We would welcome your support as you consider your end of year giving, and please know that your donation would most definitely be impactful. There is an envelope provided in this publication if you would like to mail in a donation, or donate online with this QR code.



It has truly been an amazing year and we could not have done any of it without you! Your steadfast support means the world to us. [Thank you for generously supporting our mission.](#)

Sincerely,

Diana Gray, MA
President and Chief Executive Officer

FEATURED ARTICLES

New Board Members



Deitra Matthews, MPA
CEO of The Ram Foundation

*HA's Support & Education Committee
and Advocacy Committee*

Deitra Matthews currently serves as the CEO of The Ram Foundation. The RAM Foundation was created to address the academic, social, and wellness needs of youth and their families in the Pinehurst community and surrounding areas in Columbia, SC. In her capacity as CEO, she is an active community advocate, voicing the concerns of underserved children and their families.

A graduate of Savannah State University, Deitra holds a Bachelor of Arts from Coker College, where she double majored in English and psychology. She also holds a Master's Degree in Public Administration from Savannah State University.

Deitra is married to Colonel (RET) Brian D. Matthews and they have two daughters – Caroline (16) and Claudia (12). Caroline is affected by both hydrocephalus and spina bifida.



Michael Siegel, PhD
Executive Director,
Pediatric Dermatology
Research Alliance (PeDRA)

*HA's Scientific Advisory Board
& Research Committee*

Mike Siegel is the Executive Director of the Pediatric Dermatology Research Alliance (PeDRA), a nonprofit research organization pursuing the mission to create, inspire, and sustain research to prevent, treat, and cure childhood skin disease. He holds a Bachelor of Science in Biomedical Engineering from Washington University in St. Louis, Master of Science in Biomedical Engineering from Northwestern University, and Doctor of Philosophy in Bioengineering from the University of Washington.

In 1986, at the age of six, Mike was diagnosed with hydrocephalus and has been living a happy and productive

life ever since. He navigated four shunt revisions before leaving for college and gratefully only one revision since. Mike looks forwards to contributing his experience with nonprofit management, research programs, science, and engineering to the hydrocephalus community.

Originally from Chicago, Mike left for the Pacific Northwest in 2005, and now lives outside of Portland, OR, with his wife, daughter, and an evolving lineup of pets.



Stephanie Vogt, MS
Vice President of Supply Chain
Strategy with Express Scripts at
Cigna

Chair of HA St. Louis WALK since 2008

Stephanie (Buffa) Vogt is currently the Vice President of Supply Chain Strategy with Express Scripts at Cigna. She also has served as the chair of the St. Louis WALK to End Hydrocephalus since 2008. She attended Missouri University of Science & Technology where she obtained a Bachelor of Science in Electrical Engineering and an a Master of Science in Engineering Management.

Stephanie developed hydrocephalus due to aqueductal stenosis. She was shunted at six weeks of age and has had three shunt malfunctions. Stephanie's older sister, Sarah Buffa, has hydrocephalus as well, diagnosed at age 4 also due to aqueductal stenosis. Over the years, Sarah has been faced with an abundance of challenges with her hydrocephalus and is a driving force for Stephanie's continued dedication to advocacy and chairing of the St. Louis WALK each year. She looks forward to continuing this advocacy with her role on the board.

Stephanie and her husband Christopher have three children: Ellie (9), Ryan (7), and Barrett (5). Together, they do a lot of laughing, yelling, running, and playing.

To read about our full HA Board of Directors:
hydroassoc.org/our-leadership-and-staff

HA in the UK



In June 2022, HA's President and CEO, Diana Gray, and COO, Amanda Garzon, traveled to the UK for the first ever Parliamentary Reception focused on hydrocephalus hosted by the Right Honorable Michael Gove MP, House of Commons. They were invited by the UK organization Harry's Hydrocephalus Awareness Trust (HAT) to help launch their 'Get-a-Head' campaign. The campaign aims to promote and educate the early diagnosis of hydrocephalus for children in the UK. Diana gave a speech at the reception promoting the collaboration between HA and Harry's HAT and the importance of hydrocephalus awareness and education.

Harry's HAT was founded in 2018 by Harry's family and friends after they found themselves isolated by his condition and struggling to access the support and information they needed. Harry, now 5 years old, was diagnosed with an arachnoid cyst when his mother, Caroline, was 36-weeks pregnant. Soon after Harry was born, it was confirmed that the cyst had caused hydrocephalus. Harry had his first shunt at 8 weeks old and had four brain surgeries by the age of one.

The parliamentary reception helped to stress the importance of head circumference measurement in infants which, when plotted against a baby's weight and height, can be a key indicator of hydrocephalus and can help with early intervention. Unlike in the US where baby's heads are measured at each well-baby visit, typically in the UK, babies' heads are measured at birth and then at the six/eight week check up. Babies are slipping through the net of early diagnosis. Though a straight correlation to age at diagnosis and prognosis cannot be made for every case, brain damage can happen if children are not diagnosed in time.

Emma Pilling, mother of Charlie, passionately spoke about her child at the reception and the need for head circumference measurement as a method for spotting babies showing signs of the condition at an earlier stage. Emma poignantly explained Charlie's challenges to the assembled audience, challenges which she believes may have been reduced if his condition had been spotted earlier.

Due to the hard work of Harry's HAT, progress is being made and the national press in the UK is covering the awareness of the 'Get-a-Head' campaign. So far the campaign has raised

circa \$33,600 and the Lions Club International recently donated 10,000 NHS-approved head measurement tapes. Advertisements promoting head measurement and the importance of it are also being put in the bounty packs that are sent to women in the UK during their pregnancy.

"It was such an honor to have Diana and Amanda from HA come over to the UK and support us. They endorse our mission and support what we are trying to accomplish. Their collaboration is invaluable."

— Caroline Coates

Harry's HAT is also in collaboration with HA on the next version of the HydroAssist® app. This is a mobile app that allows you to record and store your hydrocephalus treatment history and access it when you need it from your mobile device. HA looks forward to future collaboration with Harry's HAT.

To learn more about
Harry's Hat, visit harrys-hat.org



Left to right, Amanda Garzon, HA COO; Raymond R. Moser, Jr., Esq., HA Board of Directors Vice Chair; Diana Gray, HA President and CEO; Sarah Kell, adult living with hydrocephalus and previous HA intern.



The Coates Family with the Right Honorable Michael Gove MP.

HA in Attendance

HA represents the hydrocephalus patient community at key scientific and professional meetings. Here are meetings we attended in 2022.

American Association of
Neuroscience Nurses (AANN)
Annual Meeting | Phoenix, AZ
March 10-12

American Association of Neurological
Surgeons (AANS) Annual Scientific
Meeting | Philadelphia, PA
April 29 – May 2

National Health Council (NHC) Health
Leadership Conference | Coral Gables, FL
May 3-5

House of Commons, Houses of Parliament
Reception | London, UK
June 15

EMBO Neural Stem Cells: From
Basic Understanding to Translational
Applications | Kyllini, Greece
June 5-9

National Institute of Neurological
Disorders and Stroke (NINDS) Nonprofit
Forum 2022 | Virtual
July 19-20

National Health Council: Multi-Stakeholder
Dialogue on Achieving Patient-Centered
Core Impact Sets (PC-CIS) | Virtual
August 17

The 29th International Conference on Spina
Bifida and Hydrocephalus (hosted by the
International Federation for Spina Bifida
and Hydrocephalus) | Virtual
September 5-9

National Health Research Forum: Straight
Talk: Then, Now, Imagine (hosted by
Research!America) | Virtual
September 19-20

Hydrocephalus Society Annual
Meeting | Gothenburg, Sweden
September 9-12

Restoring Neurological Function (The
Crossroads of Neurology, Psychiatry and
Neurosurgery) | Warrensville Heights, OH
September 23

Heath Research Alliance: Fall 2022 Members
Meeting | New York City, NY
October 6-7

Hydrocephalus Clinical Research Network
(HCRN) Meeting | Virtual
October 6-7

Adult Hydrocephalus Clinical Research
Network (AHCN) Meeting
Salt Lake City
November 10

National Health Council
Washington Retreat | Annapolis, MD
November 17-18

AANS/CNS Section on Pediatric Neurological
Surgery | Washington, DC
December 1-4

National Health Council Annual
Meeting | Washington DC
December 6

Life-changing Impact at HA CONNECT Hydrocephalus Conference

How do you put a life-changing experience into words? The 17th National Conference on Hydrocephalus, HA CONNECT, is now in the rearview mirror for everyone in attendance from across the country and internationally, but the memories and the connections will leave a lasting impact.

HA CONNECT was the first in-person conference for HA in 4 years and the response was exceptional. There were 537 people in attendance and 75 speakers, with 43 of them being new to the conference. The conference offered 80 different sessions, including 30 that were new.

To meet the different needs of our attendees, sessions were categorized into eight different tracks. These tracks could be followed throughout the conference based on a person's relation to hydrocephalus, including individuals living with hydrocephalus, parents, siblings, caregivers, and other loved ones. A wide variety of topics were discussed, ranging from new research studies, treatment innovations, and improving

clinical care to living and thriving with hydrocephalus and related conditions.

"Personally, I got a lot of good information that I can use for myself and peers. I was able to do a tremendous amount of networking and the feedback I received from patients, families, and providers was positive. I also loved interacting with the younger patients, and it helped me gain perspective."

— Gary Chaffee

Two keynote presentations were the center point of Friday and Saturday's schedule.

On Friday, Dr. John (Jay) Wellons, III, Chief of Pediatric Neurosurgery at Monroe Carell Jr. Children's Hospital at Vanderbilt, gave an engaging and inspiring presentation sharing the lessons he has learned from patients and their families over his career, as well as reading a passage from



his new book, *All that Moves Us: Life Lessons from a Pediatric Neurosurgeon*. After his presentation, he held a book signing.

On Saturday, Dr. Michael R. Barratt, a NASA astronaut and research scientist, delivered an informative and moving keynote about how NASA's space medicine programs, Translational Research Institute for Space Health (TRISH), are contributing to hydrocephalus research and expanding our understanding of the condition.

"This was one of the best conferences that I have attended due to the patient connection and interaction. More patients, scientists, and physicians should attend."

— Dr. Brandon A. Miller,
Assistant Professor at the University of Texas

HA CONNECT was a chance for patient/peer groups to connect by age or life-stage. Patients and families had the opportunity to interact with neurosurgeons, neurologists, device companies and scientists first-hand to learn more about the latest work and gain nuanced insight on hydrocephalus. They were able to connect to others who face similar challenges, and physicians and scientists received insight on the patient's perspective on what it's like living with the condition.



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Hydrocephalus Awareness Month (HAM) 2022

HAM 2022 in September was amazing and we are so thankful to our community for helping to turn the country hydrocephalus blue! HAM is our chance to bring national attention to the more than one million Americans living with hydrocephalus and the challenges felt by all in managing this condition. We challenged our community to spread awareness on social media by getting loud and helping to turn the country hydrocephalus blue.

We are thankful to our many organizational partners across the country that got involved and helped spread awareness.

We are especially grateful for our partners at COMMIT Dance Fitness who created a fun and easy hydrocephalus dance for our community to perform and share on social media. They were motivated to get involved by a member of the COMMIT team who has a relative living with hydrocephalus. There were further moved when they learned that hydrocephalus can happen to anyone at any time. COMMIT Fitness studios across 10 states helped raise awareness and funds to support the mission of HA. Dance teams also joined some of our WALKS to End Hydrocephalus.



Here are a few more outstanding examples of how our community responded to the HAM challenge!



HAM on Capitol Hill

Representatives Chris Smith and Lloyd Doggett, co-chairs of the Congressional Hydrocephalus Caucus, made a statement in support of HAM and reaffirmed the commitment of the Caucus

to continue to make hydrocephalus programs and research a priority.



Zander Buchanan

Zander Buchanan (6) has had his shunt for 5 years and two brain surgeries to manage it. He wanted to turn his front porch HydroBlue so he could make sure to do his part in spreading awareness. Zander thinks

his shunt is the coolest thing ever and tells everyone when they meet him, "Hi, I'm Zander and I have a shunt!" Thanks for being an awareness hero Zander!

Welcome HA's New National Directors



Dr. Monica Chau *National Director of Research*

The Hydrocephalus Association welcomed Dr. Monica Chau in April 2022 as the new National Director of Research. Dr. Chau received her PhD in Neuroscience from Emory University and is a neuroscientist with more than 17 years of experience in basic science, translational, and clinical research.

Dr. Chau's scientific expertise is in the use of cell therapies for neurodegenerative conditions such as ischemic stroke, peripheral nerve injury, and Parkinson's disease. Prior to joining HA, she served as a Research Assistant Professor in the Department of Neurosurgery at the University of Kentucky where she conducted clinical research on a reparative cell therapy for Parkinson's disease. Her published research findings include the regenerative abilities of several types of cells including induced pluripotent stem (iPS) cells and bone marrow stem cells for ischemic stroke.

Among her honorifics, she was awarded a fellowship for her predoctoral work from the American Heart Association, a fellowship for her postdoctoral work from the American Cancer Society, and funding for her clinical research. She has published numerous articles on regenerative treatments, neurodegeneration, and has received more than 13 scientific and presentation awards throughout her career.



Judy Froehlich *National Director of Marketing and Communications*

The Hydrocephalus Association welcomed Judy Froehlich in May 2022 as the new National Director of Marketing and Communications. She earned her Marketing B.S. and her MBA from the University of Central Florida. (Go Knights!) She brings more than 25 years of marketing and communications experience to this position, both in the public and the private sector.

Her latest role was the Director of Marketing and Communications for the College of Sciences at the University of Central Florida (UCF). Her areas of expertise include strategic planning, marketing campaign design, messaging and branding, communication planning, project management, and website content management.

A passion for nonprofit work and a commitment to making a difference in the lives of others brings her to this role. Her commitment to raising awareness around hydrocephalus is tied to her father, who was in the early stages of diagnosis of NPH when he passed away. In this role, she hopes to help increase the awareness of HA and engage the community.

2022 Travel Award Recipients

Ten trainees were selected for a travel award to attend the National Conference, HA CONNECT.

These ten early investigators received a travel award based on their study's significance to the hydrocephalus field. They presented their findings on stage on topics including: improving on shunt devices, immune response to shunts, neural development and neural stem cells, and basic mechanism of the causes of hydrocephalus. They were also able to connect with conference attendees during the poster session. Congratulations to our 2022 Travel Award recipients!

Tyrone DeSpenza

David Mazur-Hart, MD

Angel Enriquez

Kedous Mekbib

Julianna Herman

Ajay Rajaram, PhD

Jeff Horbatiuk

Margaret Tish

Pengfei Liang, PhD

Tyler Vasas

Hydrocephalus Association and Rudi Schulte Research Institute Workshop

Honoring the legacy of Dr. Michael Pollay

In October 2022, HA welcomed 53 neuropsychologists, scientists, engineers, neurologists, neurosurgeons and patients to the Hydrocephalus Association (HA) and Rudi Schulte Research Institute (RSRI) 2022 Research Workshop in Houston, TX. The focus of the workshop was *Improving Cognitive and Psychological Outcomes in Hydrocephalus*. The workshop delved into the underlying neuropathology of the cognitive and psychological challenges individuals with hydrocephalus face across the age spectrum.

HA was delighted to be able to host this important meeting through the generous support of RSRI. The workshop was dedicated to the legacy of Dr. Michael Pollay, friend of Rudi Schulte and long-time RSRI board member until he passed away in February 2021. At the beginning of the workshop,

attendees heard more about Dr. Pollay's legacy through his dedication to patients, growing the field of neurosurgery through mentorship of medical students and residents, and his passion for making the world a better place through neuroscience. With nearly 100 publications, Dr. Pollay was an internationally recognized scientist and was funded multiple times by the National Institutes of Health and the Department of Veterans Affairs.

"Michael would have been so touched by this recognition and pleased by this valuable sharing of information between many great minds. It makes me hopeful for the future of hydrocephalus research," said Peggy Pollay.

One of the ongoing frustrations for so many of those living with hydrocephalus, their caregivers, and healthcare

continued on next page



providers is the hardship of the cognitive and psychological manifestations that too often negatively impact mental and physical health, relationships, education, and employment.

Last year, HA wrapped up a comprehensive, patient-centered study to determine the top 20 research priorities for our community. While it was expected that better treatments, fewer surgeries, and prevention would top the list, it was profoundly evident that patients care deeply about the complications of living with hydrocephalus that are caused by cognitive challenges with memory, attention, and executive function, as well as the mental health challenges that often go hand in hand with hydrocephalus and its related symptomatology. The hydrocephalus community is craving recognition and better solutions to these often disabling psychological impacts on their lives.

During the first day of the conference, attendees listened to sessions on basic and translational science, and cognitive and psychological phenotypes. They were also treated to a performance of spoken word by Dani Lucchese, a member of our hydrocephalus community reading her poem about life with hydrocephalus. On the second day of the conference, attendees listened to sessions on transitions, treatment and quality of life, and moving the field forward. Robin Ennis then shared her performance of spoken word followed by a Patient Perspective Panel that included Robin Ennis, Dani Lucchese, Amanda Garzon and Gary Chaffee.

HA would like to thank all of the workshop's speakers and attendees.



Community Research Priorities



We listened closely to the needs of our community over the last two years by conducting a study that included patients, family members, scientists, and physicians. We heard back from almost 900 respondents and the result is our Top 20 Community Research Priorities.

These priorities have been condensed into five areas of focus where HA is best poised for highest impact. These will be the guiding beacons for HA's actions in advocacy, education, fundraising, and awareness.



For more information on our actions
to address these priorities, visit
hydroassoc.org/research-priorities

Publication accepted into the Journal of Neurosurgery, in press:
Establishing Ranked Priorities for Future Hydrocephalus Research
by Noriana Jakopin, Elliot Myong, Trish Bogucki, Diana Gray, et al.

2022 Ralph Kistler Research Internship Recipient



The Hydrocephalus Association (HA) selected Kevin Miller as the recipient of the 2022 Ralph Kistler Research Internship. The internship is designed for undergraduate college students who are interested in the sciences, public health, and non-profit operations. The internship took place June through August 2022.

Ralph Kistler was a longtime friend of the Hydrocephalus Association and HA Board Member. The Ralph Kistler Research Internship commemorates Ralph's spirit and the impact he had on the hydrocephalus community.

After completing the internship, this is Kevin's perspective:

With strong aspirations to become a neurosurgeon myself, my neurosurgeon (Dr. Kristopher Kahle) introduced me to the Hydrocephalus Association. I applied for the Ralph Kistler Research Internship and was honored to be selected. My first internship task was to read all the literature I could. It was disheartening to learn that anyone, regardless of age, can develop hydrocephalus due to the various etiologies.

Combining my keen interests in health economics and data analysis, I analyzed the baseline data of the patient registry HAPPIER, with a particular emphasis on the access to care section. Thanks to the Ralph Kistler Research Internship, I am now the lead author of a scientific paper that has been submitted to the Journal of Neurosurgery!

What makes this internship so spectacular is that in addition to a research paper, I was fortunate enough to attend HA Connect in Austin, Texas, where I had exposure to researchers, physicians, advocates, and patients. My time with the Hydrocephalus Association was so memorable and inspiring that I am currently pursuing a Fulbright Scholarship to conduct hydrocephalus research on access to healthcare in Canada. This opportunity would not have been possible without the connections I made through this internship. I am extremely grateful for the Hydrocephalus Association and hope to work again with this fantastic organization.



Don't Be Left Out! Join HAPPIER

The Hydrocephalus Patient Registry

How many brain surgeries do most people with hydrocephalus have? How does hydrocephalus impact you at different stages of your life? There is so much we don't know about living with hydrocephalus. Help us solve the mystery by being part of HAPPIER – our Hydrocephalus Patient-Powered Registry – so you can share your experience of living, or caring for someone, with hydrocephalus.

By joining our patient database, you're helping scientists understand the complexities of living with this condition and where to focus their research. Our database will allow us to track long-term outcomes in a way traditional research can't. It's time to see the bigger picture!

JOIN NOW!
hydroassoc.org/happier

Secure Your Future and Leave a Legacy



The Fudge Solomon LEGACY SOCIETY

when their sons were diagnosed with hydrocephalus. This legacy fund commemorates their lasting contribution to the Hydrocephalus Association.

The Society singularly supports the Hydrocephalus Association's mission to eliminate the challenges of hydrocephalus and help ensure the growth and security of the organization's programs. Donations to this fund represent an opportunity for supporters to ensure the organization's research, support, advocacy and education work continues by placing a gift to HA in their wills, trusts or estate plans.

The Fudge Solomon Legacy Society is named for the two founders of the Hydrocephalus Association – Emily Fudge and Cynthia Solomon. Emily and Cynthia met in 1983,

Those who leave HA in their plans will automatically become a member of the Society, are recognized, if they would like to be, and receive special communications and invitations to exclusive HA offerings, such as our annual Leadership Briefing from HA's President and CEO, Diana Gray.



Left to right, Cynthia Solomon and Emily Fudge, the two founders of the Hydrocephalus Association.



Now you can create an Estate Plan online for free!

HA has partnered with FreeWill, to make your planned giving and estate planning needs easier. This free online service helps you to create a plan to secure what you value most and start your legacy today. This is a service HA is making available to our constituents, whether you include us in your plans or not.

To get started, visit hydroassoc.org/leave-a-legacy and click *Create your free plan* and start your legacy today!

Some have already thoughtfully included HA in their plans. If this is the case for you, please do let us know and we will immediately add you to the Fudge Solomon Legacy Society.

Questions? Contact Linda Riley, National Director of Development

linda@hydroassoc.org; (240) 483-4475

SUPPORT AND EDUCATION

Announcing Our 2022 Hydrocephalus Association Scholarship Recipients!

The Hydrocephalus Association (HA) is pleased to announce the 2022 Hydrocephalus Association Scholarship Award Recipients. We would like to thank everyone who applied for a scholarship and congratulate those of you who were selected this year. HA's scholarship program was established in 1994 to provide financial assistance to capable and promising teens, young adults, and adults who live with the ongoing challenges and complexities of hydrocephalus.

Since the scholarship program was established, HA has awarded 241 scholarships to future leaders of our community. We are proud to honor these remarkable young adults. In addition to successfully managing their hydrocephalus, these students continue to excel in the classroom, volunteer, and give back to help their local communities. They are an inspiration to us all, demonstrating that hydrocephalus does not stand in the way of pursuing one's goals.

These thirteen scholarships are funded by:

- Gerard Swartz Fudge Memorial Scholarship Fund, which is supported in part by Molly Mastrangelo
- Baldus Family Scholarship in Memory of Gerard Swartz Fudge
- Morris L. and Rebecca Ziskind Memorial Scholarship Fund
- Anthony Abbene Scholarship Fund
- Justin Scot Alston Memorial Scholarship Fund
- Mario J. Tocco Hydrocephalus Foundation Scholarship Fund
- Kate Finlayson Memorial Scholarship
- Jacobsen Family Scholarship
- Hydrocephalus Association Scholarship, which is provided by Erik and Lisa Chamberlain.

Our gratitude is extended to all the donors for their generosity and the Scholarship Committee for all their support and dedication.

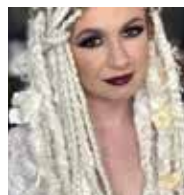


Leyra Espino-Nardi
Recipient of the Jacobsen Family
Scholarship

Leyra was diagnosed with hydrocephalus before she was born. She has had seven total surgeries, including two plastic surgeries to correct bone deformities in her skull due to craniosynostosis. She had a stroke at the age of nine and required several years of occupational and physical therapies.

Leyra's biggest frustration is the misinformation that exists about hydrocephalus and how people live with the condition. She has made it her mission to educate people about hydrocephalus and has created a website to assist with this. Leyra is currently a freshman at Johns Hopkins University, pursuing a bachelor's degree in East Asian Studies. Her career goal is to become a member of the US Foreign Service (i.e. a diplomat).

"Every part of my life has been affected by my hydrocephalus. It is an intrinsic part of my identity and should be celebrated. It has always been who I am. I am proud to tell people that I have hydrocephalus and to educate them on what life with hydrocephalus is like," Leyra said.



Anna Etheridge
Recipient of the Morris L. and Rebecca
Ziskind Memorial Scholarship Fund

A freshman at Paris Junior College, Anna hopes to transfer to Texas A&M to complete her degree in early childhood education. She was diagnosed with hydrocephalus in infancy and living with the condition has helped her to appreciate every small thing in life.

Through the years, she worked through her many challenges due to having hydrocephalus, and that fueled her to try even harder to rise above and excel. Her career goals include becoming a kindergarten teacher and eventually a music therapist, particularly for those suffering from hydrocephalus.

"As a teacher, I would like to talk more about hydrocephalus with teachers and students so they can better understand the condition and how they can help students that may have it. I want to inspire others to overcome their mental and physical challenges and that their disability does not define them," Anna said.



Xavier Grayson

Recipient of the Justin Scot Alston Memorial Scholarship Fund

Growing up wasn't easy for Xavier, who was diagnosed with hydrocephalus in infancy. He missed a lot of school and had to constantly play catch up with his studies. He struggled with teachers and people not taking him seriously, brushing off his headaches and challenges to overcome this perception. Working hard to get through these challenges made him determined to help other people avoid the hardships that he has had to overcome in his life.

Now Xavier is working toward finding success in the business world by pursuing a bachelor's degree in finance at Indiana University South Bend. Though filmmaking is his first passion, he would love to eventually use his success in business to find a way to work with and fund film projects.

"I hope to gain as much knowledge that I can while in school in order to set myself up for success. Having grown up with challenges has helped me to work harder and I am determined to be successful in whatever I am participating in," Xavier said.



Brenna (Bren) Hawk

Recipient of the Anthony Abbene Scholarship Fund

In her early childhood, Bren experienced a lot of frustration and was non-verbal in preschool and kindergarten. She had gross motor skill delays and avoided playing games with other children. In middle school, her shunt failed and the subsequent brain surgery caused all her hair to fall out. She was not prepared for the emotional and social toll it would take on her. Animation became her outlet and the way that she has expressed herself to connect with other teens. She is a storytime animator and has had her art published by Politico.



Drink Cider While Supporting HA's Efforts to Find a Cure

Do you love hard cider? Want to support hydrocephalus research, support and education?

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Fort Worth, TX | Boulder, CO | Fort Collins, CO | Lakewood, CO

Bren plans to attend Western Colorado University. She wants to be an elementary education teacher to help children with learning disabilities and special needs, including hydrocephalus.

"I would like to support young children that need extra assistance so that they can become the next generation of doctors, scientists, teachers, engineers, etc. I especially want to encourage children with hydrocephalus to be empowered and not become discouraged by their challenges," Bren said.



Vincent Lambraia
Recipient of the Hydrocephalus
Association Scholarship Fund

Special thanks to Lisa and Erik Chamberlain of Rockton, Illinois, for providing support of this scholarship.

Born prematurely, doctors told Vincent's parents that he likely would never have the ability to walk or talk. As a baby, he suffered a series of strokes that caused cerebral palsy and hydrocephalus. These conditions made it difficult for him to process information, however he always found a way to accomplish his goals.

Unable to play the sports that he loves, he found another way to enjoy them through actively following them and writing articles about them. He will pursue a bachelor's degree in English, focusing on communications or journalism. He hopes to find a career where he can write about sports as well as about hydrocephalus to raise awareness.

"I know I can help anyone who is experiencing any type of challenge in life. I hope my story and my desire to press on inspires others like me to approach problems without anxiety, in the knowledge that they can do more than they ever thought they could," Vincent said.



Allison Lawrence
Recipient of the Morris L. and Rebecca
Ziskind Memorial Scholarship Fund

After Allison and her twin brother were born prematurely at 26 weeks gestation, she was diagnosed with hydrocephalus and eventually complex epilepsy. Through her many surgeries and procedures as a young child, she always remained

resilient. She played soccer, ran track, and worked multiple part-time jobs.

She did not share her condition with many people until later in her teenage years when she was able to help a four-year-old boy that had recently had a shunt placed. This helped her understand the path that was chosen for her and how she could help others.

She is currently a sophomore at Liberty University, pursuing a bachelor's degree in strategic communication. She hopes to pursue a master's degree in library science. She currently works in the public library system and plans to continue her career there after graduation.

"My goal is to continue my career in the library and focus on working with children. I love working with children and I want to bring more awareness about hydrocephalus to children at a young age. I am currently working on a display at the library that will educate the public about hydrocephalus," Allison said.



Piper Maring
Recipient of the Gerard Swartz Fudge
Memorial Scholarship Fund

Being diagnosed in infancy, having hydrocephalus is all that Piper has known.

She was drawn to swimming at an early age and has been swimming all of her life, competing with her high school swim team. Thankfully her hydrocephalus has not had any impact on her participation in the sport she loves.

Outside of the pool, she has always loved designing and creating, which has led to her interest in pursuing a career in architecture and design. Her goal is to create structures that are eco-friendly and inviting to its inhabitants. As she has grown older, she understands the importance of design in office buildings and specifically hospitals. She relates to how the hospitals that she went to as a child made her feel happier and more at ease.

"Architects and designers use colors, windows, and open space in buildings to make people feel happier and more at ease in spaces that are usually sad or stressful. As a future architect, I want to develop eco-friendly, sustainable buildings that do just this," Piper said.



Sarah Myers
Recipient of the Baldus Family
Scholarship in Memory of Gerard
Swartz Fudge

After Sarah was born, her parents were told that she would never talk or walk after developing hydrocephalus due to a traumatic brain injury at birth. She started physical therapy and speech therapy at three months of age. Against all odds, she started walking at the age of two and speaking at three years old.

She worked extremely hard in school and, with tremendous effort, she continues to be academically successful. She also struggled with social interactions as a child, especially in school. She realized how differently people saw her because she talked slower and seemed different to them, despite feeling the same. She soon realized that her uniqueness was an asset, not a burden, and that differences in people make the world a better place. She is an activist and supporter of the underprivileged and she plans to continue this path by pursuing a degree in psychology at Colorado State University.

"I have a goal to be a counselor to children with disabilities and expand the education of hydrocephalus and other medical conditions. I hope to one day work in an environment where I can help people live out their own dreams and rise to their full potential," Sarah said.



Adrienne Prevost
Recipient of the Anthony Abbene
Scholarship Fund

The self-proclaimed smallest girl in her class with the biggest heart, Adrienne loves working with children and helping others. Hydrocephalus has presented blessings and challenges in her life. She was born three months premature and weighed two pounds. She has always found a way to overcome her challenges, through hard work, modern medicine, and the grace of God.

She has a passion for working with children and plans to pursue a degree in elementary education from Shorter University in Rome, GA. Adrienne would like to become a kindergarten teacher and plans to share her life story of

hard work and dedication to inspire others to accept and appreciate who they are and to realize we all have huge potential and purpose in life.

"Physically, it is easy to see that I am unique. But when people get to know me, they see past the short girl with tiny hands and feet and see my kind heart. I want to teach kids that it is okay to be different and to realize that we are all unique and we all have talent and potential to be our very best," Adrienne said.



Elizabeth Quijada
Recipient of the Gerard Swartz Fudge
Memorial Scholarship Fund

Special thanks to Molly Mastrangelo for contributing to this scholarship fund.

Elizabeth's life has been filled with barriers, medical issues, and great loss. Her father unexpectedly passed away from a brain hemorrhage when she was in high school, causing her to lose her way for a while until one day someone told her they believed in her. She once again started to believe in herself.

She was diagnosed with congenital hydrocephalus as a young adult and her experiences with the condition have solidified her passion for medicine. Hydrocephalus has made her life journey more difficult, but she uses her experiences to help others. She will be pursuing her doctorate degree at Arizona State and, although she may not want to become a neurosurgeon, she is looking forward to making an impact as a primary care physician for those struggling with hydrocephalus.

"My condition has made the journey to becoming a physician more difficult, but not impossible. In fact, there has been a lot of good that has come from it. I have bonded with others that share my diagnosis and each day I am able to educate yet another person on hydrocephalus and what it means," Elizabeth said.



Cassidy Smith
Recipient of the Gerard Swartz Fudge
Memorial Scholarship Fund

Cassidy was diagnosed with hydrocephalus in utero and was born a month early.

Through her childhood, her condition made her incredibly timid, believing that any injury she might incur would be detrimental. This led to difficulties engaging with her peers in her early childhood years. Continuously overcoming challenges in elementary and middle school, she was in advanced classes and proving all of her doctors wrong.

People did not understand her “invisible” illness and she did not feel comfortable sharing it with anyone for fear of negative reactions. Through these experiences, she discovered her love for psychology. She is currently a high school senior and her next step is to pursue her degree in psychology. She hopes to use her experiences and knowledge of hydrocephalus to better treat her patients.

“Information is key in supporting those with hydrocephalus. I aim to help others by being a role model and providing advice and support. By setting an example and discussing my experiences, I can help others deal with whatever challenges may be facing them,” Cassidy said.

The below scholarships were awarded to anonymous recipients:

Kate Finlayson Memorial Scholarship

Mario J. Tocco Hydrocephalus Foundation
Scholarship Fund

DOWNLOAD THE HYDROASSIST® APP FOR FREE!

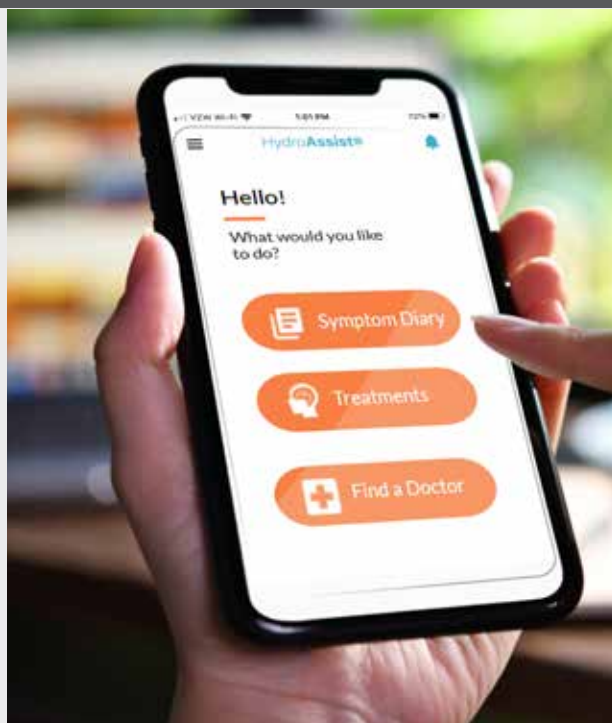


HydroAssist®

- ✓ **Symptom diary**
- ✓ **Headache tracker**
- ✓ **Physician finder based on location**

HydroAssist® is a mobile app that allows you to record and store your hydrocephalus treatment history and access it when you need it from your mobile device. Perfect for individuals living with hydrocephalus and their caregivers.

New features based on feedback from YOU!



Connect with Others Through Your Local HA Community Network

You are not alone! The Hydrocephalus Association has over 40 Community Networks across the country. Community Networks are a great way to connect with individuals and families in your local area who are impacted by hydrocephalus. Visit HA's website to find and join your local Community Network's online private Facebook group and to stay updated on local events. Don't see one in your area? Start one! **Contact info@hydroassoc.org or call (888) 598-3789 for details!**

AK Anchorage	New York City
AL Birmingham	OH Cleveland
AR Northwest	OK Oklahoma City
AZ Phoenix	OR Portland
CA Los Angeles Ventura	PA Eastern PA Central PA
CO Denver	RI Providence <i>online only</i>
CT Hartford	SC Charleston
DC Washington	SD Sioux Falls
DE Middletown	TN Chattanooga
FL Miami South Florida (St. Port Lucie)	TX Austin Dallas <i>NPH</i> Houston <i>peds/adolescent</i>
GA Atlanta	UT Salt Lake City
ID Boise	VA Richmond
IL Chicago	WA Seattle <i>pediatric</i> Eastern WA Vancouver
IN Indianapolis	WI La Crosse <i>online only</i>
MA Boston	Military Members <i>online only</i>
MD Baltimore	Nigeria Lagos <i>children/families</i>
ME Portland	Spanish-Language Network (Red de Apoyo Para la Hidrocefalia) <i>online only</i>
MI Detroit	Young Adults 20s Group <i>national - online only</i>
MN Minneapolis <i>peds/adolescent</i>	Flourishing in Mid-Life Women's Group (Age 40-59) <i>national - online only</i>
MO St. Louis	
NC Charlotte	
ND Fargo & Morehead, MN	
NE Omaha	
NJ Jersey Shore and Central North New Jersey <i>NPH</i>	
NY Western NY Long Island	

Visit hydroassoc.org/communitynetworks
to find a Community Network near you!



FIND A DOCTOR OR
SPECIALIST WITH OUR

PHYSICIANS DIRECTORY!

The Hydrocephalus Association's Physicians Directory is an interactive online tool that helps you find the specialists you need to manage your hydrocephalus. The directory includes neurosurgeons, neurologists, and neuropsychologists for all ages.

Search by location, specialty
and age range!



Visit hydroassoc.org/findadoctor

Camp Head Strong is Back!

Camp Head Strong is a fun, supportive, and empowering environment for children and teens living with hydrocephalus



Camp Head Strong is back for Summer 2023! Camp Head Strong is one of the residential camps for children with chronic health conditions hosted by Children's National Medical Center. The hydrocephalus-focused camp was developed by Brainy Camps in conjunction with

the Hydrocephalus Association. The camp offers children and teens with hydrocephalus (ages 10-17) five days and four nights of summer fun, education, and social connections. The camp is staffed by an interdisciplinary team of medical experts, professionals, college students, and graduate students to support the campers medical and emotional needs.

Campers can choose from a variety of activities including yoga, basketball, magic, crafts, soccer, and more! Campers will also have the chance to talk about their worries, fears, and reflections in support groups. Educational sessions led by medical experts will be offered to teach campers about their conditions. Every day will end with a camp-wide activity like a talent show, campfire, or dance party!

Now more than ever, kids need to feel part of this #HydroStrong community. A one-week session of Camp Head Strong costs approximately \$825. Brainy Camps offers scholarships for families who cannot cover the registration cost.

"This will be my sixth summer as a Brainy Camps and Head Strong counselor. I still have a vivid memory of my first day when we played a camper-counselor kickball game to kick off the week. It was a typical sleepaway camp atmosphere, but what I remember most is three campers out in left-field bonding over brain surgeries and headaches. That's when I realized Camp Head Strong was a special place. It is a place where kids can talk openly about hydrocephalus. It is a place where no one is afraid to show off their scars. A place where everyone 'just gets it.'"

— Jacob Walters



VISIT

brainycamps.com/camps/hydrocephalus.html

DONATE

to help a child attend Camp Head Strong.
brainy.campintouch.com/ui/forms/donor/Form



Stories from Our Community

We invite the hydrocephalus community to share their hydrocephalus journey with us so we can highlight stories of resilience! Stories are posted on HA's website, featured in our print and electronic newsletters, and shared on our social media channels.



Katiana Partis

It was my sophomore year and I was in gym class. We were playing soccer and I stood by the goalie. My arms were crossed and my weight shifted onto the right side of my body with my left leg extended. At one point, the ball made its way towards my side of the gym. I quickly decided to go after the ball. My eyes were focused on the ball and, as I approached the ball, my teammate and I bumped heads. My head swung back, my eyes closed, and I fell to the ground. I was in pain and discomfort for months thereafter.

Heavy-headed, I laid in my bed. Short shooting pains scurried to my right temple. This pain was stronger than ever. The increasing pressure on my forehead made it harder to keep my eyes open. My eyes were weighed down by a force that felt like the first streams of cool water trickling onto my head on a hot summer day. I don't remember falling asleep, but I woke up later than usual that next morning. Walking unsteadily, I used the walls as support to keep myself from falling. I made my way to the kitchen and told my mother about my symptoms. She immediately took me to see my pediatrician. After a quick examination, he sent me straight to the emergency room.

At the hospital, after hours of trying to walk in a straight line and concentrating on a gold push-pin on the wall while a bright light was shining in my eyes, I was told that I had a concussion. I was also diagnosed with a neurological condition called hydrocephalus. The neurologist explained that the ventricles in my brain were swollen, accumulating with excess spinal fluid. This extra fluid and the impact from the fall on my head in gym class had been causing my blackouts and severe headaches. She explained that a spinal tap might relieve the pressure and I should be fine.

For months afterwards my headaches got worse. My doctors told me that I needed surgery because the monthly spinal

taps were not helping anymore. The doctors told me that if my headaches came back again, then surgery was my last and only option. I couldn't understand why this happened to me. Two weeks later, on March 7, 2005, I went in for surgery. The doctors explained to my parents and me that they were going to place a permanent shunt system to regulate the pressure in my brain. The valve would be placed on the back of my head and connected to a thin flexible tube that would be placed under my skin and run down the back of my neck, over my shoulder, down my chest, and into my abdominal cavity. My body would then reabsorb the fluid. The healing process after getting my shunt surgery was long and difficult, but I eventually felt normal again. I was getting my life back.

On August 26, 2005, the pain was stronger than it ever was before. I was walking home from the hair salon and I felt like I was beaten with a cast iron pot on the back of my head. I dragged myself home with my eyes blurry and the world in front of me looked as if it was all a very large steel gray pendulum, swaying from side to side. I felt removed from the world and I thought that my life was over. On the ride to the hospital, all I could think about was my foolish decision to go after that ball in gym class. After a series of tests, x-rays, and CT-scans, I was told that the shunt was malfunctioning.

The day before surgery, the pain was unbearable. My mother was in the corner by the window with her head down praying and crying. I hated what my illness had done to my family. I remember saying "mommy" and she rushed to my side. I asked her to put her hand on my head and push down on it to perhaps relieve some of the pressure. My body tensed up, I don't remember hearing a sound and my eyes were shut tightly.

I don't know how much time had passed, but I slowly started to hear sound flowing through my ears like a crescendo. My mother was screaming in the distance and the nurses and doctors sounded frantic. I felt like the doctor was punching me in my chest. (Later, I found out that at that moment, I was being resuscitated.) I was screaming with pain, but realized

that my eyes were closed, my teeth were clenched, and I couldn't move my body. I felt like I was trapped inside of myself and not a part of the world.

After a while, I was still unresponsive and I prayed. I hadn't prayed the entire time that I was sick. I figured that praying was worthless because I used to pray all the time and then, I got sick. But in that moment, I promised God that if he let me move my body and open my eyes, I was going to live a purposeful life.

During my involuntary meditation session, I heard the doctor say, "Katiana, if you can hear me squeeze my finger." He kept repeating himself and I ended my prayer by saying, "God, if I was meant to be here and if I have a true purpose in this world, then please help me move my finger". I held his finger as tight as I could between my fingers and palm. I held on tightly so he could tell my parents that I am strong and so that I could know that I was okay.

I was rushed to emergency surgery. I woke up hearing the nurses laughing and talking. I felt little or close to no pain. They took me back to my room and I felt alive. My family was waiting in my room to see me and it became a celebration of life. I felt genuinely happy; a happiness that I had become unfamiliar with during and before this traumatic event in my life.

Ten years and another shunt malfunction later, I'm very happy that I decided to go after that ball in gym class. Since my diagnosis, we have learned that I was actually born with this condition. The fall triggered the onset of the symptoms.

This illness has affected a lot of my paternal family members who are over fifty years old. My family is Haitian and according to our neurosurgeon, hydrocephalus is common in Haiti. My family members would start slurring their speech, their hands became weak and they eventually would lose use of their legs. They usually died from it, but no one ever knew the cause until it happened to me. My dad was recently diagnosed and now has a shunt and is walking and speaking a lot better. Now my older cousins are getting treatment and everyone in the family is aware of the illness and we are collectively persevering.

When I was a child, I thought that we are born and we meander through life lackadaisically until we die. I never

understood the true purpose of living until the moment I thought that my life was over. I went after that ball in gym class and fell so that I could learn that I am here not to just exist; I am here to live and to shine my light on the world. When some days and circumstances are dark for me, I cannot give up. I have to appreciate and learn from everything that I experience because it continues me on my path to serve my purpose here on Earth.

TELL US ABOUT YOUR JOURNEY WITH HYDROCEPHALUS!

Hydrocephalus affects each of us differently. Share your story of hope and perseverance with us!

We will feature the amazing individuals in our community who are living life to the fullest, regardless of the challenges their condition brings, on our website and social media!



scan or visit
hydroassoc.org/shareyourstory
to submit your story!

WALKS AND SPECIAL EVENTS



WALK TO END HYDROCEPHALUS™



We have had an amazing 2022 WALK season so far!

To date, we have had a total of 809 teams and 6,756 participants. Every WALK we get closer to our goal of \$1.8M!

Thank you to all that have participated and helped raise critical funding for hydrocephalus research and to support the mission of HA. If you do not have a WALK near you, contact us and help start one in your area for 2023.

Please contact Marina Thompson at marina@hydroassoc.org to start a WALK in your area

Life is Better with Friends

That is true in the advocacy world, as well. HA is grateful to be part of coalitions that are leading the charge on issues important to our community. Below are some of the letters we have signed on to:



Partnership to Improve Patient Care (PIPC) is urging Congress to take steps to ensure that the US Department of Health and Human Services (HHS) provides strong safeguards for patients and people with disabilities, including people from historically underserved and marginalized groups, in any process implementing new health reform legislation that may be enacted under reconciliation rules this year.



American Brain Coalition's Innovation Initiative (ABC12) aims to stimulate investment in brain-related research and strengthen the entire research and development system for expedited translation of neuroscience research into life-changing therapies and cures. H.R. 7279, the Mental Health Research Accelerator Act, would help meet this goal by authorizing \$10 billion in tax credits for mental health and neurological research. You can support this initiative by joining us in urging your member of Congress to help spur investment in mental health and neurological research by supporting H.R. 7279, the Mental Health Research Accelerator Act.



American Academy of Neurology (AAN) circulated a letter in support of the Conrad State 30 and Physician Access Reauthorization Act. This Act, which has bipartisan support, would reauthorize this crucial program for three years. This program has successfully addressed the severe shortage of physicians across practices and specialties, especially in rural areas, by providing an opportunity for international medical graduate (IMG) physicians who complete their residency in the United States to immediately provide necessary care in underserved locations for a state-defined period of time.

Co-sponsor the CONNECT for Health Act

The challenges of providing treatment during the COVID-19 pandemic has resulted in an increase in the availability of telehealth services. As a result, there is great interest among lawmakers in both parties in extending many of the pandemic telehealth flexibilities.

Just before Congress adjourned for the August recess, the House, in an overwhelmingly bipartisan vote, passed legislation (H.R. 4040) to extend current Medicare telehealth waivers through December 31, 2024. This measure, which is strongly supported by President Joe Biden, now awaits action in the Senate. The Hydrocephalus Association is also still advocating for passage of the CONNECT for Health Act. This legislation would also help extend telehealth opportunities but still needs votes in Congress. Send a message to your representatives asking them to pass this bill soon!



Take Action on Telehealth by Cosponsoring the CONNECT for Health Act!



Research Funding Efforts With the CDMRP

Action has been taken to advocate for critical hydrocephalus research through the Congressionally Directed Medical Research Program (CDMRP). The House Committee in charge of the bill has passed its version, while the relevant Senate Committee has proposed its own bill. The bill has not yet made it through the rest of the process and has turned back to consideration. Both the House and Senate bills provide full funding for CDMRP, but with very few increases for individual programs. Among the proposals is \$370 million for the Peer Reviewed Medical Research Program (a program within the CDMRP), which provides funds for hydrocephalus research at the Defense Department.

The CDMRP Peer Reviewed Medical Research Program (PRMRP) uses consumer advocates to participate in the evaluation of research applications submitted to the PRMRP. Gary Chaffee, who lives with Normal Pressure Hydrocephalus, was one of a handful of nominees put forth by HA to serve as a consumer reviewer. As a consumer reviewer, Gary was a full

voting member, (along with prominent scientists) at meetings to help determine how the \$370 million appropriated by Congress for Fiscal Year 2022 will be awarded across the various meritorious research applications.

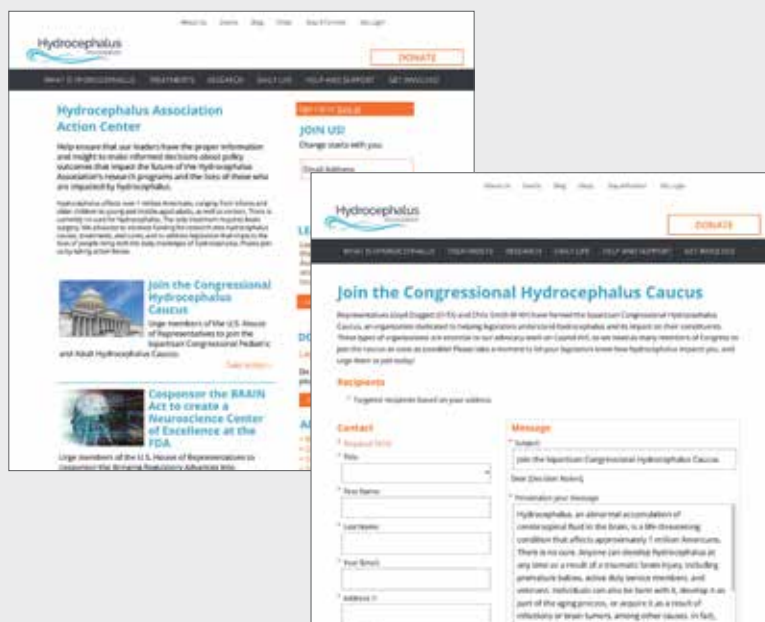
"Participating in this peer review group was extremely beneficial," said Gary. "There was a real opportunity for patients to interact directly with the researchers to help the researchers put a face and connection to their research."

We would like to thank Gary and the other nominated consumer reviewers for making sure the hydrocephalus voice is represented in the award-making process. We are currently pursuing our own funding line for hydrocephalus research under the CDMRP. You can help!

Hop on over to our action center and send a message to your member of Congress now at hydroassoc.org/actioncenter

JOIN OUR ADVOCACY EFFORTS!

Visit our new Advocacy Action Center, where you can learn more about the issues we're working on and send e-mails to your legislators about our concerns and what they can do to help. We can't get what we want if we don't ask. Now that so much is happening in Congress, we have to **be sure we have a seat at the table!**



Visit hydroassoc.org/actioncenter

COMMUNITY HIGHLIGHTS

Archery for Avery

In 2020, when COVID hit, the Dalbey family was unable to participate in their local WALK to End Hydrocephalus in Colorado. That year, HA encouraged families to do things that encouraged and empowered them; something that they enjoyed. For Avery and her twin sister, Teagan, it was archery. So, the Dalbey family got together and spent some time participating in the sport of archery that Avery knows and loves.

This sparked an idea that has grown into an annual event, **Archery for Avery**.

Avery was diagnosed with hydrocephalus in utero. Avery had her shunt placed at 7 weeks and then she had two revisions by the time she was 5 months old. Before she was born, Avery's parents, Damon and Stacey, were told that she would never walk or talk and would be in an infant state all her life. However, Avery proved them wrong and she started walking when she was 16 months old. She has had a few delays, such as her speech being affected by a hearing impairment, but not anywhere near what the doctors first said.

The 2022 Archery for Avery event was held in July at High Altitude Archery in Longmont, CO. The attendance was so high that they took up nearly the entire facility. The all ages event consisted of a Vegas 300 archery tournament for experienced archers and an area where less experienced archers could learn to shoot with the help of instructors. There was also a raffle, door prizes, swag bags for all participants and Chick-fil-A lunch.



Left is Avery, middle Emily Shern friend with hydrocephalus (went to same NICU), Teagan is on right

Around 100 people attended the event and raised over \$8,000 between funds from the lunch, raffle, open shoot, and the tournament.

"With this event, I see the pride that Avery has in feeling good about being able to do something that she loves and she is good at. She would always participate in the WALKs, but she was never able to complete them. With this event, she is involved from start to finish and that gives her a feeling of pride and accomplishment."

— Stacey Dalbey, Avery's Mother

Avery's mother Stacey is the backbone behind the planning and coordination of this event. She had volunteered with HA for many years and was previously a Community Network Leader for CO and WY. In addition to their participation in the Denver WALK to End Hydrocephalus since 2009, Stacey says this event provides so much for Avery and their community.

As to her initial prognosis of not ever being able to walk or talk, Avery not only walks and talks, but dances and runs, sings and screams, and lives life to its fullest.

To learn more about Archery for Avery, visit support.hydroassoc.org/Avery



End Hydrocephalus Bike Night



On October 15, 2022, over 100 people came together for the End Hydrocephalus Bike Night in Houston, TX. This special night was held at Reserve Supply Company, owned by the Bruen family. The Bruen's moved to Houston from Lafayette, LA, in 2010 to be closer to family and the Texas Children's Hospital medical center for their boys.

The Bruen's twin boys, Ryder and Kai (16), both have hydrocephalus. For most of their lives, the twins have endured multiple hospital stays and weekly and monthly occupational, speech, and physical therapies. Between them, they have endured 18 brain surgeries. They also both have cerebral palsy, which affects nearly 30 percent of children living with hydrocephalus.

The Bruen family opened the Reserve Supply Company in 2011, which centers around music, art, skateboarding, and early motorcycle culture. They have combined all of their passions into their business. This opened the door to hosting Bike Nights and they couldn't think of a better place to hold a fundraising event for the Hydrocephalus Association (HA).

Bike Night includes great music, food, drinks, lots of vintage motorcycles and a raffle to benefit the HA. This year's event raised just over \$4,000. This would not have been possible without the generous brands and a few local businesses that donated items for the raffle, and their supportive community that extended beyond Texas.

The Bruen Family hosts Bike Night a few times a year, but this one was specifically dedicated to the Hydrocephalus Association and it is what set it apart from others. People were eager to participate and support our cause.

Heather adds that the HA is very important to their family and they will continue dedicating Bike Night to HA each year.

To learn more about End Hydrocephalus Bike Night, visit reservesupplycompany.com

"Our family has been involved with HA's support network for many years. We wanted to use our available resources to do something good and give back. The community and support provided by HA is immeasurable," said Heather Bruen. "The Community Network meetings assured us that we are not alone in this journey. Most recently, the teen virtual meetings have given the kids an opportunity to connect with a network of peers that offer a level of support we, mom and dad, aren't able to give."

— Heather Bruen, Ryder and Kai's Mother





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NEWSLETTER
VOLUME

40



UNDER PRESSURE

Campaign to accelerate the
pace of hydrocephalus research

We're stepping up the
pressure on ourselves
to improve the lives of those
living with hydrocephalus
and find a cure.

We need your help so we can continue to
develop and grow the pipeline of promising
research that will get us ever closer to better
treatments and a cure for hydrocephalus!

Support our research efforts at
hydroassoc.org/underpressure