



Get Ready for HA CONNECT! Coming July 2022

Get excited! HA CONNECT 2022, our National Conference on Hydrocephalus, is coming to Austin, TX, July 14-16.

6 AHCNRN Awarded \$14M Grant

The Adult Hydrocephalus Clinical Research Network was awarded a major grant from NIH to study the effectiveness of shunting in NPH patients.

8 Announcing our 2021 Scholarship Recipients!

Get to know our new Hydrocephalus Association Scholarship Award Recipients.

17 Our WALKs Raise Over \$1.6 Million

Our WALK to End Hydrocephalus events were back in person, raising over \$1.6 million for HA's research, support, education and advocacy efforts.



MESSAGE FROM THE PRESIDENT AND CEO

Dear friends,

If there was one word that could describe the year we've had, it would be **grateful**. Because despite the

challenges of the COVID-19 pandemic, our organization continued to thrive and that's in large part thanks to all of YOU.

Your support means the world to us, but especially during difficult and uncertain times. Whether it was through our WALK to End Hydrocephalus events, Giving Tuesday, or other initiatives, you gave generously to our mission and for that we are eternally grateful.

Our WALK to End Hydrocephalus had a successful return, with many of our WALKs holding in-person events this year. With the pandemic forcing all of our events to go virtual in 2020, it was exciting to see the hydrocephalus community come together again! A big thank you to our amazing WALK volunteers who help make our WALKs possible! Read more about our WALK on page 17.

We know how important it is to connect and form relationships with others impacted by hydrocephalus. That's why we are thrilled to bring you another opportunity to do that at **HA CONNECT 2022**, our National Conference on Hydrocephalus. HA CONNECT will be held in Austin, TX, July 14-16, 2022. Over the past eight months, we've been busy putting together a robust program and are pleased to offer over 80 educational and interactive sessions with some of the nation's leading experts in the field. Our conference is truly special because it brings together everyone touched by hydrocephalus – from people living with the condition, parents and family members to medical professionals and scientists.

To register and learn more about our sessions and speakers, visit: hydrocephalusconference.org.

Of course, 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. Learn more on page 13.

Connecting and empowering you is what we **LOVE** to do. We also love advancing research. That's why we're ecstatic to announce that the Adult Hydrocephalus Clinical Research Network (AHCARN), one of three research networks we fund, was awarded a major \$14 million grant from the National Institute of Neurological Disorders and Stroke (NINDS) grant, the largest grant ever awarded to study adult hydrocephalus. This will help scientists finally get the answers they're looking for about whether shunting is the most effective treatment for NPH, a form of hydrocephalus which affects older Americans. See page 6 to read more about this exciting research advancement.

In this issue of **Pathways**, you'll also learn about what we've been up to on Capitol Hill (page 19). We've been busy fighting for legislation that benefits our community!

It's been an amazing year and we couldn't have done it without you! From all of us at HA, thank you for supporting our efforts and we wish you a healthy and happy 2022.

Sincerely,

Diana Gray, MA
President and Chief Executive Officer

VISIT

www.hydroassoc.org/get-involved

to learn about the various ways you can get involved with HA.

FEATURED ARTICLES

HA CONNECT is Coming to Austin, TX, July 2022!

Are you ready to connect with others impacted by hydrocephalus and to take your knowledge to the next level? Then join us at our 17th National Conference on Hydrocephalus, HA CONNNECT, which takes place July 14-16, 2022 at the Austin Marriott Downtown.

We're excited to offer over 80 new educational and interactive sessions with some of the nation's leading experts in the field. Our extensive program will cover topics of interest to all members of the hydrocephalus community, whether you're a parent of a child living with hydrocephalus or an adult living with the condition.

To make our conference accessible to as many people as possible, this year we will be awarding a limited number of scholarships. Conference scholarships are made possible through the generosity of donors and can be used to help cover conference registration, lodging and travel costs. The number of scholarships and type of financial assistance received will depend on the applicant's needs and available funds.

Registration and financial aid will be available starting on January 6, 2022! Be sure visit our conference website to sign up to receive important news and updates, including speaker announcements, event highlights, registration, financial aid, and much more!

www.hydrocephalusconference.org



WHY ATTEND?

Connect

with others, be understood by, and learn from people living positively with hydrocephalus.

Network

and interact directly with world-renowned medical professionals and researchers.

Expand

your awareness about hydrocephalus from leading experts in the field.

Learn

the best strategies and share your insights for living and coping effectively with hydrocephalus.

Gain

the necessary resources and tools needed to navigate the medical, educational, and social challenges of living with hydrocephalus.

Be motivated

by inspiring keynote speakers.

Explore

the Live Music Capital of the World! Austin also offers world-class dining, art, museums, shopping, and more.

HA CONNECT Highlights

New Participant Orientation

If this is your first time attending HA CONNECT, or if you've come to Conference on your own and you want to make some connections early, be sure to attend this introductory session. This session will give you an opportunity to meet others and hear ideas about how to get the most from Conference.

Welcome Reception

Reunite with old friends and make new connections! This is the time conference attendees, speakers, and exhibitors meet for the very first time.

Interpersonal Connection Sessions

Meet individuals like yourself who share similar situations living with or caring for someone with a neurological condition, and learn from their personal experiences and knowledge.

Kids Camp

We are pleased to offer a fun-filled Kids Camp, which is run by experienced volunteers who will provide the best care for your child. It is offered to all children with or without hydrocephalus between the ages of 3 and 11 years old.

New Track En Español

For the first time, we're excited to offer sessions completely in Spanish! This track will include sessions about shunt systems and possible complications, how to live an active life while living with hydrocephalus, an Ask the Expert session with a medical professional, and a session on making connections so you can meet others impacted by hydrocephalus.

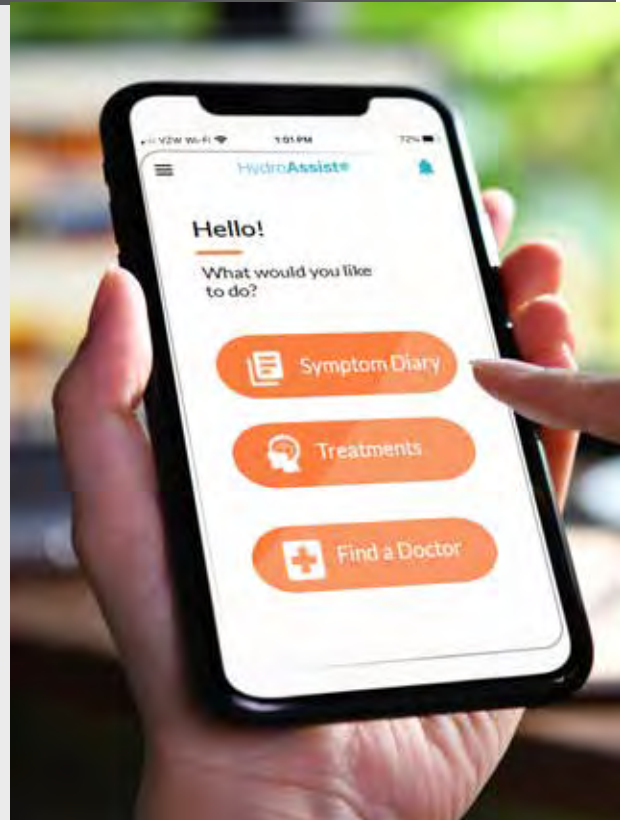
DOWNLOAD THE NEW HYDROASSIST APP!



HydroAssist®

- ✓ Symptom journal
- ✓ 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. Based on feedback from YOU, we made several improvements! **New features available January 2022!**



HA's Medical Advisory Board Issues New Statements for People Living with Hydrocephalus



The Medical Advisory Board (MAB) is an independent advisory board to the HA Board of Directors and staff. The MAB is composed of 25 leading medical professionals who serve hydrocephalus patients and families across the US and Canada. The MAB is a multidisciplinary group, composed of neurosurgeons, neurologists, neuropsychologists, and advanced practice providers. A key role of the MAB is to assist in the development of HA educational materials and review of HA literature, resource materials, and newsletter articles for accuracy and timeliness, allowing our community to trust the information disseminated by HA.

To view the current members of the MAB, visit [About Us on our website. www.hydroassoc.org/medical-advisory-board](#)

MAB Consensus Statements

HA receives questions or requests from our community for information on various topics, ranging from medical to lifestyle. To address these topics, the MAB occasionally issues consensus statements based on a combination of expert opinion, review of research literature, and review of guidance from respected and reliable authorities, such as the FDA, NIH, or CDC.

MAB Consensus Statements regarding Covid-19

Covid Vaccination for Children with Hydrocephalus

Consistent with CDC and FDA guidance, the Medical Advisory Board encourages parents to obtain a COVID vaccination for their children with hydrocephalus, provided they have no other medical conditions that their primary care providers or other treating physicians consider to be a medical contraindication to the vaccine.

Covid Boosters for Individuals with Hydrocephalus

Consistent with CDC and FDA guidance, the Medical Advisory Board encourages persons with hydrocephalus and their families to receive the COVID-19 booster vaccination when they become eligible according to federal, state, and local guidelines, provided they have no medical conditions that their primary care providers or other treating physicians consider to be a medical contraindication to the booster vaccine.

Visit our website to read the [HA Medical Advisory Board Recommendations Regarding COVID-19 for Patients with Hydrocephalus.](#)

www.hydroassoc.org/covid-19-guidance-for-people-living-with-hydrocephalus

AHCRN Awarded \$14 Million NINDS Grant to Study Effectiveness of Shunt Treatment for idiopathic Normal Pressure Hydrocephalus

Largest grant ever awarded to study adult hydrocephalus.

Idiopathic Normal Pressure Hydrocephalus (iNPH) is a complex disorder of the elderly that is caused by an excess accumulation of cerebrospinal fluid in the brain and includes symptoms of dementia, difficulty walking, and impaired bladder control that affects as many as 700,000 persons in the U.S. The only treatment is for a neurosurgeon to implant a permanent internal drainage system called a shunt into the brain to drain the excess cerebrospinal fluid. However, not everyone in the medical community agrees that shunt surgery is an effective treatment for iNPH, and, as a consequence, many patients who could benefit from shunt surgery do not receive it. Now, thanks to a \$14 million National Institute of Neurological Disorders and Stroke (NINDS) grant, the largest grant ever awarded to study adult hydrocephalus, the 8 sites of the Adult Hydrocephalus Clinical Research Network (AHCRN), working with 13 other health centers, hope to change that perspective with a study designed to prove conclusively whether shunt surgery for iNPH is beneficial.

“This grant will allow the AHCRN to use its network of neurosurgeons, neurologists, and medical institutions to conduct a clinical trial that will finally give us the answers we’re looking for about whether shunting is an effective treatment for iNPH,”

— Dr. Mark Hamilton, AHCRN Chair,
Vice Chair of HA’s Medical Advisory Board

The NINDS funded grant, called “A Placebo-Controlled Efficacy in iNPH Shunting (PENS) Trial” will be the first large scale, multi-center, blinded, randomized controlled trial to evaluate the true response of shunting in patients with iNPH.

The study is being conducted in partnership with the Johns Hopkins Cerebral Fluid Center. Johns Hopkins will also serve as the primary coordinating center.



“This study is important because right now some in the medical community are not convinced that shunts are an effective treatment for iNPH. Much of this uncertainty is due to the lack of a high-quality randomized controlled trial,”

— Dr. Mark Luciano, Neurosurgeon,
Director of the Cerebral Fluid Center at Johns
Hopkins and Principal Investigator of the study

During the PENS trial, 100 patients with iNPH who are undergoing shunt surgery will be randomly assigned to one of two groups, either with the shunt valve open (on) or closed (off) for the first 3 months after surgery, after which all shunts are in the open setting. The shunt valves can easily be adjusted to an open setting in the clinic with a simple tool that does not require additional surgery. Evaluations before and after surgery will compare the response of iNPH symptoms such as slowed walking speed, impaired cognition, mood, and bladder control at the end of 3 months in the two groups and will continue to follow the symptom response in all patients for the following year while all shunts are in the open setting.

The AHCRN, one of three research networks funded by the Hydrocephalus Association (HA), is a network of eight hospitals that conducts clinical research to improve treatment for the adult forms of hydrocephalus.

TECHNOLOGY UPDATE:

Rhaeos, Inc. Awarded NIH Grant to Advance Development of FlowSense Wireless Sensor

On September 16, 2021, Rhaeos Inc., a medical device company focused on the development of a device to rapidly monitor shunt function in people with hydrocephalus, announced that they were awarded a \$4 million grant from the National Institutes of Health (NIH) Small Business Innovation Research (SBIR) program. The program is run through National Institute of Neurological Disorders and Stroke (NINDS) and is designed to accelerate the development of new medical devices.

Rhaeos will use the funding to further the development of FlowSense™, a wireless noninvasive device that assesses CSF shunt function. This flexible sensor is placed on the skin directly over the shunt tubing and sends data related to CSF flow to a mobile app for review by a doctor. FlowSense™ is not yet FDA approved, but the ultimate goal of this work is to bring the technology to the clinic to improve care for hydrocephalus patients.

Concurrent with the work to expand the functionality of their sensor, Rhaeos is currently conducting a clinical trial to assess the diagnostic performance of FlowSense™ in patients experiencing shunt failure symptoms. The study is enrolling at three hospitals, two in Illinois and one in California.



View their September press release at www.rhaeos.com/press-releases

HA in Attendance

HA represents the hydrocephalus patient community at key scientific and professional meetings. Here are meetings we have attended over the last six months:

FDA Virtual Public Meeting on Patient-Generated Health Data Throughout Total Product Life Cycle

May 4

Hydrocephalus Clinical Research Network Meeting

May 14

Adult Hydrocephalus Clinical Research Network Meeting

May 21

Research!America Alliance Member Meeting

June 17

NINDS Nonprofit Forum

July 7-8

Hydrocephalus Society Meeting

September 10-12

Science of Patient Engagement Symposium: Achieving Trust in and Trustworthiness of Science

October 13 & 14

Hydrocephalus Clinical Research Network Meeting

October 22

ISPN 2021 Meeting

November 5-7

Adult Hydrocephalus Clinical Research Network Meeting

November 19

American Association of Neurological Surgeons/Congress of Neurological Surgeons Pediatric Section Meeting

December 7-10

SUPPORT AND EDUCATION

Announcing our 2021 Hydrocephalus Association Scholarship Recipients!

The Hydrocephalus Association (HA) is pleased to announce the 2021 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 228 scholarships to deserving 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 the: Gerard Swartz Fudge Memorial Scholarship Fund, which is supported in part by Molly Mastrangelo; Baldus Family Scholarship in Memory of Gerard Swartz Fudge Scholarship; 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; and the Hydrocephalus Association Scholarship, which is provided by Erik and Lisa Chamberlain.

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



Tino Balestrini
Recipient of the Justin Scot Alston
Memorial Scholarship Fund

Tino didn't let his hydrocephalus and learning difficulties define him. He learned how to overcome some of the challenges he faced in school and was accepted at the University of Windsor where he will complete a five-year dual degree program, Bachelor of Arts (Psychology)/Bachelor of Education, in Early Childhood Education. His goal is to become an elementary school teacher and eventually a school principal.

"I have chosen to go into education because of my many positive experiences with teachers that have helped me to overcome barriers to learning and develop necessary learning strategies, study habits, time management and more," Tino said.



Emily Deitsch
Recipient of the Kate Finlayson
Memorial Scholarship

Growing up, Emily had to endure many hospitalizations and brain surgeries due to her hydrocephalus. She used art as a way to cope during those difficult times and developed a passion for the arts, even taking AP art courses in school.

Now Emily hopes to take her passion for art and turn it into a career in mental health therapy to help other kids going through tough times. She is pursuing a degree in Sociology at Mount Royal University to eventually become an Art Therapist.

"My ideal career once I graduate from this program will be as an Art Therapist for children, who like myself have had to spend lengthy amounts of time in hospital dealing with illness. I think art is an amazing outlet for both children and adults and I know that during my hospital stays, it helped me immensely," Emily said.



Jinean Dirbas
Recipient of the Mario J. Tocco
Hydrocephalus Foundation
Scholarship Fund

Diagnosed with hydrocephalus as a teen, doctors didn't always take Jinean's

symptoms seriously and she never wants anyone to go through what she went through. That's why she aspires to become an emergency room nurse.

"As a patient, my pain was ignored and I was set aside due to health care providers not believing my complaints because I was female. When I become a healthcare provider, I would get to help individuals no matter their capacity or background, and I would be able to use my experience as a patient and knowledge of neurological conditions," Jinean said.

She will attend a two-year program at Las Positas Community College and then transferring to a four-year university to major in Biology to become a nurse.



Robert Lodge
**Recipient of the Baldus Family
Scholarship in Memory of Gerard
Swartz Fudge**

Excelling in school and making friends wasn't always easy for Robert. Due to

his hydrocephalus, he had coordination issues, social issues, and severe non-verbal learning disorder (NVLD), which made learning and socializing with his peers challenging. But overtime, through hard work, he learned to overcome his challenges and made it on the honor roll throughout high school.

Now he has set his sights on attending the New Jersey Institute of Technology to major in Biochemistry with a premedical focus. His ultimate goal is to become a neurosurgeon so he can help find a cure for hydrocephalus and improved treatment options.



Elizabeth Philpot
**Recipient of the Morris L. and Rebecca
Ziskind Memorial Scholarship Fund**

Growing up, Elizabeth always loved to sing, play the piano and guitar, and now she's studying to turn her love of music

into a career. She is currently a freshman at Baldwin Wallace University in Berea, OH, studying music therapy.

"Through my observations, I was able to witness the healing power of music firsthand. I am beginning to learn the



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 registry, you're helping scientists understand the complexities of living with this condition and where to focus their research. Our registry 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!

www.hydroassoc.org/happier

foundational information and skills that I will need as a music therapist, and next semester I will have my first field work placement as I begin to get my feet wet in the world of music therapy outside of the classroom," Elizabeth explained.



Malini Popat
Recipient of the Anthony Abbene Scholarship Fund

While Malini hasn't decided on a major yet, she is certain of one thing – that she wants to pursue a career where she can help other kids be confident and overcome challenges. She applied at several universities and plans on majoring in either Psychology, Economics or Education.

In addition to taking AP courses in high school, and participating in varsity swimming and other activities, she also enjoys volunteering. One of her volunteer experiences involved tutoring a young girl. That experience sparked her interest in studying education and possibly becoming a teacher.

"As someone who has undergone treatment for a brain tumor, I find joy in giving back to others who are going through their own struggles. My ultimate occupational goal is to find a service-oriented career, where I can see the difference that I am making in my work," Malini said.



Eric Rhee
Recipient of the Gerard Swartz Fudge Memorial Scholarship Fund

Born weighing just three pounds and 26 weeks premature, Eric developed hydrocephalus from a brain bleed.

His parents were told he had a 10% chance of developing normally and leading a normal life. But with help from his doctors, parents and physical, speech and occupational therapy, he defied the odds and became stronger. He excelled in school, becoming class valedictorian, and went on to graduate from UC Berkeley.

Now, he's in medical school at Temple University/St. Luke's School of Medicine, studying to become a doctor and possibly even a professor so he can help shape future medical professionals.



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

Do you love hard cider? Want to support hydrocephalus research, support and education? Buy Locust Cider! The company donates a portion of their proceeds, and \$25 from each club membership, to the Hydrocephalus Association!

Visit www.locustcider.com

ORDER ONLINE OR VISIT ONE OF THEIR TAPROOMS IN:

- Redman, WA | Seattle, WA | Spokane, WA | Tacoma, WA
- Vancouver, WA | Walla Walla, WA | Woodinville, WA
- Fort Worth, TX | Boulder, CO | Fort Collins, CO | Lakewood, CO

"It is through years of learning that I hope to become a member of medical faculty someday who is able to pass down his own expertise, perspective, and knowledge to others," Eric said.



Kristen Samar
Recipient of the Hydrocephalus Association Scholarship

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

Imagine being told you have a brain tumor while in a hospital where no one speaks your language? That's what happened to Kristen while living in Japan with her family. After flying back to the U.S., she was diagnosed with hydrocephalus, likely caused by a benign tumor she had in the third ventricle of her brain. She then had two brain surgeries to have a shunt placed and returned to Japan for an intensive course of chemotherapy.

Her chemo was challenging but she credits her support system of family, doctors, teachers and counselors with helping her through it.

"I plan to attend Salisbury University where I will major in elementary education and gain the necessary certifications to become a teacher who helps, inspires, and educates in the best way possible," Kristen said.



BriAnna Saner
Recipient of the Gerard Swartz Fudge Memorial Scholarship Fund

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

After undergoing brain surgery for hydrocephalus, the entire right side of BriAnna's body was impaired, which made it difficult for her to walk and to use her right hand. She spent the majority of her life in physical and speech therapy, and wore a brace on her foot and leg until age 13. However, those disabilities only made BriAnna stronger and more determined.

She excelled in school, receiving an Outstanding Student Award and the Presidential Award, and was inducted into the National Honors Society. Now she will attend Kent State University, majoring in Speech Pathology and Audiology.

"Through years of physical and speech therapy, it inspired me to help others with similar problems. My career goal is to use my college education to help children and adults with disabilities. I would like to help them overcome the hardships they may face in their life," BriAnna said.



Antonio Sanfilippo
Recipient of the Jacobsen Family Scholarship

Antonio has always had a passion for sports but due to his hydrocephalus he never played contact sports. Ask him any stat about football, though, and he'll likely know it. So it's no surprise that when he shadowed his cousin, who was an equipment manager for all athletics at San Diego State University, a light bulb went off.

"From that point on, I knew what I wanted to do for my career. I also knew that if I wanted to attend my dream school and pursue my aspirations, that I would have to work even harder. That meant getting extra tutoring, staying up late to study, and to not lose focus of my goal," he said.

His hard work paid off. He was accepted at San Diego State University, where he will major in Business Administration to pursue his dream of becoming a sports equipment manager.



Claire Scognamiglio
Recipient of the Gerard Swartz Fudge Memorial Scholarship Fund

Claire grew accustomed to the hospitalizations and constant pain from her hydrocephalus. However, that didn't stop her from playing soccer and ultimate Frisbee, and eventually joining a nationally competitive acrobatic gymnastics team and becoming a cheerleader.

She knows that anything is possible if you have encouragement, support and work hard. That's why she is studying to become an elementary special education teacher at the University of Missouri at Columbia (Mizzou).

"I look forward to being a teacher and having that special bond with kids that says 'I've been there' and with parents who will know I truly understand them and the different accomplishments their kids achieve," Claire said.



Gabe Tejada
Recipient of the Anthony Abbene Scholarship Fund

Growing up, Gabe remembers often being excluded from activities because his teachers were overly cautious about

his hydrocephalus and shunt. He vividly remembers not being allowed to participate when the local fire department came to his school to demonstrate how to exit a home during a fire. Little did he know how much that moment would shape him.

"I was so upset that I cried. My mom helped me learn how to advocate for myself when I needed accommodations and when I did not need them," he said.

He became a fierce self-advocate, fighting for what he wanted and needed. Now, he looks forward to completing his first two years of college at Truckee Meadows Community College in Reno and then transferring to the University of Nevada to major in Education to become a high school history teacher.



Amelia Vacca
Recipient of the Morris L. and Rebecca Ziskind Memorial Scholarships

Having hydrocephalus wasn't always easy for Amelia. Fortunately she found a hobby that helped her through the

difficult times – field hockey. She was a varsity goalie for her high school's field hockey team and won Athlete of the week and other accolades. She also developed a love of art and photography, participating in her school district's advanced art program.

Now she's excited to attend James Madison University to pursue her dream of becoming an Occupational Therapist.

"I, myself, went to an occupational therapist and seeing how much it changed my life, it made me want to do the same for other children out in the world," Amelia explained.



HELP IS A PHONE CALL AWAY!

It's not uncommon to feel overwhelmed when dealing with a chronic medical condition, and we want you to know that we're here to help! In addition to educational resources, the Hydrocephalus Association offers a toll-free helpline to provide support when you need it most. Through the helpline, we answer your questions and refer you to helpful educational resources and support programs.

The helpline is available via phone and email.



(888) 598-3789

to speak to a support staff member.



info@hydroassoc.org

for support, resources and answers to your questions.

Join Us Online for These Fun and Interactive Events!

In response to the current COVID-19 pandemic and the social distancing guidelines, many of our community networks are hosting meetings virtually. Here are some of the events taking place this year! Join your local community network to participate and learn more, and be sure to follow HA on Facebook (@HydroAssoc) to join our Facebook-only events.

Flourishing in Mid-Life: Group for Women Age 40- 59!

Held the 4th Thursday of the month

Hydrocephalus is a complex and unpredictable condition that requires lifelong management. For women in particular, middle-age can impact us emotionally, socially, physically, relationally, and professionally in combination with managing the day to day challenges of living with a chronic condition. Do you have questions about how hydrocephalus impacts you as you age? Join us for a chance to connect with other women who share similar experiences. This group will be a place to learn, share, and support other women ages 40-59 navigating the journey of hydrocephalus and mid-life.

Contact: Elana Schwartz, NYC Community Network Leader or Felicity Gorham, IL Community Network Leader, info@hydroassoc.org

Parents Supporting Parents of Adult Children with IDD

Held the 4th Wednesday of the month.

Open to all parents of adults living with hydrocephalus and intellectual and developmental disabilities. Our community is diverse in the many ways and degrees that hydrocephalus impacts our loved ones. For those of us supporting children who are adults with intellectual disability (ID), physical disability, and/or learning challenges (LD), the road can be challenging and lonely. Questions of managing their care, self-advocacy, independent living, and finding success in the workforce all loom large. Join other parents on a similar journey for connection and great discussion.

Contact: Jackie Mullock, PA Community Network Leader, easternpacommunity@hydroassoc.org

Adults with Hydrocephalus Meet-Up (for residents of DC, MD, VA, PA, DE, NJ)

Held every Saturday

Lively and engaging conversation! We all need to see old friends, new faces, and have some fun with a community that knows us in a way that only those living the hydrocephalus journey do.

Contact: Sierra Smith, PA Community Network Leader or Sara Curran-Kellogg, MD Community Network Leader, easternpacommunity@hydroassoc.org

Adults with Hydrocephalus Meet-Up (for residents of WA, OR, ID, CA, NV, UT, NM, AZ)

Held the 1st Friday of the month

Lively and engaging conversation! We all need to see old friends, new faces, and have some fun with a community that knows us in a way that only those living the hydrocephalus journey do.

Contact: Kelly Varga, UT Community Network Leader, info@hydroassoc.org

Adults with Hydrocephalus Meet-Up (for residents of FL, GA, AL, SC, MS)

Held the 4th Sunday of the month

Lively and engaging conversation! We all need to see old friends, new faces, and have some fun with a community that knows us in a way that only those living the hydrocephalus journey do.

Contact: Jessica Coffaro, FL Community Network Leader, info@hydroassoc.org

Young Adults in their 20s Meet-Up

Held every Saturday

Come hang out with us and meet other young adults in their 20s living with hydrocephalus. We will have fun intros, icebreakers, and conversation. Let's get to know each other!

Contact: Lauren, Kaitlyn, Ian, Elizabeth, Genesis, and Sierra 20s, CN Co-Leaders, info@hydroassoc.org

Teens Hang-Out

Held the 1st Sunday of the month

Come meet other teens with the condition! We'll hangout, maybe play an icebreaker game, talk, and hopefully make some new friends.

Contact: Olivia Maccoux and Tomas Rodriguez, Teen CN Co-Leaders, info@hydroassoc.org



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 www.hydroassoc.org/underpressure.

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](mailto:info@hydroassoc.org) or call (888) 598-3789 for details!

AK	Anchorage	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	Dallas <i>NPH</i> Houston <i>peds/adolescent</i>
GA	Atlanta	UT	Salt Lake City
IL	Chicago	VA	Richmond
IN	Indianapolis	WA	Seattle <i>pediatric</i> Eastern WA Vancouver
MA	Boston	WI	La Crosse <i>online only</i>
MD	Baltimore	Military Members	<i>online only</i>
ME	Portland	Nigeria	Lagos <i>children/families</i>
MI	Detroit	Spanish-Language Network	(Red de Apoyo Para la Hidrocefalia) <i>online only</i>
MN	Minneapolis <i>peds/adolescent</i>	Young Adults 20s Group	<i>national - online only</i>
MO	St. Louis	Flourishing in Mid-Life Women's Group (Age 40-59)	<i>national - online only</i>
NC	Charlotte		
ND	Fargo & Morehead, MN		
NE	Omaha		
NJ	Jersey Shore and Central North New Jersey <i>NPH</i>		
NY	Western NY Long Island New York City		

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

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.



Danielle, 29

Born premature, I spent the first two months of my life as a #NICUwarrior and, other than coming home attached to a special monitor, there wasn't much more concern. By all accounts, my first seven years of life

were relatively uneventful. But the calm didn't last. By the third grade, I started exhibiting debilitating migraines and abdominal pain that would follow me into adulthood.

At first, the doctors attributed the frequent headaches to family history and hormonal fluctuations. They diagnosed the abdominal pain as IBS, food intolerances, and Gastroparesis. And when I started having eyesight problems, going legally blind in high school, we thought it was a bad reaction to medication or a temporary or an idiopathic neurological problem.

I struggled to graduate high school after withdrawing completely more than once to address health issues at home. Then, in college, I would go to school for a semester or two and withdraw for surgeries. I was put on total parenteral nutrition (tpn) twice during hospital stays but each time, when symptoms receded, we thought we had found effective treatment for the collection of conditions that had been diagnosed. It was a perpetual cycle of "try, try again."

But after seven years of desperately trying to earn my degree, I hit a wall. Because just when I really began to feel like a thriving, normal college student, I had to change course again. I started having weird "episodes" in which my body

would completely shut down. I couldn't walk, shower or use the restroom alone. I couldn't talk properly or see clearly. So, I moved back in with my parents to see yet more doctors.

At the age of 23, I had seen multiple doctors in a wide variety of specialties, in different states, and had a medical record over 1,000 pages long. I had a list of diagnoses, but no treatment had yet to be effective. After more tests, my neurologist decided I had Narcolepsy in Status Cataplecticus. It was a working diagnosis good as any, but even with treatment, I struggled to regain normal function. When the pain got worse, doctors re-ran MRIs and CT scans to see if there was something else.

Finally, medical professionals agreed that something else had to be done and they presented the idea of an Endoscopic Third Ventriculostomy (ETV). They weren't sure if I really had hydrocephalus or if I just had large ventricles from premature birth, but the former sounded like it might be responsible for some of my symptoms and we had exhausted our options. So, we gave it a shot! Soon after my first brain surgery, my symptoms got better and we knew we were on the right track! Unfortunately, my ETV failed two years later and symptoms once again returned.

This time, my surgeon suggested placing a VP shunt so that there was a more permanent solution to draining the excess fluid. My family and I were terrified to make such a big decision but we went forward with the plan. My second brain surgery at the age of 25 sent me into an interesting new life. I was finally symptom free enough to start living again! I never went back to school, but I worked part-time for a family-owned company, dated, and went out with friends.

It is now two years after that and I am on top of the world! I fell in love with an amazing man, moved in with my love, got married, started being myself again, and became a mom! Now I have a new diagnosis of Neurocardiogenic Syncope and I still wonder if we made the right decision to place the

shunt. After all, a lot of dysautonomia symptoms mimic hydrocephalus symptoms. However, imaging confirms that the shunt is doing its job and we have faith that if I didn't need it I would be having even more problems. I feel like I am now living my absolute best life! I wake up every day knowing that I am loved!

Through this experience, I have met an amazing array of spectacularly strong #HydroWarriors who lift me up and remind me to keep fighting like they do. I have learned to be a patient advocate and I have even started a blog to spread awareness of my many chronic conditions. It's a work in progress just as I am, but I am excited to share my story with others who desperately need to know that there is a light at the end of a long and bleak tunnel. Life is worth living!

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!

Visit [hydroassoc.org/
shareyourstory](http://hydroassoc.org/shareyourstory)
to submit your story!



FIND A DOCTOR OR SPECIALIST WITH OUR PHYSICIAN'S DIRECTORY!

The Hydrocephalus Association 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 [www.hydroassoc.org/
findadoctor](http://www.hydroassoc.org/findadoctor)

WALK TO END HYDROCEPHALUS

2021 WALK to End Hydrocephalus Raises over \$1.6 Million

Thanks to our passionate volunteers, we were able to hold 41 WALK to End Hydrocephalus events this year. Most of HA's WALKs were held live and in person, bringing together the hydrocephalus community in cities across the country. In total, the WALKs raised over \$1.6 million, with 734 teams participating and 6,500 registered participants and volunteers.

As of this writing, HA's top WALK to End Hydrocephalus site (drumroll, please) was Long Island, co-chaired by Mia Padron and Jackie Davidson, raising \$131,056. The success of this WALK is especially significant since WALK volunteer Co-Chairs, Mia and Jackie announced this was their last year to lead the event. They will definitely be missed but they are going out on a high note! We know the new volunteer leadership for this event will continue to build upon the foundation that's been laid and make them proud.

"It is gratifying that the WALK program continues to serve a dual purpose – raising money to provide the resources required for HA to continue its work, and bringing the hydrocephalus community together," said Randi Corey, HA's National Director of Special Events.

This year one of HA's long term WALKS did something very different. The South Florida WALK to End Hydrocephalus held

a Golf Tournament and Celebration. Due to the generosity of the Jacaranda Golf Club, the expenses for the event were very low. After golfing the community gathered for kid's activities, games, group photos and snacks, as well as the renowned South Florida HA Raffle! Special thanks to volunteer leaders Kasey Andrew, Lisa Piazzese, Ronda Sobel, and Eileen Rodger. The event brought in almost \$94,000 with donations continuing to arrive.

"Although 2020 was a difficult year for the WALK to End Hydrocephalus program, the hydrocephalus community rallied. Now in 2021 we are beginning to regain momentum. For WALKS that were held live and in person, the hydrocephalus community rejoiced in being able to renew connections and make new ones." — Randi Corey

Congratulations to the Denver WALK to End Hydrocephalus (chaired by volunteer Phyllis Rogers) which achieved a cumulative total of \$1,000,000. In 2021, the Denver WALK raised over \$100,000. Denver has come a long way since its first WALK in 2004, when it raised \$3,900. Phyllis is retiring as the volunteer Chair after 18 years but her leadership and mentorship will allow Denver to continue to flourish.



Families came together for the Long Island WALK to End Hydrocephalus in Belmont Lake State Park. Pictured here: the Padron family.



The Davidson family is one of many families who participate in the Long Island WALK.

Top Ten WALK to End Hydrocephalus Sites

(based on amount raised):

Long Island

Led by Mia Padron and Jackie Davidson

Orange County (Virtual)

Led by Erin Berger and Heather Kluter

Seattle

Led by Betsy Conyard

Los Angeles

Led by Jennifer Pope
(with special thanks to the Los Angeles Kings)

National Capital

Led by Susan Fiorella and Amanda Garzon

Denver

Led by Phyllis Rogers

South Florida

Led by Kasey Andrew, Lisa Piazzese,
Ronda Sobel and Eileen Rodger

Western NY

Led by Larry McKenzie, Stacy Fonagy,
and Kelly McKenzie

Baltimore (Virtual)

Led by Jodi Heston and Gina Moorhead

Cincinnati

Led by Mike and Heidi Knapke

Learn more about the WALK to End Hydrocephalus at

[www.hydroassoc.org/
hydrocephaluswalk](http://www.hydroassoc.org/hydrocephaluswalk)

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HA Holds Virtual Hydrocephalus Day on Capitol Hill

Despite the fact that we couldn't get on trains, planes, and automobiles to come together in Washington, DC, 180 advocates representing 30 states from across the country participated in a "Virtual Fly-In" on July 20th. If you were one of those advocates, THANK YOU! Hydrocephalus patients, along



Advocates from Michigan meet with Representative Rashida Tlaib (MI-13).

with caregivers, doctors, and others, participated in 78 online meetings with staff and legislators in the U.S. House of Representatives and Senate. 10 Members of Congress personally joined the meetings. Advocates shared

their personal experiences, leaving many policymakers stunned at the hardship of a condition they knew little about. As part of the event, advocates urged legislators to join the Congressional Pediatric and Adult Hydrocephalus Caucus, co-sponsor a Hydrocephalus Awareness Month resolution, and support hydrocephalus-related research funding.

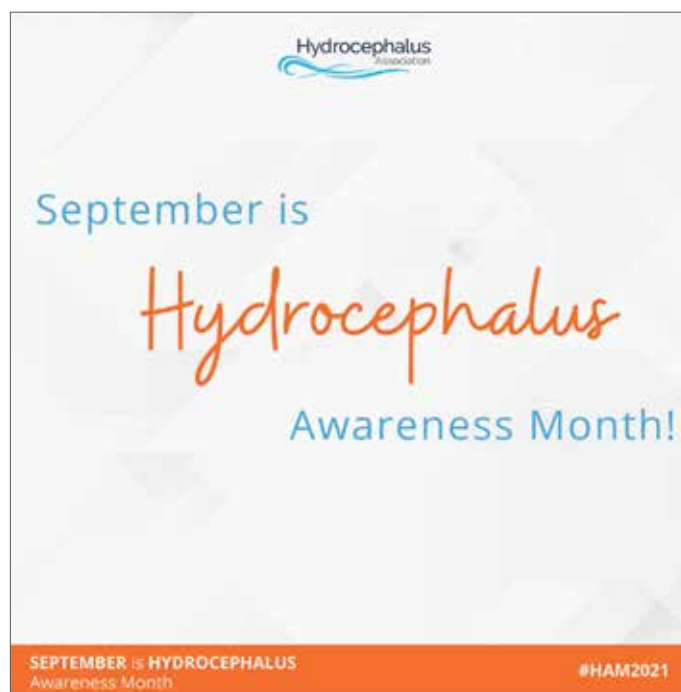
New Bill Introduced in Congress

On October 1st, Representative Earl Blumenauer, along with Representatives Bill Pascrell and Don Bacon, introduced the bipartisan Bringing Regulatory Advances Into Neuroscience (BRAIN) Act, to establish a Neuroscience Center of Excellence (NCOE) at the Food and Drug Administration (FDA). This is important for our community because the NCOE would spur much-needed innovation to speed access to safe and effective treatments for patients with brain and central nervous system

conditions, including hydrocephalus. This important bill focuses on patient-centered decision-making, with the goal of bringing the right treatments and cures to patients who desperately need them.

Congress Shows Some Love for Hydrocephalus Awareness Month

In between battles over keeping the government open and passing an infrastructure bill, members of Congress took some time during September to recognize National Hydrocephalus Awareness Month. To honor and raise awareness of our cause, the Hydrocephalus Association worked with U.S. Representative Lloyd Doggett (D-TX) and U.S. Representative Chris Smith's (R-NJ) offices to introduce House Resolution 20, Expressing support for the goals and ideals of "National Hydrocephalus Awareness Month." This congressional resolution highlights and elevates our efforts by allowing members of Congress to cosponsor and show support for the hydrocephalus community.



New Members Join Congressional Hydrocephalus Caucus

We are excited to have new members join the Congressional Pediatric and Adult Hydrocephalus Caucus. **Representative Mike Levin (D-CA), Representative Cindy Axne (D-IA) and Representative Mariannette Miller-Meeks (R-IA)** are the newest members of our caucus. Thank you to the advocates who asked these members to join! The Congressional Pediatric and Adult Hydrocephalus Caucus informs Congress about the needs of those living with hydrocephalus, their families and caregivers, and is an important way for members of Congress to show their support of our issues and to elevate the discussion about our key legislative priorities. The Caucus has been instrumental in helping the hydrocephalus community advocate for legislation that benefits families and opens doors to new research opportunities that could result in new treatment options, forms of prevention, and a cure.



Rep. Mike Levin (D-CA)



Rep. Cindy Axne (D-IA)



Rep. Mariannette Miller-Meeks (R-IA)

Visit our website for the latest list of congressional offices that are on the Caucus: www.hydroassoc.org/congressional-pediatric-and-adult-hydrocephalus-caucus



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 www.hydroassoc.org/actioncenter

Teen Raises the Stakes for HA

Bryce Devlin, a junior at Rumson-Fair Haven Regional High School in Rumson, NJ, has always enjoyed playing poker with his friends. This year, he took his hobby to the next level by hosting a poker tournament to raise funds for the Hydrocephalus Association.



While the game did not involve actual gambling, he was able to raise \$2,000 by charging an entry fee. He also used the opportunity to educate participants about hydrocephalus.

"When it became apparent to me that I needed leadership hours for my school, I couldn't think of a better opportunity to host a poker tournament, and it only made it better that I was able to center the tournament around a charity that had a great impact on my family's life," — Bryce Devlin

The cause is personal for Bryce, whose brother has hydrocephalus. His grandmother, who died in 2019, also had hydrocephalus.

"This condition has obviously impacted the lives of the people around me and I knew that when presented with this opportunity to raise money for a charity, the Hydrocephalus Association was the obvious choice," he explained.

HydroWarrior Golf Tournament Raises \$12,000

On July 30th, 200 people came together for a round of golf to raise funds for the Hydrocephalus Association. The HydroWarrior Golf Tournament, held in Middlefield, CT, was organized by HydroMom Janine Koczik.

Janine, whose 15-year-old son developed hydrocephalus in 2019 as a result of a brain tumor procedure, wanted a way to raise funds for hydrocephalus research in hopes of a better future for people living with hydrocephalus.

"I wanted to raise funds for this cause because we would like to move forward with better ways of managing this condition. Of course a cure would be ideal, but for now we are just hoping for new technology to detect when a shunt is failing ASAP or perhaps a device that won't fail at all," Janine said. "Not only did we raise over \$12,000, we raised awareness of a condition that very few knew anything about but that affects people of all ages."



Isabella Advocates for Children in Congress

Like many children living with hydrocephalus, Isabella Ferris is a fighter. This year, she brought her fighting spirit to Congress to advocate for health care services for children.

Isabella was just two months old when she developed hydrocephalus after contracting bacterial meningitis. Now, at 12 years old, she's no stranger to adversity, having endured multiple hospital visits throughout her life and five brain surgeries. She also deals with other conditions, including spastic diplegic cerebral palsy, which affects her ability to walk properly, and strabismus, which affects her eye sight.



Earlier this year, Isabella and her mom Gloria participated in the Speak Now for Kids Family Advocacy Week, representing UCLA Mattel Children's Hospital. They met virtually with Members of Congress to discuss Isabella's health journey, and Isabella shared her story with Representatives Adam Schiff, Ted Lieu, Lucille Roybal-Allard, Judy Chu, Diane Feinstein, as well as a staffer from House Speaker Nancy Pelosi's office.

"Congresswoman Lucille Roybal-Allard thanked Isabella for sharing her story and for being an advocate. She mentioned the difference it makes to connect a face with the issues, and hopes Isabella can go next year in person to Congress so that she can give us a tour of Congress," Gloria explained.

Isabella and her mom also took part in the Hydrocephalus Association's Hydrocephalus Hill Day in July. Isabella shared the impact living with hydrocephalus has had on her life, and

explained what a shunt is and treatment options for kids with hydrocephalus. Isabella advocated for more research to find a cure for hydrocephalus and asked members to join the Hydrocephalus Caucus.

Gloria said they want to do their part to raise awareness of the condition so that lawmakers understand the needs of people living with hydrocephalus and their parents and caregivers.

"Hydrocephalus is a lifelong condition that my daughter will have to live with. She is doing okay now but has had to overcome many challenges because of it. As a hydrocephalus family, we are strong, we're fighters, and we strive to live our best lives. And while we are hopeful for the future, we know that there is much work to be done to better the lives of those living with the condition,"

— Gloria, Isabella's mother



Isabella and her mom Gloria (pictured bottom left corner) shared what it's like to live with hydrocephalus with various members of Congress, including Rep. Adam Schiff (D-CA) (pictured top middle photo).

Get to Know Our Support Volunteers



AMY SPENCER

Q: Tell us a little bit about you and your journey with hydrocephalus. When were you diagnosed with hydrocephalus and how many brain surgeries have you had?

A: I was first diagnosed by my pediatrician when I was six weeks old. I received my first shunt a week later. I have had a total of 16 hydrocephalus-related surgeries throughout the course of my life. The first 13 were brain surgeries, the latest three surgeries were abdominal only. As of March 7, 2021, my current shunt is 10 years old. May it last at least another decade! My longest gap between surgeries was 20 years, seven months; my shortest was two days.

Q: When did you start volunteering for the Hydrocephalus Association?

A: I first learned about the Hydrocephalus Association in 2011, when I was having my two most recent brain surgeries. I attended my first walk-a-thon later that year, and I am happy to say I have not missed a year since. I have been a Peer Support Volunteer ever since the program started a few years ago.

Q: What made you want to be a Peer Support Volunteer?

A: I could have used a program like this both when I was a teenager, and during my last few brain surgeries. I was happy to hear the program was started, and wanted to be a part of it. Also, meeting and speaking to others with hydrocephalus makes me feel more normal.

Q: What do you like most about being an HA Peer Support Volunteer?

A: Interacting with patients and their families.

Q: What do you like to do in your spare time when you're not serving the hydrocephalus community?

A: When we are not in a global pandemic that has led me to spending too much time at home, watching more television than I would like to admit, I love to travel and hang out with friends. My most recent trip was to Iceland; my favorite was London. I also enjoy reading and hiking. If you are looking for me during the warmer weather, you should check the beach.

Q: Describe your home life for us.

A: I live in North Andover, MA, and work as a corporate paralegal.

Q: Why is it important to you to support HA's mission?

A: I support it for selfish reasons. I don't like having brain surgeries and would love to see a day when there is a cure and brain surgeries become part of my past, and not my present or future. I am not the researcher that will find the cure, but I hope people consider me someone they can talk with to help them through their current situation. We have all been there, but many people haven't. There are some things outsiders will not understand.



4340 East West Highway, Suite 905
Bethesda, Maryland 20814



The Fudge Solomon
LEGACY SOCIETY

Leave Your Legacy

Consider how you can help ensure future support of the Hydrocephalus Association by remembering HA in your long term estate plans. In doing so, you will become a member of the Fudge Solomon Legacy Society, established to honor HA's pioneering founders, Emily Fudge and Cynthia Solomon.

Making a bequest to HA is easy and the options are endless, including bequests of cash, stock or other property, proceeds from a life insurance policy or retirement plan, to name a few. Giving can be customized to suit your specific situation and wishes.

To find out how you can include HA in your estate plan today, please contact the Hydrocephalus Association at (888) 598-3789 or development@hydroassoc.org

