

## HONORING OUR LEGACY AND shaping the future

HYDROCEPHALUS ASSOCIATION'S 40TH ANNIVERSARY



40 years

NEWSLETTER  
VOLUME

42

## Special 40th Anniversary Edition

Our journey from a volunteer led organization to one shaping the future of hydrocephalus.

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## MESSAGE FROM THE PRESIDENT AND CEO

Dear friends,

It's quite moving to reflect on our organization's early days when determined families

united to bridge resource gaps in hydrocephalus. In 1983, before the ease of accessing the internet, families faced fear for their loved ones, grappling with scarce information and the urgent need to comprehend how to navigate this condition. Above all, they longed for connections with others on a similar journey. I recently had the privilege of meeting Pip Marks, the first staff member dedicated to providing support and hope to those in need. Her impact on the families she supported has been transformative and profound. As anticipated, she exuded warmth and compassion, leaving a lasting impression.

In the process of crafting a video for our 40th anniversary gala, I had the pleasure of spending time with the Hydrocephalus Association (HA) founders Emily and Russell Fudge, Pip, and Dr. Michael Edwards, a steadfast supporter of HA's initiatives since its inception. Witnessing the camaraderie among this group was heartwarming, especially as they shared their stories and memories, including those of Cynthia Solomon, who sadly passed away in 2014. This experience was incredibly valuable, and their satisfaction with the growth of HA and our expanded programs was heartening to hear. During the gala, we honored Emily and Russell for their dedication and foresight in establishing HA, alongside remarkable families like the Solomons and the Marks.

Although HA formalized its research program in 2009, Cynthia recognized the significance of inspiring neurosurgical residents to delve into hydrocephalus research early on. In 1988, she initiated the Resident's Prize, aiming to motivate young neurosurgeons to dedicate their research efforts to advancing hydrocephalus treatment and care. This prestigious prize is awarded annually and since its inception, 32 residents have been honored. During our gala, we commemorated Cynthia's visionary contributions by renaming this award the Cynthia Solomon Resident's Prize. Nathan, her eldest son, graciously accepted this posthumous award on her behalf.

We continue to be proud of the success of research supported by HA. We now host an annual research workshop which brings together existing and new scientists, through the generous sponsorship of the Rudi Schulte Research Institute. The focus of our recent workshop held in September was *Developing Non-Invasive Hydrocephalus Therapies: Molecular and Cellular Targets*. More than 60 delegates attended the meeting and we left with a sense of optimism that phenomenal science is occurring and together we can tackle these complex issues.

Further, we have funded 62 grants to worthy scientists since our research program inception, as well as our continued support of three networks. Our total investment is \$14M and those scientists and networks have gone on to secure follow-on funding totaling \$74M for an infusion of \$88M in hydrocephalus research. And the impact of this funding is starting to take hold. While there are several stories of success, one recent result we are celebrating is the first-ever human clinical trial of a drug combination to prevent hydrocephalus after a brain bleed that is happening NOW. Even twenty years ago, we did not believe we would be talking about actual non-invasive therapies for hydrocephalus.

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 the QR code below.](#)

As we move through the holiday season and ring in another new year, I feel enormous gratitude for our scientists, healthcare providers, board members, staff, volunteers, and mostly YOU for believing and investing in our future.

Sincerely,

Diana Gray, MA  
President and Chief Executive Officer

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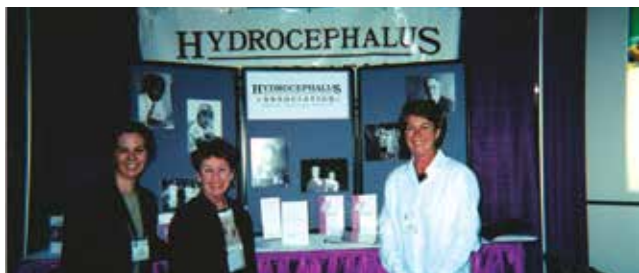


# Celebrating Our 40th Anniversary

40  
years

## Connecting With Our Past

In 1981, Emily and Russell Fudge's profound journey with hydrocephalus began when their son, Gerard Swartz Fudge, received a diagnosis at the age of 11. Not far from them, Cynthia Solomon's son Alex, 7 years old, had also been diagnosed with hydrocephalus. This was a time very different from today. In the early 1980s, there was no internet, leaving parents, patients, and loved ones to seek out the scant information available in medical books and from their doctors. There was no widespread public acknowledgment that the majority of shunts would need to be revised multiple times during a lifetime. There were no programmable or adjustable valves. There were no MRIs. There were no such people as Board Certified Pediatric Neurosurgeons and no Patient's Bill of Rights. And there was nowhere to turn for support and guidance.



Jennifer Henerlau, Emily Fudge, and Pip Marks beginning connections with neurosurgeons at the American Association of Neurological Surgeons (AANS) Meeting.

Both families were under the care of Dr. Michael S.B. Edwards, at the University of California San Francisco (UCSF). After Gerard's second shunt revision, Emily and Russell expressed their feelings of isolation and frustration, spurring Dr. Edwards and his neurosurgical nurse, Lori Howell, to host a few small, informal gatherings of his patients. Emily met Cynthia at one of the very first meetings and the seeds of the Hydrocephalus Association were planted. It was 1983.

In 1984, they decided to host a more formal meeting, asking Dr. Edwards to speak about hydrocephalus and invite a large number of his patients. At that meeting, they proposed the idea to create an independent, patient-focused organization with the goal of providing personal support for families affected by hydrocephalus.

It was met with great enthusiasm. With a \$1,000 grant from UCSF and Dr. Edwards, and organized out of the basement of the Fudge home by a dedicated core group of individuals that included Emily and Russell Fudge, Cynthia Solomon, Pip Marks, and Jennifer Henerlau, they set their early priorities. Namely, to connect individuals and to provide resources.

"We realized that as parents we were out here in the dark. We felt that someone needed to be interviewing doctors, doing research, and writing down information. Since no one else was doing it, we decided that it had to be us."

— Emily Fudge, Co-Founder

In 1986, the Hydrocephalus Foundation of Northern California was incorporated and received non-profit status. (Our name would change to the Hydrocephalus Association (HA) in 1991 to reflect our expansion and growth). In this same year, *About Hydrocephalus - a Book for Families* was published. These two events were significant in the future trajectory of the association because it served to connect two key stakeholders to the fledgling group. Namely, the families, who now had an invaluable resource about hydrocephalus, and the pediatric neurosurgeons, who had a trusted resources to help their patients.

The theme of connection became central to the formation of the association and the development of its programs. With the *About Hydrocephalus* book in hand, Emily, Cynthia, Pip, and Jennifer began attending the professional neurosurgical society meetings. By connecting with neurosurgeons, they were able to recruit the best doctors, many of whom were the pioneers of pediatric neurosurgery, to serve on a newly established

"We created a community where doctors talked to patients. The doctors came to our conferences. Seeing a patient talking to a neurosurgeon, one-on-one, at our conference was powerful. A neurosurgeon spent five minutes just talking to a family."

— Emily Fudge, Co-Founder



Medical Advisory Board (MAB). Soon doctors wanted to be involved with the association; it was an honor for them. This opened new avenues for collaboration, fostering partnerships between the association and the medical community, and ultimately enhancing understanding and support for individuals with hydrocephalus.



Jim Kranz, Pip Marks, Ralph Kistler, Russell and Emily Fudge at one of the first National Conferences on Hydrocephalus.

When Cynthia's son's shunt kept failing, she decided to call the manufacturer and spoke with Marvin Sussman, a vice president with Cordis. It was apparent that he cared deeply about these patients and Cynthia realized that industry partners brought great value to the association, as well. In the early days, an industry representative served on the Board of Directors. Now our relationships endure through support of and collaboration on our support and educational programs. Connecting the companies with the patient community allowed for an exchange of information and learning for both the patients and the company executives, and it deepened a commitment to improve lives.

The founding members had the foresight to connect the three key groups who could improve care for the patients, thereby creating a strong organizational foundation for HA. These early connections - connecting families to each other and connecting the medical professionals and industry representatives to the families - facilitated growth and reach into new areas where gaps existed, specifically, with the federal government and the scientific community. The first significant achievement in this area was Cynthia's tireless work to have hydrocephalus officially recognized by the National Institutes of Health (NIH) as an eligible condition to receive research funding. Since that time, HA has continued to serve as a catalyst for increased research dollars from NIH, other federal agencies, and the Department of Defense. We do this through direct advocacy as well as by connecting and inspiring scientists to focus on hydrocephalus through the Hydrocephalus Association Cynthia Solomon Resident's Prize, our various funding mechanisms, and the three research

networks. Those networks include the pediatric-focused Hydrocephalus Clinical Research Network (HCRN), the Adult Hydrocephalus Clinical Research Network (AHCN), and the HA Network for Discovery Science (HANDS).

Over the last 40 years, we grew as our mission grew, working through new connections to build an international reach and reputation in both the patient and scientific communities. Forty years ago, could this group of determined and committed individuals have imagined that the Hydrocephalus Association would become the nation's largest and most widely respected advocacy organization dedicated to hydrocephalus? We have brought on professional staff to work daily on our mission. We have a Board of Directors composed of business and legal professionals, entrepreneurs, and doctors, the majority with a direct connection to hydrocephalus as either individuals living with the condition themselves or loved ones. We have a Medical Advisory Board composed of 25 of the leading neurosurgeons, neurologists, neuropsychologists, neonatologists, and nurses. And we have deep relationships with both established and newly emerging industry partners who are working to improve the management of hydrocephalus.

At the core of all of these connections is the individual living with hydrocephalus, their family members, and their care providers. True to the initial intent, HA continues to bring the patient voice to every aspect of our work. And the staff honors the legacy of the founders by continuing to develop trusted resources for navigating the journey with hydrocephalus.



Visit our 40th  
Anniversary page on  
our website.

[hydroassoc.org/40thanniversary](https://hydroassoc.org/40thanniversary)

# HA's Founders and Visionaries

Meet the Founders and Visionaries of the Hydrocephalus Association - Trailblazers who ignited the path towards a brighter future for those affected by hydrocephalus. Their dedication and innovation have shaped our journey, and their legacy continues to inspire us.



**Emily and Russell Fudge**

Emily served as the Executive Director of the Hydrocephalus Association from 1989 to 2004. Russell served on the Board of Directors from its inception to 2013. Their son, Gerard, passed away in 1992. The first Hydrocephalus Association Scholarship was established in 1994 by the Fudge Family and their friends in memory of Gerard.



**Pip Marks**

Pip served as the Outreach Coordinator and then the Director of Support and Education from 1988-2012. She was a lifeline for countless families who called the association. She also raised awareness with the medical community for a greater understanding of hydrocephalus.



**Michael S.B. Edwards, MD**

Dr. Edwards was one of the first pediatric-focused neurosurgeons in California and provided the seed funds to support the Hydrocephalus Association so that patients could receive the information and support they need.



**Cynthia Solomon**

Cynthia was a nationally recognized health advocate who founded FollowMe™ (2000), a health information technology provider for vulnerable populations. Her entrepreneurial spirit drove many of the early accomplishments of the association.

# Celebrating Milestones and Empowering Hope at Our 40th Anniversary Gala

The Westin Anaheim Resort was ablaze with excitement and purpose on November 10, 2023, as the Hydrocephalus Association (HA) commemorated four decades of impact, dedication and support for our community at our 40th Anniversary Gala. The event brought together a diverse ensemble of researchers, physicians, industry partners, individuals living with hydrocephalus, their families, and esteemed supporters for an evening that blended celebration, gratitude, and a resounding call for progress.

The night unfolded with an atmosphere of warmth and socialization, fostering connections among attendees as they mingled and engaged in the silent auction, igniting the spirit of generosity right from the start.

The Gala program, steeped in reverence for HA's legacy, began with a touching video chronicling the history of the association. Embracing our founders and the visionary leaders who pioneered HA's journey, the video served as a testament to their tireless dedication and the impactful strides made over the years, while setting the stage for the work left ahead.



A heartfelt moment unfolded as Emily and Russell Fudge were honored for their invaluable contributions. Individuals living with hydrocephalus from their young teens to adulthood took the stage to express their gratitude for how HA has touched their lives and been uplifted by the Fudges' steadfast support and visionary leadership.

In a deeply moving tribute, the Hydrocephalus Association honored Cynthia Solomon, a cherished founder whose passing left a profound legacy resonating within our community. In recognition of Cynthia's strategic impact, HA



announced the renaming of the Hydrocephalus Association Resident's Prize to the *Hydrocephalus Association Cynthia Solomon Resident's Prize*, a testament to her remarkable character and contributions. Cynthia's son was invited to the stage, graciously accepting the honor. He shared the pride that his mother would have in the growth of the association and its vision for the future.



The evening continued with a delightful dinner, complemented by the excitement of a dynamic live auction. Attendees were captivated by a moving video presentation that showcased the poignant stories of families navigating life with hydrocephalus. The presentation was followed by Erin and Pieter Berger who shared their personal journey with the audience, offering a touching testament to the resilience and challenges faced by those living with hydrocephalus. Moved by the moment, actor Debbie Allen joined them on the stage to say a few words. The presentations emphasized the crucial need for advancements in treatments and emphasized the urgency of finding a cure, shining a spotlight on HA's central role as the primary force propelling research and fostering hope. A high-energy Fund A Cure paddle raise followed, where attendees united in a collective effort, raising funds to bolster HA's critical mission.





Closing the evening on a whimsical note was the performance by Justin Willman, creator and star of the Netflix hit *Magic for Humans*, whose blend of comedy and mesmerizing magic enthralled and captivated the audience, leaving a lasting magical impact.



The 40th Anniversary Gala was a testament to HA's steadfast dedication, uniting hearts and minds in a shared vision for a future free from the burdens of hydrocephalus. As the night concluded, attendees departed, carrying with them a renewed sense of purpose and resolve to continue the fight for advancements and hope.

In celebrating this milestone, the Hydrocephalus Association reaffirmed its pledge to persist in driving forward research, support, and advocacy, ensuring that every step brings us closer to a world where hydrocephalus is a thing of the past.



Watch our "Fund a Cure 2023"  
Video on YouTube

## Thank You to Our Gala Sponsors!

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# Introducing the Hydrocephalus Association Cynthia Solomon Resident's Prize



Cynthia Solomon understood very early that we needed to be connected with neurosurgeons, and that encouraging young neurosurgeons to pursue research would be beneficial. In 1988, she generated the idea of the Resident's Prize in Hydrocephalus to inspire neurosurgical residents

to engage in research. This prize is awarded each year to the most promising hydrocephalus-related research paper presented by a neurosurgical resident at the Pediatric Section meeting of the American Association of Neurological Surgeons. The prize is designed to encourage young doctors to focus their research efforts on advancing the treatment and care of individuals living

with hydrocephalus. Since its inception, 32 residents have been honored with the Resident's Prize and Cynthia herself funded the first five years of this prize. To honor Cynthia Solomon's strategic impact, HA has renamed this prize to be the Cynthia Solomon Resident's Prize in Hydrocephalus.



## Start your free will today!

### Questions?

Contact Linda Riley, National  
Director of Development  
[linda@hydroassoc.org](mailto:linda@hydroassoc.org)  
(240) 483-4475

## FREEWILL Make a Will, Make a Way

Your will is your way to protect your loved ones, ensure your wishes are honored, and even make an impact with your legacy. FreeWill's complimentary estate planning tool, accessible to all HA supporters, provides a straightforward and no-cost method for you to plan your estate according to your preferences.



The Fudge Solomon  
LEGACY SOCIETY

If you leave an estate gift to HA in your plans, you will automatically become a member of The Fudge Solomon Legacy Society. As a member of this society you will be recognized, if you 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.



## FEATURED ARTICLES

### New Board Members



**Kipp Coco**  
Senior Manager, Process  
Improvement, Sam's Club

Kipp Coco has worked for Walmart for over 17 years; he is currently the Senior Manager, Process Improvement at Sam's Club. He holds bachelor's

and master's degrees in supply chain and operations management from the University of Arkansas. Kipp lives in Bentonville, Arkansas, with his wife Amanda, children Jack and Emma, and their dog Trooper. He coaches youth sports, teaches at his church, and enjoys a variety of activities.

Kipp's daughter, Emma, was diagnosed with hydrocephalus and underwent a shunt placement at Arkansas Children's Hospital at three weeks old. Inspired by her journey, he brought the WALK to End Hydrocephalus to Arkansas and has been its chair for eight years. He also serves as a WALK Mentor to new chairs and a strategic advisor to HA's WALK team. Kipp is dedicated to the Hydrocephalus Association's mission of finding a cure and improving lives.



**Tammy Lee**  
Founder and CEO, Xena Therapies

Tammy Lee is the Founder and CEO of Xena Therapies, a Red Wing, Minnesota-based Class 1 medical device company specializing in FDA-registered wearable therapies,

Opal and ONYX COOL, with innovative plant-based cooling technology. She previously served as the President and CEO of Recombinetics, a biotech firm, where she successfully raised a \$34 million Series A round. Tammy has a strong background in executive leadership, having held senior positions in multinational companies like Carlson Companies and Delta Air Lines during the Northwest-Delta merger. She is an influential figure, named among Twin Cities Business Magazine's Top 100 People to Know in 2018.

Tammy holds an MBA from the University of St. Thomas and sits on the Board of Regents at Concordia College, her alma mater. Her daughter, Lissa, a sophomore at Concordia

College, shares her passion for healthcare breakthroughs, particularly for hydrocephalus, having been diagnosed with the condition at age 2 ½. She's had seven revision surgeries, but has been blessed with fast recovery and good outcomes.



**Jason Spears**  
CEO, Locust Cider

Jason is the CEO of Locust Cider, a beverage manufacturing and wholesale company he founded in 2015. His connection with the

Hydrocephalus Association (HA) began when his daughter Lucy was born with hydrocephalus. Locust Cider has contributed over \$100k to HA and local WALKs through sales percentages and customer donations.

Jason's background is diverse, having graduated with a mechanical engineering degree from the Colorado School of Mines. He previously worked for Ingersoll Rand, founded BSB Restaurants in Colorado Springs, and created the Colorado Springs Music Coalition. His experience also includes restaurant consulting, store development and design at Starbucks Coffee, and supply chain leadership in Starbucks' global expansion efforts.

Jason resides in Washington state with his wife Rebecca Spears and two children, Elliott (12) and Lucy (8). Lucy has bravely faced hydrocephalus and craniosynostosis, undergoing multiple surgeries, including a spinal fusion and VP shunt procedures.



To read about our full HA Board of Directors:

[hydroassoc.org/  
our-leadership-and-staff](https://hydroassoc.org/our-leadership-and-staff)

# The Hydrocephalus Association Earns a Prestigious Four-Star Rating from Charity Navigator



The Hydrocephalus Association is proud to share that we have earned a top-rated Four-Star status from Charity Navigator, one of the most trusted charity evaluators in the U.S. What does this mean for you and our mission?

Charity Navigator serves as the quality checkers for charities. For over 20 years, they've helped more than 11 million donors make smart choices about where to give their hard-earned money. They look at four important factors to measure how well a charity is doing its job. One of those is "Accountability & Finance." In simple terms, it means they check if we are using your donations wisely. Are we making sure every dollar goes to where it matters most, like finding a cure for hydrocephalus or improving the lives of those who live with it? The answer is a resounding "Yes!"

"We are delighted to provide the Hydrocephalus Association with third-party accreditation that validates their operational excellence," said Michael Thatcher, President and CEO of Charity Navigator. "The Four-Star Rating is the highest possible rating an organization can achieve. We are eager to see the good work that the Hydrocephalus Association is able to accomplish in the years ahead."

Being a Four-Star charity is a big deal. It's like Charity Navigator's gold star. With your support, we've become a strong national organization. We're the top resource for our community and the largest non-governmental contributor to

hydrocephalus research in the U.S. We're proud to be among the best charities in the nation.

"As we mark our 40th anniversary this year, achieving a Four-Star Charity Navigator rating serves as an additional affirmation of our steadfast dedication to sound governance and fiscal responsibility," remarked Diana Gray, President and CEO of the Hydrocephalus Association. "We aspire for this recognition to introduce our mission to fresh supporters, individuals who can join us in advancing our quest to discover a cure for hydrocephalus and enhance the quality of life for those affected by this condition."

So, what's the takeaway? When you donate to the Hydrocephalus Association, you can be confident that your money is making a real difference. It's helping us work towards a cure and improve the lives of those living with hydrocephalus. Thank you for being a part of our mission!



If you want to check out our rating and learn more about giving to our cause, you can visit [charitynavigator.org](https://charitynavigator.org)



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# Inaugural World Hydrocephalus Day Brings Increased Visibility to Hydrocephalus Awareness Month



On September 20, 2023, the world came together to observe the inaugural World Hydrocephalus Day, a day dedicated to raising global awareness about hydrocephalus and showing support for individuals living with this complex neurological condition. This designated annual awareness day garnered participation from

numerous countries worldwide, including Australia, Canada, Great Britain, Israel, Nigeria, and Sweden.

World Hydrocephalus Day welcomes all to unite in shaping a brighter future for those with hydrocephalus. Through heightened awareness, deeper understanding, and dedicated research funding, we can positively impact the millions touched by this condition.



For more information about World Hydrocephalus Day and how to get involved, please visit:

[hydroassoc.org/whd](https://hydroassoc.org/whd)





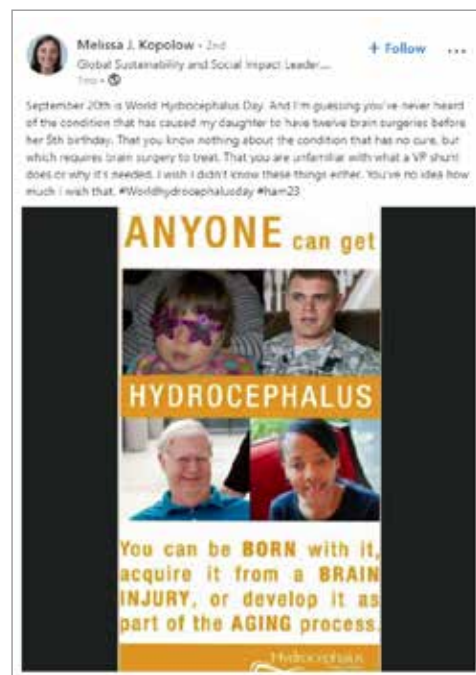
# Hydrocephalus Awareness Month (HAM) 2023

## September is Hydrocephalus Awareness Month and This Year's was a Resounding Success.

Our theme this year was "Take Control. Flip the Script." We invited those touched by hydrocephalus to share their authentic stories, defying limitations, and challenging the myths that surround the condition. HA complimented the stories by sharing valuable information and resources to highlight some of the ways in which this invisible condition impacts our daily lives and provides our community with support and answers.

Our community came through! We saw an increase in our impressions and engagements across social media. We are so thankful to our community for telling their own personal stories on these public platforms to help educate and raise awareness about hydrocephalus. We are also grateful to Congresswoman Abigail Spanberger (VA) and our Caucus Co-Chair Congressman Lloyd Doggett (TX) for their support by sharing our posts.

Through amplifying our diverse voices, challenging stereotypes, and fostering understanding, we helped reshape the narrative surrounding hydrocephalus.



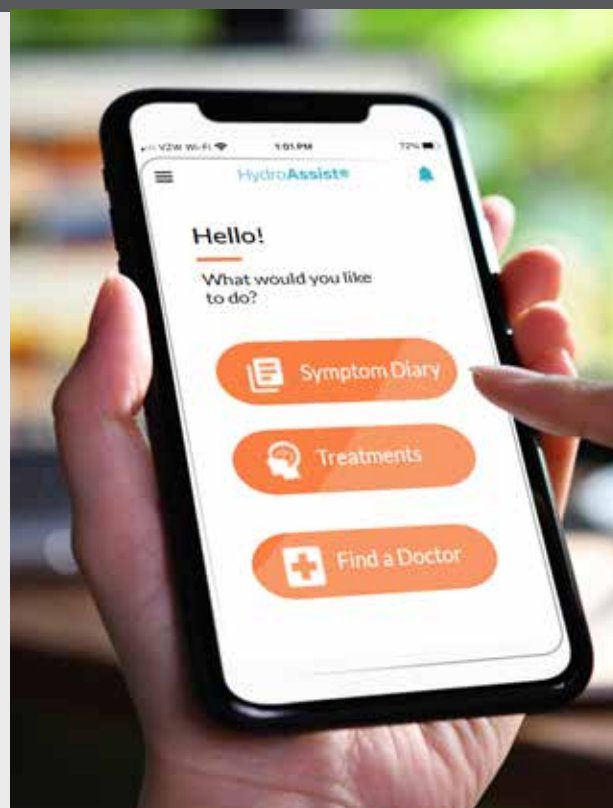
## DOWNLOAD THE HYDROASSIST APP!



# HydroAssist®

- ✓ Symptom journal
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**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!



# Welcome New Staff

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**Kate Bianchi**  
Digital Marketing Manager

Based in the metro Detroit area, Kate Bianchi is a dedicated marketing leader with over 15 years of experience educating audiences across the nation. As HA's Digital Marketing Manager,

Kate is responsible for managing the overall digital marketing strategy for the association, including tracking vital performance metrics, managing paid digital marketing channels, and social media properties. Kate is a devoted wife and mother of two. Her precious daughter, Alena, is a 3-year-old Hydro-Warrior, embarking on life's beautiful journey.

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**Davis Kaderli**  
Advocacy Engagement Manager

Davis is a recent graduate from George Mason University (GMU), where he received his bachelor's degree in government and international politics. He will

complete his Masters in Public Policy from GMU in June. As the Advocacy Engagement Manager, Davis is responsible for growing a grassroots advocacy network and strengthening HA's relationship with federal, state, and local lawmakers. Davis has legislative experience working in both the U.S. Senate and the House of Representatives. He also interned with the Tourette Association of America. Davis' own experience living with a neurological condition has inspired him to work in a space that creates stronger congressional representation for those with health challenges and disabilities.

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**Veronika Ross**  
Operation Manager and Executive Assistant

Veronika joined the Hydrocephalus Association in April 2023. She comes with over 15 years of management experience in the healthcare field. Veronika has

a passion for leadership and communication, especially in the non-profit sector. As the Operation Manager and Executive Assistant, Veronika is responsible for assisting and organizing the office, as well as completing projects and specialized tasks for the executive team. She has a bachelor's degree in English from the University of Maryland, College Park, and recently received her certification as an associate in project management. She currently resides in the suburbs of Maryland where in her free time she enjoys all outdoor activities as well as spending time with her 2-year-old son and husband.

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**Catrine Wilford**  
Research Programs Administrator

As the Research Programs Administrator, Catrine assists the National Director of Research Programs in a variety of tasks relating to HA's research initiative.

Catrine brings a wealth of experience and expertise to our organization, with a strong background in health program management. She has a proven track record of utilizing data visualization techniques to enhance the effectiveness of preventive health and safety programs, as well as collecting, analyzing, and interpreting data using a wide range of statistical techniques. Her analytical skills and proficiency in assessing the feasibility of healthcare programs are instrumental in driving our research programs forward and making a meaningful impact on the lives of those affected by hydrocephalus. Catrine enjoys traveling, taking care of her family and researching/keeping up with the latest healthcare/medical news.

# HA in Attendance

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

**National Health Council (NHC) Health Leadership Conference**  
Coral Gables, FL | February 7-9

**Defense Health Research Consortium Annual Meeting**  
Washington, DC | February 8

**National Health Council (NHC) Board of Directors Meeting**  
Washington, DC | March 28, July 25 & December 12

**American Association of Neurological Surgeons (AANS) Annual Scientific Meeting** | Los Angeles, CA | April 21 – 24

**Adult Hydrocephalus Clinical Research Network (AHCNRN) Meeting** | Salt Lake City, UT | May 19-20 & November 9

**Hydrocephalus Clinical Research Network (HCRN) Meeting**  
Virtual | June 1 & November 13

**International Federation for Spina Bifida and Hydrocephalus Annual Meeting**  
Virtual | June 7

**National Institute of Neurological Disorders and Stroke (NINDS) Nonprofit Forum** | Bethesda, MD | July 24-25

**Hydrocephalus Society Annual Meeting**  
Hamburg, Germany | August 25-28

**Congress of Neurological Surgeons Annual Meeting**  
Washington, DC | September 11-12

**Somewhere to Go: Identifying the Gaps in Care that Adults with Childhood-Onset Rare | Diseases Conference**  
Arlington, VA | October 19 - 20

**National Health Council (NHC) Washington Retreat**  
Annapolis, MD | November 16-17

**AANS/CNS Section on Pediatric Neurological Surgery**  
Oklahoma City, OK | November 28 - December 1



## Your Story Matters! 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 that traditional research can't. It's time to see the bigger picture!

## JOIN NOW

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



## Honoring our Legacy: Research

Hydrocephalus garnered minimal attention in research during the inception of the association in the early 1980s. The shunt became commercially available in the late 1950s and patients had a treatment that allowed them to live. Federal funding was scant, at best, as the urgency to save lives diminished. HA's earliest priority for research was to grow the research ecosystem by attracting scientists to the condition and by finding or creating the grant opportunities to fund their studies. In 1988, Cynthia Solomon spearheaded the annual Resident's Prize in Hydrocephalus, designed to encourage young doctors to focus their research efforts on advancing treatment and care of individuals with hydrocephalus. In 2005, HA forged a relationship with NIH when it played a pivotal role in initiating and presenting the NIH-sponsored workshop, "Hydrocephalus Myths, New Facts, Clear Directions." This groundbreaking event brought together diverse scientific and medical stakeholders to identify research

gaps and priorities, thereby extending our reach into the federal government and its funding mechanisms. The formal inclusion of research into HA's mission in 2009, permitted the organization to aggressively grow the research ecosystem by providing research grants directly to scientists through our various award mechanisms, and investing in the creation of two clinical research networks and one basic science network to move innovative research from an idea to a new treatments for patients.



See our Research milestones on our journey to shape the future.

[hydroassoc.org/history](https://hydroassoc.org/history)

## Research Workshop Entitled Developing Non-Invasive Therapies

More than 60 distinguished professionals gathered in Dallas, TX, for the 2023 Hydrocephalus Association and Rudi Schulte Research Institute (RSRI) Research Workshop *Developing Non-Invasive Hydrocephalus Therapies: Molecular and Cellular Targets*. This included scientists, educators, engineers, neurologists, neurosurgeons, and patients who came together to explore advancements in non-invasive hydrocephalus treatment research.

The workshop served as a catalyst for knowledge exchange and collaboration during the presentations of cutting-edge scientific findings. Understanding the root causes of

hydrocephalus and identifying molecular and cellular targets for therapy will bring us closer to new treatments.

"We are immensely proud of the strides made during this research workshop. The synergy of minds from various disciplines fuels our drive for meaningful progress in hydrocephalus research and patient care. There aren't many hydrocephalus treatment research groups out there, and we are leading the charge in non-invasive therapies."

— Monica Chau, PhD

National Director of Research, Hydrocephalus Association

Attendees engaged in robust discussions on the critical aspects of hydrocephalus research, with a focus on the following key areas:

#### Artificial Intelligence (AI), Machine Learning, and Big Data

Ongoing research endeavors in AI, machine learning, and big data were prominent as scientists learned more about the possibilities of these emerging technologies to enhance diagnosis, treatment, and management strategies for hydrocephalus.

#### Emerging Targets in Drug and Gene Therapies

Advances in the preclinical and clinical arenas of drug and gene therapies for hydrocephalus were shared. Presentations highlighted promising targets at various stages of development for the different etiologies of hydrocephalus.

#### How to Advance into Clinical Trials

Scientists currently conducting clinical trials shared their process in navigating the many steps required in initiating and conducting clinical research. Presentations on clinical trials past and present in hydrocephalus clarified the context and highlighted the remaining work needed.

#### Funders Panel

Representatives from governmental agencies including Jill Morris [National Institutes of Health (NIH) National Institute of Neurological Disorders and Stroke (NINDS)] and PJ Brooks [NIH National Center for Advancing Translational Sciences (NCATS)], and Cecilia Dupecher [Department of Defense Congressionally Directed Medical Research Programs (CDMRP)] spoke about their respective program's scopes and upcoming funding opportunities.



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TO HELP  
CREATE  
CHANGE.**

Family owned and operated since 2015, specializing in bold hard cider made with real ingredients, with a community of taprooms in Washington, Colorado, and Texas. A portion of our proceeds are donated to the Hydrocephalus Association, in support of a personal cause for owners Jason and Rebecca Spears whose daughter lives with hydrocephalus.



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# Announcing the 2023 Innovator Award Recipients

The Hydrocephalus Association Innovator Awards are a testament to the spirit of innovation within the scientific and medical community. They provide a platform for visionaries to turn their groundbreaking ideas into reality, offering the crucial seed funding and support. This year, we received a multitude of exceptional submissions from across the globe. These submissions were rigorously reviewed by a panel of experts who evaluated alignment with the Hydrocephalus Community Research Priorities, potential for transformative impact, and the promise of improving the lives of those affected by hydrocephalus.

The Innovator Awards are for one year of support at a \$50,000 level. The Hydrocephalus Association would like to extend a thank you to Team Hydro and the Rudi Schulte Research Institute for their generous support. Collectively, we were able to fund seven Innovator Awards.



**Tim Cherry, PhD**

*Assistant Professor of Pediatrics at the University of Washington*

**The MicroMRNA, MIR9 as a Network Regulator in Hydrocephalus**



**Maria Lehtinen, PhD**

*Professor of Pathology at Boston Children's Hospital*

**Cellular and Molecular Characterization of Human and Porcine Choroid Plexus to study Post-Hemorrhagic Hydrocephalus (PHH)**



**Mercedeh Movassagh, PhD**

*Associate Research Scientist at Yale University, Department of Neurosurgery (faculty role)*

**Improving Neonatal Hydrocephalus Diagnosis, Treatment, and Prevention Through Metagenomics and Genetic Characterization in Ugandan Cohorts**



**Ronald Parchem, PhD**

*Associate Professor of Molecular and Cellular Biology at Baylor College of Medicine*

**MicroRNA Regulation of Neural Fate Specification in Congenital Hydrocephalus**



**Andreas Rauschecker, MD, PhD**

*Assistant Professor at the University of California, San Francisco*

**Automated Volumetric Measurements for Early Diagnosis and Identification of Fetal Hydrocephalus Requiring Intervention**



**Jennifer M. Strahle, MD**

*Associate Professor of Neurological Surgery at Washington University in St. Louis*

**Amniotic fluid and CSF Factors Responsible for Hydrocephalus and Altered Brain Development in Myelomeningocele**



**Jonathan R. Sukovich, PhD**

*Assistant Research Scientist of Biomedical Engineering at the University of Michigan (faculty role)*

**Histotripsy for the Treatment of Hydrocephalus**



## Department of Defense Awards \$15.3M for Hydrocephalus Research

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Since 2015, hydrocephalus has been eligible to receive funding through the Peer Reviewed Medical Research Program (PRMRP) within the Department of Defense's Congressionally Directed Medical Research Program (CDMRP). The PRMRP funds research with the potential to further the development and implementation of medical devices, drugs, and clinical practice guidelines to improve diagnosis and treatment in healthcare settings. The goal is to accelerate research that will advance cures, improvements, and breakthroughs now.

The FY2022 funding total of \$15.3 million from the PRMRP marked the largest ever funding year for hydrocephalus-related research within the program. This is a significant increase in funding from past years and demonstrates the quality and caliber of research being put forward by the scientific community.

### Funding Highlights

Dr. Shenandoah Robinson and Dr. Lauren Jantzie will begin the first human clinical trial of a drug combination to prevent the development of hydrocephalus after a brain bleed. Recruitment has begun at Johns Hopkin's University in Baltimore. The initial trial will be in premature babies and the long-term goal is to apply this to the adult population, ultimately benefiting individuals across the age spectrum.

Drs. Robinson and Jantzie are also collaborating with Dr. Bonnie Blazer-Yost and Dr. Teri Beleck Adams at Indiana University, Indianapolis (IUI) to test the effectiveness of three drug combinations for three types of hydrocephalus - post-hemorrhage, congenital, and post-traumatic hydrocephalus. The goal is to prevent the development of hydrocephalus and to improve brain function.

Dr. Blazer-Yost received funding to support the establishment of a Hydrocephalus Research Center at IUI's School of Science. The goal of the center is to foster collaborative efforts in hydrocephalus research locally and globally and to train members of the next generation of hydrocephalus researchers. The center officially launched in October.

## UNDER PRESSURE

Campaign to accelerate the  
pace of hydrocephalus research

**Under Pressure: A Campaign to Accelerate the Pace of Research** is a national research campaign that is driving the development of non-invasive and/or one-time therapies, addressing the screening and diagnosis of hydrocephalus, and improving access to care and quality of life for patients.

Hydrocephalus knows no geographic boundaries, impacting countless individuals and families worldwide. Similarly, innovation can occur anywhere. Investors can be sure that they are putting their contributions toward research that will fill critical funding gaps and accelerate the pace of research, whether in your backyard, the U.S, or the world.

This research has been made possible because of your support in the Under Pressure campaign.

Please join us on this journey  
and take action today.

You may contact  
Linda Riley, National Director of  
Development, at (240) 483-4475, or  
[linda@hydroassoc.org](mailto:linda@hydroassoc.org), to make an  
appointment with our leadership  
team to learn more.

# SUPPORT AND EDUCATION

## Honoring our Legacy: Support and Education

Building a community and developing trusted information and resources to support families was - and still is - at the heart of the association. In 1983, the Neurosurgery Parent Support Group's inaugural newsletter set the tone for information dissemination, covering diverse topics like travel advice, blood transfusions, and fostering inclusivity with a teen-authored piece on celebrating differences. In 1986, HA released its first educational booklet titled "About Hydrocephalus – A Book for Parents," which became the first in a series of doctor-reviewed trusted publications offered for free to families. The first National Conference on Hydrocephalus convened in San Francisco in 1988, initiating a legacy of connecting medical professionals, industry partners, and affected individuals and loved ones. As teens thrived in high school, HA launched the scholarship program to support these youth in pursuing their dreams. In 1994, the Fudge Family Scholarship was

awarded in memory of Gerard Swartz Fudge. Listening to our community's needs grew our support and education programs, from the creation of our Physicians Directory in 1991 to a robust network of support groups across the country, to the launch of the first mobile app, HydroAssist, to manage patient care.



See our Support and Education milestones on our journey to shape the future.

[hydroassoc.org/history](https://hydroassoc.org/history)

## New Educational Resources

The Support and Education team is committed to providing up-to-date trusted information to meet the needs of our community. We've enhanced our existing website content to provide newly updated articles. These include updated information in 'What is Hydrocephalus?', 'Hydrocephalus in Pregnancy,' 'Hydrocephalus in Infants and Children,' 'Shunt Systems,' and 'Shunt Complications.'

Other updated areas to explore include Research and Advocacy. Learn how you can participate in research under 'Get Involved in Research.' If Advocacy sounds exciting, we have revamped our Advocacy area to get you to the resources you need to engage with your elected officials.

Stay tuned for more exciting updates! We're revamping our 'Adults with Hydrocephalus' and 'NPH' articles, and much more. Keep coming back to our website for the latest and greatest!

## New Video About Hydrocephalus!



Experience hydrocephalus like never before in our newly released video. Learn about the condition, treatment methods, and how to spot signs and symptoms of complications.

# 2023 Virtual Conference on Hydrocephalus

The Hydrocephalus Association successfully piloted its Virtual Conference on Hydrocephalus, HA CONNECT, from November 3-5, 2023. This innovative event brought together participants from six different countries, including medical professionals, researchers, patients, and family members, marking a unique addition to an off-conference year.

The virtual conference ran over three days, for two to five hours each day. Friday opened with networking sessions for our community to connect. The educational core of the conference took place on Saturday over a five hour period. Sunday wrapped up with an interactive online Kids Camp for our youngest attendees. One striking observation was the notable increase in adult participation, constituting more than 50% of all registrants. This demographic shift underscores a changing trend, showing greater engagement from adults living with hydrocephalus. Our programming reflected the topics requested most by this demographic.

While the conference featured cutting-edge research, showcased by Dr. Young-Kwon Hong's insights into potential treatments for abnormal brain fluid accumulation, the standout sessions were our lifestyle-focused ones. These sessions provided patients and their families with invaluable advice, essential tools, and effective strategies for navigating the challenges of school and work. Additionally, the conference recognized the importance of addressing mental health in the context of hydrocephalus.

As we reflect on the event, we are grateful to our speakers and to all those who attended. Our virtual HA CONNECT allowed us to evaluate the interest in multi-day and multiple hour events. The feedback we collected has also played a pivotal role in shaping a more comprehensive program for our upcoming in-person conference. We eagerly anticipate your participation in Tampa and the exciting possibility of welcoming some of our virtual speakers to the in-person event.

We would like to thank our sponsors for supporting our virtual conference: **Medtronic, Codman Specialty Surgical, an Integra Life Sciences Company, and Anuncia.**

## 2023 Conference Program

### ETV and ETV/CPC

Abhaya Kulkarni, MD, PhD, FRCSC  
and Benjamin C. Warf, MD

### Going to College

Annie Tulkin, MS

### How to Manage Hydrocephalus in the Workplace

Preston Calhoun, PHR, SHRM-CP and Jennifer  
Thomas, FPC

### IEP Strategies and Dealing with the School System

Ashley VanCleeef, Esq and T. Andrew Zabel, PhD, ABPP

### Mental Health and Hydrocephalus

Katherine McClure, LMSW, MAPP

### The NPH Road to Recovery

Nickolas Dasher, PhD, ABPP  
and Michael A. Williams, MD

### Testing a Potential Treatment for Reducing Abnormal Brain Fluid Accumulation

Young-Kwon Hong, PhD

### My Shunt is Failing: What Happens Next?

Lauren Barbieri, CRNP and  
Jennifer Marshall, MSPAS, MSJ, PA-C

## Virtual Kids Camp

Our Virtual Kids Camp captured the attention of our youngest learners. Children actively engaged in online activities led by HA's Support Program Manager, Lakisha Harris, and HA Board Member, Pam Finlayson. They explored the intricacies of the brain, learned all about germs, and even had the opportunity to create their own song with the team from Hear Your Song. Additionally, they enjoyed an exciting live virtual tour of Dr. Carolyn Harris' Research Lab.



# HACONNECT

**July 25-27th, 2024**

**18TH NATIONAL CONFERENCE ON HYDROCEPHALUS**

Tampa Marriott Water Street | Tampa, Florida

Join the largest worldwide online conference about hydrocephalus!

**Mark your calendar - registration and financial aid opening soon.**



## Why Attend

Expand your awareness about hydrocephalus from leading experts and peers.



## Who Attends

Open to everyone impacted by hydrocephalus from patients and families to medical professionals.



## Learn

Offering more than 70 interactive sessions, learning labs, research updates, and plenaries.



**Stay Connected. #HACONNECT**



To learn more and register visit [hydrocephalusconference.org](https://hydrocephalusconference.org)

# Magic Happens at Educational Events

The Hydrocephalus Association partners with hospitals around the country to host full or half day education events. This year the association has partnered on four events that provided information and much needed connection to the local communities.

## Southern California



Across the street from Disneyland, HA partnered with Dr. Michael Muhonen, Children's Hospital Orange County, to host an educational event infused with both information and laughter. The day brought together speakers from across Southern California and representatives from Medtronic, Codman, and Anuncia to interact with the attendees. Our youngest participants got a surprise visit from Choco, the CHOC bear, and Minnie Mouse!

The event culminated in a presentation on The Power of Laughter by Dr. Muhonen. Laughter has been proven to have therapeutic abilities. Dr. Muhonen showed the value of laughter on our medical journey. With a smooth delivery of jokes and leading the audience through "Guided Laughitation," he had the audience laughing out loud... laughter is contagious!

The day ended with a beautiful musical performance by Will Gunnell dedicated to his son, Chrisno, who he and his wife Darlene adopted from Haiti. To keep the music going, Sophia DeAraujo from Anuncia led a dance competition with the kids while the adults mingled and chatted with the doctors, exhibitors, and HA team.

Thank you to all of the doctors who joined us in Anaheim to engage with our community.

## Let's Talk About Hydrocephalus

Dr. Michael G. Muhonen, Children's Hospital Orange County

## Journey Through the Brain

Dr. Brian W. Hanak, Loma Linda University Medical Center

## Shunt or ETV: Choosing a Treatment

Dr. Peter Chiarelli, Children's Hospital Los Angeles

## Why Do Shunts Fail?

Dr. Michael Levy, Rady Children's Hospital

## Living with Hydrocephalus Ask the Expert Panel

Dr. Joffre Olaya, CHOC

Dr. Aria Fallah, UCLA Mattel Children's

Dr. Mark Luciano, Johns Hopkins

## To Infinity and Beyond! Advances That Will Change the Future

Dr. Ramin Eskandari, Medical University South Carolina

Dr. Leandro Castaneyra-Ruiz, CHOC





## Washington, DC



**Children's National**™

HA partnered with Children's National Medical Center on April 15 for their annual Living with Hydrocephalus event. Dr. Daniel Donoho, pediatric neurosurgeon, provided a general overview of hydrocephalus, treatment methods and ongoing management of care. He even took a little deep dive into how artificial intelligence will change medicine. He was followed by Dr. Hallie Morris, neonatologist, and Dr. Tayyba Anwar, neurologist, who led a conversation on our experiences of first learning of our children's diagnoses and explored how our children have done. The community enjoyed an interactive panel of patients of all ages who shared their experiences before the attendees broke into groups to connect with each other.



## Columbia, SC



HA partnered with Prisma Health on April 29 for a half day educational event. Dr. Catherine McClung-Smith, pediatric neurosurgeon, provided a general overview of hydrocephalus and then opened the floor for an active question and answer session. Then parents got to deep dive into IEPs and 504 plans with an education specialist from the Richland County School District 2 who provided tips on how to effectively advocate for a child in the school system.



## Neptune, NJ



Dr. Lawrence Daniels of the New Neurons Neurosurgical Institute hosted his Annual Hydrocephalus Symposium at Hackensack Meridian Health on September 16. The day delivered an international panel of speakers covering pediatric to normal pressure hydrocephalus. The event was capped by two inspirational speakers. Carly Weisman, our very own Jersey Shore WALK to End Hydrocephalus Chair, shared her journey with hydrocephalus followed by Julian Drucker, a world recognized musician who is living with hydrocephalus. His band joined him and treated the audience to a mini-concert to end the event.





# Announcing our 2023 Hydrocephalus Association Scholarship Recipients

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The Hydrocephalus Association is pleased to announce the 2023 Hydrocephalus Association Scholarship Award Recipients. Since the scholarship program was established in 1994, HA has awarded 253 scholarships to future leaders of our community. 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. We are proud to honor these remarkable young adults.



**Amanda Arvelo**  
Recipient of the Baldus Family  
Scholarship in Memory of Gerard Swartz  
Fudge

Amanda was diagnosed with hydrocephalus at just three weeks old.

Despite missing countless days of school and enduring numerous health challenges, she pursued an aggressive high school academic workload that included college-level courses and advanced placement classes. She also was the captain of the varsity volleyball team, involved in track and field, played the viola in her school's orchestra, and was a member of prestigious honor societies such as the National Honor Society, Math Honor Society, and Tri-M Music Honor Society.

A pivotal turning point in Amanda's life occurred during eighth grade when she underwent three shunt revisions. These experiences exposed her to the work of healthcare professionals and the intricate science behind her medical care. In high school, she eagerly sought opportunities which included internships, shadowing her neurosurgeon, and she

is working with a resident to help write a research paper on the effective techniques of tapping shunts. Amanda plans to continue her education as a student at Johns Hopkins University where she is majoring in molecular and cellular biology.

*"In the future, I hope to use my ability to relate to patients and their families by working in a pediatric intensive care unit and doing research on the effect that hydrocephalus has on children."*



**Anya Behringer**  
Recipient of the Hydrocephalus  
Association Scholarship, Supported by  
Erik & Lisa Chamberlain

Anya, diagnosed with hydrocephalus at just 15 months old, has displayed

remarkable perseverance throughout her life. Her journey has been marked by routine neurosurgery checkups, MRIs, and medical tests. Relentless headaches and migraines accompanied her condition. These physical struggles took a toll on her mental health, leading to more school absences than usual. Despite these challenges, she remained steadfast in her commitment to academic excellence and was active in school clubs, including the National Honor Society and Rho Kappa social studies honor society. Additionally, she served as the senior editor for her high school's literary magazine.

Her true passion lies in animal behavior, training, and welfare. Her commitment to improving the well-being of animals and their human companions is evident through her impressive record of over 1,000 hours of community service at local animal shelters and a nearby dog rescue. She is currently pursuing a bachelor's degree in animal behavior and political science at Carroll University, a choice influenced by her proximity to the cherished dog rescue. Anya aspires to a career focused on enhancing the lives of animals and their human caregivers. She is equally dedicated to raising awareness about hydrocephalus, furthering her mission to support those impacted by the condition.

*"I will always do my best to not let hydrocephalus negatively affect my goals, aspirations and relationships with friends and family. I want to be able to raise awareness for hydrocephalus while also proving that it does not have to define or limit my success and dreams."*



**Aparna Srinivasan**  
Recipient of the Gerard Swartz Fudge  
Memorial Scholarships

Aparna's journey has been defined by her remarkable resilience in the face of hydrocephalus, a condition that

has shaped her life. Throughout her undergraduate years, she confronted multiple revision surgeries, challenging the delicate balance between her studies and health. She received multiple academic honors and scholarships for her outstanding performance. She has also excelled in leadership roles within student organizations, showcasing her ability to make a positive impact in her community.

Aparna's diverse talents span music, theater, and art, complemented by her degree in neuroscience and psychology from Vanderbilt University. Now on the path to becoming a physician at Meharry Medical College, her personal experiences with congenital hydrocephalus fuel her dedication to helping others. As a board member of Project Sunshine, she volunteers at Vanderbilt Children's Hospital, offering comfort and support to children facing extended hospital stays.

Aparna actively engages in the hydrocephalus community, participating in events like the Chicago WALK to End Hydrocephalus and attending Hydrocephalus Association conferences. Her journey reflects resilience, self-advocacy, and empathy, qualities that drive her goal of becoming a psychiatrist and providing compassionate, patient-centered care.

*"My experiences cultivated a passion for the art of medicine in me, to be an advocate, and to be compassionate and supportive for those combating illness and disability."*



**Audrey Labbe**  
Recipient of the Morris L. and Rebecca  
Ziskind Memorial Scholarships

Audrey has faced and overcome significant challenges in her life. She courageously battled cancer and a brain

tumor, which ultimately resulted in acquired hydrocephalus. Her journey is a testament to her exceptional resilience and determination. In addition to her personal triumphs, Audrey is a passionate advocate for environmental conservation. She serves as the soil and land use specialist on her Envirothon

team, demonstrating her commitment to protecting our planet. Beyond her academic pursuits, Audrey is deeply engaged in fencing and education, teaching at the American Robotics Academy. She possesses a deep love for nature, having explored 26 national parks and monuments and earning her Junior Ranger certification.

Audrey's educational and career aspirations are deeply rooted in her twin passions for engineering and environmental conservation. She envisions a future in mechanical engineering where she aims to lead the development of sustainable technologies, prioritizing energy efficiency and eco-friendly materials. As she embarks on her academic journey at The University of Texas at Austin, majoring in mechanical engineering, this scholarship will provide invaluable support.

*"I look forward to working with peers, developing ideas, and gaining experience that will help me become productive in the field of engineering and progress toward my goal of helping to preserve the planet."*



**Connor Youngren**  
Recipient of the Morris L. and Rebecca  
Ziskind Memorial Scholarships

Connor's life has been profoundly shaped by his own encounter with hydrocephalus, which instilled in him a

sense of resolve. His family's steadfast support, especially from his mother, has been a pillar of strength throughout this challenging journey. This experience has kindled his passion for auditory health, a deep commitment to community service, and a mission to raise awareness about hydrocephalus.

Connor aspires to become a role model and supporter for children with hearing challenges, drawing inspiration from his own experience. He hopes to pursue a doctorate in audiology, focusing on pediatric audiology, at Western Washington University. He also harbors an interest in research, particularly in cochlear implantation and early language and literacy development in children with hearing loss. Committed to assisting others with hydrocephalus, Connor intends to persist in advocacy and outreach efforts while working towards a career in audiology, where he can provide essential care and support to those affected by the condition.

*"I'm driven to pursue a degree in audiology to be a figure of inspiration to others. I see myself serving as a role model and supportive figure to other children just like the ones I had."*



**Dalja Parks**  
Recipient of the Kate Finlayson  
Memorial Scholarship

Hydrocephalus has indelibly marked Dalja's life, diagnosed during her teenage years as a result of complications from brain cancer treatment. Multiple surgeries and shunt revisions were part of her formidable struggle, but she persevered in her academic pursuits, even while undergoing chemotherapy. Excelling in a rigorous high school course load with several AP classes, she showcased her determination and academic excellence despite her health battles.

Dalja's resolute commitment to community service is evident through her active involvement with organizations like Make-A-Wish and Cancer for College. These experiences, inspired by the support she received during her health challenges, have propelled her toward a future in pediatrics. She co-founded Student Advocates for Interdisciplinary Learning (SAIL), an organization dedicated to assisting students facing educational disadvantages, and volunteers at a free clinic in Pacific Beach, ensuring access to essential medications.

With a goal of becoming a hematologist/oncologist or an endocrinologist, Dalja hopes to serve underserved communities, offering mentorship, resources, and healthcare services while emphasizing the importance of diversity and raising awareness about healthcare disparities. She is poised to make a significant impact in the medical field and the lives of those she serves.

*"My goal is to spark change in health systems by making them more accessible and responsive to the community's needs, fostering trust and stronger physician-patient relationships."*



**Doug Kozik**  
Recipient of the Justin Scot Alston  
Memorial Scholarship

Doug's life took an unexpected turn with a hydrocephalus diagnosis during his first high school basketball season, stemming from a brain tumor diagnosis. This condition has posed significant challenges, impacting his education, career

aspirations, social interactions, and overall well-being. His family, especially his neuroscience-studying older sister, has provided unconditional love and support throughout this journey, which included numerous surgeries and disruptions to his high school athletic career. Doug's inner strength and personal growth have enabled him to overcome these obstacles, achieving high honors and regaining confidence and physical abilities.

One standout achievement in Doug's life is his family's commitment to organizing two successful Hydro Warrior Golf Tournaments, raising over \$25,000 for HA and increasing awareness about the condition. Doug remains actively involved in planning this year's tournament to uphold the tradition of support and advocacy. His potential career paths include business, with a focus on commercial real estate finance and entrepreneurship, or a career in sports psychology, drawing from his personal experiences. Doug's personal experience with hydrocephalus motivates him to seek ways to make a positive impact, including participation in clinical studies for early shunt failure detection to ease the anxiety faced by individuals with hydrocephalus and their caregivers. He is determined to inspire others, demonstrating that they can overcome challenges and lead fulfilling lives, just as he aims to do.

*"While my journey to this point has been challenging, I persevered. I am a survivor. I am prepared to handle any challenge thrown my way. I am excited to see what my future holds."*



**Jayne Crouthamel**  
Recipient of the Gerard Swartz Fudge  
Memorial Scholarships

Jayne's path has been defined by resilience, academic dedication, and a deep commitment to disability rights and the hydrocephalus community. Diagnosed with hydrocephalus before birth, she has undergone 14 brain surgeries stemming from this condition. Despite these difficulties, Jayne's determination has propelled her to pursue a major in neuroscience and a minor in Spanish at Washington University in St. Louis. She actively engages in hydrocephalus research, with the goal of attending medical school for an MD/PhD to enhance treatment options and improve the lives of those affected.



As a prominent member of her college's executive board for disability advocacy, Jayne collaborates with other organizations to address accessibility concerns, particularly in areas like accessible clothing. Her dedication to the hydrocephalus community is evident through her participation in HA's National Conference on Hydrocephalus, HA CONNECT, her local WALK to End Hydrocephalus event, and her Instagram account dedicated to raising hydrocephalus awareness.

Jayne's passion for neuroscience and disability advocacy, coupled with her personal experiences with hydrocephalus, fuels her commitment to creating a meaningful impact. Her vision promises a future of innovation and support for the community.

*"I hope to contribute to hydrocephalus research in a way that improves the public understanding of the condition and enhances treatment options. My aspiration is to one day establish my own laboratory, dedicated to advancing knowledge about hydrocephalus and finding better treatment options."*



**Landon Kohlhoff**  
Recipient of the Mario J. Tocco  
Hydrocephalus Foundation Scholarship

Landon's journey has been a testament to his relentless spirit, beginning with his diagnosis of hydrocephalus in infancy

and multiple brain surgeries. He is a multifaceted individual, and his interests span a wide spectrum, from experimenting with new recipes in his kitchen, playing the piano, or delving into the world of Computer-Aided Design (CAD). His goal is to pursue a career in architecture, supported by his CAD skills and hands-on project involvement.

Throughout his high school journey, Landon learned to navigate the educational landscape while dealing with the challenges posed by hydrocephalus, including memory issues and difficulty following verbal instructions. He also had to learn to cope with anxiety and the daunting task of accepting physical differences, such as his head size and scars. Over time, he embraced his uniqueness and became an advocate for self-acceptance. He also dedicated free time to serving others in his small hometown.

As he begins his college journey at Glen Oaks Community College, Landon remains dedicated to his educational and

career aspirations. He plans to continue to raise awareness about hydrocephalus and other neurological conditions through educational talks.

*"I want to encourage people with any brain condition, that you can still do amazing feats and there are no limits to what you can accomplish. Work hard and success is possible."*



**LaSaundra Criswell**  
Recipient of the Jacobsen Family  
Scholarship

LaSaundra's journey has been characterized by remarkable fortitude and an abiding love for the performing

arts, notably choral ensembles and theatrical performances. Growing up in a sports-centric school environment, she faced difficulties in making friends due to her lack of athletic abilities and the fears associated with her medical condition. Additionally, coping with the uncertainty of shunt malfunctions often led to hospitalizations and the need to miss important social events. She overcame these hurdles by finding solace and confidence in the performing arts, which allowed her to express her true self. Actively participating in her school's music and theater programs, her leadership qualities shine through her role as a Lindblom Teaching Assistant, mentoring fellow curriculum choirs.

LaSaundra is actively involved with HA. Participating in the local annual WALK to End Hydrocephalus opened her eyes to the significant impact of the condition on the community. This motivated her to organize events such as snack sales and hydrocephalus-themed game nights to raise funds and awareness. She has also been part of a documentary that highlights the challenges of living with medical conditions like hydrocephalus, with the aim of erasing the stigma associated with them.

LaSaundra's educational and career aspirations are intertwined with her love for the performing arts, aiming to major in theater and use her career to inspire inclusivity and contribute to the community.

*"Through my career in the entertainment industry, I hope to eventually expand my documentary further and give back to the community on a larger scale. This way, other kids like me will see that they are not alone."*



**Madeline Hommel**  
Recipient of the Anthony Abbene Scholarships

Madeline Hommel, an aspiring orchestra teacher, has been deeply shaped by her enduring passion for music and her perseverance in the face of hydrocephalus. Proficient in various string instruments, including the cello, violin, viola, and string bass, she has not only excelled in her musical pursuits but also surmounted the physical challenges posed by her medical condition. For Madeline, playing the cello transcends a mere musical endeavor; it serves as a therapeutic outlet, providing comfort through the intricate muscle movements required for the instrument.

Outside the realm of music, Madeline cherishes her dog's company, enjoys running, and nourishes her curiosity with fun facts and knowledge. As a college senior with plans to pursue graduate studies next year, her goal is to become a certified K-12 music teacher in New York. Her dream role is to teach orchestra in middle or elementary school settings, emphasizing inclusivity and support for students with diverse needs and abilities.

*"The message that I want to instill in my students and my peers is that you genuinely have the capability to achieve anything you set your mind to. If you put forth your best effort, you can reach your desired destination."*



**Seamus Morrison**  
Recipient of the Anthony Abbene Scholarships

Seamus' journey through the challenges of hydrocephalus unearthed his passion for language, poetry, and assisting others. Overcoming a malignant brain tumor surgery at age 10 and enduring numerous health struggles, Seamus has emerged as a compassionate and resilient individual, reshaping his life choices toward language, literature, and education.

These trials have served as a wellspring of inspiration. Seamus attended a transformative 10-day writing conference, honing his skills as a writer and a poetry teacher. Yet, the most fulfilling role he's embraced is as a poetry workshop facilitator for brain tumor survivors. Week after week, he guided these survivors through poetic

exploration, witnessing their remarkable creativity as they expressed their challenges and experiences.

Seamus's academic journey led him to major in Spanish and ignited a commitment to Teaching English to Speakers of Other Languages (TESOL). Seamus will pursue his master's degree in TESOL at Pepperdine University. He envisions teaching and empowering immigrant students in the U.S., bridging language gaps, and fostering better understanding, ensuring that everyone finds their voice.

*"I mentor teen and young adult brain tumor survivors at a summer camp in Montana. Giving back to this community has given me a profound sense of gratitude for my condition, while at the same time inspiring me to work harder to improve life for other brain tumor survivors."*

## PEN PAL PROGRAM

### For Kids Ages 7- 12

The Pen pal program is designed to support kids ages 7- 12 in finding real and lasting friendships with others that understand the journey with hydrocephalus.

If your child would like a pen pal or to become a pen pal volunteer, submit a pen pal request on our website to get started.

**IT'S VERY EASY TO GET CONNECTED!**



[hydroassoc.org/penpalprogram](https://hydroassoc.org/penpalprogram)

## My Husband's NPH Diagnosis Journey

*Written by John's wife, Sukey Jamison, in July 2023*



Day by day, I try to imagine how these past six months may have unfolded differently. There are so many ways it could have gone wrong. John went

from a carefree sheep farmer looking at retirement late last summer to wheelchair-bound in a matter of weeks, looking for a diagnosis of brain malfunction by Christmas. Was it all good? Not necessarily, but in the end, we had the best result we could have hoped for. Was it easy? There is nothing easy about day-to-day living with and watching the one you love and have devoted your life to deteriorate in front of your eyes in a slow and steady daily decline. Ever hopeful, I held on to the dream that we would get through this dark tunnel, in hopes that at the end of the tunnel, there was not a train.

NPH was the suspected diagnosis early in October 2022, but there were questions about that due to the sudden onset of symptoms. Parkinson's was ruled out due to the suddenness of symptoms. Tumors and cancer were ruled out also after CT scans and MRIs. We had to go through the proper medical channels, exercises, and regimens pertaining to getting an accurate diagnosis with blessings of insurance. Thank goodness for insurance! After numerous doctor visits, CT scans, MRIs, and bloodwork, we secured a scheduled hospital visit at the Cleveland Clinic on January 9, 2023.

This whole drama began to unfold in mid-September. October turned into November, which led to the December holidays with little celebration as my job as sole caregiver was to keep him safe – Do Not Fall! By December 27th, I knew from John's debilitated condition (he was now wheelchair-bound) that he could not make it to January 9th. We went to Forbes Hospital ER, knowing we could wait hours for service. When we drove up to the entrance to the Emergency Room, the security guard met us at the car and said, "You might want to go somewhere else! We have just had a shooting!" I said, "Truly, I have nowhere else to

go." So, he said to pull around, and they would be out to help us in a few minutes, which they did. We did wait over 5 hours in the waiting room and then another 10 hours in an annex before he was finally admitted to the Hospital. The treatment that followed was professional and expert, as we had prayed and hoped for. The first procedure scheduled for Friday, December 30, was a lumbar puncture to determine if a shunt would be a feasible treatment. As scheduled, the procedure was done on Friday, and John showed slight improvement. He was more alert and communicative almost immediately. The shunt was scheduled for Tuesday, January 3, 2023, with PT, OT, and ST on standby after establishing a baseline, then checking in daily to monitor John's progress. The first sessions were painful to watch. We were all hoping for improvement, which did begin to show after the surgery for the shunt.

John was in the hospital for a few days on floor five and then was moved to floor seven for rehabilitation. He stayed at Forbes Hospital for almost three weeks. Improvement was monitored daily by all involved, and it was truly miraculous. Progress on walking was slow but steady. We kept reminding him that three months of decline could not be rectified in a few days. We were looking at months to regain his strength, but what are a few months when the results could have gone without improvement? It is a miracle, thanks to God and the doctors, nurses, PT, OT, ST, and everyone helping with his diagnosis.

It is now spring, and John is mobile again, walking without help and regaining strength and mental capacities, as we all can say, "better every day!" We don't have sheep anymore. At my low point, I sold our 300 + sheep, realizing I had to devote all my time and energy to my one little lamb. We will decide where we go from here once John is back on the tractor again. It has been a long winter, and we look forward to a healthy, happy, carefree summer!

If you or a loved one is living with NPH, visit our [website](https://hydroassoc.org/about-normal-pressure-hydrocephalus). You will find a section full of helpful resources.



# Community Networks

Our Community Networks, also known as support groups, provide localized and online support, education, and empowerment through community. Our network hosts educational events, support group meetings, and other

gatherings that enable individuals and families to connect. It's important to know that you're not alone on your journey with hydrocephalus. Find your local group on our website [hydroassoc.org/find-a-community-network](https://hydroassoc.org/find-a-community-network)

## National Virtual Meetups

### TEENS

#### Teens Hang-Out

**When:** 1st Sunday of the month

**Contact:** Elizabeth Holthouse, Olivia Maccoux, and Tomas Rodriguez, Teen CN Co-Leaders

**Email:** [info@hydroassoc.org](mailto:info@hydroassoc.org)

### ADULTS WITH HYDROCEPHALUS

#### Breaking Barriers Men's Talk (Adults 19 and older)

**When:** 4th Wednesday of the month

**Contact:** Alex Trujillo, Peer Support Volunteer and Group Lead

**Email:** [mensgroup@hydroassoc.org](mailto:mensgroup@hydroassoc.org)

#### Young Adults in their 20s Meet-Up

**When:** Every Saturday

**Contact:** Lauren, Kaitlyn, Ian, Elizabeth, Genesis, MacKenzie, and Aparna, 20s CN Co-Leaders

**Email:** [info@hydroassoc.org](mailto:info@hydroassoc.org)

#### 30ish-Living Life to the Fullest HANG-OUT

**When:** 3rd Sunday of the month

**Contact:** Dani Lucchese, Sara Stottler, and Janay Harris, 30s CN Co-Leaders

**Email:** [info@hydroassoc.org](mailto:info@hydroassoc.org)

#### Flourishing in Mid-Life: Group for Women Age 40-65

**When:** 4th Thursday of the month

**Contact:** Patricia (Patty) Jillson and Lynn Beirl, Group Co-Leaders

**Email:** [info@hydroassoc.org](mailto:info@hydroassoc.org)

### PARENT'S GROUPS

#### Parents of Middle School Age Children Group

**When:** 2nd Tuesday of the month

**Contact:** Susan Fiorella and Sonja Niemi  
**Email:** [info@hydroassoc.org](mailto:info@hydroassoc.org)

#### Parents Supporting Parents of Adult Children with IDD

**When:** 3rd Thursday of the month

**Contact:** Jackie Mullock, PA Community Network Leader  
**Email:** [easternpacommunity@hydroassoc.org](mailto:easternpacommunity@hydroassoc.org)

### FAMILY AND RELATIVES GROUP

#### L1CAM Family and Relatives Meet-Up

**When:** Every 3 months on the 3rd Tuesday of the month

**Contact:** Alison Kandrov

**Email:** [info@hydroassoc.org](mailto:info@hydroassoc.org)

### NPH

#### National NPH Meet-Up

**When:** 3rd Wednesday of the month

**Contact:** Gary Chaffee

**Email:** [dallasnphcommunity@hydroassoc.org](mailto:dallasnphcommunity@hydroassoc.org)



For a complete list of  
HA events online

[hydroassoc.org/events](https://hydroassoc.org/events)

## Honoring our Legacy: Advocacy

Our advocacy journey began in the late 1990s, initially representing the patient community at select federally-hosted events. This included a significant presentation at the Federal Drug Administration (FDA) sponsored conference titled *Shunt Technology: Challenges and Emerging Directions*. However, it wasn't until 2004 that we began solidifying our advocacy strategy, laying the groundwork for the first NIH-sponsored workshop on hydrocephalus in September 2005. This workshop was pivotal, raising the profile of the condition's needs within the NIH framework.

In 2006, our inaugural Hill Day saw over 120 advocates converging on Capitol Hill, marking a significant milestone in our advocacy efforts. The year 2009 brought a crucial achievement through collaborative endeavors between HA and Dr. Michael Williams. This collaboration resulted in the International Classification of Disease - Centers for Medicare and Medicaid Services issuing the ICD-9 Code for Normal Pressure Hydrocephalus, formally recognizing the condition within the healthcare system. Our advocates persistently pressed for acknowledgment and funding from the Federal Government, culminating in a landmark success in 2014. After an extensive two-year collaboration with Senator Patty Murray (D-WA),

hydrocephalus was authorized as an eligible condition for research funding through the Department of Defense (DOD). This monumental achievement came to fruition on December 14, 2014, when President Obama signed the Omnibus Bill, including the authorization.

Around 2012, NIH funding for hydrocephalus research stood at approximately \$6 million. Over time, thanks to our unwavering persistence and relationship-building efforts, scientists secured multimillion-dollar awards from NIH, the Patient-Centered Outcomes Research Institute, and the DOD. These funds have propelled their research endeavors, steering us closer to groundbreaking treatments and potential cures for hydrocephalus.



See our Advocacy milestones on our journey to shape the future.

[hydroassoc.org/history](https://hydroassoc.org/history)

## Advocacy in Action

### Carly Weisman Meets with the District Office of Representative Chris Smith



Carly Weisman has emerged as one of the most passionate advocates for HA's Hydrocephalus Action Network (HAN). Despite her demanding schedule in nursing school, Carly joined Amanda Garzon, Lakisha Harris, and Davis Kaderli at a meeting with the district office of

Representative Chris Smith (NJ-4), co-chair for the Pediatric and Adult Hydrocephalus Caucus and Carly's Representative in Congress. As a dedicated member of the hydrocephalus community, Carly eloquently addressed the challenges faced by the community, focusing on legislation in the 2024 Congressional session that will be important to us. She also shared upcoming events in the district. In doing this, she was able to educate Representative Smith's District Director and help move our legislative priorities forward within his office.

# Four Representatives Join the Congressional Hydrocephalus Caucus

The Congressional Pediatric and Adult Hydrocephalus Caucus serves to inform the congressional community about the needs of those living with hydrocephalus, their families, and caregivers. This includes funding for research from the National Institutes of Health and the Department of Defense, as well as other key health policy priorities impacting the community, such as Medicare and Medicaid access, special education, and rehabilitation services. **We are excited to announce that four members of Congress — August Pfluger (TX-11), Representative Brad Schneider (IL-10), Representative Ritchie Torres (NY-15), and Congresswoman Chrissy Houlahan (PA-6) — have joined the Pediatric and Adult Hydrocephalus Caucus** to represent the families in their district living with hydrocephalus. The Caucus currently has 16 members. We are looking to bolster these numbers as we meet with more offices going into 2024. The support of new members will be crucial as we work to strengthen research avenues and push our congressional policy agenda forward in 2024.



August Pfluger (TX-11)



Brad Schneider (IL-10)



Ritchie Torres (NY-15)

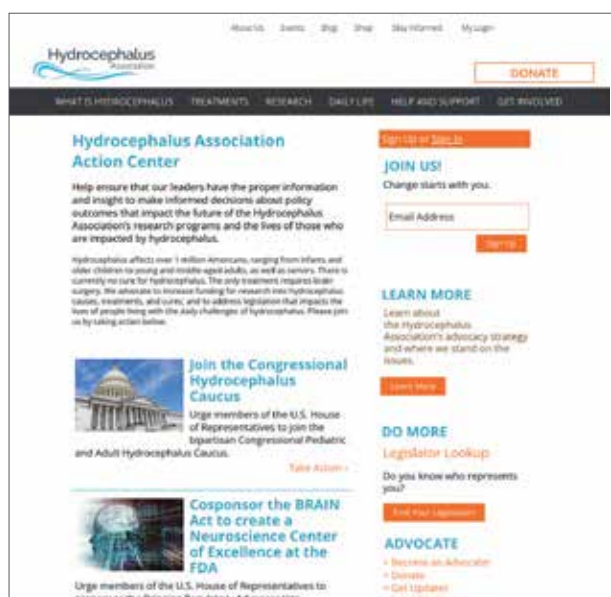


Chrissy Houlahan (PA-6)



Visit the Advocacy section of our website to see the members of the Caucus.

[hydroassoc.org/congressional-pediatric-and-adult-hydrocephalus-caucus](https://hydroassoc.org/congressional-pediatric-and-adult-hydrocephalus-caucus)



## Become an Advocate for Hydrocephalus

Join the Hydrocephalus Action Network to receive:

- monthly advocacy newsletters
- six online advocacy meet ups with the HA team to ask questions and meet other advocates
- advocacy training sessions and tools
- invitations to advocacy events
- and support in engaging with your member of Congress

Visit [www.hydroassoc.org/actioncenter](https://www.hydroassoc.org/actioncenter)

# HA Pursues an Aggressive Advocacy Agenda in 2024

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Advocacy was formally established as a strategic pillar for HA by the Board of Directors in 2011. Our primary advocacy goal is to ensure that the federal government is investing adequate funds into hydrocephalus research and into the appropriate programs that will support those affected by hydrocephalus. These goals require targeted awareness campaigns to ensure that decision makers understand that hydrocephalus is a condition that affects a broad array of people, is not cured with the insertion of a shunt, and is a growing problem with a significant burden on our people and the economy. We work directly with members of Congress and through coalitions that pursue legislative strategies in-line with our priorities. In 2024, we are looking forward to a busy legislative agenda, led by a new HA staff member, Davis Kaderli, who has energized our advocacy work on Capitol Hill. Below we outline our planned activities. We invite everyone in our community to join our advocacy efforts next year.

## CDMRP Focused Caucus Briefing : February 2024

To begin the year, the Congressional Pediatric and Adult Hydrocephalus Caucus will host our first caucus briefing since 2019! The event, which will take place in mid-February in the United States Capitol, serves as an effort to educate congressional staffers and members of Congress about the issues directly affecting the hydrocephalus community.

The first caucus briefing will center around the recent momentum we have had on the research front. In FY2022, hydrocephalus research received \$15.3 million from the Congressionally Directed Medical Research Program (CDMRP). The briefing will explain the importance of increased hydrocephalus research funding within the program. The briefing will also feature CDMRP funded hydrocephalus researchers who received grants during the FY2022 cycle. More information about the briefing's date and time will be provided soon.

## Rare Disease Advocacy Week: February 25-28, 2024

The Everylife Foundation for Rare Diseases will host their Annual Rare Disease Advocacy Week in Washington, D.C. from February 25-February 28. Although hydrocephalus as a whole is not considered a rare disease due to the over

1 million individuals who have the condition, the various medical classifications (etiologies) of hydrocephalus are considered rare. For example, hydrocephalus caused by a brain bleed (post hemorrhagic hydrocephalus) or X-Linked Hydrocephalus.

The event will allow advocates across the rare disease community to share their stories with U.S. House and Senate Offices. It will also allow them to educate staffers and members of Congress about legislation that is important to the rare disease community. We are looking forward to participating in this event with our other allies in this space. Registration for the event will open at the beginning of January. In the meantime, you can view the 2024 agenda on the EveryLife website: <https://everylifefoundation.org/rare-advocates/rare-disease-week-2023/rare-disease-week-agenda-2024/>

## Joint Caucus Briefing with the Spina Bifida Association: Date to be Announced

We are also looking forward to partnering with the Spina Bifida Association to plan a joint caucus briefing between the Congressional Pediatric and Adult Hydrocephalus Caucus and the Congressional Spina Bifida Caucus. The briefing will focus on the work of our new coalition, the National Partnership for Pediatric to Adult Care Transition (NPPACT), and the challenges regularly faced by individuals with a chronic condition while transitioning from pediatric to adult care within the healthcare system. More information about the briefing will be provided soon.

## Rally for Medical Research: September 2024

We are excited to once again bring advocates to Capitol Hill to participate in the Rally for Medical Research. The event brings together individuals within the medical advocacy community to meet with U.S. Senate and House Offices to advocate in favor of increasing the budget for the National Institutes of Health (NIH). The NIH funds a variety of groundbreaking research that brings us closer to eventually finding a cure for hydrocephalus. New increases in the NIH budget will expand funding opportunities for hydrocephalus research and provide more resources to our research community. September is a perfect time to plan a trip to D.C.! More information about the event will be provided soon.



## WALKS AND SPECIAL EVENTS

### Honoring our Legacy: WALK to End Hydrocephalus

In 1994, a collective known as TEAM Hydrocephalus initiated a fundraising walk across the Bay Bridge, raising \$5,000—an inaugural event that birthed the TEAM Hydrocephalus program, later renamed the WALK to End Hydrocephalus. The expansion of this initiative unfolded in 2002 with the first walk outside of San Francisco, hosted in Burke Lake, VA, and led by Mimi Kramer Roberts under the banner of Team East Coast.

In a desire to educate their classmates and help raise funds, our youngest walkers hold events at their local elementary schools, starting in 2008 at Helen Wilcox Elementary School in Orville, CA. All 600 students participated and raised an impressive \$4,300. This milestone became the genesis of our Kids to Cure Hydrocephalus walk events which blend education about hydrocephalus with physical activity - from walking to obstacle courses.

Today, we host over 40 WALKS to End Hydrocephalus and Kids to Cure Hydrocephalus events across the country. These events not only amplify awareness but also significantly boost fundraising efforts, instrumental to advancing HA's mission. For our WALK participants, the events serve as an annual celebration of our resiliency.



See our WALK to End Hydrocephalus milestones on our journey to shape the future.

[hydroassoc.org/history](https://hydroassoc.org/history)



The 2023 WALK to End Hydrocephalus season is ALMOST in the books! And what a year it was!

Thanks to the Hydrocephalus Association's wonderful volunteers, **40 WALKs** were held across the U.S., with nearly **7,000 participants** representing over **800 teams**.

The WALKs are projected to raise nearly **\$1.8 million** for HA's research, education and support programs.

## Top 10 Teams

Team Spenser  
Kasey & Kathy Andrew  
\$80,892

Team Alex  
Eileen & Mike Rodger  
\$36,663

Tyler's Warriors  
Mia & Henry Padron  
\$32,358

Charlie's Angels  
Jennifer & Matt Pope  
\$30,395

Team Owen  
Michael & Heidi Knapke  
\$29,412

Team Bruen  
Heather & Jason Bruen  
\$23,322

Team Mary  
Betsy & Lou Conyard  
\$22,523

Brave Like Braxy  
Amanda & Shawn Holloway  
\$21,100

Jake Town  
Jodi & Todd Heston  
\$20,652

Hydro Cure  
Clifford, Amy, & Katie Goldman  
\$20,513

## Congrats to Our Highest-Grossing WALKS

### South Florida

Kasey Andrew, Lisa Piazzese, & Eileen Rodger  
(Co- Chairs) – raising \$159,010

### Long Island

Carissa Bently & Melissa Arato  
(Co-Chairs) - raising \$147,279



## WALK Sites With the Highest Growth in a Single Year

### St. Louis, MO

Stephanie Vogt (Chair) – posted a \$79,220 total – a 66% increase over prior year

### Charlotte, NC

Christy Ruth, Melenie Dailey, & Susan Slattery Rogers (Co-Chairs) – raised \$70,198

### Columbia, SC

Jessica Caulder, Emma Caulder, & Kelly Northcutt (Co-Chairs) – raised \$44,570

**No WALK to End Hydrocephalus in your community? START ONE!**

Please contact Marina Thompson, [marina@hydroassoc.org](mailto:marina@hydroassoc.org)  
to discuss how you can start a WALK in your area.

# WALK Anniversaries

## San Francisco

the founding site, commemorated 30 years of dedicated WALKing!

## Denver

commemorated 20 years of WALK leadership by the Rogers family, marking two decades of dedicated WALKing and raising nearly \$1.2 M throughout its journey.

Dallas/Fort Worth, TX, and Cleveland, OH both commemorated their 10-year milestones.



Cleveland WALK Family



Denver WALK Family



Dallas/Fort Worth WALK Family



San Francisco Hydro Hero



Denver WALK Family



San Francisco WALK Family

## Newest WALK Site

HA's newest WALK site, Greater **Oklahoma City**, (Ryan Massad & Megan Giles, Co-Chairs), broke all records for new HA WALKS in markets of that size – with over **120 registered participants and 12 Teams**, raising nearly \$13,000.

Congratulations to Greater Oklahoma City for this incredible inaugural WALK!



San Francisco WALK Team



## GOLF to End Hydrocephalus and Community Event



South Florida WALK Chairs

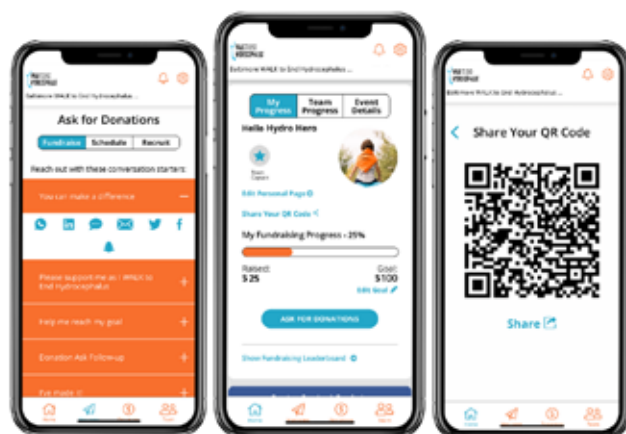


South Florida Hydro Heroes

South Florida WALK Family



## CHECK OUT THE WALK MOBILE APP TODAY!



**PLEASE NOTE:** The app is **only available to registered WALK participants**. Look for our current schedule coming in early 2024! Visit [hydroassoc.org/walk](https://hydroassoc.org/walk).

**TO START A WALK IN YOUR AREA**

Please contact Marina Thompson  
at [marina@hydroassoc.org](mailto:marina@hydroassoc.org)

## Fashion and Philanthropy in Chicago



On Saturday, October 21, more than 700 people gathered for the Holy Apostles Philoptochos Society's annual fashion show and luncheon, themed *A Mediterranean Adventure*. And what an adventure it was! Pam Crouthamel, a good friend of HA, was invited to co-chair the event this year, and HA was designated as one of the two beneficiaries. She took her role seriously, leading the group to their most successful event to date.

Sponsorships were secured, and they offered a variety of desirable auction and raffle items, along with cash prizes. Delicious lunch and an entertaining fashion show rounded out the afternoon.

When all was said and done, HA received \$40,000 from the proceeds of this delightful event. Kudos and gratitude to Pam and her team for their wonderful work!



# Coast to Coast Tour with Todd Touchberry

## An Amazing Family's Journey



November 17, 2023, marked the beginning of an extraordinary expedition for the Touchberry Family, a voyage that would redefine their lives. Their mission? To drive across the country in their century-old Model T Ford, a symbolic quest advocating for awareness

and critical funding for hydrocephalus – a condition that profoundly touched their daughter, Elizabeth.

Did they achieve their ambitious goal? Absolutely! Defying all odds, the Touchberry Family accomplished the seemingly impossible, navigating from Sumter, SC, to the shores of Huntington Beach, CA, in a record-breaking 12 days (previous record was 14 days). Their cross-country trek wasn't merely a physical feat; it epitomized resilience, determination, and an emotional roller coaster of experiences.

Elizabeth's journey living with hydrocephalus began with a challenging diagnosis in utero, which cast a shadow of uncertainty. Doctors offered discouraging odds, even suggesting termination of the pregnancy, but for her parents, terminating was never an option. Their unwavering love propelled them forward, embracing the amazing child they were blessed with.

At 21, Elizabeth's story is one of defying the odds. Despite initial projections, she spent just ten days in the NICU,

underwent her first brain surgery at two days old to alleviate excess pressure from accumulating cerebrospinal fluid, and courageously braved 19 surgeries, most before her 13th birthday.

The idea for this epic coast-to-coast journey sparked when the Touchberry family acquired two Ford Model-Ts, uncovering a historic tradition of transcontinental travel in these iconic vehicles. Their vision was to honor Elizabeth while advancing hydrocephalus research. Fast forward to November 2023, Todd and Elizabeth's stepmom, Jennifer, embarked on the road in their Model T, averaging 34 miles per hour. They were accompanied by a dedicated crew and a second 1923 Ford Model T for quick roadside assistance.

Their voyage was more than miles covered; it was an expedition filled with remarkable encounters and a constant connection to many members of the hydrocephalus community. Including close family friends and HydroWarrior Harper Hodge. Harper was diagnosed with hydrocephalus at birth and is now seven years old. Up until now, her journey involved a single brain surgery at six weeks old, involving a minor incision near her hairline. The procedure aimed to enhance ventricle drainage efficiency.

A poignant moment unfolded in Palm Springs, CA, as they met HydroWarrior Shane, an 11-year-old living with Dandy-Walker malformation and hydrocephalus. Shane was diagnosed with hydrocephalus at age 2. He has had one brain surgery to manage his hydrocephalus — an Endoscopic Third Ventriculostomy (ETV) to create an opening in the floor of the third ventricle in the brain. This allows



cerebrospinal fluid trapped in the brain's ventricles to escape into its normal pathway. Shane's resilience and his journey of bravery resonated deeply with the Touchberry family.

Reflecting on their emotional journey, Todd shared, "Words can't describe the roller-coaster of emotions that this fundraising tour had on me and my family. I often use the hashtag #FriendsAreFamily. I'm blessed with having a national network of people that went above and beyond to help find parts or better routes while planning our #coast2coast4hydrocephalus trip. I can't thank my immediate family (Jennifer, Elizabeth, Addison, Will, and

my father in law) enough for allowing me and at times encouraging me to plan this crazy adventure. A huge thank you to "The Crazy Crew" for taking time away from their family, friends and jobs - Patrick, Philip, and Jasmin. I can only hope for continued support for the Hydrocephalus Association from everyone that we have talked with, laughed with, hugged and cried with. This was the biggest adventure yet..."

Their mission wasn't just a road trip; it was an odyssey, aiming to raise awareness across the country and \$10 per mile for the Hydrocephalus Association. Remarkably, their efforts, including trip expenses, have garnered over \$30k, with hopes to raise more.

As we read Todd's heartfelt words, the question lingers: what's next for this remarkable family? Stay tuned for the continuation of their inspiring journey.

**For more information on the Coast to Coast Tour and to donate:** <https://www.hydroassoc.org/coast-2-coast/>

**You can also follow Todd Touchberry on Facebook for exciting updates!**

<https://www.facebook.com/todd.touchberry>







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Bethesda, Maryland 20814

NEWSLETTER  
VOLUME  
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Join us in  
2024!

# HACONNECT

July 25-27th, 2024

18TH NATIONAL CONFERENCE ON HYDROCEPHALUS

Tampa Marriott Water Street | Tampa, Florida



Registration and financial aid opening soon!

Mark your calendar and sign up for updates at [hydrocephalusconference.org](https://hydrocephalusconference.org).