

## Celebrating a Major Milestone With Over \$107M in Hydrocephalus Research Impact!



HA's \$16M Investment  
in Hydrocephalus  
Research Has  
Generated \$91M in  
Additional Grants —

Creating a \$107M  
Impact in Advancing  
Hydrocephalus Research!

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### HA CONNECT Recap

The 18th National  
Conference on  
Hydrocephalus was  
held in July and  
attracted nearly  
600 attendees!

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### Our WALKs Project to Raise More Than \$1.8 Million

Our WALK to End  
Hydrocephalus events  
project to raise more  
than \$1.8 million for  
HA's research, support,  
education, and  
advocacy efforts.

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### Unprecedented Investment in Hydrocephalus Research

Reflecting our  
commitment to advancing  
hydrocephalus research,  
fostering innovation, and  
expanding the research  
ecosystem.

# MESSAGE FROM THE PRESIDENT AND CEO



Dear Friends,  
As we reflect on the second half of 2024, I am incredibly proud of the strides we have made together. Our journey has been marked by remarkable achievements, driven by the passion and support of our community, and fueled by a shared vision for a world without hydrocephalus.

We are thrilled to celebrate a new milestone in hydrocephalus research funding, with over \$107 million invested since our program launched in 2009! HA's \$16 million investment helped our scientists and clinical networks secure an additional \$91 million in grants from the NIH, DOD, and other foundations, totaling \$107 million. This funding has driven clinical trials and potential drug therapies, bringing hope to countless individuals.

Our Board of Directors also experienced a consequential transition, as we bid farewell to five long-serving members — Pam Finlayson, Teresa Mastrangelo, Jason Preston, Michael A. Williams, and Tessa van der Willigen—who all have played a vital role in shaping our organization. We welcome two new board members, Peter Finlayson and Timothy Harris, who bring fresh perspectives and a strong commitment to our mission.

In July, we came together as a community in Tampa at HA CONNECT, the 18th National Conference on Hydrocephalus. This gathering was a reminder of our collective resilience, uniting members of our community from across the country for education, connection, and support. We also saw impactful collaborations during Hydrocephalus Awareness Month and World Hydrocephalus Day, where nationally known television personalities Danny Bonaduce and Caterina Scorsone joined as advocates to amplify our message and bring new visibility to this lifelong condition.

Thanks to our dedicated volunteers and participants, our WALK to End Hydrocephalus events once again united

thousands of people across 42 U.S. locations, **projecting to raise more than \$1.8 million to fund critical programs.** Our gratitude for these tremendous volunteer WALK leaders is immeasurable.

In partnership with the Rudi Schulte Research Institute, HA hosted a research workshop in October on idiopathic normal pressure hydrocephalus (iNPH), gathering experts across the globe to explore advancements in diagnostics, potential biomarkers, and innovative treatments. Focused on setting priorities for the next 10–20 years, the workshop emphasized the need for improved screening and enhancing the quality of life for those with iNPH, and laid the groundwork for a white paper to guide future research.

Our commitment to empowering individuals in the hydrocephalus community continues to grow. This year, **we proudly awarded 13 scholarships to a diverse group of recipients**, supporting their educational journeys and recognizing their resilience and contributions to their communities.

In advocacy, we've made significant strides on Capitol Hill. Through the work of our passionate advocates and tireless team, **the Hydrocephalus Caucus now includes 39 Congressional members.** Together, we're pushing forward on key initiatives to secure more research funding, address the challenges of healthcare transition for our youth who age out of pediatric care, and increase among our members of Congress.

As you read this issue of *Pathways*, I hope you feel the power of what we have accomplished together and the momentum that we carry forward. **Every effort and every step we take brings us closer to transforming lives and redefining what's possible for the hydrocephalus community.**

With gratitude,

Diana Gray, MA  
President and Chief Executive Officer  
Hydrocephalus Association

DONATE



# Collective Infusion of Over \$107M into Hydrocephalus Research

2024 has been an amazing time to witness HA's return on research investment

The Hydrocephalus Association (HA) is thrilled to highlight the continued success of past Innovator Award recipients who have recently secured substantial grants from the National Institutes of Health (NIH) and the Department of Defense (DOD), including multi-million dollar grants.

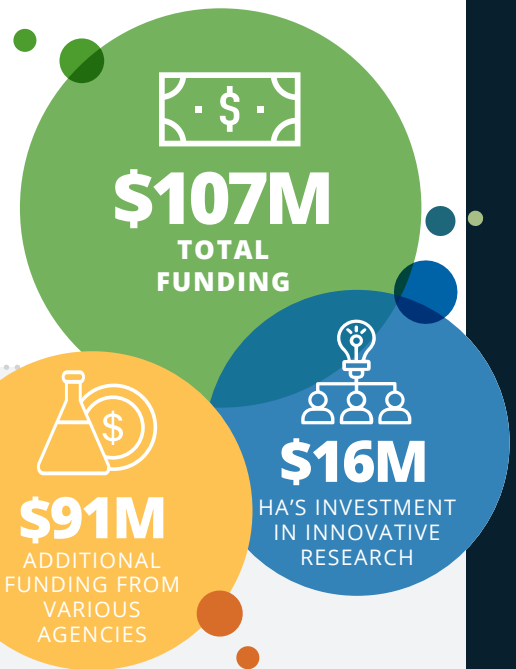


These grants not only validate the innovative work initiated through the Innovator Awards but also pave the way for research that will greatly enhance our understanding of hydrocephalus.

Since the launch of our research program in 2009, HA has made a significant impact on the hydrocephalus research field, investing \$16 million in research. This investment has yielded a remarkable return of \$91 million, with our funded scientists and clinical networks securing additional funding from the NIH, DOD, and other foundations. Altogether, this amounts to a total infusion of \$107 million into hydrocephalus research. Thanks to this support, we've seen advancements such as new clinical trials to investigate shunting and explore drug therapies.

*"This achievement wouldn't have been possible without the unwavering support of the Hydrocephalus Association and the foundation laid by the Innovator Award. Thank you once again for your partnership and support. I am truly excited about the pioneering research we are about to embark on with this grant."*

— Sheng Chih (Peter) Jin, PhD



## National Institutes of Health

### June Goto, PhD

Assistant Professor of Neurosurgery  
Cincinnati Children's Hospital Medical Center

### Sheng Chih (Peter) Jin, PhD

Assistant Professor of Genetics and Pediatrics  
Washington University in St. Louis

### Maria Lehtinen, PhD

Professor, Hannah C Kinney  
Chair in Pediatric Pathology Research  
Boston Children's Hospital  
Harvard Medical School

### Brandon Miller, MD, PhD

Associate Professor of Pediatric Neurosurgery  
Medical University of South Carolina

## Department of Defense

### Maria Bonilla Garcia, PhD

Assistant Professor of Neurosurgery  
Virginia Commonwealth University

### Carolyn Harris, PhD

Professor of Chemical  
Engineering and Materials Science  
Wayne State University

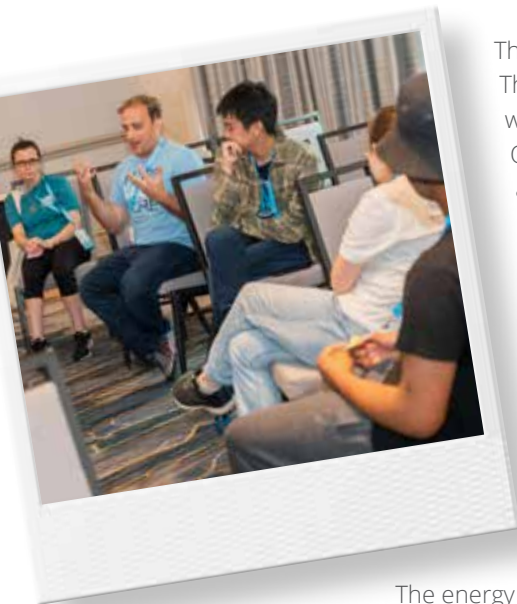
# HACONNECT

RECAP



## 18th NATIONAL CONFERENCE ON HYDROCEPHALUS IN TAMPA, FLORIDA

The Hydrocephalus Association's (HA) 18th National Conference on Hydrocephalus, HA CONNECT, took place from July 25-27 in Tampa, FL. Hosted in collaboration with presenting sponsors Tampa General Hospital and USF Health, the event attracted nearly 600 attendees, including patients, caregivers, medical professionals, scientists, medical device representatives, and other organizations.

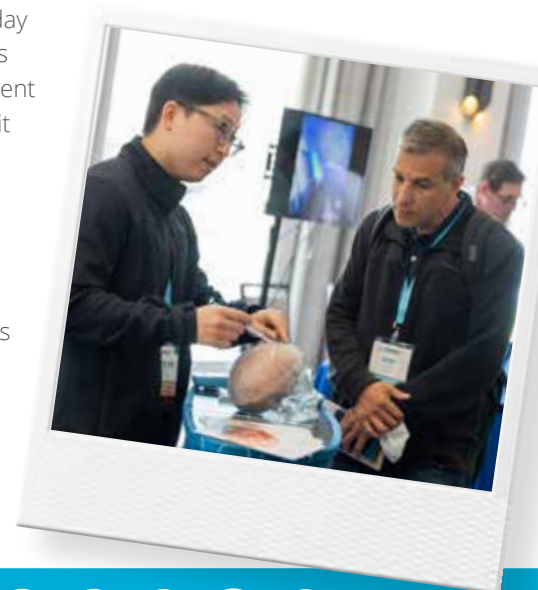


The conference began Thursday afternoon with a New Participant Orientation, allowing attendees to connect and learn how to maximize their experience. Following this, Diana Gray, President and CEO of HA, and Jason Preston, Chair of the HA Board of Directors, delivered a heartfelt welcome address.

The energy ramped up during the 'Making Connections – Person to Person' sessions, where participants shared stories and supported one another based on their connection to hydrocephalus, creating a profound sense of community. This emotional engagement was followed by a lively reception, allowing attendees to explore and chat with sponsors and exhibitors.

With over 80 educational sessions, the conference covered a wide range of topics, including updates on the PENS Clinical Trial for Normal Pressure Hydrocephalus and Dr. Lauren Jantzie's groundbreaking clinical trial aimed at preventing hydrocephalus after brain bleeds in premature babies. Additional highlights included discussions on how AI can enhance diagnostic accuracy for hydrocephalus and the unveiling of a potential treatment that may delay the onset of Alzheimer's and Parkinson's disease.

Throughout the three-day conference, participants delved into the excitement of our interactive exhibit hall, where they could touch a shunt, perform an endoscopic third ventriculostomy (ETV), and measure CSF flow. Sponsors and exhibitors showcased their latest products and technologies, offering attendees a chance to ask questions and



Stay Connected. #HACONNECT





learn more about advancements in the field.

For the first time ever, a clinical study was conducted at the conference. Rhaeos, a clinical-stage medical device company spun out of Northwestern University, sponsored IRB-approved studies on non-invasive,

wireless monitoring of CSF shunts. The trial focused on the effectiveness of FlowSense, a noninvasive wearable skin sensor for the hydrocephalus community. Our community members were thrilled to participate and felt empowered by contributing valuable data that could one day simplify hydrocephalus management.

Always a conference favorite, our Kids Camp offered fun, hands-on activities while fostering lifelong friendships. Highlights included a Brain Lab, where children performed brain surgery on skull and brain models, practicing the intricate process of implanting a shunt. Many doctors enjoyed sharing their expertise with the younger members of the community and mentioned that this was one of their conference highlights.

Dr. Myron Rolle, a former Florida State University football standout and NFL player turned neurosurgeon, was a highlight of HA CONNECT as the keynote speaker. Now residing in the Tampa/St. Petersburg area and serving as the Pediatric Neurosurgery Fellow at Johns Hopkins All Children's Hospital, Dr. Rolle inspired attendees with his extraordinary journey from the football field to the operating room.



He also signed copies of his book, "The 2% Way," which explores his philosophy of achieving success through small, incremental improvements. His unique perspective and commitment to helping patients with similar injuries resonated deeply with the hydrocephalus community.

The highly anticipated grand finale of HA CONNECT, the Family Dinner Dance and Talent Show, brought together community members, families, doctors, researchers, and sponsors in a highly anticipated celebration of support. This cherished event provided a platform for attendees to showcase their talents, creating lasting memories and reinforcing the strong sense of community that HA CONNECT fosters.



One of the most cherished aspects of HA CONNECT is the opportunity to forge meaningful connections among patients, families, doctors, and researchers, fostering invaluable support and a strong sense of community. The 18th National Conference on Hydrocephalus in 2024 was a resounding success, providing education,

connection, and inspiration to all attendees. The Hydrocephalus Association extends heartfelt thanks to everyone involved and looks forward to continuing the journey of improving the lives of those affected by hydrocephalus.



## FEATURED ARTICLES

# Danny Bonaduce and Caterina Scorsone Champion Hydrocephalus Awareness

## Danny Bonaduce Joins the Hydrocephalus Association to Raise Awareness for Normal Pressure Hydrocephalus

**Beloved actor and TV/radio personality Danny Bonaduce** has teamed up with the Hydrocephalus Association to shine a spotlight on normal pressure hydrocephalus (NPH), a condition he was recently diagnosed with. NPH affects approximately 800,000 Americans, yet 80% of cases go undiagnosed or are misdiagnosed as Alzheimer's, Parkinson's, or dementia.



Our President and CEO, Diana Gray, sat down with Danny Bonaduce to record a video where he shared his journey with NPH, specifically for us to use in raising awareness and educating the public about this condition. His story is both inspiring and eye-opening, bringing much-needed attention to this often misunderstood condition. Danny's openness about his experience underscores the importance of awareness, proper diagnosis, and continued research into NPH and hydrocephalus as a whole.

In addition to sharing his story, Danny has recorded two public service announcements (PSAs) to help spread awareness—one for Hydrocephalus Awareness Month and another for World Hydrocephalus Day. We are grateful for his advocacy and look forward to the impact his voice will have in helping to drive research, improve treatments, and support those living with hydrocephalus.



Watch Diana's  
Interview with Danny  
[youtu.be/2gsQxPgkTdk](https://youtu.be/2gsQxPgkTdk)

## Caterina Scorsone Lends Her Voice for Hydrocephalus Awareness

**Caterina Scorsone, best known for her role as Dr. Amelia Shepherd on Grey's Anatomy,** recently teamed up with the Hydrocephalus Association to help raise awareness about hydrocephalus. She generously recorded a PSA that we were able to feature in our awareness campaigns, helping to shine a spotlight on this lifelong condition.



Our connection with Caterina began after an episode of *Grey's Anatomy* featured a character with hydrocephalus. Sierra Smith, our Support & Education Program Assistant, wrote a blog post as part of her series *Sierra Speaks Out*, reflecting on the episode and the discussions it sparked. After sharing the blog on our social media accounts using the #GreysAnatomy, one of the show's writers noticed our post, liked it, and reshared it on his own platforms. This opened the door for us to reach out, and through those conversations, we were thrilled to gain Caterina's support in recording the PSA for us.



Thanks to Caterina's involvement, we've been able to amplify our efforts in raising awareness, inspiring others to learn more about hydrocephalus and the importance of research, better treatments, and early diagnosis.



View Catarina's PSA  
[youtu.be/iM6ngEpWbDk](https://youtu.be/iM6ngEpWbDk)

# Hydrocephalus Awareness Month 2024: Faces of Strength, Voices of Hope

This September, we came together for **Hydrocephalus Awareness Month (HAM)**, dedicated to raising awareness, educating the public, and highlighting ongoing research efforts aimed at better treatments and, one day, a cure. Our campaign, Faces of Strength, Voices of Hope, shined a light on the diverse experiences of those living with hydrocephalus, showcasing the many faces and stories of resilience within our community.

Throughout the month, we shared powerful stories from individuals of all ages who navigate life with hydrocephalus. These personal stories highlighted their unique journeys, offering a glimpse into the strength and courage that define our community. From infants to seniors, each story reminded us that hydrocephalus impacts people of all ages, and every

voice matters in the fight for awareness and understanding.

In a significant show of support, members of the Hydrocephalus Caucus took to their social media platforms to amplify our voices and bring attention to the cause. This advocacy, combined with the incredible engagement from our community, helped raise awareness across new audiences and elevated the importance of continued research and funding.



## Top 3 Posts from Hydrocephalus Awareness Month



## Hydrocephalus Awareness Month House Resolution

Chris Smith (NJ-04) and Lloyd Doggett (TX-37), co-chairs of the Congressional Hydrocephalus Caucus, introduced H. Res 1479 - Expressing support for the goals and ideas of “National Hydrocephalus Awareness Month” and “World Hydrocephalus Day”. The resolution brings awareness to the over 1 million individuals with hydrocephalus in the United States and highlights the importance of September for hydrocephalus awareness.

# World Hydrocephalus Day 2024: A Global Movement to Raise Awareness



On September 20, 2024, people across the globe came together in solidarity for World Hydrocephalus Day, a global initiative dedicated to raising awareness about hydrocephalus and supporting those living with this lifelong neurological condition. This year saw even broader participation, with more countries joining

the effort, including Australia, Belgium, Canada, Ireland, Israel, the Netherlands, Nigeria, Scotland, Sweden, Ukraine, and the United Kingdom.

World Hydrocephalus Day serves as a powerful reminder of the importance of global collaboration in addressing the challenges faced by the hydrocephalus community. With millions

affected by this condition worldwide, including one in every 770 babies born in the U.S., the need for increased awareness, understanding, and research funding is crucial.

By coming together, we continue to shape a brighter future for individuals with hydrocephalus, working toward better treatments and ultimately, a cure. With more countries participating in 2024, the momentum is building, and the hope is stronger than ever for improved outcomes for those living with this condition.



For more information about World Hydrocephalus Day and how to get involved, please visit: [hydroassoc.org/whd](http://hydroassoc.org/whd)

## Top 3 Posts From World Hydrocephalus Day



## Thank you to our World Hydrocephalus Day Partners and Corporate Supporters

### The World Hydrocephalus Day Partners



### The World Hydrocephalus Day Corporate Supporters



# 2024 WALK TO END HYDROCEPHALUS™

**THANKS** to the Hydrocephalus Association's wonderful volunteers, 42 WALKs were held across the U.S., with more than 6000 participants representing over 785 teams. The WALKs are projected to raise more than \$1.8 million for HA's research, education, and support programs.

## WALK Anniversaries This Year

### Chicago



**\$1.26M+**  
RAISED

**20**  
YEARS

Celebrating 20 years of the Chicago WALK to End Hydrocephalus! Thanks to our dedicated participants and hardworking volunteers, this event has raised an impressive \$1,125,696 over the past two decades, supporting vital research and community programs.

Here's to many more years of impact!

### Cincinnati



**10**  
YEARS

RAISED  
NEARLY

**\$440k**

Celebrating 10 years of the Cincinnati WALK to End Hydrocephalus! With nearly \$440,000 raised in a decade, this milestone was made possible by our dedicated participants and hardworking volunteers. Here's to many more years of impact and partnership!

# NEWEST SITES: A Powerful WALK Weekend in November



## Virginia Beach

Sunday, November 3rd!

Virginia Beach showcased its spirit with its inaugural walk down the boardwalk on Sunday, November 3rd! This event establishes Virginia as a key location for those who previously traveled to D.C. or the Carolinas to participate in WALK events. A heartfelt thank you to Natasha Buchanan for her exceptional leadership in making this happen!

*"Serving as WALK Chair has been humbling and inspiring. When my son was diagnosed, I felt isolated, but HA gave us a community. I'm committed to bringing that same support to others because my son, Zander, and everyone facing hydrocephalus deserve better treatment options—and a future without 'another brain surgery.'"*

Natasha Buchanan, VA Beach WALK Chair

## Indianapolis

Saturday, November 2nd

Indianapolis is back on the map! After a brief hiatus, we were thrilled to see the event return on November 2nd, energizing a growing movement within this vibrant community. We extend our heartfelt gratitude to Kelly Leard, Jennifer Reid, and the entire IU committee for their support in making this comeback possible!



## Thanks For Running

The annual Thanks For Running 5K is a beloved family and community event that takes place every Thanksgiving morning in Medford, Massachusetts. Organized by the Maynard family for over 20 years, the run not only brings neighbors together for a fun morning filled with bagels, pies from a local bakery, and the famous Turkey Soup, but it also raises crucial awareness and funds for hydrocephalus. Spearheaded by Amy Maynard, whose niece Caitlin lives with hydrocephalus, and the whole Maynard family, the event has raised over \$100,000 for the cause. With the support of local businesses and donors, the race continues to grow each year, creating a special tradition that celebrates both community and giving. As Amy explains, "We aim to keep the event loving, joyful, and we are especially thankful for the support of our race day friends."



WE ARE **#HYDROSTRONG**

# Virtual WALK To End Hydrocephalus is TAKING OFF...

The Virtual WALK to End Hydrocephalus is gaining momentum, and Bethany Buchanan and her family are a perfect example of how to get involved in the WALK to End Hydrocephalus, even without an official WALK nearby.

Bethany shared, "It was a beautiful day to celebrate Layla Grace and others living with hydrocephalus! Thank you to everyone who donated and walked with us." #TeamLaylaGrace

Since Layla's birth in 2014, the Buchanan family has made it their mission to raise as much money as possible each year to support better treatments and, ultimately, a cure. Their dedication shows how easy it can be to participate in this meaningful event from anywhere!



Learn more.

[hydroassoc.org/find-a-walk-near-you](https://hydroassoc.org/find-a-walk-near-you)

## WINGSTOP Supports the Hydrocephalus Association

On September 23, Shantil and Nate Garn, along with their hydro warrior, Peyton, celebrated the opening of two new WINGSTOP locations in the Salt Lake City area. Together with all WINGSTOP locations in Utah, they raised an incredible \$24,000 to support the Hydrocephalus Association in finding better treatments and ultimately a cure while spreading awareness about hydrocephalus.

When asked how the WALK has impacted their family, the Garns shared, "This has been such a great event for our family to support our son Peyton and to raise more awareness in the community for this condition. We have loved meeting amazing people in our community with hydrocephalus and their friends and family as well. The day of the walk has become a really special day for our entire family."

A huge thank you to WINGSTOP and the Garn family for their incredible support! Together, we're raising awareness and advancing research for hydrocephalus.



## Scientists Uncover Emerging Insights on Fluid Systems in the Brain at the iNPH Research Workshop

The Hydrocephalus Association (HA), with support from the Rudi Schulte Research Institute, hosted our second research workshop of 2024, bringing renewed attention to iNPH— a condition often overlooked in the broader dementia spectrum.

Through collaborative discussions and expert insights, the goal of this workshop was to establish clear research priorities for iNPH over the next 10-20 years, setting a strategic path for future advancements in diagnosis, treatment, and patient care. These efforts will culminate in a comprehensive white paper, outlining the collective vision for advancing research and improving outcomes and quality of life for individuals affected by iNPH.

The workshop wasn't just about science; it was about building a community of experts and advocates in diverse fields passionate about advancing iNPH research. One of the key outcomes is a plan to create a set of research priorities for iNPH, which will guide scientists and doctors in better understanding and treating this condition. This workshop offers a glimpse into the

future of iNPH research, highlighting advanced diagnostic technologies and the growing role of AI in medicine. As the population ages and awareness of iNPH grows, these advancements could significantly impact patients by facilitating earlier diagnoses and improving their quality of life. HA is committed to driving progress in iNPH research, bringing together top experts to find better solutions for this often-underdiagnosed condition.



HA Board Member Tessa van der Willigen and Dr. Abhay Moghekar, Johns Hopkins University



Dr. Michael Williams, University of Washington, in his *Back to the Future* themed presentation



## Key Workshop Highlights

### Advancing Diagnostic Tools Using AI

Experts discussed innovations in current diagnostic methods, exploring how artificial intelligence (AI) and machine learning can improve accuracy in detecting and measuring iNPH progression. The goal is to make early detection more accessible and reliable.

### Incorporating the Patient Perspective

The patient and caregiver panel focused on topics surrounding delayed care, navigating healthcare, supporting caregivers, and research priorities. Hearing from a dedicated panel underscores the importance of understanding the lived experience of iNPH patients and their caregivers, highlighting areas where healthcare can better support these individuals.

### Biomarkers as Key to Non-Invasive Therapies

The latest research on biomarkers for iNPH promises new pathways to identify potential drug targets and non-invasive treatment options. Expert physicians-scientists presented their research in genetic and protein biomarkers of iNPH.

### CSF Circulation, Glymphatics, and Lymphatics

The workshop also delved into the role of CSF dynamics and the glymphatic and lymphatic systems in iNPH, providing new insights into the disease's mechanisms and potential treatment approaches.

### Funding and Advocacy

Representatives from the National Institutes of Health and Department of Defense shared information about their programs and upcoming funding opportunities. Additionally, Erin Darbouze, Senior Director of Policy and Advocacy at Research!America, highlighted how clinicians and scientists can advocate for increased hydrocephalus research funding. HA's advocacy team, Amanda Garzon (COO) and Davis Kaderli (Advocacy Engagement Manager) highlighted HA's actions in advocacy.

## HA's Corporate Council PROGRAM



HA's expanding network of partners collaborates to advance hydrocephalus therapies and support the community.

Through HA's Corporate Council Program (CCP), we enhance these partnerships with year-round benefits, including event access, community engagement, and industry-relevant meetings. By joining CCP, partners play a vital role in advancing our mission, strengthening connections with scientific and patient communities, and showcasing their industry contributions.

### Current Corporate Council Partners

#### PLATINUM PARTNER



#### GOLD PARTNER



#### SILVER PARTNERS

Aesculap | Medtronic  
Rhaeos

#### BRONZE PARTNER

Anuncia



Use the QR code or contact [linda@hydroassoc.org](mailto:linda@hydroassoc.org) to find out more about the program.

Or visit [hydroassoc.org/corporate-council-program/](https://hydroassoc.org/corporate-council-program/)

*"The Hydrocephalus Association plays a vital role — connecting those who live with the condition to much-needed resources, education, advocacy, and clinical research. We are proud to partner with HA to find solutions that have the potential to improve the lives of the hydrocephalus community."*

— DJ Cass, Cera Vasc, Platinum Corporate Council Partner

# Unprecedented Investment in Hydrocephalus Research: A Record Number of Funding Awards in 2024

The Hydrocephalus Association is proud to announce an unprecedented number of research funding awards in 2024, reflecting our commitment to advancing hydrocephalus research, fostering innovation, and expanding the research ecosystem.

This year, we were able to offer seven different types of prestigious awards, which is a testament to our mission of improving the lives of individuals affected by hydrocephalus by supporting researchers at various stages of their careers and across multiple disciplines.

## Announcing the 2024 Innovator Award Recipients

The Innovator Awards highlight the remarkable creativity and innovation within the scientific and medical fields. These awards provide critical seed funding for researchers to turn their visionary ideas into tangible projects. *We are deeply grateful for our collaboration with Team Hydro and the Rudi Schulte Research Institute (RSRI) to collectively fund these awards.*



**Mohammed Alshareef, BSE, MD**  
Assistant Professor in the School of Medicine at University of Colorado Denver

**Complement Alternative Pathway Initiation Contributes to Post-Hemorrhagic Hydrocephalus in a Neonatal GMH Model**



**Peter Chiarelli, MD, PhD**  
Assistant Professor in the Department of Surgery, Division of Pediatrics at Children's Hospital Los Angeles

**Quantitative, Non-Invasive Shunt Flow Measurement for Improved Management of Shunted Hydrocephalus**



**Geoffrey Colby, MD, PhD**  
Full Professor in the Department of Neurosurgery at University of California, Los Angeles

**Validation of a Novel Implantable Ventriculo-peritoneal Shunt Flow Sensor**



**Maria Garcia Bonilla, PhD**  
Assistant Professor of Pediatric Neurosurgery in the Department of Neurosurgery at Virginia Commonwealth University

**Targeting Neuroinflammation in PHH: a Novel Immunomodulatory Approach**



**Mercedeh Javanbakht Movassagh, PhD**  
Associate Research Scientist (faculty role) in the Department of Neurosurgery at Yale University

**The Role of Pathogens and Non-Coding RNAs in Neonatal Hydrocephalus**



**Jennifer Kong, PhD**  
Assistant Professor of Biochemistry University of Washington

**Leveraging a Cortical Spheroid System to Understand the Pathogenesis of Hydrocephalus**



**Cameron Sadegh, MD, PhD**  
Neurosurgeon and Assistant Professor in the Department of Neurological Surgery at UC Davis

**Utilizing Neurosurgical Specimens to Study Intraventricular Hemorrhage and the Feasibility of Targeted Gene Therapy**

## Announcing the 2024 Accelerator Award Recipients

In 2024, the Hydrocephalus Association (HA) launched the new Accelerator Award, designed to support established investigators in advancing their research on hydrocephalus prevention or non-invasive treatments. Generously supported by the Batterman Foundation and Team Hydro, this prestigious award grants \$85,000 for a one-year project, enabling researchers to propel their work forward along the bench-to-bedside research pipeline. The Accelerator Award specifically funds projects that demonstrate clear potential for advancing current research to the next stage, such as transitioning from in vitro studies to animal models, from small to large animal models, or from animal studies to human clinical research. This award represents HA's commitment to driving innovation and bringing transformative treatments for hydrocephalus closer to reality.

We are pleased to announce that the recipients of the 2024 Accelerator Award are:



### Mark Johnson, MD, PhD

*Professor and Chair, Neurological Surgery, University of Massachusetts Chan Medical School*

#### Interplay Between Genetics and Alcohol Consumption in INPH



### Maria Lehtinen, PhD

*Professor, Hannah C Kinney Chair in Pediatric Pathology Research, Boston Children's Hospital, Harvard Medical School*

#### A Large Animal Model of Germinal Matrix Hemorrhage for the Advancement of Choroid Plexus Therapies



### Shenandoah Robinson, MD (Co-Principal Investigator)

*Professor of Neurosurgery, Neurology and Pediatrics, Johns Hopkins University*

AND



### Lauren Jantzie, PhD (Co-Principal Investigator)

*Associate Professor of Pediatrics, Neurology, and Neurosurgery, Johns Hopkins University*

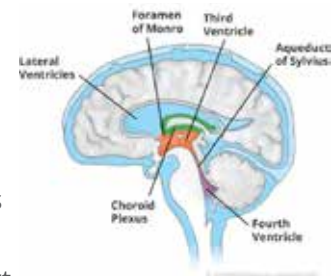
#### Inflammatory Lipids as Targets & Biomarkers for Acquired Hydrocephalus

## — NEW ARTICLE —

### Understanding the Choroid Plexus: Function, Location, and its Role in Hydrocephalus

Did you know the choroid plexus plays a vital role in your brain's health?

This network produces cerebrospinal fluid (CSF), which protects the brain and helps transport nutrients. But how does it relate to hydrocephalus? Read our latest article to learn about the choroid plexus' function and location and the link between CSF production and hydrocephalus.



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## Engineering in Hydrocephalus Prize

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Launched in 2024 as part of HA's strategic plan to expand our research ecosystem, the Engineering in Hydrocephalus Prize supports undergraduate and graduate research projects that highlight possible engineering solutions to hydrocephalus challenges.

This award not only gives student engineers recognition, but also offers mentorship from experts in bioengineering and hydrocephalus and the opportunity to attend HA's 2025 Engineering Research Workshop. The goal of this award is to encourage young scientists to think creatively about new treatments or devices. By fostering diverse perspectives in the field, this prize plays a critical role in pushing the boundaries of hydrocephalus research and treatment.

Three outstanding projects were awarded this year's Engineering in Hydrocephalus Prize:



**Haritosh Patel, BASC**  
AND

**Amy Huang, BASc**

**Test Bench Development for Enhancing Sensor and Catheter Design to Prevent Hydrocephalus Shunt Blockages**



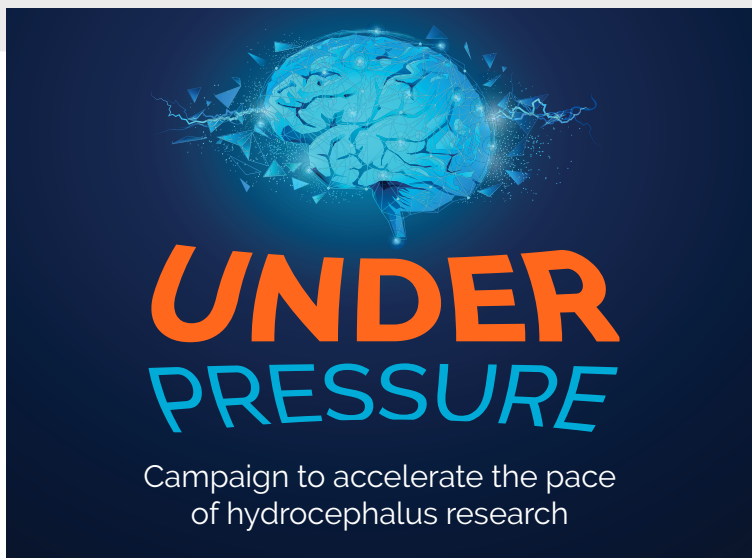
**Yuli Wang, MS**

**Artificial Intelligence for Monitoring and Predicting Disease in Patients with Idiopathic Normal Pressure Hydrocephalus Using Imaging and Clinical Data**



**Bianka Valecruz**

**Test Bench Development for Enhancing Sensor and Catheter Design to Prevent Hydrocephalus Shunt Blockages**



Hydrocephalus affects individuals and families across the globe, and the path to better treatments and a cure lies in accelerating the pace of research. Through our Under Pressure campaign, we are focused on developing non-invasive, one-time therapies, improving diagnostic methods, and enhancing access to care for all who are impacted by this condition.

The need for innovative research has never been greater. Thanks to your generous support, our Under Pressure campaign has already made significant strides, as illustrated in this publication, but we must keep the momentum going. With your help, we can continue funding critical projects that will fill research gaps and move us closer to new therapies and, ultimately, a cure.

We ask you to be part of this vital movement! Whether you are a current supporter or have just gotten involved, every contribution plays a pivotal role in advancing hydrocephalus research. If you've already given through our fundraisers or individual gifts, we encourage you to consider an additional donation specifically for research. If you haven't yet contributed, now is the time to take that first step.

Let's come together to make a profound impact on the future of hydrocephalus care and treatment. Share your story, invite others to join, and help us continue this important journey. Every gift, every conversation, and every bit of advocacy brings us closer to life-changing breakthroughs.



Please reach out to Linda Riley, National Director of Development at [linda@hydroassoc.org](mailto:linda@hydroassoc.org).

Or visit [hydroassoc.org/underpressure](https://hydroassoc.org/underpressure)

## Next Generation Scientists Travel Award

The Next Generation Scientists Travel Award enabled 12 early-career researchers, including undergraduate students, PhD students, postdocs, and medical residents and fellows, to attend the 2024 National Conference on Hydrocephalus (HA CONNECT).

This conference fosters critical engagement between scientists and the hydrocephalus community, helping researchers strengthen their commitment to a career focused on hydrocephalus. The trainees had the opportunity to give an oral and/or poster presentation, allowing them to present their groundbreaking research to peers and patients alike and expand their professional networks.

This year's twelve awardees are:

**Timothy Heck, MD**

*Johns Hopkins University*

**Elizabeth Ricci, BS**

*Yale University*

**Hawley Helmbrecht, PhD**

*Johns Hopkins University*

**Christopher Roberts, MS**

*Wayne State University*

**Amy Huang, BASc**

*University of Toronto*

**Brady Rivkin**

*Carleton College*

**Jeffrey Horbatiuk, BS**

*Wayne State University*

**Riccardo Serra, MD**

*University of Maryland*

**Verayna Newland, BS**

*Indiana University, Indianapolis*

**Gwendolyn Sebring, BS**

*University of Cincinnati*

**Leah Pendl-Robinson, BS**

*Yale University*

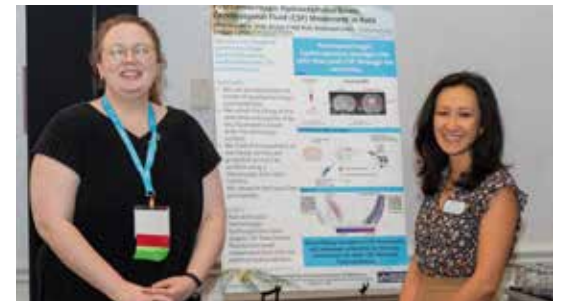
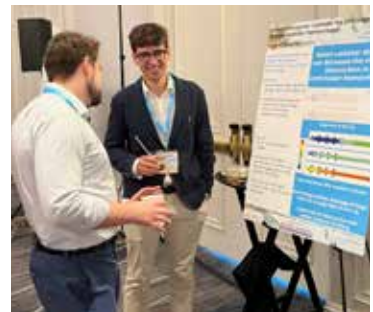
**Bianka Valecruz**

*University of North Dakota*

These awards represent an unprecedented number of research grants from the Hydrocephalus Association in a single year, reflecting our deep commitment to advancing hydrocephalus research at all levels and disciplines. Through these initiatives, we aim to foster innovation, drive collaboration, and build a robust research ecosystem that will improve care and outcomes for individuals affected by hydrocephalus.



Learn more about all our awardees on our [Research We Fund](https://hydroassoc.org/research-we-fund) page  
[hydroassoc.org/research-we-fund](https://hydroassoc.org/research-we-fund)



## Board of Directors Milestones: Honoring Legacies and Welcoming New Leaders

### Honoring our Retiring Board Members



#### Pam Finlayson

Since 2015, Pam Finlayson has been a committed member of the Hydrocephalus Association Board of Directors, making meaningful contributions through her diverse roles and

responsibilities. Since 2018, she has played a key role in coordinating the HA CONNECT conferences. Pam has also been an active member of the planning committee for Kids Camp since 2022, creating a fun and engaging environment for young attendees. Additionally, she has served on both the Scholarship and Support and Education Committees, further advancing awareness of hydrocephalus.

Beyond her board duties, Pam participates in and volunteers for the National Capital WALK to End Hydrocephalus. And nearly 20 years ago, she and her family founded the Team Hydro Foundation, known for its daring swims across San Francisco Bay from Alcatraz Island. This initiative has generously supported hydrocephalus research and garnered several awards for its impactful efforts.

We sincerely thank Pam for her invaluable contributions to the Association Board and wish her all the best as her son, Peter Finlayson, steps into this role.



#### Teresa Mastrangelo

Teresa Mastrangelo has been a dedicated member of the Hydrocephalus Association's Board of Directors since 2015. She served as Vice Chair of the Governance Committee

from 2016 to 2017 and as Chair from 2018 to 2019. In her roles on the Audit and Executive Committees, Teresa has helped guide the Association in staying focused on its mission. Teresa also dedicated her leadership expertise to advising staff in the planning of the HA CONNECT conferences.

Beyond her administrative duties, Teresa has been a committed volunteer and fundraiser for the National Capital and San Francisco WALKs since 2010. In 2021, she represented the Association at the National Health Council Conference and further demonstrated her dedication with her generous financial support.

The Hydrocephalus Association extends its heartfelt gratitude to Teresa Mastrangelo for her leadership and many contributions. We wish her all the best in her next adventure.



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## Jason Preston

Jason Preston's leadership and service have been instrumental in advancing the mission of the Hydrocephalus Association. Since joining the Board of Directors in 2015 and serving as Board

Chair since 2023, his expertise has strengthened key initiatives, including his role as Chair of the Communications Committee and as a valued member of the Finance Committee.

His contributions have spanned multiple areas, from advising conference planning to expertly facilitating the Hydrocephalus Association's inaugural Emerge 2022 Session in Austin, where he supported new companies with innovative devices and products in the early stages of production. In 2024, he launched a strategic group to examine the Hydrocephalus Association's role in the commercialization of treatments, facilitated by Claus Torp Jenson, a C-suite executive with extensive financial, technology, and health experience.

As a fundraiser, Jason has helped reach the goals for the Seattle WALK and personally invested in various HA initiatives. His visionary leadership and advocacy continue to shape the future of hydrocephalus research and treatment, significantly enhancing the organization's impact.



## Michael A. Williams

In recognition of Dr. Michael Williams' extraordinary service, the Hydrocephalus Association extends its deepest gratitude for his significant contributions

during his tenure on the Board of Directors, which began in 2015. Throughout his time with HA, Dr. Williams has played numerous pivotal roles, from co-chairing HA CONNECT since 2006 and presenting multiple sessions over this time, to shaping the future of research and care through his leadership on the Research Committee and contributions to multiple key publications.

He co-led HA's Transition Summit in 2017, helping to improve transitional and longitudinal care for adolescents and young adults with hydrocephalus, and was instrumental in supporting the community during the COVID-19 pandemic. Dr. Williams is a founding member of the Adult Hydrocephalus Clinical Research Network since 2012 and the Medical Advisory Board liaison to the Support and Education Committee since 2019.

His ongoing advocacy, combined with his generosity as a dedicated supporter and fundraiser for HA research and programs, has significantly propelled advancements in hydrocephalus research and education. His dedication and leadership leave a lasting legacy in the field. Thank you, Dr. Williams, for your unwavering commitment to finding better treatments and ultimately a cure for hydrocephalus.



## Tessa van der Willigen

Since joining the Board in 2015, Tessa van der Willigen has played an instrumental role in shaping the direction and success of the Hydrocephalus Association. She has contributed her expertise as chair of the Finance, Governance, and Research committees, and a Vice Chair on the Executive Committee. Beyond her role on the board, Tessa has supported the Association in many ways for over 15 years. Her many contributions include developing the patient registry and initial surveys for the Hydrocephalus Association Patient-Powered Interactive Engagement

Registry (HAPPIER), raising funds for the National Capital and New York City WALKs since 2018, and making a significant donation to the Under Pressure Research Campaign.

The Hydrocephalus Association extends heartfelt thanks to Tessa for her commitment to the community and wishes her all the best in her future endeavors.

# Welcoming our New Board Members



## Peter Finlayson

We are excited to welcome Peter Finlayson to the Hydrocephalus Association Board of Directors. Peter is a commercial leader in the biotechnology and pharmaceutical industry, specializing in launching and commercializing new medicines and

diagnostic tests across various therapeutic areas, including neuroscience and oncology. He has held leadership roles at companies ranging from Fortune 500 firms to startups, including Vir Biotechnology and Roche/Genentech.

Peter has a personal connection to the hydrocephalus community; his sister Kate lived with shunted hydrocephalus and faced significant health challenges before passing away in 2010. Inspired by her strength, Peter co-founded The Team Hydro Foundation in 2008, where he serves as Board Chair and Executive Director. Team Hydro has raised astounding sums for hydrocephalus research, primarily through open water swims, including their flagship event from Alcatraz to San Francisco.

Peter holds both graduate and undergraduate degrees from Stanford University, where he met his wife, Nina. They reside in the Philadelphia suburbs with their four sons. An active community member, Peter coaches youth sports and holds leadership positions in his church. He is also a two-time national champion on Stanford's Varsity Water Polo Team and enjoys fly fishing in his free time.



## Timothy Harris

We are pleased to welcome Timothy J. Harris to the Hydrocephalus Association Board of Directors. Tim is a litigation attorney with over thirty-five years of experience, representing a diverse range of clients, including utility companies,

municipalities, and manufacturers. For the past twenty years, he has focused extensively on the natural gas industry, representing the two largest providers in northern Illinois.

Tim graduated from the University of Illinois at Urbana-Champaign (B.A. 1984) and DePaul University College of Law (J.D. 1988). He is a founding partner of Donnelly & Harris, LLC, with offices in Chicago and Mokena, Illinois.

Tim and his wife, Mary Beth, have four adult sons and four grandchildren. Their youngest son, Joseph, has hydrocephalus and underwent his first shunt surgery at just three days old, followed by several neurosurgeries during childhood. Joseph studied biomedical sciences at Marquette University and is currently in his third year of medical school at the Medical College of Wisconsin. The Harrises have been longtime HA supporters, and we are so glad Tim has joined the board!



**CRAFTED  
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.



[www.locustcider.com](http://www.locustcider.com) | [@locustcider](https://twitter.com/locustcider) [f](https://www.facebook.com/locustcider)

# Welcoming our New Staff Members



**Andrea Crossland**  
Donor Relations Manager

We are excited to welcome Andrea as the Donor Relations Manager at HA, where she plays a key role in driving the organization's fundraising success. Andrea supports revenue growth through administrative expertise, prospect research, data management, and building strong donor relationships.

With over 20 years of experience in the nonprofit sector, Andrea holds a degree in Business Administration with a focus on Information Technology from Bryant & Stratton. Her passion for philanthropy was ignited during an internship with the Cleveland Pops Orchestra, leading to roles at the Sisters of the Humility of Mary, Saint Ignatius High School, and Padua Franciscan High School.

Andrea, who lives in Greater Cleveland with her husband and two children, draws inspiration from her family's story. Her grandparents and mother were sponsored by Catholic Charities to immigrate to America after surviving a refugee camp following World War II. Andrea honors their legacy through her committed work in the nonprofit sector, giving back to the community as they once received.




**Amy Britt**  
Donor Services & Database Specialist

We are thrilled to welcome Amy Britt as the Donor Services & Database Specialist at HA. Amy's role is critical for promoting strong donor relations and supporting fundraising activities across the Development Department. This role ensures the accurate recording, processing, and acknowledgment of all donations at HA.


Amy brings over 20 years of extensive database management experience, with a specialized focus in Raiser's Edge. Throughout her career, she has worked with both large and small nonprofit organizations, embracing the unique challenges each database presents and helping to streamline data processes that drive organizational success.

Amy lives in Minnesota with her husband, Dan, and their dog, Trouble. She is the proud mother of three adult children and a devoted grandmother to two lively grandchildren, who keep her on her toes. Amy's passion for database management is matched only by her dedication to supporting the missions of nonprofits, ensuring that their data systems run smoothly and efficiently.




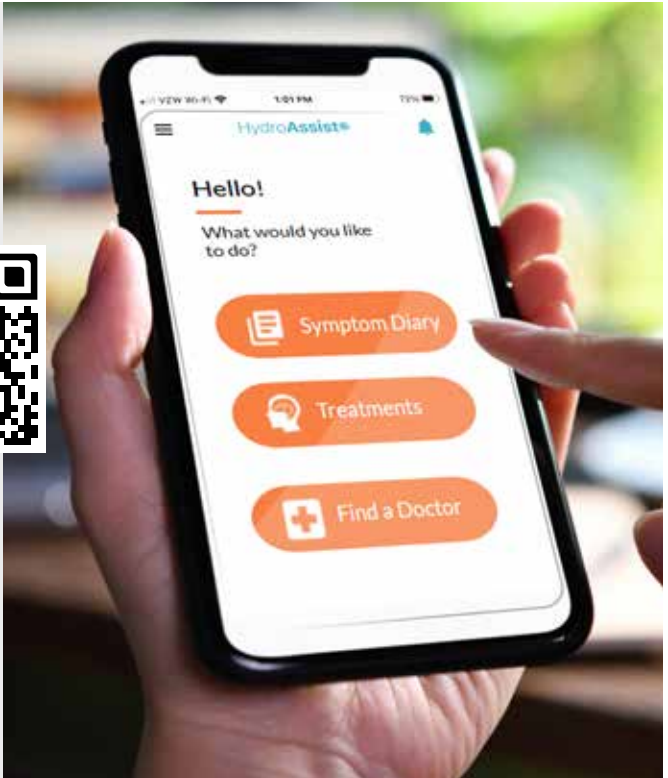
DOWNLOAD  
**HydroAssist**

- ✓ Symptom journal
- ✓ Headache tracker
- ✓ Hydrocephalus treatment history
- ✓ Image and document library
- ✓ Physician finder based on location



**HydroAssist** is a mobile app that allows you to record and store your hydrocephalus treatment history and access it when you need it from your mobile device. Perfect for individuals living with hydrocephalus and their caregivers. Based on feedback from YOU, we made several improvements!





## The Congressional Pediatric and Adult Hydrocephalus Caucus Grows to 39 members!

**Congressman Don Bacon (NE-02)** became the first member from the Nebraska delegation to join the Caucus. His commitment to bipartisanship will be a major asset to the Caucus. Additionally, he represents the district of the Omaha Walk to End Hydrocephalus.

**Congresswoman Suzanne Bonamici (OR-01)** became the second member from Oregon to join the Caucus. Her membership will be integral in promoting policies that support hydrocephalus patients who receive routine care at Oregon Health and Science (OSU). A big thanks to Oregon advocates, Chase Swearington and Nicole Anderson, who helped educate the Congresswoman's staff on the hydrocephalus community.

**Congresswoman Becca Balint (VT-AL)** became the first member from Vermont to join the Caucus. During her time in Congress, she has been a staunch supporter of legislation that increases access to mental healthcare and supports the disability community. We want to give a big thanks to hydrocephalus patient advocate and Vermont constituent, Matt Mulligan, who was integral in bringing the Congresswoman on to the Caucus.

**Congressman Andre Carson (IN-07)** became the first member from Indiana to join the Hydrocephalus Caucus. His membership underscores the robust hydrocephalus research network present in the state. Among the research in the state is the IU School of Science's Hydrocephalus Research Center, which is located directly in Representative's Carson district.

**Congressman Jason Crow (CO-06)** became the 3rd member from Colorado to join the Hydrocephalus Caucus. His district covers the Denver Walk to End Hydrocephalus, which represents one of our largest awareness walks in the United States. His robust experience in Congress will be integral in moving forth Hydrocephalus policy issues moving forward.

**Congressman Ted Lieu's (CA-36)** addition makes him the third California member of Congress to join the Hydrocephalus Caucus. His membership underscores the robust hydrocephalus community in California, and additionally LA where the Southern California Walk to End Hydrocephalus is located. The Congressman has been a leader on important issues like the use of AI in healthcare.

**Congressman Seth Moulton (MA-06)** became the first member from Massachusetts to join. A former marine officer and champion in the mental health space, he will be a major asset moving forward. We want to give thanks to two Massachusetts advocates, Jennifer Miles and Gabriel Abott, who were instrumental in his new membership.

**Congresswoman Lisa McClain (MI-09)**, became the first member from Michigan. Her commitment to the Caucus reinforces the strong hydrocephalus community present in the state. Michigan's advocates, Janay Harris, and Emily Sajor, were integral in educating the Congresswoman's office about the hydrocephalus community.



Don Bacon (NE-02)



Suzanne Bonamici (OR-01)



Becca Balint (VT-AL)



Andre Carson (IN-07)



Jason Crow (CO-06)



Ted Lieu's (CA-36)



Seth Moulton (MA-06)



Lisa McClain (MI-09)



Kevin Mullin's (CA-15)



Brittany Pettersen's (CO-07)



Paul Tonko (NY-20)

continued..

**Congressman Kevin Mullin's (CA-15)** membership makes him the 4th member from California on the hydrocephalus Caucus. As a freshman member of Congress, he will be integral in supporting the hydrocephalus community present in Northern California.

**Congresswoman Brittany Pettersen's (CO-07)** membership became the second member from Colorado to join the Caucus. Her strong roots in Colorado politics will be integral in her work on issues important to the Colorado hydrocephalus community. The work of Colorado advocates, Steph Munch and Jorja Harrison, were key in educating the Congresswoman's office on the importance of hydrocephalus awareness.

**Congressman Paul Tonko (NY-20)** became the 3rd member from New York to join the Caucus. As a veteran in the U.S. In The House of Representatives, he has been a staunch champion promoting important issues affecting the aging community. His leadership will be key for the Caucus's emphasis in promoting issues important to the approximately 800,000 Americans living with normal pressure hydrocephalus (NPH).



Scan to urge your member of Congress to join the Hydrocephalus Caucus, or visit [hydroassoc.org/congressional-pediatric-and-adult-hydrocephalus-caucus/](https://hydroassoc.org/congressional-pediatric-and-adult-hydrocephalus-caucus/)

## National Partnership for Pediatric to Adult Care Transition (NPPACT) Congressional Briefing

In June, HA joined forces with the Spina Bifida Association, Arthritis Foundation, Tourette Association of America, and the NPPACT to host a Capitol event titled **Healthcare Transition: A Care Cliff for Pediatric Onset Conditions**. Speakers included:

**Annie Kennedy**  
*Chief of Policy, Advocacy, and Patient Engagement at the EveryLife Foundation for Rare Diseases*

**Erin Teeple, MD**  
*Pediatric and Adult Colorectal surgeon and Director of the Colorectal Transition Program at Children's National Hospital in Washington, D.C.*

**Domonique Robinson**  
*Spina Bifida and Hydrocephalus Patient Advocate*



Capitol event titled *Healthcare Transition: A Care Cliff for Pediatric Onset Conditions*.

Their discussion provided insights on the various barriers present for young adults with complex needs while transitioning to the adult healthcare system including reimbursements incentives, lack of transitional coverage, and workforce challenges.

The panel's testimony also underscored the importance of report language that would survey the Department of Health and Human Services on their current programs and policies assisting pediatric to adult transition. The briefing capped off a month-long advocacy campaign led by HA and NPPACT members to members of the LHHS Appropriations subcommittee. The proposed report language was successfully included in the FY2025 Senate LHHS Appropriations Bill proposal.



NPPACT is a coalition co-chaired by HA CEO, Diana Gray and SBA CEO, Sara Struwe with the goal of joining forces with other nonprofit patient organizations to improve the systemic and public policy challenges related to pediatric to adult healthcare transition for medically complex patients.

Learn more.  
[nppact.org](https://nppact.org)



## HA at the Table

National Health Council Washington  
Representatives Summer Meeting  
June 17, 2024

Johns Hopkins Medicine Digital and Community  
Engaged Approaches to Support Research  
Recruitment | Baltimore, MD  
September 11-12, 2024

Engineering roadshow to University  
of Washington biomedical  
engineering students | Seattle, WA  
October 2, 2024

MDIC 2024 Annual Patient Summit | Virtual  
(MDIC is the Medical Device Innovation  
Consortium)  
October 29, 2024

Adult Hydrocephalus Clinical Research Network  
(AHCN) Meeting | Seattle, WA  
University of Washington  
November 15-16, 2024

Hydrocephalus Clinical Research Network (HCRN)  
Meeting | Deer Valley, UT  
November 7-8, 2024

Aesculap Academy: Hydrocephalus Management  
Course | Dallas, TX  
November 1-2, 2024

National Health Council Washington  
Representatives Retreat | Annapolis, MD  
November 15-16, 2024

Defense Health Research Consortium (DHRC)  
Annual Meeting | Washington, DC  
December 10, 2024

American Association of Neurological Surgeons  
(AANS) Joint Pediatrics Section  
Annual Meeting | New York City, NY  
December 12-15, 2024

## Hydrocephalus Association Advocates at the Rally for Medical Research

The Hydrocephalus Association brought over 10 advocates from across the country in September to participate in the Rally for Medical Research Hill Day event in Washington, D.C.

The event engaged stakeholders from the research, healthcare policy, and patient advocacy space to urge members of Congress and their staff to support robust funding increases to the National Institutes of Health's (NIH) 2025 budget.



NPH Patient Advocate, Rich Mulholland, pictured with Congresswoman Andrea Salinas (OR-06)

The NIH funds a wide array of impactful hydrocephalus research throughout the country. However, funding barriers in Congress present a major challenge for new forms of research. 2024 was the first year since 2013 where the NIH budget was cut meaning that innovative science

was left unfunded. Funding barriers create less opportunities for new, young investigators looking to enter the biomedical research field. Inflationary challenges present additional cost challenges for scientists looking to investigate new cures for conditions like hydrocephalus.

Our advocates met with over 40 different Congressional offices to share their stories with hydrocephalus.



Lakisha Harris and research advocates pictured with Senator Bill Cassidy (LA)

# HA Champions Patient-Centered Care at National Health Council Symposium

HA attended the National Health Council's Science of Patient Engagement Symposium to support patient-centered policies in healthcare:

Pictured left to right in photo below:

**Annie Kennedy**

EveryLife Foundation for Rare Diseases

**Jonathan Shepherd, MD**

District of Columbia, Department of Behavioral Health

**Elsa Kendall**

The Red Ink Project

**Teressa Jackson**

Caregiver, Hydrocephalus Association

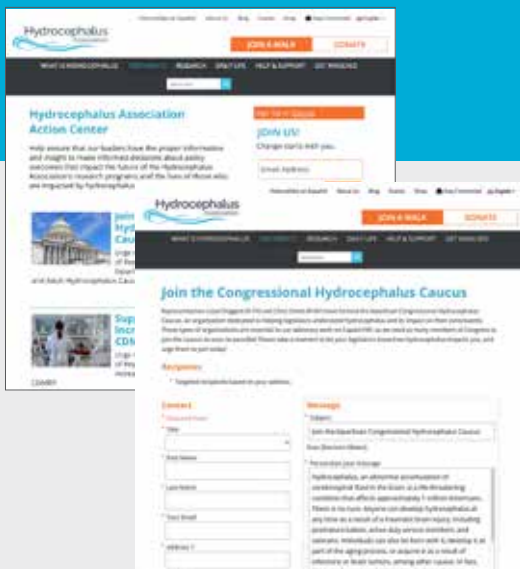
Panels covered key topics, including the challenges of care transitions and ageism in healthcare. Teressa Jackson shared her family's hydrocephalus journey, emphasizing the need for care tailored to each patient's unique needs. The event highlighted how listening to patient voices can lead to better policies, foster trust, and improve healthcare outcomes for all.

*"Being invited to share our family's story of living with hydrocephalus was truly heartwarming. Doctors and policy makers need firsthand insight from patients and caregivers living with this rare condition to create positive change in healthcare and policy. I am looking forward to hydrocephalus being discussed in more of these important forums!"*

Teressa Jackson, Panel member (far right)



## JOIN OUR ADVOCACY EFFORTS ONLINE!



Visit our new Advocacy Action Center, where you can learn more about the issues we're working on and send e-mails to your legislators about our concerns and what they can do to help. We can't get what we want if we don't ask.



Now that so much is happening in Congress, we have to be sure we have a seat at the table!

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

# SUPPORT AND EDUCATION

## Announcing Our New Hydrocephalus Resource Library!

We're thrilled to introduce our new Hydrocephalus Resource Library—a comprehensive, up-to-date collection of resources designed to empower and support you at every stage of your hydrocephalus journey.

Whether you're newly diagnosed, living with normal pressure hydrocephalus, or navigating life as a parent, this resource library has something for everyone.

Discover expert insights on a wide range of topics, including understanding hydrocephalus, exploring treatment options, managing care, and handling important transitions—like navigating school, starting college, and gaining independence. You'll also find personal stories, the latest research, and practical tips to help you thrive.

Whatever guidance you're seeking, our Hydrocephalus Resource Library brings it all together in one accessible place.



Scan the QR code to explore the library today!

Or visit [hydroassoc.org/hydrocephalus-library](https://hydroassoc.org/hydrocephalus-library)



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



**JOIN NOW!**  
[hydroassoc.org/happier](https://hydroassoc.org/happier)

# Announcing our 2024 Hydrocephalus Association Scholarship Recipients

## The Hydrocephalus Association (HA) is pleased to announce our 2024 Hydrocephalus Association Scholarship Award Recipients.

Since the scholarship program was established, HA has awarded 266 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.



### Lily Adkins

#### Recipient of the Kate Finlayson Memorial Scholarship

Lily is studying special education at Dominican University, aiming to become a special education teacher and adaptive sports coach. Diagnosed with hydrocephalus and a brain tumor as a child, Lily has overcome significant challenges, including two shunt failures. Her passion for rowing has led her to compete as a paraworker, defying expectations of her physical abilities. Lily is also an advocate for childhood cancer and hydrocephalus awareness, using her experiences to mentor children, raise funds, and volunteer in her community, including with Alex's Lemonade Stand Foundation.

*"After college graduation, I see myself teaching children with disabilities, coaching rowing or another sport at an adaptive sports center and continuing to find ways to advocate for more inclusion for children and adults with disability."*



### Lizzie Armor

#### Recipient of the Anthony Abbene Memorial Scholarships

Lizzie is a biomedical engineering student at the University of Michigan, determined to improve medical technology for individuals with hydrocephalus. Diagnosed with hydrocephalus as an infant, Lizzie struggled with isolation before embracing her diagnosis and becoming an advocate. She is passionate about developing safer medical devices and connecting with others in the hydrocephalus community. Lizzie is also an athlete, having played varsity soccer,

basketball, and golf, and is actively involved in volunteering through clubs like NHS and DECA.

*"When I was finally old enough to understand the diagnosis I received when I was two months old, I knew what I wanted to spend my life doing. I knew I wanted to make a difference in the lives of those like me and play my part in improving the world of medical technology."*



### Benjamin Bachmore

#### Recipient of the Baldus Family Scholarship in Memory Gerard Swartz Fudge Scholarship

Benjamin is a neuroscience student at Virginia Tech, where his passion for the field is rooted in his personal experience with hydrocephalus, diagnosed during his teens. After undergoing multiple brain surgeries, Benjamin became dedicated to raising awareness for the condition, participating in local walks and events. An avid swimmer and former National Honor Society president, Benjamin is also a community volunteer, lifeguard, and active learner. His interests include playing piano, reading, video games, and writing, all of which contribute to his well-rounded academic and personal life.

*"The intricacies and capabilities of the human body have always piqued my interest, and undergoing 3 brain surgeries has only affirmed my desire to follow a path in medical neurology. Just as my neurosurgeon taught me, I am driven to pass my knowledge of the neurological field on to others who also require brain surgery."*



### Elena Bowles

#### Recipient of the Kate Finlayson Memorial Scholarship

Elena, a biochemistry major at Stevenson University, is driven to pursue a career in healthcare as a neurosurgery-focused physician assistant (PA), inspired by her own journey with hydrocephalus and a recent impactful interaction with a PA who brought her comfort during a challenging surgery. Diagnosed at six months old, she has endured multiple surgeries, the constant fear of complications, and the need to keep her struggles private, all of which have fueled her resilience and determination. Elena has actively supported the Hydrocephalus Association for over 13 years, participating in the DC WALK, delivering speeches, sharing her

continued...

story through PSAs, and engaging in advocacy, which continues to shape her passion for making a difference in the lives of others.

*"My career will give me the opportunity to have an impact on others because I know firsthand what it feels like to be helpless. I want to work closely with others with my condition and do everything in my power to help better others lives."*



### Kayla Gray

#### Recipient of the Mario J. Tocco Hydrocephalus Foundation Scholarship

Kayla is pursuing a PhD in Nursing with a focus on healthcare innovation at Arizona State University. Diagnosed with hydrocephalus at age 15, her experience has fueled her passion for transforming healthcare education, patient safety, and care quality. As the operations manager of Creighton University's anatomy lab, she co-created the Knowledge Donor Program and Health Sciences Academy. Outside her academic work, Kayla enjoys hiking and acting, and she remains committed to mentoring underrepresented students and raising hydrocephalus awareness through advocacy and public speaking.

*"Having conducted rigorous research at the lab bench and taught hundreds of medical students, I have witnessed gaps in clinical readiness that lead to errors and communication breakdowns. Earning this degree will position me to innovate curricular models and training protocols."*



### Alyssa Hatfield

#### Recipient of the Morris L. and Rebecca Ziskind Memorial Scholarships

Born with hydrocephalus, Alyssa has faced numerous challenges, including multiple surgeries and bullying, yet her resilience shines through. She is determined to use her journey to inspire others, particularly as she pursues her dream of becoming a speech and language therapist. Alyssa plans to major in communication sciences and disorders at a four-year university and hopes to return to her hometown to support children in her community. Her experiences have shaped her passion for making a difference, and she remains driven to help others thrive despite adversity.

*"There have been many amazing people in my life that have made a huge impact and I want to be that person for others. As a result, helping people is my passion, my dream is to positively impact any and all the people I can."*



### Brayden Locricchio

#### Recipient of the Gerard Swartz Fudge Memorial Scholarships

Brayden is pursuing a Bachelor's degree in History at the University of Wisconsin - Platteville, with aspirations to work at a museum, like the Smithsonian, as an artifact director. As a first-generation college student born with hydrocephalus, Brayden takes pride in his academic success, being on the Dean's List and earning Learner of the Year in 2023. He is an active participant in the San Francisco WALK and joins HA's Young Adults in their 20s virtual meeting, finding community and support through these connections.

*"I hope to work at a museum and someday be an artifact director at the Smithsonian because I am fascinated by the history behind artifacts." He adds, "I want to share my love for history and help inspire others to appreciate it as much as I do."*



### Grace McCombs

#### Recipient of the Hydrocephalus Association Fund Scholarship Supported by Erik & Lisa Chamberlain

Grace is a dedicated dancer, artist, and educator who aims to become a dance teacher and choreographer. Living with hydrocephalus has influenced their journey, but Grace's passion for movement, fitness, and advocacy continues to grow. Active in Hydrocephalus Association support groups and fundraising, they find comfort in connecting with others who share similar experiences. Grace hopes to inspire others by pursuing their dreams in dance, Pilates, and yoga, while also being open about their condition to show younger children with hydrocephalus that success is possible.

*"I grew up having such a negative relationship with exercise, and my journey to learning to love it has been so exciting. I enjoy sharing this passion with others and hope to teach pilates and yoga by getting a certification someday."*



### Ashlei McGhee

#### Recipient of the Morris L. and Rebecca Ziskind Memorial Scholarships

Ashlei is pursuing a Master's degree in Communication Sciences and Disorders at the University of Central Florida, with a goal of becoming a speech-language pathologist and opening her own private practice. Born with cerebral palsy and hydrocephalus, Ashlei's personal journey has fueled her passion for helping others with communication disorders and disabilities. She actively

volunteers with organizations like Orange Ribbons for Jaime and is committed to raising awareness through her nonprofit work. In her free time, Ashlei enjoys painting, photography, and graphic design, which reflect her creativity and dedication to self-expression.

*"From overcoming personal challenges to aspiring to innovate in the field of speech therapy, my journey has been anything but ordinary. Ashlei adds "The impact of speech therapy on my life was monumental, providing me with the fluency and confidence that once seemed unattainable. This transformation fueled my desire to ensure that others facing similar challenges could also find their voices and their confidence"*



### Kyleigh Morgan

#### Recipient of the Jacobsen Family Scholarship

Kyleigh is studying nursing at St. Lawrence College - Kingston, with the goal of becoming a pediatric nurse practitioner. Living with hydrocephalus has provided her with unique insights into overcoming challenges, both academically and socially. Kyleigh's involvement with the Hydrocephalus Association, including participating in HA's monthly Teens Hang-Out and writing for the 40th-anniversary campaign, has strengthened her advocacy efforts. In her free time, Kyleigh enjoys music, writing, and volleyball, passions that complement her dedication to her studies and helping others.

*"I want to be someone who instills hope in their patients when they have none, who listens to them the first time so they do not have to fight with their words when they already have to do so with their bodies. Ultimately, I want to be someone in authority that patients can trust."*



### DeAndre Oliver

#### Recipient of the Anthony Abbene Memorial Scholarships

DeAndre is a nursing student at Pima Community College, aspiring to become a flight nurse or critical care nurse. Diagnosed with hydrocephalus at birth, DeAndre has faced numerous health challenges, including nearly 20 brain surgeries, but remains committed to his goal of helping others. His experience in the NJROTC and fire service programs, combined with his resilience, have shaped his passion for healthcare. DeAndre is eager to participate in hydrocephalus awareness activities and advocate for the community, building on his involvement in teen meetings and congressional advocacy.

*"Recently, I was in the intensive care unit for nearly a month. While in the hospital, it opened my eyes to a world of healthcare beyond Emergency Medical Services. My new passion is clear and focused now: I want to apply for nursing school. I feel like I would be able to make an impact on patients' lives—I feel like that is my purpose."*



### Tai Parsley

#### Recipient of the Justin Scot Alston Memorial Scholarship

Tai, a sophomore at the University of Tennessee at Chattanooga, was born with hydrocephalus and spina bifida, undergoing life-saving surgery as an infant. Despite these challenges, he has demonstrated incredible resilience, excelling academically with a near-perfect GPA. His experiences living with hydrocephalus have fueled his passion for international relations and U.S. foreign policy. Tai aspires to work with governmental or non-governmental organizations, like the Department of State, to make a meaningful impact on global issues. With plans to pursue a master's and possibly a doctorate, Tai is determined to use his education and personal journey to enact positive change worldwide.

*"I try not to let hydrocephalus get in the way for me to achieve great things and to be able to make a difference in my community, state, country, and world. I pride myself on my ability to bring people together rather than tear them apart."*



### Parker Shubin

#### Recipient of the Gerard Swartz Fudge Memorial Scholarships

Parker, a neuroscience student at UCLA, draws inspiration from his own journey with hydrocephalus to pursue a career in pediatric neuro-oncology. Diagnosed due to a brain tumor, he has faced significant health challenges, fueling his drive to support others on similar paths. Active in the Cancer Awareness Club and Children's Brain Tumor Foundation, Parker shares his story to inspire resilience. He also tutors Spanish-speaking immigrants in English, and enjoys cooking traditional Filipino dishes with his mom, which helps him stay connected to his heritage.

*"This is a hefty ambition, but I truly believe I can achieve it — I've faced much adversity in my life and persevered. I want to empower others to navigate their own challenges."*

## COMMUNITY HIGHLIGHTS

# Swimming the Unswimmable: Team Hydro's Commitment to Hydrocephalus Research

For nearly two decades, Team Hydro has united individuals nationwide to swim from Alcatraz Island to San Francisco, raising over \$1 million for hydrocephalus research and awareness.

Co-founded by brothers Peter and Sam Finlayson, the team has grown from just four swimmers in 2008 to a thriving 501(c)(3) organization that hosts its own annual event.

Peter recalls the motivation behind their first swim, which was sparked by his sister's battle with hydrocephalus. Today, Team Hydro's mission is to educate the public about the urgent need for better treatments and cures, evidenced by a record turnout this year, including the Stanford Water Polo team and hydrocephalus research grant recipients.

Since its inception, Team Hydro has played a significant role in advancing hydrocephalus research, funding initiatives like the Mentored Young Investigator Award. Tragically, Peter's sister passed away before she could see the impact of their efforts, but her memory fuels their commitment to the cause.

With ongoing partnerships and new research centers emerging, Team Hydro remains optimistic about discovering non-surgical treatments and potential cures for hydrocephalus. The team's journey exemplifies the power of community and dedication in driving meaningful change.



Dare to swim the unswimmable?  
Learn more about team hydro  
and how to get involved at  
[teamhydro.org](https://teamhydro.org)



Swimmers unite in the name of hydrocephalus research



Team Hydro in the 20th Swim from Alcatraz

## RAISE Resilience Program

The RAISE Resiliency Program is dedicated to enhancing the resilience of caregivers of children with hydrocephalus.

RAISE is a six-module skills training program that will cover topics of Resilience, Agency, Intentional Thinking, Strengths, and Engagement. Within these modules, participants will learn about the protective factors of resilience, agency and self-efficacy, thinking traps and reframing strategies, and the VIA character strengths.



Interested in joining?  
Scan the QR code above.

# A Mother's Story

## Navigating the Potential Genetic Links of Hydrocephalus

Story Written by Mother, Caitlin

**In December 2018, my husband and I welcomed our son, Cavan, who was diagnosed with aqueductal stenosis and hydrocephalus at four months old. Despite my nursing background, this was unfamiliar territory for us, and we were reassured that his condition was unlikely to be genetic. After discussing treatment options, we chose a shunt system.**

By age 2.5, Cavan was thriving. We lived in an RV while I worked as a travel nurse, and he was a happy, easy-going kid starting kindergarten. He even discovered a classmate with hydrocephalus during show-and-tell, showcasing his friendly nature.

When I became pregnant with Breccan, my OB referred me to a high-risk doctor as a precaution. Despite additional ultrasounds, all prenatal imaging appeared normal. However, at two months, it became evident Breccan had hydrocephalus, also due to aqueductal

stenosis. We initially attempted an endoscopic procedure, but he was shunted at four months old.

Breccan is now a lively 2-year-old, and I worry about his safety as he admires Cavan. Concerned about the possibility of a genetic link, we pursued genetic testing but faced insurance challenges. Eventually, we connected with a genetic study through the Hydrocephalus Association.

In November, we were surprised to learn I was pregnant again. This time, we found out we were having a girl, Teagan. During her pregnancy, I remained hopeful given the research I had done. However, at her two-month checkup, Teagan was diagnosed with hydrocephalus, and we opted for a shunt procedure, as the ETV had failed for her brothers.

Teagan, now a joyful baby, is deeply loved, and I often reflect on the challenges we've faced. While navigating their care, I keep current MRI scans with me for emergencies. I remain hopeful that we will one day understand the cause of hydrocephalus in our children, providing them valuable insights for their futures. Until then, we will continue to support them in leading fulfilling lives despite their challenges.





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## The Fudge Solomon

LEGACY SOCIETY

The Fudge Solomon Legacy Society singularly supports the Hydrocephalus Association's efforts to eliminate the challenges of hydrocephalus and help ensure the growth and security of the organization's programs. Donors to this fund take this opportunity to ensure the continuation of HA's work in research, support, education and advocacy, by placing a gift to HA in their wills, trusts or estate plans—and it costs them nothing now.

We have partnered with FreeWill to make your planned giving and estate planning needs easier. In minutes, and at no cost, you can document your future wishes.

*"It did my heart good to include HA in my estate plan in memory of my nephew Gerard Fudge, son of my sister Emily Fudge and her husband Russell, founders of this organization. I also know that by taking this step, I had the opportunity to impact the future of hydrocephalus in such a meaningful way. As we say 'HA is our family business.'"*

— Sally Baldus, Legacy Society Chair

## NEW!

HA has developed a webpage to put resources at your fingertips for various ways to build the estate plan that suits your needs.



Please visit to  
learn more!  
[hydroassoc.org/  
planned-giving](https://hydroassoc.org/planned-giving)



Create your free plan and  
start your legacy today!