Hydrocephalus
Association

PATHWAYS

Hydrocephalus Association Newsletter, Volume 45, Winter 2025

VOLUME
45
EDITION 1

Engineering Innovation

HA is pushing the envelope on research and development by supporting new research awardees and convening engineers who bring fresh perspectives.

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Join us at HA CONNECT in July

Our 19th National Conference on Hydrocephalus heads to Indianapolis, home of the first Hydrocephalus Research Center at Indiana University.

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Ending the Debate over NPH

The PENS study results show that shunting works to treat normal pressure hydrocephalus.

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Smart Shunts Could Change Lives

Integrated sensors could offer real-time data to patients and doctors.

Message from the President and CEO

Diana Gray, MA

> “Medical science has proven time and again that when the resources are provided, great progress in the treatment, cure, and prevention of disease can occur.”
>
> — Michael J. Fox

As we close another year of progress and perseverance, this issue of Pathways is filled with stories that bring our mission to life. I’d like to highlight two remarkable research achievements that exemplify how collaboration and investment drive real change for the hydrocephalus community.

In August, we convened more than 90 engineers, neurosurgeons, scientists, industry leaders, and patient advocates to explore innovative solutions to two of the greatest challenges in hydrocephalus treatment—shunt failure and device monitoring. This dynamic gathering united experts across disciplines to think boldly and creatively. Participants were deeply moved by the stories of heartbreak and resilience shared by individuals living with hydrocephalus, reminding everyone of what’s at stake. Importantly, this meeting was not a one-time discussion. It sparked the creation of a Synergy Circle—a working group of engineers and scientists now collaborating regularly to advance these ideas toward tangible solutions. This milestone was made possible through the leadership of Dr. Carolyn Harris, Chair of our planning committee; Dr. Monica Chau, our National Director of Research; and our generous benefactor, the Rudi Schulte Research Institute.

Another major advancement this year addresses a long-standing challenge in diagnosing and treating idiopathic normal pressure hydrocephalus (iNPH)—a condition that may affect nearly one million older Americans, yet is frequently misdiagnosed. For decades, lack of consensus about the effectiveness of shunt treatment led to delays in care. That changed with the landmark Placebo-Controlled Efficacy in iNPH Shunting (PENS) Trial, led by three founding members of the Adult Hydrocephalus Clinical Research Network (AHCRN): Dr. Mark Luciano of Johns Hopkins University School of Medicine, Dr. Michael Williams of the University of Washington, and AHCRN Chair, Dr. Mark Hamilton of the Cumming School of Medicine in Calgary. This $14 million NIH-funded study, involving 21 centers, confirmed what many patients and physicians have long believed—that shunt surgery is a safe and effective treatment for iNPH. The results, published in the prestigious New England Journal of Medicine, represent a transformative step forward for patient care.

I began with Michael J. Fox’s words because they capture a truth at the heart of our mission: progress happens when research is fueled by both vision and investment. Public and private funding—working hand in hand—are essential to advancing care, improving lives, and ultimately finding a cure for hydrocephalus.

To everyone who has given, walked, volunteered, or lent your voice to this cause—thank you. Your support makes every success in these pages possible.

With gratitude and warmest regards,

Diana Gray

Diana Gray, MA
President and Chief Executive Officer
Hydrocephalus Association

Your donation helps fuel life-changing research, advocacy, and care for people living with hydrocephalus.


Hydrocephalus Association
THIS IS WHAT STRONG LOOKS LIKE
I LOVE SOMEONE W
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CONTENTS

Landmark Study Ends Decades of Controversy around the Treatment of iNPH

A condition that develops for unknown reasons as people age and causes dementia-like symptoms now has a clear path toward recognition and effective treatment by the medical community.

Idiopathic normal pressure hydrocephalus (iNPH) is a form of hydrocephalus that impacts individuals age 60 and older. iNPH is typically characterized by a triad of symptoms that include difficulty walking, cognitive impairment, and impaired bladder control.

Nearly one million older Americans may be living with iNPH, with more than 80% of cases going unrecognized or untreated. The likelihood of developing iNPH increases with age; by age 86 and older, about one in 13 people (7.7%) are affected. Left untreated, iNPH can cause falls, loss of independence, and eventually severe neurological disability and death. With early treatment, however, most patients experience meaningful improvement, often with partial to complete reversal of symptoms.

Without appropriate diagnostic testing, iNPH is often misdiagnosed as Alzheimer's disease, Parkinson's disease, stroke, or dismissed as "normal aging." The primary treatment, the placement of a shunt, has been clouded by controversy regarding its effectiveness and safety.

Now, a landmark international study funded by the National Institutes of Health (NIH) and led by Johns Hopkins University School of Medicine along with the Adult Hydrocephalus Clinical Research Network (AHCRN), has clearly demonstrated that shunt surgery improves walking and balance, restoring mobility, reducing falls and thus improving safety and independence in older adults with iNPH. The Placebo-Controlled Efficacy in iNPH Shunting (PENS) Trial is the first large, double-blind, placebo-controlled study to resolve decades of debate on whether shunts truly help patients. The results are published in the prestigious The New England Journal of Medicine.

> *"Completing this randomized clinical trial was necessary because many neurologists and neurosurgeons were unsure if shunts could effectively treat iNPH, which greatly affected patient access to diagnosis and care," stated Dr. Mark Hamilton, MD, Director of the Calgary Adult Hydrocephalus Program at the Cumming School of Medicine, Calgary, Alberta, Canada and Chair of the AHCRN. "Now, there is no doubt. Shunt surgery for iNPH has been confirmed to improve walking and balance, decrease falls, and restore independence. Shunt surgery for patients with iNPH is both safe and effective."*

The Road to PENS

Normal pressure hydrocephalus was first described in 1964 by Salomon Hakim, MD, PhD, ushering in early enthusiasm in the 1960s and 70s for a treatment that could relieve, and even reverse, symptoms in the aging population. By the 1980s, however, skepticism took hold due to inconsistent outcomes and high complication rates.

The PENS Trial was designed to resolve this long-standing uncertainty through the most rigorous form of clinical research—a double-blind, randomized, placebo-controlled trial. The concept originated in 2008, led by Dr. Mark Luciano, MD, PhD, Director of the Cerebral Fluid Center at Johns Hopkins Medicine; Dr. Michael Williams, MD, FAAN, Director of Adult and Transitional Hydrocephalus and CSF Disorders at the University of Washington; and Dr. Mark Hamilton. All three, founding members of the AHCRN and leading experts in iNPH neurology and neurosurgery, were committed to validating the improvements they had repeatedly observed in their own patients. Yet, despite their persistence, early proposals to the NIH were dismissed as "unnecessary."

In 2012, the Hydrocephalus Association supported the start of the AHCRN. For the first time, leading experts from the United States, United Kingdom, and Canada joined forces, pooling their data, resources, and patients to tackle the most pressing research questions in adult hydrocephalus. The AHCRN completed a PENS pilot study with the financial support of the Hydrocephalus Association and an unrestricted grant from a medical device company – Codman, a division of Integra LifeSciences. With data in hand and AHCRN's proven ability to collaborate across institutions, enroll patients efficiently, and maintain a centralized data coordinating center, a new proposal was submitted to NIH.

In 2021, the NIH awarded $14 million — its largest-ever grant for hydrocephalus research — to launch PENS under the leadership of Dr. Mark Luciano, along with Dr. Michael Williams, Dr. Mark Hamilton, and the AHCRN. Six AHCRN sites—which included Johns Hopkins University, University of Washington, University of Calgary, University of British Columbia, New York University, and the Cleveland Clinic—participated in the PENS trial. The University of Utah Data Coordinating Center and the Johns Hopkins BIOS Clinical Trials Coordinating Centre coordinated the PENS trial. There were 21 active sites in the United States, Canada, and Sweden in the study.

New Hope for Patients: Improving Mobility

The incidence of iNPH for individuals age 85 and older is comparable with that of Alzheimer's disease. Yet, a lack of understanding and recognition of iNPH often puts patients on a multi-year diagnostic odyssey trying to find the cause of the triad of symptoms they are experiencing. Left untreated, iNPH can cause progressive disability, loss of independence, and early death for the individual, and an increasing burden of care and medical expenses for loved ones.

The PENS trial enrolled 99 patients across 17 sites. Every participant received a programmable shunt. On the day of surgery, the patient's shunt was randomized to either open or placebo, with the placebo setting effectively preventing the shunt from functioning. The main outcome of the study was the speed of walking (gait velocity). After three months, the gait velocity in the open shunt group was significantly faster than before surgery, while in the placebo group, gait speed was virtually unchanged. Patients in the open shunt group also had improved balance and reported fewer falls. Eventually, after three months, all patients had their shunts opened. Neither patients nor their doctors knew which group they were in to avoid biasing the results.

> *"We hear testimonials from individuals who are active with the Hydrocephalus Association that their iNPH diagnosis and subsequent treatment allowed them to slowly return to the activities that they loved," shared Diana Gray, President and CEO of the Hydrocephalus Association. "This study is an important step in raising awareness of iNPH among the medical community so that individuals can be referred early in order to get the treatment they need. We are proud to have played a critical role in funding research that directly improves the lives of the community we serve."*

The PENS Trial will continue to follow participants for 12 months to measure long-term outcomes, including cognition, daily functioning, and quality of life. Early findings already suggest gains beyond walking.


L-R: Dr. Mark Hamilton, Dr. Michael A. Williams, Dr. Mark Luciano

HACONNECT

19th NATIONAL CONFERENCE ON HYDROCEPHALUS

July 23-25, 2026 • JW Marriott • Indianapolis, IN

Join us for the world's largest conference on hydrocephalus — HA CONNECT 2026, the 19th National Conference on Hydrocephalus! Discover breakthroughs in research, connect with peers, and celebrate the strength of our community. Leave feeling supported and re-energized on your hydrocephalus journey — you are not alone!

NPH Session Highlights

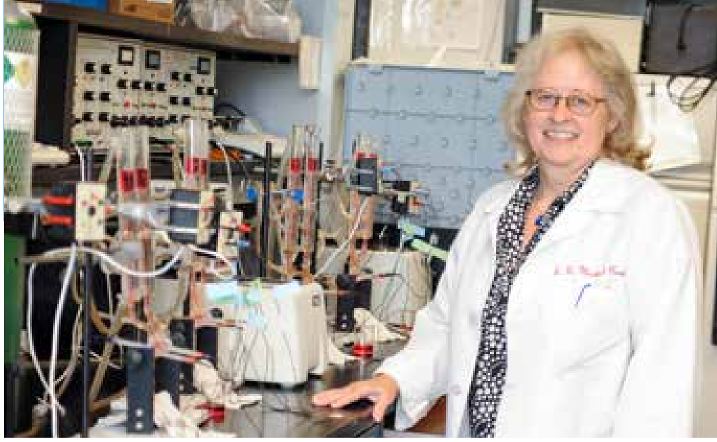
A track just for those living with or supporting someone with normal pressure hydrocephalus (NPH).

1. The Largest Clinical Trial for NPH: Hear the Long-Awaited Results
2. NPH: Living Your Best Life
3. Normal Pressure Hydrocephalus: Looking Beyond the Triad of Symptoms
4. Understanding Your Treatment: Inside the Mind of NPH Doctors

Supporting Your Whole Crew

An entire track for teens and special programming for siblings.

Stay Connected. #HACONNECT



Don’t Miss These NEW Sessions!

- You’re Not Just a Patient, You’re a Partner in Research (All Ages, Research)
- Staying on Track: Managing Memory and Executive Function as an Adult (Adults)
- Beyond Graduation: Planning Your Future, Your Way (Parents, Teens)
- Advocating for Yourself or Your Child: Partnering with Your Care Team (All Ages)

Kids Camp

A nurturing environment for children ages 3-11 with or without hydrocephalus. Experience hands-on educational programming.

THANK YOU TO OUR PRESENTING SPONSORS!

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The Hydrocephalus Research Center

Scientists Meet and Greet with Lab Tours

(Limited Spots Available!)

Ever wonder what goes on behind the scenes in hydrocephalus research? Here’s your chance to find out! We’re offering an exclusive opportunity to go inside the Hydrocephalus Research Center at Indiana University for a one-of-a-kind experience. Meet the brilliant scientists leading cutting-edge research, explore state-of-the-art labs where discoveries are made, and ask your burning questions directly to hydrocephalus researchers. Round-trip transportation will be provided from the conference venue to IU. Spots are very limited and will go fast — registration is on a first-come, first-served basis, so don’t wait! Be sure to register early to secure your spot!

To learn more and register, visit hydrocephalusconference.org

William Vincent

A Lifelong Journey with Hydrocephalus and a Legacy of Hope

Born in the late 1960s when hydrocephalus was still poorly understood and treatment options were limited, William Vincent's life has been a testament to perseverance, curiosity, and gratitude. Diagnosed as an infant and shunted at just four months old, he underwent multiple surgeries in his first years of life before finally achieving stability with a ventriculoperitoneal (VP) shunt at age six. For 35 years, he lived symptom-free, building a full and meaningful life as an educator, husband, and father. Looking back, he reflects on his early years with both wonder and humility: "I realize how fortunate I am to have been very stable and healthy overall. Each person's journey with hydrocephalus is unique, and every story is worth sharing."

Bill's natural curiosity led him to learn more about hydrocephalus as an adult, eventually connecting with the Hydrocephalus Association through one of our conferences. For the first time, he met others living with the condition and discovered that his experiences, once isolating, were shared by many. Through that connection, he found both community and purpose. "I knew next to nothing about hydrocephalus until adulthood," Bill shared. "Although technology and information are much more available now, I hope to inspire more development of longitudinal care and better transitions between pediatric and adult care, and between primary care, neurology, neurosurgery, patients, and parents."

Bill's commitment to improving understanding and care for people with hydrocephalus inspired him to include the Hydrocephalus Association in his estate plans, ensuring that his legacy will help future generations. As someone who has experienced firsthand both the progress and the gaps in hydrocephalus care, he hopes his planned gift will fuel continued research and advocacy.

We are profoundly grateful to Bill for his generosity and for sharing his journey with honesty and courage. His story reminds us that every person living with hydrocephalus has a voice that deserves to be heard—and that together, we can create a future where no one faces this condition alone.

FREEWILL

Ready to make your will?

Your will is your way to protect your loved ones, ensure your wishes are honored, and even make an impact with your legacy. HA has partnered with FreeWill to offer **complimentary estate planning** tools that provide a straightforward and no-cost way for you to plan your estate according to your preference.

If you leave an estate gift to HA in your plans, you will automatically become a member of The Fudge Solomon Legacy Society, where you will receive special communication and invitations to exclusive HA offerings.

Start your free will today!

Questions? Contact Linda Riley,
National Director of Development
linda@hydroassoc.org (240) 483-4475

NPH vs. Alzheimer's and Parkinson's

Spotting the Difference

For many adults and families navigating memory loss, difficulty walking, or bladder control issues, it can be difficult to tell what's really going on. Is it Alzheimer's? Parkinson's? Or could it be idiopathic normal pressure hydrocephalus (NPH)—a condition that mimics both but is often treatable?

That distinction matters. While Alzheimer's and Parkinson's are progressive and irreversible, NPH symptoms can often improve - sometimes dramatically - with proper diagnosis and treatment. Yet even today, NPH remains misunderstood and frequently mistaken for other conditions. Further complicating matters, NPH can co-exist with Alzheimer's, Parkinson's, or other conditions, worsening symptoms and speeding their progression.

What Is Normal Pressure Hydrocephalus (NPH)?

In NPH, excess cerebrospinal fluid (CSF) builds up in the brain's ventricles—those small, fluid-filled chambers deep within the brain. This causes the ventricles to enlarge, sometimes with little or no increase in intracranial pressure (ICP). The enlargement puts pressure on surrounding tissue, leading to symptoms that affect walking, thinking, and bladder control.

Most often seen in adults over 60, NPH affects an estimated 800,000 older Americans, though more than 80% of cases go undiagnosed. Because symptoms appear slowly, it's easy to attribute them to "normal aging." But the earlier NPH is identified, the better the chances of mitigating its effects.

Recognizing the Hallmark Symptoms

People with NPH typically experience three main problems, often referred to as the classic triad:

- **Difficulty walking –** Difficulty walking or making turns, feeling like it's hard to take the first step, balance issues, falling, a slow shuffling gait, trouble lifting feet, or feeling like your feet are "stuck" on the floor.
- **Cognitive changes –** Problems organizing or planning tasks, hard time multitasking, trouble listening or paying attention, short-term memory issues, feeling withdrawn, talking less, poor handwriting, trouble with simple math calculations.
- **Bladder problems –** Trouble "holding it," not able to get to the bathroom fast enough, experiencing accidents.

Since these symptoms develop gradually, they are often mistaken for Alzheimer's or Parkinson's. However, there are key differences.

How Normal Pressure Hydrocephalus (NPH) Differs from Alzheimer's

SYMPTOMS	NPH	ALZHEIMER'S
Memory Problems	Mild to moderate, may improve with treatment	Progressive, worsens over time
Walking Issues	One of the first symptoms	Not common in early stages
Bladder Problems	Frequent, may start early	Rare in early stages
Response to Treatment	Often improves with a shunt	Newer medications slow progression, but do not cure

Key Differences

Memory issues in NPH are milder and can improve with treatment, while Alzheimer's leads to severe, irreversible memory loss. Walking problems in NPH appear early, while Alzheimer's patients may not struggle with movement until much later.

How Normal Pressure Hydrocephalus (NPH) Differs from Parkinson's

SYMPTOMS	NPH	PARKINSON'S
Walking Issues	Slow, shuffling gait with balance problems	Small, rigid steps, often with tremors
Hand Tremors	Not present	Common, especially at rest
Muscle Stiffness and Slowness	Not a major symptom. Upper limbs not affected.	Significant stiffness (rigidity) affecting upper and lower limbs
Response to Treatment	Does not respond to medication but can improve with shunt surgery	Initially responds to medication but worsens over time

Key Differences

Both conditions can cause walking difficulties, but NPH does not cause tremors or muscle stiffness—two hallmarks of Parkinson's. NPH patients tend to walk with a wider stance and feel as though their feet are "glued" to the ground. Parkinson's patients, by contrast, exhibit stiffness and slowness of the arms and legs and have a narrower gait. Additionally, they can also show decreased facial expressivity, trouble swallowing, difficulty controlling salivation, and might also have low blood pressure upon standing.

Getting the Right Diagnosis

Because NPH symptoms overlap with Alzheimer's and Parkinson's, proper testing is key. A neurologist or neurosurgeon may use:

1. **Brain Imaging (MRI or CT Scan) –** Checks for enlarged brain ventricles, a sign of NPH.
2. **Lumbar Puncture (Spinal Tap) –** A large amount of CSF is removed to see if symptoms improve, which suggests NPH.
3. **Extended CSF Drainage (Drain Trial) –** A temporary spinal drain is placed for a few days to assess whether removing excess fluid leads to improvement.

If walking, memory, or bladder issues improve significantly after these tests, a shunt procedure may be recommended to provide long-term symptom relief.

Why Early Diagnosis Matters

While Alzheimer's, Parkinson's, and NPH have no cure, NPH is treatable for most patients. Many patients experience meaningful improvements in walking, thinking, and bladder control after shunt surgery, regaining independence and mobility.

If you or someone you care about is living with NPH, help spread the word. Too often, these symptoms are brushed off as "just aging," delaying the chance for recovery. Awareness and early diagnosis can make a life-changing difference.

A Month of Connection, Knowledge, and Global Impact

September was Hydrocephalus Awareness Month

HA challenged our community and the public at large with a series of online quizzes testing medical knowledge to our own understanding of the diverse day to day experiences of our community. The quizzes drew more than 3,000 participants.

The results? Most knew that hydrocephalus results from a buildup of cerebrospinal fluid — proof that awareness efforts are working — though fewer realized it isn't rare, showing that education must continue. Nearly all participants showed deep empathy: 98% acknowledged the mental health challenges of living with hydrocephalus, and 95% recognized the impact of invisible symptoms like fatigue and pain. These insights reflect a growing awareness that life with hydrocephalus is about more than diagnosis or surgery — it's about the whole person.

World Hydrocephalus Day Celebrates Global Partnerships

Nestled within our awareness month is World Hydrocephalus Day. What began as a call to connect across national borders has became a worldwide movement. On September 20, people from more than 18 countries joined together to raise awareness. Our global partners included hydrocephalus-focused nonprofits from other countries, international professional societies, and individual doctors and research scientists.

Visit our website to learn more about World Hydrocephalus Day.

worldhydrocephalusday.org

The Future of Hydrocephalus Care

How "Smart Shunts" Could Change Lives

For people living with hydrocephalus, every day can bring uncertainty. Many rely on shunts to drain extra cerebrospinal fluid from the brain and keep pressure in balance. First introduced in the 1950s, these lifesaving tools have helped millions. Yet, they are not perfect.

The Limitations of Traditional Shunts

Traditional shunts can fail or become blocked without warning, causing pressure in the brain to rise dangerously. The signs - headaches, sleepiness, nausea - can look like everyday ailments, especially in babies and young children. Parents and loved ones often face sleepless nights, wondering: *Is this just a cold or a shunt malfunction?* Too often, the only way to find out is through urgent hospital visits or even emergency surgery.

What Smart Shunts Offer

Now, a new wave of innovation is offering hope. Researchers are developing "smart shunts" equipped with built-in sensors that can monitor things like pressure and fluid flow in real time. Imagine a device that could send updates directly to a phone or tablet, helping patients, families and doctors detect problems before they turn serious.

Future versions may even be able to adjust automatically when the person moves, reducing the risk of overdrainage that can happen just from standing up or going for a walk. That's the vision. For patients, that could mean fewer surgeries, fewer hospital stays, and a better quality of life.

What Smart Shunts Aim to Do

While each design is different, most smart shunt projects share the same mission:

- Make fluid drainage more personalized and precise
- Give doctors accurate, real-time data to guide care
- Offer patients and families greater peace of mind
- Reduce emergency surgeries and hospital visits

Still, There's Work to Be Done

As exciting as the technology sounds, it's not without challenges. The devices are more complex, which could make surgery a bit trickier. There's also the risk of false alarms, mechanical issues, or battery problems. And before any smart shunt reaches patients, it must go through rigorous testing and regulatory approval to ensure it's safe and reliable. We still have a way to go.

HA's Role in Driving Innovation

The Hydrocephalus Association (HA) supports technologies that improve patient outcomes. In 2024, HA awarded its Innovator Award to Dr. Geoffrey Colby (UCLA) for research on a novel shunt flow sensor that precisely monitors CSF movement. This is an important step toward preventing shunt failure.

Through funding, advocacy, and collaboration with patients, caregivers, researchers, and industry, HA is pushing to improve treatments and make devices like the smart shunt a reality. By investing in innovation, HA aims to lighten the emotional, physical, and financial burdens of hydrocephalus and to move us closer to a cure.

Ooh-rah for the HA Endurance Team

This year, we launched our Endurance Program with fifteen passionate runners represented HA at the 50th anniversary of the 2025 Marine Corps Marathon in Washington, DC. Collectively they raised over $24,000 to support our mission.

The race team included two individuals with hydrocephalus, four parents, one son of a parent living with NPH, 5 family members, and three friends. Their dedication on race day — and throughout the months of training and fundraising — reflects the growing energy around HA's endurance efforts. Each mile they ran helped raise awareness and funds that bring us closer to better treatments and, one day, a cure.

Building on that success, HA will be participating as an official charity partner for several 2026 races, including:

- Grandma's Marathon (Duluth, MN) – Saturday, June 20, 2026
- Portland Marathon - Sunday, October 24, 2026
- Marine Corps Marathon (Washington, DC) - Sunday, October 25, 2026
- Seattle Marathon - Friday, November 27, and Saturday, November 28, 2026

If you've ever dreamed of running for HA — or supporting someone who is — the Endurance Program is a powerful way to make every mile count.

Learn more about joining or supporting the HA Endurance Team

Designing Hope: Engineers Drive Bold Collaboration to Reinvent Hydrocephalus Care

For the first time ever, engineers have been invited into the heart of hydrocephalus research and the results could be game-changing.

In August 2025, the Hydrocephalus Association (HA) and the Rudi Schulte Research Institute hosted the Engineering in Hydrocephalus Research Workshop at Nationwide Children's Hospital in Columbus, Ohio. Over two days, more than 90 engineers, neurosurgeons, scientists, industry leaders, and patient advocates came together to do something extraordinary: think outside the box to develop innovative, cross-disciplinary strategies addressing the pressing challenges of shunt failure and device monitoring.

This approach reflects the hydrocephalus community's top priorities: creating non-invasive monitoring systems and designing shunts that resist blockage and mechanical failure. Dr. Carolyn Harris, Professor of Chemical Engineering from Wayne State University, chaired the programming committee.

Putting Patients at the Center

What made this workshop stand out was its commitment to centering the patient voice. Before each session, participants heard directly from individuals and families living with hydrocephalus. Their stories of perseverance, frustration, and hope helped ground every technical discussion in real-world experience.

For many engineers, it was the first time they'd met the people who depend on the devices they design. And for patients, it was a chance to see science and compassion working hand in hand.

Looking Ahead: Collaboration in Action

The energy and optimism from the workshop didn't end when the sessions did. Participants formed a new cross-disciplinary group that will meet every one to two months to keep the conversation and innovation going.

A forthcoming priorities paper will outline key findings and next steps, guiding the next generation of hydrocephalus research and engineering.

Sessions Highlights:

Bridging Gaps in Hydrocephalus and Engineering

TOPICS: Emphasizing the importance of collaboration and integrating engineering methods into hydrocephalus research. Pam Finlayson from Team Hydro shared the story of her daughter Kate in "Don't Not Try!," a powerful reminder of why perseverance and innovation matters.

Shunt Occlusion

TOPICS: Neurosurgical challenges and strategies to minimize shunt revisions; shunt obstruction mechanics; biocompatible materials aimed at preventing occlusion; and techniques to reduce infection risks in adult iNPH cases. Dr. Kyle Gospodarek, MD, of Indiana University, shared how frequent shunt revisions affected his own quality of life, giving powerful context to the technical conversation.

Overdrainage

TOPICS: Burden of overdrainage and current work focused on mitigating this; cerebral flow dynamics; and benchtop modeling of shunt dynamics. Jennifer Bechard of the Hydrocephalus Association recounted firsthand challenges with overdraining and resulting headaches.

Modeling

TOPICS: Combining high-performance computing and AI to personalize treatment; benchtop to bedside perspectives; in vitro models of the blood–CSF barrier; and engineering-informed animal models of hydrocephalus.

Patient & Caregiver Panel: Real-Life Experiences

A panel featuring Pam Finlayson, Kyle Gospodarek, MD, Jennifer Bechard, Stephanie TerMaath, PhD, and Jim Devine, BBA, discussed how everyday life, activity, and posture affect device function, and what changes they hope engineers prioritize in future designs.

Diagnostics: Monitoring & Imaging

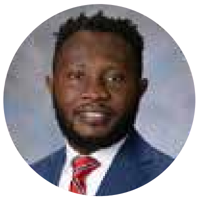
TOPICS: Practical sensor use in clinical monitoring; shunt flow and pressure sensing; sensing technology challenges and future directions; real-time in vivo CSF circulation detection; smart shunt technology; overview of diffusion tensor imaging for hydrocephalus; and MRI innovations that inform better device design. Patient advocate Ivelisse Lazzarini, EdD, highlighted the difficulties in diagnosing NPH through personal experience. Amanda Garzon (HA) discussed the resource burden of over-imaging.

Industry Perspectives & Funding Opportunities

A panel with emerging technology companies focused on how industry can collaborate with physicians and academics. They discussed essential needs and strategies for academic–industry collaboration. DJ Cass, MBA, (CereVasc) spoke on moving hydrocephalus treatment from the OR to the angio suite, showcasing minimally invasive industry pathways.

Announcing HA's Recent Research Award Recipients

Awards in epidemiology, neuropsychology and engineering fill much needed gaps in HA's research grant portfolio.



Epidemiology Challenge Award

Albert Isaacs, MD, PhD, a pediatric neurosurgeon at Nationwide Children's Hospital, received the 2024 **Epidemiology Challenge Award** to lead a landmark study titled "Comprehensive Epidemiological and Economic Assessment of Non-Normal Pressure Adult Hydrocephalus (NNPAH) in the United States." His research will analyze national databases and existing studies to determine how common NNPAH is, identify patterns across different age groups and causes, and explore the economic burden, including medical expenses, lost income, and costs related to disability. The results of this study will raise awareness of NNPAH, and help doctors, patients, and policymakers improve care, support earlier diagnosis, and develop better treatment strategies to reduce the condition's impact on individuals and the healthcare system.

> *"The epidemiology and economic burden of adults aged 18 to 64 living with hydrocephalus remains poorly characterized… these adults often face fragmented care, limited access to specialized providers, and minimal research attention. The HA Epidemiology Award is supporting our study that seeks to close this gap by combining large national datasets, systematic review and metanalyses, and economic modeling to define the true scope and impact of non-normal pressure adult hydrocephalus. The resulting data will provide an evidence-based foundation for healthcare planning, funding priorities, and future mechanistic research into the lifelong continuum of hydrocephalus."*

Neuropsychology and Cognition Award

To advance research on quality of life aspects of hydrocephalus across the lifespan, HA launched the **Neuropsychology and Cognition Award** in 2024. The goal of this award is to support innovative research that broadly addresses the utility and development of neuropsychological and cognitive assessment tools, in alignment with our Research Priorities to Improve Neuropsychological and Cognitive Outcomes in Hydrocephalus. The first recipient, **Dr. Jeffrey Schaffert,** a neuropsychologist at UT Southwestern Medical Center, is studying how thinking and memory patterns—known as "cognitive profiles"—show up in people with idiopathic normal pressure hydrocephalus (iNPH). By identifying which patterns respond best to cerebrospinal fluid (CSF) removal trials and shunt surgeries, his work could help doctors diagnose the condition sooner and predict which patients are most likely to benefit from treatment—giving individuals and families clearer answers and new hope.

> *"I was honored to receive the 2024 Neuropsychology and Cognition Award to study cognitive changes in NPH. I have developed both a strong interest in academic research with these patients and a deep passion to serve them clinically in order to optimize treatment outcomes and quality of life. In fact, the initial data from this project is already paying dividends, as pilot data from the ongoing award has been used to secure additional funding to expand our clinical-research infrastructure to include additional biomarker analysis (in both blood and cerebrospinal fluid) and advanced imaging techniques to better understand the mechanisms driving cognitive difficulties in those with NPH. As such, I am extremely grateful for the opportunity to receive funding from the Hydrocephalus Association!"*

Engineering in Hydrocephalus Prize

The **Engineering in Hydrocephalus Prize** supports undergraduate and graduate research projects that explore potential engineering solutions to hydrocephalus challenges. This award highlights the innovative work of student engineers and provided awardees the opportunity to present their research at HA's 2025 Engineering in Hydrocephalus Research Workshop. By encouraging creative thinking around new treatments and devices, this award plays an important role in inspiring the next generation of hydrocephalus researchers and pushing the field forward. Three outstanding projects were awarded this year's Engineering in Hydrocephalus Prize.

Ahmad Alhayek, Neal Tsai, Jess Goldberg, and Nicholas Demetriou from Northwestern University are developing a small, non-invasive device that attaches to shunts and uses gentle vibrations to help prevent blockages.

Yihan Wu from Johns Hopkins University is developing a new, non-invasive MRI technique called velocity-selective spin labeling (VSSL) to safely visualize CSF flow in the brain.

Fabian Flürenbrock from ETH Zürich is developing a smart shunt research platform that could be used to test CSF flow dynamics and regulate intracranial pressure.

HOPE NEEDS HEROES

With shifts in NIH and government funding, researchers are looking to the Hydrocephalus Association to keep their work alive. Your gift today helps fill the gap so we can fund the discoveries that can't wait.

DONATE TODAY

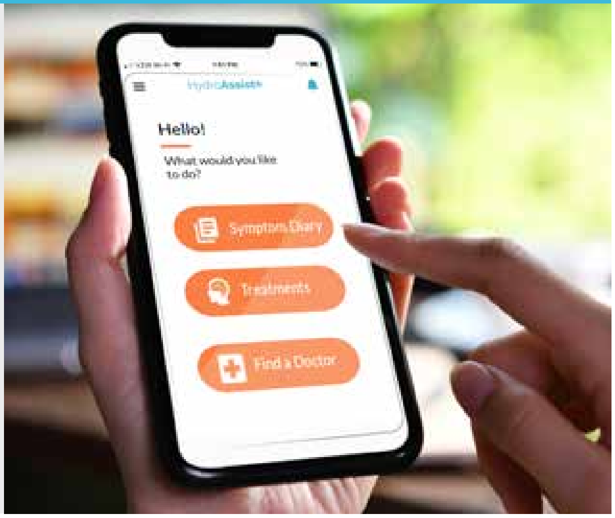
DOWNLOAD THE HYDROASSIST APP!

HydroAssist®

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 loved ones

GET IT ON Google Play

Available on the App Store



WALK TO END HYDROCEPHALUS™

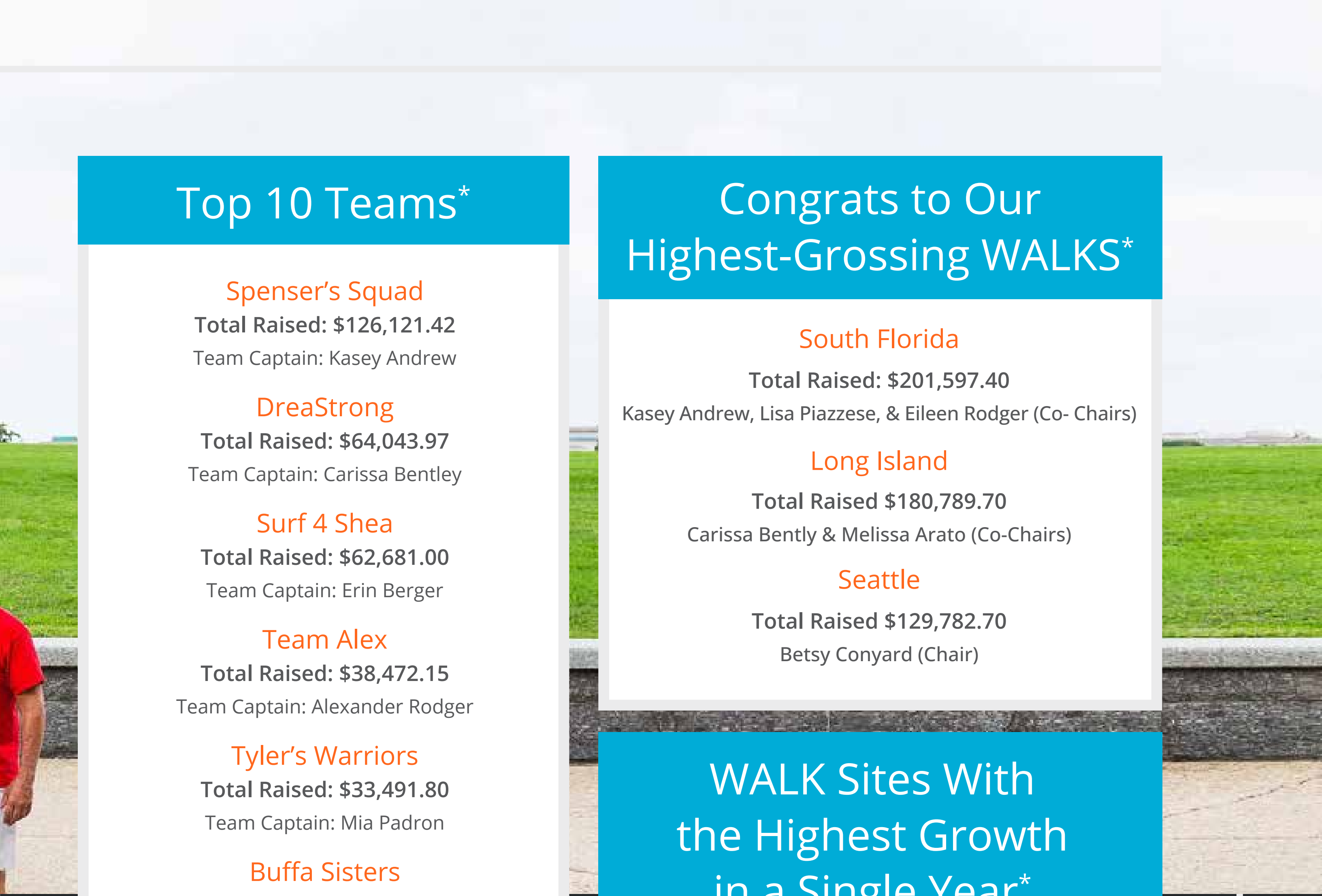
The 2026 WALK to End Hydrocephalus season is in the books! And what a year it was!

Thanks to the Hydrocephalus Association's wonderful volunteers, **45 WALKs** were held across the U.S., with nearly **6,981 participants** representing over **808 teams**.

The WALKs raised **$1,761,000** for HA's research, education, and support programs. There is still time to make a year-end gift to help us reach our **$1.9 million.**

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

Please contact our WALK team at walk@hydroassoc.org
to discuss how you can start a WALK in your area.



Top 10 Teams*

Spenser's Squad

Total Raised: $126,121.42

Team Captain: Kasey Andrew

DreaStrong

Total Raised: $64,043.97

Team Captain: Carissa Bentley

Surf 4 Shea

Total Raised: $62,681.00

Team Captain: Erin Berger

Team Alex

Total Raised: $38,472.15

Team Captain: Alexander Rodger

Tyler's Warriors

Total Raised: $33,491.80

Team Captain: Mia Padron

Buffa Sisters

Total Raised: $33,014.90

Team Captain: Stephanie Vogt

Team Joshasaurus Rex

Total Raised: $23,623.89

Team Captain: Emily Sajor

Hydro Cure

Total Raised: $23,405.00

Team Captain: Clifford Goldman

Jaketown

Total Raised: $22,656.05

Team Captain: Jodi Heston

Ashley and the Rockin' Ruths

Total Raised: $21,893.05

Team Captain: Christy Ruth

* Totals on these three WALK pages are at the time of print and may change

Congrats to Our Highest-Grossing WALKS*

South Florida

Total Raised: $201,597.40

Kasey Andrew, Lisa Piazzese, & Eileen Rodger (Co- Chairs)

Long Island

Total Raised $180,789.70

Carissa Bently & Melissa Arato (Co-Chairs)

Seattle

Total Raised $129,782.70

Betsy Conyard (Chair)

WALK Sites With the Highest Growth in a Single Year*

New Orleans

Lori Logan (Chair) raised $15,509.96

95% increase

Iowa

Dhuha Tawil & Jolene Grau (Co-Chairs) raised $38,549.73

67% increase

Boston

Jennifer Martinage (Chair) raised $56,829.90

57% increase

WE ARE **#HYDROSTRONG**

WALK Anniversaries

20 Years
Salt Lake City, Long Island

15 Years
Wichita, Seattle, Central PA

10 Years
Northwest Arkansas,
Indianapolis, Pittsburgh

5 Years
St. Petersburg/Tampa Bay

Newest WALK Sites

Central Valley
Raised: $20,223.76
10 Teams
143 participants

Alabama
Raised $19,870.96
12 Teams
127 Participants

Oregon
Raised $3,800.03
9 Teams
47 Participants

WALK Sponsors

National Partner

WING STOP

Silver Sponsors

AESCULAP
Medtronic
Codman Specialty Surgical
An Integra LifeSciences Company

Bronze Sponsor

LOCUST CIDER


Virginia Beach Walkers


Seattle Family Walkers


Chicago Family of Walkers


Detroit Walkers

Boston Walkers

WE ARE #HYDROSTRONG

Introducing RAISE

A New Program for Parents and Caregivers of Children with Hydrocephalus

Hydrocephalus.

For many parents, that word is one they will never forget—the moment they first heard it, everything changed. The uncertainty, the questions, the fear of what comes next. As a parent or caregiver, your world may have shifted in that instant. Words often fall short in describing that mix of emotions. You may wonder if anyone truly understands.

We want you to know that, yes—others do understand.

That's why the Hydrocephalus Association is proud to launch RAISE, a new program designed to support parents and caregivers who are navigating the complex emotions and challenges that come with raising a child diagnosed with hydrocephalus.

What is RAISE?

- R – Resilience
- A – Agency
- I – Intentional Thinking
- S – Strengths
- E – Engagement

This research-informed course offers a safe, supportive space for parents and caregivers to learn, connect, and grow with others who "get it." Through small-group online sessions, participants will explore tools and strategies for strengthening resilience, building community, and finding empowerment amid uncertainty. Each class is facilitated by fellow parents who understand this journey firsthand.

The Inspiration Behind RAISE

This program was inspired by the work of Dr. Brandon Rocque, a pediatric neurosurgeon at Children's of Alabama, who discovered that parents of children with hydrocephalus often experience high levels of post-traumatic stress symptoms. His research underscored a hopeful truth: resilience can be taught.

Building on this insight, the University of Pennsylvania Positive Psychology Program collaborated with Dr. Rocque, Tessa van der Willigen (former member of the HA Board of Directors), Amanda Garzón (HA Chief Operations Officer), and Lakisha Harris (HA Support Programs Manager) to create a curriculum designed to teach resilience as a set of skills—skills that can help parents and caregivers move beyond just coping.

RAISE

Resilience Program

Who can join: Parents and primary caregivers of children ages 0–18 with hydrocephalus

Format: Small-group online classes

Schedule: Multiple start dates available from November 2025 through March 2026

Availability: Limited spots are available due to small class sizes

COURSES ARE ALREADY UNDERWAY, SO WE ENCOURAGE YOU TO SECURE YOUR PLACE IN ONE OF THE UPCOMING SESSIONS.

Scan the QR code to learn more, meet the facilitators, and sign up.

College Acceptance Time! Which College Do You Choose?

You've just been accepted to three colleges. Congratulations! It's an exciting milestone, but also one that comes with big decisions. For students living with hydrocephalus, the choice isn't just about majors, cost, or campus life. It's about finding a school that supports you as a student and as a person managing a lifelong condition. So how do you choose the right college for you?

Start with the Big Questions

For students living with hydrocephalus, confidence in both the academic experience and the health-care environment is key. This balance can shape whether you (and your parents) feel comfortable choosing a school close to home or across the country.

Here are a few important questions to start with:

- **How close is the campus to a medical center experienced in neurosurgical care?**
  Proximity to quality care as a key factor for students with hydrocephalus.
- **What supports and disability services are available on campus?**
  Some students with hydrocephalus may need accommodations, flexibility and a support team around them.
- **Is the college flexible and what are the leave policies?**
  Because of unexpected health challenges, it's important to know the college's policies on reduced course loads, leaves of absence and medical withdrawal. Ask: If you miss part of a semester due to a hospitalization, what will happen academically and financially?

Know Before You Go

Everyone's experience with hydrocephalus is different. Some students may need more support than others. Visiting or talking to campus services will provide you with more detailed information relevant to your individual needs that you wont get from the website or a college brochure.

- Visit the **student health center** and ask if they've supported students with hydrocephalus and what their emergency plan is. This will let you know what information about hydrocephalus and your personal medical history you will need to bring to campus to help their staff support you should a medical emergency arise.
- Map out **local medical care**, especially if the college is far from home. Identify a neurosurgeon or hospital nearby where you would feel comfortable receiving care. Know where the nearest pharmacy is for prescriptions or switch to mail order.
- Contact the **Disability Services Office (DSO)** and ask how they handle medical-based accommodations, not just learning disabilities.
- Look into **academic supports.** Tutoring, writing centers, workshops for executive function or memory (which may be affected by hydrocephalus), etc. can make a big difference. Programs vary widely so know what the school offers… or doesn't.
- Think about **campus layout and accessibility**. Steep hills, older buildings (e.g. with stairs or without A/C), or long walks between classes may affect your day-to-day comfort and energy.

Preparing for Independence Starts Now

Heading off to college means more than just figuring out where you'll do laundry. It also means figuring out who you will tell about your hydrocephalus, how to get appropriate support if you need it, and how you'll get to class and perform academically when you're not feeling your best. Keep these things in mind when determining a school that can meet your needs:

- **Know your role as the student.**
  In college, you are your own advocate. That means talking directly with professors about your needs and/or accommodations. There are no IEPs in college, and your parents can't access your records unless you give permission.
- **Balance academics and self-care.**
  Social and academic transitions happen all at once. Plan for rest, self-care and manageable course loads so you're not over-committing. Use tools like your online calendar to schedule dedicated study time and support time management.
- **Parents, this is your shift from doing to coaching.**
  Encourage your student's independence now so their ready when they leave home. It's a big and beautiful part of the college experience.

A Conversation, Not a Decision

Parents and students, think of choosing a college as launching a partnership with the school—one in which you bring your goals, your health needs, your plans, and the school brings its environment, supports, and services. Instead of simply picking a college, you're choosing a place you'll live, grow, and manage life for the next several years. With thoughtful planning, smart questions and a strong support network, choosing the college for this next chapter can be both exciting and manageable.

Visit our series of articles on College on our website for more information and guidance.

Patient Perspectives Drive Research

The HAPPIER Registry Paper Is Now Published!

We're excited to share that the Hydrocephalus Association Patient-Powered Interactive Engagement Registry (HAPPIER) has been officially published in a scientific journal!

This marks a huge milestone, ensuring that the voices of people living with hydrocephalus, and the loved ones who care for them, are truly heard in research. It's also a celebration of every person who has shared their story, their struggles, and their strength in the registry.

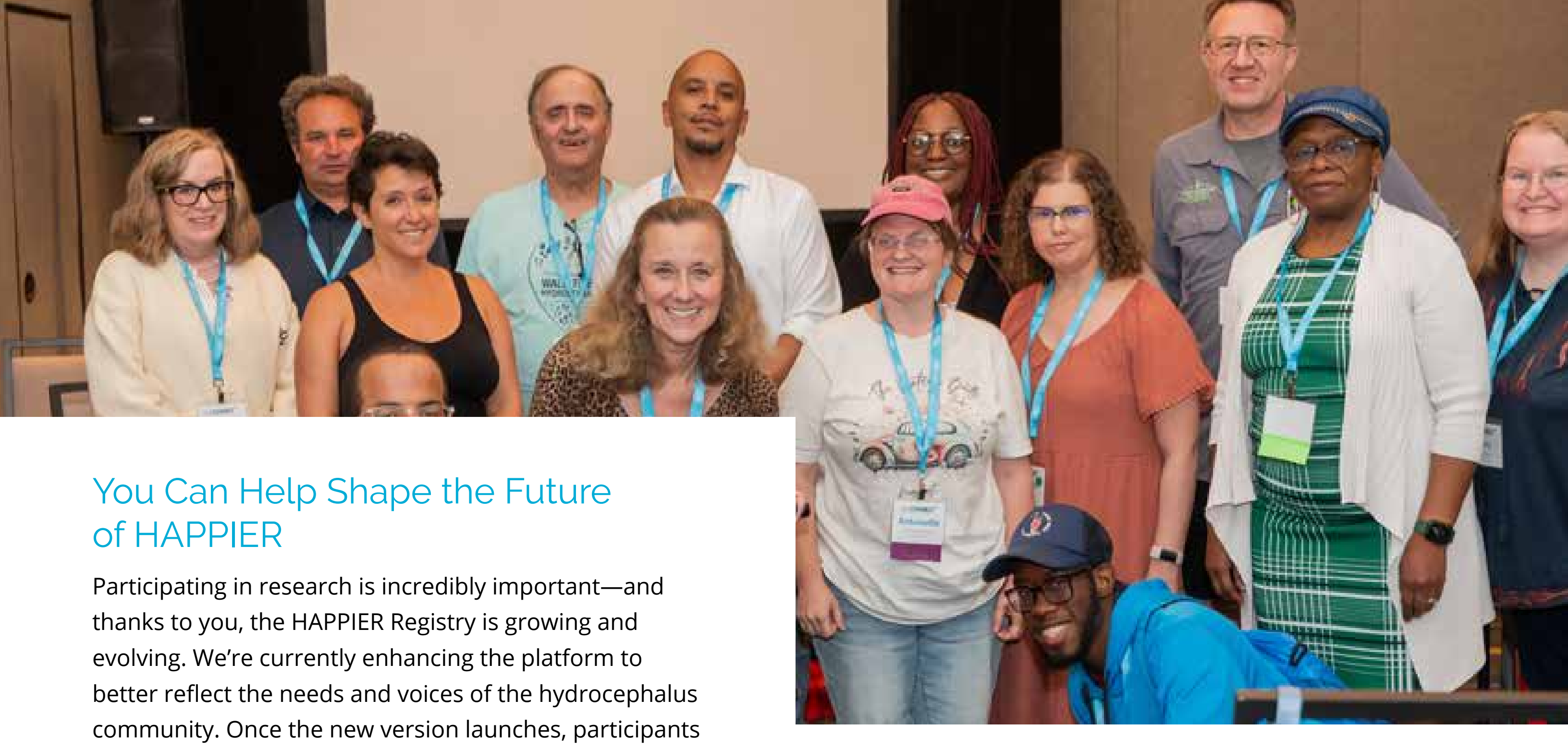
What Is HAPPIER?

HAPPIER is an online patient registry created by the Hydrocephalus Association to collect information directly from people living with hydrocephalus and their caregivers. It helps researchers understand what daily life is like with this condition—from symptoms and surgeries to challenges with movement, learning, and emotional health. The goal is simple but powerful: to put patients and caregivers at the heart of research, so that care, treatment, and innovation reflect real life, not just clinical statistics.

What Have We Learned So Far?

HAPPIER collects data on demographics, etiology, symptoms, comorbidities, and treatments. More than 690 people living with hydrocephalus or their caregivers have already joined HAPPIER, offering a clearer picture of what it means to live with hydrocephalus. Here are a few insights:

- Most participants were diagnosed in infancy (between birth and 11 months) and have congenital hydrocephalus.
- The most common form of treatment was a shunt, and nearly 70% of participants reported undergoing at least one shunt revision.
- The most common symptoms reported were headaches, tiredness, memory problems, and problems concentrating.
- More than two-thirds also live with movement difficulties or other diagnosed health conditions.



You Can Help Shape the Future of HAPPIER

Participating in research is incredibly important—and thanks to you, the HAPPIER Registry is growing and evolving. We're currently enhancing the platform to better reflect the needs and voices of the hydrocephalus community. Once the new version launches, participants will be able to more easily share their experiences, update their information, and contribute to studies that aim to:

- Shape the future of hydrocephalus research
- Improve the understanding of daily life with hydrocephalus
- Guide scientists, doctors, and policymakers
- Advocate for patient and caregiver voices to be at the center of care decisions

No matter your age, diagnosis, or where you live, you can participate.

Thank YOU!

We want to extend a heartfelt thank you to every individual and family who has participated in HAPPIER so far and those that are joining now. Your willingness to share your stories, experiences, and challenges has made this publication—and this entire registry—possible. Every data point represents a real person, and together, you are helping to paint a fuller, more accurate picture of what it means to live with hydrocephalus. Your voice is not only being heard, it's driving change.

Scan here to view the published paper

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 a part of HAPPIER.

JOIN NOW

hydroassoc.org/happier

Going the Distance

How far would you go to raise awareness about hydrocephalus? Would you drive one lap around the country?

That's exactly what Hydrodad Ray Moser and his son, Raymond, set out to do this year. Known as "The Rays," this father-and-son team took on the legendary Tire Rack 2025 One Lap of America - a grueling eight-day, 3,500-mile endurance challenge that tests both driver and machine.

The One Lap of America combines cross-country travel with timed competition events like autocross, drag racing, and time attack at racetracks across the U.S. Eighty teams participated, each driving for passion, performance, and often a greater cause. For The Rays, that cause was raising awareness and funds for the Hydrocephalus Association behind the wheel of their Nissan 350Z.

Along the way, they faced more than their fair share of challenges. The One Lap is famously brutal on both vehicles and drivers. The Rays had to serve as their own pit crew, making repairs between stages and racing to the next location on little sleep. At one point, a power steering malfunction made the already demanding course even tougher.

Their determination paid off. Not only did Ray and Raymond cross the finish line, but they also raised an incredible $13,625 for the Hydrocephalus Association. Daughter Jessica, a graduate student at Wayne State University who developed hydrocephalus as an infant, even joined them trackside at Grattan Raceway, cheering on her dad and brother as they pushed through the fatigue and mechanical setbacks.

"Overall, it was an excellent two weeks — tiring, but fun," reflected Ray. "Many ups and downs, but we made it through to the end. Thanks for following along and providing your supportive comments and emojis."

To learn more about the race and their preparation, watch a pre-race interview

The Alston Family Hosts a Backyard Bash

For Briana Alston and her parents, El-Rhonda and Arnold, raising awareness for hydrocephalus is personal.

Longtime participants in the Philadelphia WALK to End Hydrocephalus, the family took their advocacy further this year by hosting their first Do-It-Yourself (DIY) Hydrocephalus Fundraiser—a joyful backyard celebration of hope, faith, and community.

Born prematurely with hydrocephalus caused by a ruptured brain tumor, Briana's early prognosis was grim. Doctors said she would never walk, talk, or live independently. But her parents refused to give up. Now 34, Briana has undergone 15 brain surgeries, earned a college degree in Theater and History, and built a successful HR career with the State of New Jersey. She's also an actress, homeowner, and proud woman of faith—a testament to resilience and determination.

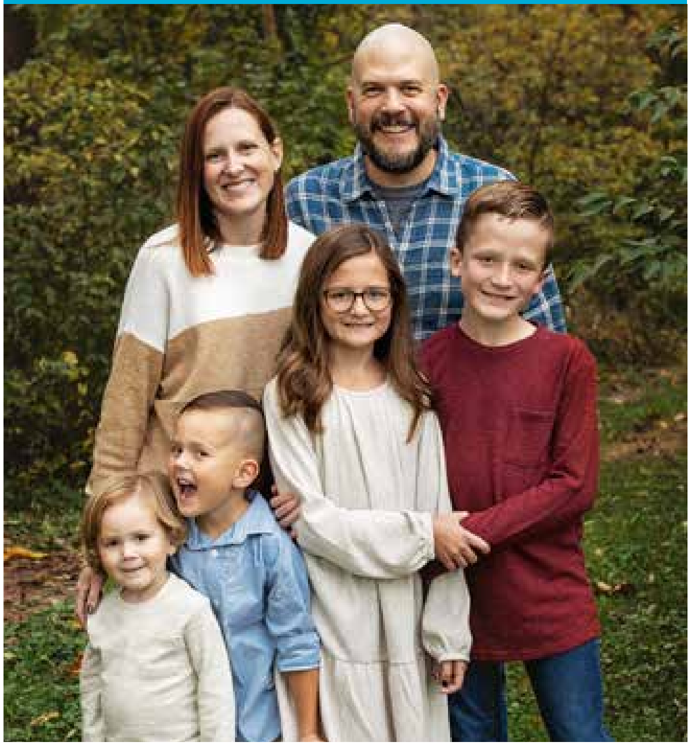
What began as a modest "ham dinner" evolved into a full BBQ with trivia, dancing, raffles, and a signature "Brain Freeze" margarita. Expecting 25 guests, the Alstons welcomed over 100, with 20 more donating remotely. Together, they raised more than $4,000 for the Hydrocephalus Association. "People came as strangers and left as friends," says Arnold.

For Briana, it's about more than money—it's about hope. At one of her first HA WALKs, she met a tearful mother of a newly diagnosed baby. "I told her, 'She'll be fine—she can thrive,'" Briana recalls. That encounter continues to inspire her to share her story and uplift others.

Looking ahead, the Alstons plan to expand their event and connect with more families, especially in communities of color. "If our story helps even one family feel less alone," says El-Rhonda, "then we've done what we were called to do."

Volunteers in Action

Community Network Spotlight



Sarah McClellan

Sarah McClellan lives in Indianapolis, IN, with her husband and 4 kids. Her oldest son, Oliver, has hydrocephalus. They discovered his hydrocephalus when he was 18 months old, because he suddenly developed trouble walking. She started volunteering for HA as a WALK Chair and eventually transitioned into the Indianapolis Community Network Leader. Her and her husband decided to start a local group because there was not one when their son was diagnosed. Sarah is also a facilitator for our new RAISE Resilience Program. In both of these roles, Sarah hopes to help others realize that they aren't alone when going through diagnosis and navigating the different challenges hydrocephalus can bring.

Announcing our 2025 Hydrocephalus Association Scholarship Recipients

The Hydrocephalus Association (HA) is pleased to announce the 2025 Hydrocephalus Association Scholarship Award Recipients. Since the program's inception, HA has awarded 279 scholarships to future leaders of our community.

We are proud to honor these remarkable young adults, who, in addition to successfully managing their hydrocephalus, continue to excel in the classroom, volunteer, and give back to help their local communities. They are an inspiration to us all, proving that hydrocephalus does not stand in the way of pursuing one's goals.

We're deeply grateful to our generous donors for making these scholarships possible and to the Scholarship Committee for their ongoing dedication and support.

Adelaide O'Neal

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

Adelaide is studying Communications at Centenary College of Louisiana. Diagnosed with congenital hydrocephalus due to aqueductal stenosis before birth, she has navigated challenges with concentration, ADHD, and anxiety.

"Ultimately, my experiences with hydrocephalus have instilled resilience in me and shaped my ambitions," she explains. Adelaide discovered her passion for writing in middle school and went on to contribute to her school newspaper and its Instagram page. Her long-term goal is to work for a major news publication, travel the world, and eventually run her own business.

Adelaide actively raises awareness about hydrocephalus through presentations and participation in the Greater Dallas/Fort Worth WALK to End Hydrocephalus. In addition to her studies, she engages in many community activities, including choir, Book Club, Hearts of Servants, Best Buddies, inclusive cheerleading, and completed the Richardson Youth Leadership Program, building skills in leadership, business, and advocacy.

Brea McGinnis

Recipient of the Justin Scot Alston Memorial Scholarship

Brea is earning her bachelor's degree in Chemical Engineering at North Carolina Agricultural and Technical State University. She plans to specialize in chemotherapeutic engineering to develop innovative cancer treatments in honor of her late father, while also inspiring more females to pursue STEM careers and raising awareness of hydrocephalus through advocacy.

Diagnosed with hydrocephalus as an infant, Brea has faced numerous surgeries and school-related challenges, yet she remains resilient. "Living with hydrocephalus requires ongoing management and support, but it is not a life sentence of limitations," she notes. "With the right care and resources, individuals like myself can thrive and live fulfilling lives."

Brea's experiences have strengthened her determination, problem-solving skills, and empathy, which she applies through the Champion's Program at Cincinnati Children's Hospital. In addition to her studies, Brea has excelled in leadership and extracurricular activities, including serving as varsity basketball captain, yearbook editor, media arts intern, and youth leader, and participating in STEM programs and internships.

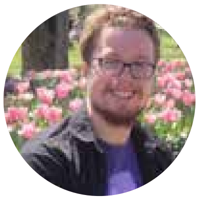
Dana Fink

Recipient of the Morris L. and Rebecca Ziskind Memorial Scholarship

Dana is earning her Master of Public Administration with a concentration in nonprofit management at George Washington University while serving as a Senior Subject Matter Coordinator at the Substance Abuse and Mental Health Services Administration (SAMHSA). Diagnosed at birth with congenital hydrocephalus due to spina bifida and Chiari II Malformation, Dana has navigated both visible and invisible challenges, which have shaped her dedication to public service and disability justice.

From interning with Senator Tom Harkin on ADA research to advancing federal programs at SAMHSA, she strives to create more inclusive systems for people with complex disabilities. Dana shares, "We deserve spaces where hydrocephalus is not just understood, but where our whole selves are welcomed."

Outside of work and academics, she participates in adaptive sports, mentors young adults with disabilities, and is training a new service dog to stay active and engaged.



Matthew R. Jewell

Recipient of the Jacobsen Family Scholarship

Matthew is pursuing a bachelor's degree in Environmental Science at the University of North Texas. Diagnosed with congenital hydrocephalus as an infant, he has overcome developmental delays, speech challenges, and periods of social isolation due to hospitalization.

"Hydrocephalus has had a profound impact on my life—physically, emotionally, and academically," Matthew reflects. His passion for nature and education began in biology class and has grown through volunteering in conservation projects and leading outreach programs at the River Legacy Nature Center.

Matthew aims to combine his background in environmental science with public education to inspire care for the natural world. He has participated in the Dallas-Fort Worth WALK to End Hydrocephalus, organized awareness events, and coordinated educational speakers. He also finds fulfillment in community service, seasonal mothing events, Broadway shows, and tabletop games with friends.

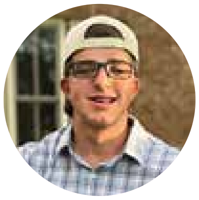
Shea Moran

Recipient of the Mario J. Tocco Memorial Scholarship

Shea is enrolled in the five-year accelerated Physician Assistant program at the University of Detroit Mercy while completing a bachelor's degree in Biology. Driven by a lifelong passion for medicine, Shea aspires to become a Physician Associate (PA), also known as a Physician Assistant, who listens, teaches, and treats patients as partners in their care.

Diagnosed with hydrocephalus in infancy due to aqueductal stenosis, she has faced migraines, hospitalizations, and a peritoneal pseudocyst. "Living with hydrocephalus has shaped me into someone who is strong, empathetic, and ready to use my experiences to help others," Shea expresses.

Beyond academics, she enjoys music, plays bass in a rock band, and participates in STEM activities such as Destination Imagination. Shea is also actively involved in leadership, community service, and healthcare experiences that reflect her dedication to helping others.



Michael "Steele" Funches

Recipient of the Gerard Swartz Fudge Memorial Scholarship

Steele is pursuing a bachelor's degree in Business Finance at Lipscomb University with plans to earn an MBA and combine his business expertise with his passion for music. Diagnosed at birth with Crouzon Syndrome and hydrocephalus, Steele has undergone multiple surgeries but has excelled academically, athletically, and musically.

A talented musician, songwriter, and producer, Steele has released two songs and is currently working on an album. He is also a leader on campus, founding and leading a chapel band. "Hydrocephalus and Crouzon Syndrome have presented challenges throughout my life, but they have also taught me resilience, creativity, and perseverance," Steele shares.

Dedicated to giving back, Steele has also fundraised for the Partners in Africa Cleft-Training Craniofacial Outreach Program through Seattle Children's Hospital.

Avery Sycko

Recipient of the Anthony Abbene Memorial Scholarship

Avery is attending the University of Michigan, where she is majoring in Biology with an interest in medicine. From the start of high school, she knew she wanted to study healthcare. Avery gained hands-on experience through a full-time internship at Henry Ford's Pancreatic Cancer Center, where she learned about laboratory research and the real-world impact of medicine, sparking her curiosity to explore the many areas of healthcare.

Growing up with congenital hydrocephalus has instilled resilience, empathy, and determination. "Although hydrocephalus has caused many ups and downs, those trials and tribulations have allowed me to grow into a more empathetic person," she explains. Despite health-related struggles such as tremors, hospital visits, and uncertainty about her condition, Avery has remained focused on education and personal growth while raising awareness through the Detroit WALK to End Hydrocephalus, support group participation, and a school project website for HA.

In addition to her studies, she loves to dance, bake, play pickleball, listen to music, and spend time with her family and dogs.

Norah Williams

Recipient of the Logan Aamot Memorial Scholarship

Norah is studying genetics at Iowa State University and plans to earn a PhD in genetic engineering so she can lead research that improves treatment options for complex conditions. Diagnosed with acquired hydrocephalus at eight due to a brain tumor, she underwent multiple surgeries and a coma—experiences that fueled her passion for science. She shares, "Living with hydrocephalus has given me an appreciation for life and how it prevails against all odds, and inspired me to want to do something great." A dedicated student and active community member, Norah participated in PRISMA, NHS, the Equity and Diversity Club, HOSA, and music, experiences that have shaped her into a motivated, curious, and compassionate leader.

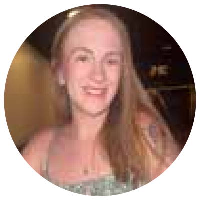
Lucy Bremberg

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

Lucy is studying Special Education at Franciscan University of Steubenville, inspired by her own experiences navigating school with hydrocephalus. She has taken dual enrollment courses in education and disabilities and plans to become a licensed special education teacher and private tutor for children with disabilities.

Diagnosed with hydrocephalus as an infant, Lucy received her first shunt at 12 weeks old and has undergone three brain surgeries, experiences that led to significant anxiety, which she learned to manage through therapy and coping skills. "Would I have been so gifted with language without my hydrocephalus? I guess I'll never truly know, but I have decided to chalk it up to the pros column when thinking of my hydrocephalus, " she reflects.

Lucy is an active member in the hydrocephalus community, participating in the National Capital WALK to End Hydrocephalus and attending HA's National Conference on Hydrocephalus, HA CONNECT. She enjoys reading, writing, and musical theater, believing that living fully and bravely can inspire others with hydrocephalus.



Marissa Rouse

Recipient of the Morris L. and Rebecca Ziskind Memorial Scholarship

Marissa is enrolled in a bachelor's program in Criminology and Criminal Justice at Arizona State University, with aspirations to work in parole or as a post-incarceration advocate. Diagnosed with hydrocephalus as a senior in high school, she has experienced challenges with memory, focus, headaches, and vision changes.

"Hydrocephalus has been a constant companion in my life...These challenges have shaped me into the person I am today – resilient, empathetic, and determined to make a positive impact on the world," she emphasizes.

Marissa has found connection and purpose through the HA, participating in the Young Adults in their 20s Zoom group, advocacy efforts, and the annual WALK to End Hydrocephalus in Fresno, CA. When she's not studying, she loves to paint, hike, and explore new cuisines and recipes, combining creativity, nature, and culinary experimentation.

Cassandra Troy

Recipient of the Kate Finlayson Memorial Scholarship

Cassandra is a medical student at Lake Erie College of Osteopathic Medicine, working toward her Doctor of Osteopathic Medicine (DO) degree. Inspired by her experiences, Cassandra aims to provide compassionate, patient-centered care in neurology or emergency medicine and eventually open her own practice.

Diagnosed with acquired hydrocephalus at age nine due to a brain tumor, she faced medical and personal challenges that affected her physical activity and academics, yet she remained committed to her education, athletics, and community involvement. “Hydrocephalus has given me a unique perspective and has shaped my approach to both personal and professional relationships, emphasizing the importance of empathy, patience, and perseverance,” she reflects.

Outside of academics, she stays active through hockey, lacrosse, working out at the gym, and finds relaxation in cooking and reading, continuing to grow personally and professionally.

Hope Hancock

Recipient of the Anthony Abbene Scholarship

Hope is majoring in Applied Exercise Science at Oklahoma State University, with plans to become a pediatric chiropractor, inspired by her late aunt. Diagnosed with hydrocephalus at ten days old and undergoing her first surgery at 21 days old, Hope has encountered challenges, including severe migraines and academic setbacks, ultimately finding relief through a successful endoscopic third ventriculostomy (ETV).

“My experience taught me that you never know what someone is going through. I want to be the type of person that is kind and compassionate,” she expresses. Hope is committed to using her knowledge and empathy to help children facing challenges similar to her own, and she looks forward to engaging with the Hydrocephalus Association community.

Beyond her studies, she is active in athletics, leadership, and community service, serving as a four-year varsity tennis player and senior team captain, volunteering with Aceing Autism, supporting mental health awareness through Hope Squad, and participating as a Lubbock Symphony Debutante.

Kassandra Baker

Recipient of the Gerard Swartz Fudge Memorial Scholarship

Kassandra recently earned her Master of Science in Biomedical Visualization from the University of Illinois at Chicago. She discovered her passion for medical illustration during her undergraduate studies and aims to create impactful 2D and 3D visuals that educate patients, healthcare professionals, and the public, with hopes of establishing her own freelance business.

Kassandra was diagnosed with hydrocephalus due to aqueductal stenosis, experiencing symptoms of daily headaches, vision problems, pulsatile tinnitus, and fatigue before undergoing an endoscopic third ventriculostomy (ETV). “Hydrocephalus challenged me in ways I never expected, but it taught me resilience and the importance of advocating for my own health,” she shares.

Despite these obstacles, Kassandra has used her skills to support the hydrocephalus community, creating surgical illustrations to educate medical students, residents, and surgeons. Alongside her professional pursuits, Kassandra volunteers, leads student exhibitions for the Student Association for Medical Artists, and plays the violin in church, continuing to raise awareness and provide support for those affected by hydrocephalus.

Apply for an HA Scholarship!

Our 2026 Scholarship cycle opens on December 15th.

Visit our Scholarship page to learn more.

hydroassoc.org/scholarship

Hydrocephalus Association

6903 Rockledge Drive, Suite 740
North Bethesda, MD 20817

NEWSLETTER
VOLUME
45

Tune in to Hydro Heroes Unite, a new bi-weekly podcast created in partnership with actor and podcaster, Taisha Cameron.

Scan to listen now!

HA'S CORPORATE COUNCIL PROGRAM

The Hydrocephalus Association extends its sincere gratitude to our corporate sponsors for their ongoing partnership and commitment to the hydrocephalus community. Their support empowers us to deliver essential programs and drive innovative research—advancing our shared mission to improve lives and accelerate the search for cures.

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Use the QR code to find out more about the program, or contact linda@hydroassoc.org to learn more.