Hydrocephalus
Association

PATHWAYS

Hydrocephalus Association Newsletter, Volume 43, Spring 2024

July 25-27th, 2024 | 18th National Conference on Hydrocephalus | Tampa, Florida

NEWSLETTER
VOLUME
43

Join us at HA CONNECT in July

Our 18th National Conference on Hydrocephalus is right around the corner. Don't miss out on this life-changing event!

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MESSAGE FROM THE PRESIDENT AND CEO

Dear Friends,

Welcome to the Spring 2024 edition of Pathways, your gateway to the latest updates and insights from the Hydrocephalus Association.

As we embark on this journey together, I am thrilled to share with you the wealth of knowledge and inspiration contained within these pages. This edition of Pathways is brimming with articles that capture the essence of our mission and the remarkable progress we've made in the fight to find a cure for hydrocephalus.

First and foremost, I invite you to join in the excitement surrounding our **18th National Conference on Hydrocephalus, HA CONNECT.** Set to take place from July 25th to the 27th in the vibrant city of Tampa, Florida, this conference promises to be a pivotal experience for our community. Discover what awaits you at this unforgettable event as we come together to learn, connect, and empower one another.

In addition, I am delighted to spotlight our upcoming 2024 WALK to End Hydrocephalus season, a cornerstone of our fundraising efforts. With a goal of $1.9M, this annual initiative is a testament to the immense dedication of our community. **Join us as we step up and make a difference in the lives of those affected by hydrocephalus.**

Our Research Program continues to spearhead groundbreaking initiatives that push the boundaries of scientific discovery. From our illuminating Research Report covering 2021-23, to our recognition of Women of Impact in Research, we are at the forefront of innovation.

Further, we have been tirelessly advocating for change, welcoming new members to our Pediatric and Adult Hydrocephalus Caucus, now up to 28 representatives, and championing increased federal funding for hydrocephalus research. From Congressional Briefings to impactful meetings with esteemed leaders such as Senator Maggie Hassan and Congresswoman Jennifer McClellan, **our efforts are making waves on Capitol Hill.**

As you peruse this edition of Pathways, I encourage you to immerse yourself in the stories of resilience, hope, and progress that define our community. **Together, we are forging a path towards a brighter future for all those impacted by hydrocephalus.**

Sincerely,

Diana Gray

Diana Gray, MA
President and Chief Executive Officer
Hydrocephalus Association

FEATURED ARTICLES

Hydrocephalus Association's WOMEN *of* IMPACT

In March, to celebrate Women's History Month, HA launched our Women of Impact social media series, celebrating pioneering medical researchers driving progress in hydrocephalus treatment and the quest for a cure.

Drs. Lauren Jantzie & Dody Robinson

Johns Hopkins University

This dynamic duo collaborated seamlessly, leveraging their extensive expertise and resources to initiate the FIRST human clinical trial testing a drug combination to prevent hydrocephalus development post-brain bleed.

Dr. Carolyn Harris

Wayne State University

Dr. Harris has dedicated years to evaluating and refining shunt designs, while also spearheading efforts to expedite pharmaceutical drug development for hydrocephalus patients.

Dr. Bonnie Blazer-Yost

Indiana University–Purdue University Indianapolis (IUPUI)

Dr. Blazer-Yost and her team are conducting government-funded research to advance hydrocephalus treatment through a new drug target.

Stay informed about the latest hydrocephalus news, highlights, and research by visiting our blog at hydroassoc.org/blog

HA at the Table

Defense Health Research Consortium (DHRC) Organizational Meeting | Washington, DC
January 31

National Health Council (NHC) Health Leadership Conference | Scottsdale, AZ
February 21-23

Rosalynn Carter Institute for Caregivers Centering Caregivers in Policy Roundtable | Virtual
February 22

Rare Disease Week | Washington, DC
February 25-29

American Association of Neuroscience Nurses (AANN) | Salt Lake City, UT
March 17-18

National Academies of Science Workshop: Exploring the Bidirectional Relationship Between Artificial Intelligence and Neuroscience | Washington, DC
March 25-26

American Association of Neurological Surgeons (AANS) Annual Scientific Meeting | Chicago, IL
May 3-6

Rudi Schulte Research Institute (RSRI) Board Meeting | Virtual
May 31

Adult Hydrocephalus Clinical Research Network (AHCRN) Meeting | Salt Lake City, UT
May 17-18

Hydrocephalus Clinical Research Network (HCRN) Meeting | Houston, TX
June 6-7

American Academy of Clinical Neuropsychology | Scottsdale, AZ
June 5-8

HACONNECT

18th NATIONAL CONFERENCE ON HYDROCEPHALUS

July 25-27th, 2024

Tampa Marriott Water Street
Tampa, Florida

Be a part of the 18th National Conference on Hydrocephalus, HA CONNECT, in Tampa, Florida, happening from July 25th to 27th. Experience a transformative event where you'll uncover insights, foster lifelong connections, and receive invaluable support on your hydrocephalus journey. You are not alone! Reserve your spot today.

4 REASONS TO ATTEND

if you're living with or supporting someone with normal pressure hydrocephalus (NPH).

ALL NEW Sessions!!

1. Navigating Life After Shunt Surgery: Your Roadmap to Recovery.
2. Regaining Normalcy After NPH Surgery: Strategies for a Fulfilling Recovery.
3. Understanding Your Treatment: Inside the Mind of NPH Doctors.
4. Living with NPH and the Occupational Therapy (OT) Perspective.

SOMETHING FOR ALL:

An entire track for teens and special programming for siblings.

Stay Connected. #HACONNECT

DON'T MISS THESE NEW SESSIONS!

- Beyond the Horizon: Innovations in Hydrocephalus Treatment and Management
  Audience: Research *(All Ages)*
- Living with Uncertainty: Mental Health and Coping Strategies **Audience: Adults**
- Getting Across the Finish Line: Clinical Trials in Humans **Audience: Research** *(All Ages)*
- Impact of Hydrocephalus on the Growing Brain
  Audience: Parents

THANK YOU TO OUR SPONSORS!

PRESENTING SPONSORS

TGH Tampa General Hospital

USF Health

PLATINUM SPONSOR

RSRI Rudi Schulte Research Institute

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COPPER SPONSORS

Anuncia Medical

Creating Connections. Empowering Patients.

VISIT THE EXHIBIT HALL

Touch a shunt. Perform an ETV. Measure the flow of your CSF. So many cool exhibitors will be bringing their products for hands-on exhibits and your chance to ask questions.

KIDS CAMP

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

To learn more and register visit hydrocephalusconference.org

2024
WALK TO END HYDROCEPHALUS™

JOIN US for the 2024 WALK TO END Hydrocephalus

The 2024 WALK to End Hydrocephalus is just around the corner, and we're thrilled to invite you to join us for this incredible event! With 40 different WALKs happening across the country in cities near you, as well as the option to participate virtually, there are plenty of ways to get involved and show your support.

The WALK to End Hydrocephalus is much more than just walking; it's an opportunity to come together as a community and make a difference in the lives of those affected by hydrocephalus. This annual fundraiser is the largest for the Hydrocephalus Association (HA), generating nearly half of our annual revenue, with a goal of **$1.9 million for 2024.**

Not all participants physically walk during the event; some choose to register, fundraise for the cause, and engage with the community on WALK day. It's the one time each year that we gather in our local areas, providing a place for hydro warriors to meet and support one another. You're not alone on this journey, and the WALK is a powerful reminder of the strength and resilience of our community.

At the event, you'll have the chance to educate your friends and family about hydrocephalus by visiting our mission table, where you can find the latest information about HA's programs and services. You can also meet with local shunt and device representatives to ask questions and learn about the products offered.

This year, we're excited to announce a new WALK site: Virginia Beach! Led by advocate and hydro mother Natasha Buchanan, this event will take place in November on the VA Beach boardwalk at 24th street. It's sure to be an unforgettable experience for all involved.

Kick-Off WALK Season with

WALK WEEK

AUGUST 5-10, 2024

A SOCIAL MEDIA CELEBRATION

Let’s talk WALK! Our goal is to encourage new and current members of our community to learn more about HA’s WALK program and join in on the local fun, support, and advocacy. That’s where you come in!

During WALK WEEK, we are asking all WALKers throughout the nation to participate by supporting YOUR local WALK on social media.

Tell us WHY you WALK and have fun!

- Collaborate with local WALK teams
- Share awesome memories & photos
- Go LIVE wearing WALK shirts

Use the hashtag #hydrocephalusWALK with every post so we can re-share your creative content. Join in on the fun, story-telling, and contests all WALK WEEK long this August!

Follow the WALK to End Hydrocephalus on Facebook @hydrocephaluswalk

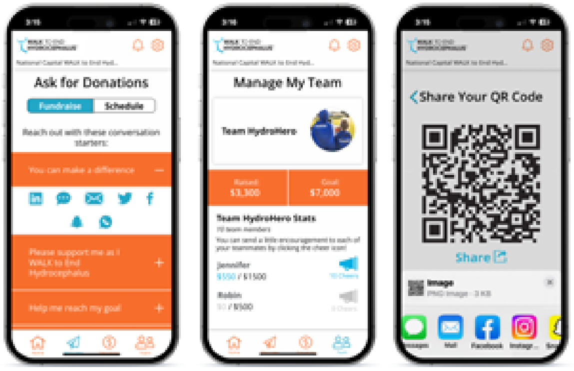
Kick-Start Your WALK Fundraising with HundredX™ Causes

Help us raise money without spending money! You can earn up to $120 simply by clicking on a few emojis on your cell phone or computer, and by sharing your opinion on popular products and brands. Join us in teaming up with HundredX™ Causes again this year from June 3 – July 2, 2024. Funds you generate can also support WALK to End Hydrocephalus participants in reaching their fundraising goals. ***Stay tuned for more information!***

Register for a WALK near you!

hydroassoc.org/find-a-walk-near-you

THE **NEW** AND **IMPROVED WALK APP** IS HERE!



Reach out with these conversation starters:

You can make a difference

Please support me as I WALK to End Hydrocephalus

Help me reach my goal

Send messages through Facebook, email, text, X, Snapchat, WhatsApp, and LinkedIn.

View individual and team fundraising progress and encourage your team members with texts and cheers.

Easily share your fundraising page with a QR code.

GET IT ON Google Play   Available on the App Store

PLEASE NOTE: The app is **only available to registered WALK participants**.

If you haven't registered, please register for an event near you at hydroassoc.org/walk.

TO START A WALK IN YOUR AREA

Please contact Marina Thompson
at marina@hydroassoc.org

The Fudge Solomon Legacy Society

The Fudge Solomon
LEGACY SOCIETY

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

As a member of this society you will be recognized, if you would like to be, and receive special communications and invitations to exclusive HA offerings, such as our annual Leadership Briefing from HA's President and CEO, Diana Gray.

FREEWILL

FreeWill's complimentary estate planning tool, accessible to all HA supporters, provides a straightforward and no-cost method for you to plan your estate according to your preferences.

Start your free will today!

Questions?

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

Visit hydroassoc.org/leave-a-legacy

RESEARCH

Elevating Research Impact: 2021-2023 Research Report

We are excited to share our 2021-23 Research Report. The report showcases our latest research, revealing significant advancements in understanding the causes of hydrocephalus, enhancing care, and developing treatments for hydrocephalus.

Research Report Highlights

- **Overview of our Research Networks (AHCRN, HCRN, HANDS, and HAPPIER)**
- **Return on Investment of research funding**
- **Featuring funded scientists' successes**
- **Community Research Priorities**
- **Research Strategic Plan**
- **HA Rudi Schulte Research Institute (RSRI) Annual Research Workshops**
- **Innovator Award Recipients**
- **New National Director of Research**

Download the research report here.

HA'S CORPORATE COUNCIL PROGRAM

HA's expanding network of committed partners actively collaborates on advancing effective therapies for hydrocephalus and supporting the community.

Through HA's Corporate Council Program (CCP), we aim to enhance these partnerships and advance our mission further. CCP partners will receive year-round benefits, including access to events and programs, as well as engagement opportunities with our patient and provider community through surveys and focus groups. Additionally, partners will have annual virtual and in-person meetings to discuss industry-relevant topics.

By joining CCP, partners will play a crucial role in advancing our shared mission and strengthening their connections with scientific and patient communities, while showcasing their contributions to the industry.

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

Research Workshop: Developing Non-Invasive Hydrocephalus Therapies

Advancing Towards Clinical Trials

Over 75 distinguished professionals convened in Cincinnati, OH for the 2024 Hydrocephalus Association and Cincinnati Children's Hospital Research Workshop on Developing Non-Invasive Hydrocephalus Therapies: Advancing Towards Clinical Trials.

This gathering marked a significant continuation of the momentum generated by the successful 2023 workshop, underscoring the pressing necessity for non-invasive interventions in hydrocephalus treatment. Participants, including scientists, educators, neurologists, neurosurgeons, patients, funders, and industry representatives, united in a collaborative effort to propel advancements in therapeutic strategies.

The workshop addressed crucial aspects of advancing towards clinical trials, emphasizing consensus models, endpoint measurements, and fostering external collaborations. Through robust discussions and knowledge exchange, participants sought to bridge the gap between preclinical investigations and clinical implementation, paving the way for more effective treatments for hydrocephalus patients.

It also offered invaluable direction for navigating regulatory approvals and securing financial support, with the goal of facilitating a smoother transition from scientific discovery to patient care. This was achieved by promoting strategic partnerships among academia, industry, and regulatory bodies, ultimately expediting the development and adoption of non-invasive hydrocephalus treatments.

Attendees actively engaged in discussions focused on the following key areas:

Animal Models, Techniques, and Endpoint Measurements

Assessing the strengths and weaknesses of various hydrocephalus models, along with endpoint measurements, sparked engaging discussions aimed at building consensus on the most effective techniques, models, and assessments of hydrocephalus.

Lessons from Current and Past Clinical Trials

Scientists involved in both past and present clinical trials presented their experiences, with a particular emphasis on lessons learned. They shared insights into navigating the intricate steps involved in initiating and conducting clinical research.

Patient Panel

Our patient panel provided attendees with invaluable insights into the patient perspective, shedding light on the motivations that drive patients to participate in clinical studies.

Building Collaborations to Advance to Clinical Trials

Integrating industry, government, and academic perspectives, experts laid out roadmaps for progressing towards clinical trials in hydrocephalus research. Discussions highlighted an increased need for collaboration and strategic partnerships between sectors.

Funders Panel

Representatives from governmental agencies, including Jill Morris (National Institute of Neurological Disorders and Stroke) and Cecilia Dupecher (Department of Defense Congressionally Directed Medical Research Programs), and private funding agencies, including Scott Davis (Sontag Foundation) and Monica Chau (Hydrocephalus Association), spoke about their respective programs and upcoming funding opportunities.

UNDER PRESSURE

Campaign to accelerate the pace of hydrocephalus research

The majority of the promising research found in the surrounding pages was made possible by private funding from individual donors and foundations, and our corporate partners. The research results have catapulted hydrocephalus into the sphere of interest and ideas from additional disciplines, as noted, which means the number of funding opportunities has grown by leaps and bounds as well.

This is an excellent place for HA and hydrocephalus research, but it is also clear that the funds required for new and continuing research has also grown at a rapid rate. As evidenced by our aptly-titled research campaign, we are under pressure to find this funding so that we can maintain this encouraging trajectory.

Together, we can change the future of hydrocephalus, improving the lives of those impacted by hydrocephalus, and ultimately finding a cure.

Let’s do this!

You can help make it possible!

If you currently support HA through one of our fundraisers, like the WALK, or through an individual gift, we ask that you continue to do so, and even consider increasing your investment, even making a second donation specifically for research.

If you have not dipped in your toe yet, please consider making your first gift today, in support of the Under Pressure campaign.

Share your story with family, friends and co-workers... why do you support HA, and won’t they join you? If you know someone who might be interested in investing in hydrocephalus research, we’d love to talk to them.

Please reach out to Linda Riley, National Director of Development at linda@hydroassoc.org.
Or visit hydroassoc.org/underpressure

Engineering RoadShow

As a part of our strategic plan at the Hydrocephalus Association (HA), the research department reached out to experts beyond physicians and scientists to bring bioengineers into their network.

HA hopes to inspire a new generation of engineers to take the lead on device development and improvement for hydrocephalus.

Hydrocephalus is primarily managed through surgical interventions, often involving the placement of shunts to redirect cerebrospinal fluid. Unfortunately, shunts frequently fail, leading to medical emergencies and necessitating multiple neurosurgeries. HA wants to facilitate engineering solutions that could enhance hydrocephalus treatment and the quality of life for those affected by the condition. We believe that engaging with students and faculty members could bring fresh perspectives and innovative solutions to this critical medical issue.

Dr. Carolyn Harris, a bioengineer and associate professor in chemical engineering and material sciences from Wayne State University, Jennifer Bechard, HA's Education Manager and an individual living with hydrocephalus, and Dr. Monica Chau, Director of Research at HA, presented pressing engineering research challenges related to hydrocephalus at the University of Chicago. They spoke to three bioengineering classes and presented at the bioengineering department seminar to an undergraduate, graduate and faculty audience.

HA was also invited to speak to two biomedical engineering design classes at the University of Michigan about design challenges and solutions for hydrocephalus. Speakers included Drs. Carolyn Harris, Aditya Pandey and his neurosurgery colleague, and Monica Chau. The presentation included introducing shunt problems with elaboration on fluid flow (mass transport problem), disconnection, pressure/flow, CP dysfunction, etc. Dr. Chau presented the patient perspective by introducing HA, community research priorities, patient perspective, and the urgency for better treatments.

HA will award a prize to selected hydrocephalus projects in engineering. This opportunity is open to graduate and undergraduate engineering students with a mentored project.

SCAN ME

CONNECT WITH US
@HYDROASSOC

PRMRP CDMRP Awarded $11.7 Million to Hydrocephalus Research in 2023

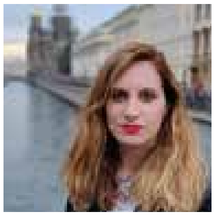
Since 2015, hydrocephalus has been eligible to receive funding through the Peer Reviewed Medical Research Program (PRMRP) within the Department of Defense's Congressionally Directed Medical Research Program (CDMRP).

The PRMRP funds research with the potential to further the development and implementation of medical devices, drugs, and clinical practice guidelines to improve diagnosis and treatment in healthcare settings. The goal is to accelerate research that will advance cures, improvements, and breakthroughs.

The FY2023 funding total of $11.7M from the PRMRP marks another multi-million dollar funding year for hydrocephalus-related research within the program. This large amount awarded demonstrates the quality and caliber of research being put forward by the scientific community.

FY2023 Award Recipients

Cerulean Scientific (formerly FreeFlow Medical Devices)
Awarded the **Technology/Therapeutic Development Award** to fund the finalization of a coating that will prevent the growth of cells on shunt tubing in the brain and ultimately decrease shunt revisions.



Maria Garcia Bonilla
Awarded the **Discovery Award** to study ependymal cell dysfunction and the root causes of hydrocephalus.

Carolyn Harris
Awarded the **Discovery Award** and aims to reduce shunt failure by targeting specific biological mechanisms of the cells that attach and grow in the shunt lumen and in the shunt catheter holes that cause shunt obstruction and failure.

Senseer Health
Awarded the **Technology/Therapeutic Development Award** to fund the finalization of an internal monitor that works with a shunt to capture information about an individual's intracranial pressure and CSF flow.

The SCEMPI Clinical Trial for Preterm Infants


Dody Robinson and Lauren Jantzie

The Safety of Combined Therapy with Erythropoietin & Melatonin for Preterm Infants with Intraventricular Hemorrhage (SCEMPI) has now launched and is currently enrolling participants. Drs. Shenandoah Robinson and Lauren Jantzie of Johns Hopkins are leading SCEMPI trial, a blinded, randomized, controlled research study to test whether high-dose melatonin and erythropoietin (EPO) are safe when given together to very preterm infants with severe intraventricular hemorrhage (IVH). The objectives of this study are safety during the neonatal admission and evaluating the rates of other common comorbidities of very preterm infants with severe IVH. Babies who were born between 23-0/7 and 31-6/7 weeks of gestation, are less than 21 days old, and have severe (at least unilateral grade III) IVH on their head ultrasound within 5 days are eligible to participate in this study.

High-dose enteral melatonin will be given up to 34 weeks in the study, and EPO will also be given up to 34 weeks. Safety will be monitored during treatment and after. The first group of babies will be treated open label and the second group will be randomized 3:1 to treatment versus placebo. All study participants including physicians and staff will be blinded to the treatment group except the research pharmacy. This study is funded by NIH NICDH and the Johns Hopkins Children's Center.

Scan to learn more about the SCEMPI clinical trial.

Record-Breaking $14 Million Grant for iNPH Clinical Trial in Full Swing


Mark Luciano

Groundbreaking research in idiopathic normal pressure hydrocephalus (iNPH) is well underway thanks to a $14M grant, the largest grant ever awarded to study adult hydrocephalus, funded by the National Institute of Neurological Disorders and Stroke (NINDS) of the National Institutes of Health (NIH). The grant was awarded to the Adult Hydrocephalus Clinical Research Network (AHCRN) to conduct the first largescale, multi-center, blinded, randomized, controlled trial aimed at evaluating the true response of shunting in patients with iNPH and identifying factors that improve diagnosis.

The study, titled "A Placebo Controlled Efficacy in idiopathic Normal Pressure Hydrocephalus Shunting (PENS)", is being conducted at 21 centers located in the US, Canada, and Sweden. The lead site is the Johns Hopkins Cerebral Fluid Center, with Dr. Mark Luciano serving as the principal investigator. To date, 61 participants have been randomized for the trial. The study aims to include a total of 100 participants, and recruitment will continue until this target is met, expected to be around March 2025. Results from the trial are anticipated to be reported by the end of 2026.

The AHCRN, comprised of eight member institutions, played a pivotal role in identifying the need for this study, leading discussions, and ultimately pursuing it. The AHCRN is one of three research networks funded by the Hydrocephalus Association, dedicated to conducting clinical research to improve treatment for adult forms of hydrocephalus.

Scan to learn more about the PENS trial.

HA Offers an Unprecedented Number of Funding Opportunities

To strategically expand the research ecosystem into disciplines not previously targeted by HA, we have allocated funding toward research conducted by bioengineers, health economists, epidemiologists, and neuropsychologists. This initiative aims to address the urgent challenges faced by individuals living with hydrocephalus. This year, the Hydrocephalus Association is offering an unprecedented number of funding opportunities spanning diverse fields related to hydrocephalus research.

Funding Opportunities

Innovator Award
Accelerator Award
Next Generation Travel Award
Health Economics & Epidemiology Award
Neuropsychology & Cognition Award
Engineering in Hydrocephalus Prize
Cynthia Solomon Resident's Prize in Hydrocephalus

RAISE Resiliency 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.

Coming in the Fall!

Highlighting the New Hydrocephalus Association Accelerator Award

This year, HA is excited to announce a new academic faculty award.

Through generous funding from the Theodore W. Batterman Family Foundation, HA is able to provide funding for established investigators to advance their ongoing research in hydrocephalus to the next level. These proposals will undergo rigorous evaluation by a panel of expert reviewers, assessing their alignment with treatment and prevention community research priorities.

The HA Accelerator Award provides funding for those who are developing a non-invasive treatment at any stage of the bench-to-bedside research pipeline or researching the prevention of hydrocephalus. HA aims to accelerate scientific progress by asking applicants to demonstrate how the award will advance their research to the next level. Examples of this include transitioning research from in vitro studies to animal models, advancing from small animal models to larger species, or progressing from animal models to clinical research.

Don't Be Left Out!

Join HAPPIER

The Hydrocephalus Patient Registry

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

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

JOIN NOW!
hydroassoc.org/happier

Introducing HA's New Research Programs Manager, Dr. Samantha Lanjewar


Dr. Samantha Lanjewar

As HA's Research Programs Manager, Dr. Samantha Lanjewar is responsible for administrative and programmatic aspects of the Research Programs Department, including grants administration, program planning, and fostering collaboration with physicians and scientists.

Earning her PhD in Genetics and Molecular Biology from Emory University, Dr. Lanjewar focused her research on human brain development. Her scientific expertise is in the use of human stem cells to study glia, CRISPR technologies, and computation analyses of sequencing data.

Dr. Lanjewar has served in various leadership roles and actively participates in STEM outreach programs, demonstrating a specific dedication to enhancing representation from underrepresented groups. Her strategic planning, collaboration, and commitment to diversity, equity, and inclusion, create an environment conducive to impactful research and community engagement.

Dr. Lanjewar has collaborated with several nonprofit organizations and is passionate about continuing the impactful research and outreach efforts for individuals affected by hydrocephalus. In her free time, she enjoys engaging in sports, exploring new restaurants, and volunteering.

Mary Decker Mentorship Award

Kim Apurado has been awarded the prestigious Mary Decker Mentorship Award. This accolade, open to all AANN members, celebrates neuroscience nurses who exemplify excellence in mentoring. Named after Mary Decker, a devoted nurse practitioner and Hydrocephalus Association Medical Advisory Board member, the award honors individuals who passionately guide both novice and experienced nurses.

As the recipient, Kim will receive complimentary registration to the AANN Annual Meeting and a $600 stipend for travel expenses. Additionally, he will be granted a $500 scholarship from the Hydrocephalus Association, along with complimentary registration to their biennial national conference. Join us in congratulating Kim Apurado for his outstanding dedication to mentorship in neuroscience nursing!

Celebrating Neuroscience Nurses

Nurses play a critical role in our care. They can make time in the hospital less stressful. They often serve as one of our primary contacts in a doctor's office, spending time with us to answer questions and provide information that sometimes the doctors don't have the time to do. The nurses we most often interact with when we're managing our hydrocephalus are neuroscience nurses, commonly known as neuro nurses in our community. They have various specialized roles, including Nurse Practitioners (NPs), Clinical Nurse Specialists, and Neuro ICU nurses. You can find neuro nurses in hospitals, independent practices, and in long-term care facilities such as nursing homes. They care for patients with neurological diagnoses, which include the brain, spinal cord, and nerves. They play a key role in assessing, diagnosing, and treating patients dealing with various neurological issues, like hydrocephalus.

What sets neuro nurses apart is their specialized education and training in the neurosciences and their ability to provide a special touch in patient care. So where will you find a neuro nurse? Frontline caregivers on hospital floors provide hands-on assistance pre- and post-op, while those in clinics offer ongoing education and support to patients and families managing hydrocephalus beyond hospital walls. In the ICU, neuro nurses are trained in advanced skills to care for critically ill patients with neurological issues, delivering specialized care. This includes monitoring and managing hydrocephalus-related interventions like external ventricular drains (EVDs) and intracranial pressure (ICP) monitors. Whether on hospital floors, in clinics, or ICU settings, they offer essential support tailored to the unique needs of individuals affected by hydrocephalus.

At the annual American Association of Neuroscience Nurses (AANN) conference in Salt Lake City, Amanda Garzon, HA's Chief Operations Officer, and Jennifer Bechard, HA's Education Manager, deepened HA's connections and strengthened our partnership with the neuro nurse community. They shared patient-focused resources, like our mobile app HydroAssist, to support neuro nurses in providing holistic care to their patients. Additionally, Cathy Cartwright, DNP, RN-BC, PCNS, FAAN, and Paula Peterson, NP, two members of HA's Medical Advisory Board, delivered a talk on hydrocephalus. The enthusiasm shown by nurses to explore our organization and access free resources highlights the importance of our presence at events like AANN's annual meeting. Plus, we were able to see old friends, such as Kentlee Battick MSN, RN, CCRN, CNL, CNRN, Neuroscience Clinical Nurse Leader at Johns Hopkins All Children's Hospital in Tampa. Kentlee, our former Tampa/St. Petersburg WALK to End Hydrocephalus Chair, is excited to welcome everyone to Tampa for this year's National Conference on Hydrocephalus in July.

Thank you to all of the neuro nurses who go beyond their duties to ensure patients receive personalized attention, comfort, and knowledgeable care. Their commitment to improving patient outcomes and enhancing quality of life is truly commendable, making them invaluable members of the healthcare team.

Learn about other important members of the healthcare team.

Visit hydroassoc.org/your-healthcare-team-2

DC Education Day Has a Global Twist

Children's National Hospital and HA partnered for their annual Living with Hydrocephalus event on March 2, 2024. The event brings together individuals and families in the Washington, DC metropolitan area to learn from experts and from each other as we navigate raising children with hydrocephalus. The program featured a presentation on the various developmental outcomes that can occur with hydrocephalus by Dr. Melissa O'Connell Liggett, a Developmental Psychologist. Her presentation was given a real-world lens through a panel featuring Dr. Deborah Phillips, mom to a young adult living with hydrocephalus, leading a discussion with Cree, a junior at Howard University, and Aqil, a middle school student.

Dr. Daniel Donoho, pediatric neurosurgeon, elevated the discussion of current treatment methods to focus on the impact technology and artificial intelligence (AI) are having on moving treatment and ongoing management of care forward. The talk highlighted trends in using technology to bring doctors together virtually for training and professional development. Examples include creating online storage of hundreds of recorded surgical procedures to having doctors participate in surgeries virtually half-way around the globe. Dr. Donoho was joined by Derek Johnson, CEO of NeuroKids, a nonprofit dedicated to addressing the wide disparity in accessing pediatric neurosurgical care in other parts of the world. NeuroKids conducts virtual reality surgical training and mentorship to neurosurgeons in countries desperate to educate and train new neurosurgeons in order to meet the care needs of their pediatric populations. The organization was founded by Dr. Benjamin Warf who standardized the endoscopic third ventriculostomy (ETV). It was an informative talk and a peek into the future of neurosurgery.

HA partners with hospitals around the country to host full or half day education events. We are grateful for Children's National Hospital for co-hosting this annual event.

Online Educational Resources

Explore our newest website updates showcasing informative articles on *"Hydrocephalus in Adults"* and *"Normal Pressure Hydrocephalus (NPH)."* Gain valuable insights into managing these conditions and stay empowered.

Stay tuned for further updates and new resources on our website!
hydroassoc.org/understanding-hydrocephalus

COMMUNITY HIGHLIGHTS

Miss New York Delegate, Cassidy Territo

Cassidy Territo, a delegate competing for the 2024 Miss New York title, champions hydrocephalus awareness and strives to enhance accessibility opportunities for all as her service platform. Here is the story of her sister, a tribute to the miraculous life of Carla Territo, written by Cassidy and their Grandmother.

In Memory of Our Miracle Carla Territo

Diagnosed In-Utero

Story Written by Her Grandmother and Sister

Carla's journey began with a revelation that resonated with uncertainty. Carla was diagnosed with congenital hydrocephalus in utero in the first trimester. Their physician cited a bleak prognosis for her quality of life. Even though there were unknowns in her medical situation, her family stayed strong and hopeful, holding onto the fragile possibility of her recovery.

The family consulted the chief of neurosurgery, who recommended an early delivery pending the receipt of necessary records. However, despite weekly sonograms, the required documentation was not forwarded, leading to Carla's full-term birth. Specialists initially doubted Carla's brain function and quality of life but were surprised by her attentive response to sound at birth. The medical team offered a reassuring perspective: "We can always be surprised by the quality of life."

Hours later, the family went to visit Carla, finding her isolated in a room apart from the other newborns. Surprisingly, there had been no communication with the neurosurgeon. The family asked the doctor to reach out to the neurosurgeon to ask why Carla was in isolation. Shortly after, Carla was swiftly taken for her first shunt surgery, leaving the family distraught as she emerged crying. Despite the delicate nature of her head, reminiscent of tissue paper, the surgeon remained hopeful for Carla's strength. By 10 months old, Carla had undergone 13 shunt revisions.

At this time, Carla and her older sister Cassidy found themselves under the loving guardianship of their grandparents, who wholeheartedly embraced the role of full-time parents, despite having limited background information. While Carla displayed the ability to hold a bottle, she struggled to achieve typical developmental milestones such as sitting up. However, her journey was marked by small victories, as she began to utter her first words at just one year old.

At 18 months, Carla underwent corrective eye surgery to address strabismus, commonly known as crossed eyes, paving the way for clearer vision. By the age of two, she demonstrated remarkable determination, learning to sit up and navigate her surroundings by "scooting" on her bottom. To safeguard against head injuries during her explorations, Carla wore a soft helmet, a symbol of her resilience in the face of adversity.

For Carla's third birthday, she received a tricycle that resembled a big wheel. With her hands and feet secured by Velcro to prevent

continued...

slipping, Carla eagerly embraced her new wheels. After just a week of practice, she confidently maneuvered her bike, using it as her preferred mode of transportation everywhere she went—whether it was to daycare, around the house, or out with her family.

By age four, Carla used a posterior walker until overcoming balance challenges by five, showing her tenacity. Despite an IQ score of 58 in second grade, she defied expectations with her articulate speech and excelled in physical activities like running and jumping, embodying determination.

At 11 1/2 years old, Carla's shunt malfunctioned without detection despite normal readings. Over the next decade, her gait changed, requiring more assistance. Despite extensive testing and therapies, Carla and her family relentlessly sought answers, leaving no avenue unexplored.

In January of 2020, Carla endured a rough week with vomiting, seizures, and muscle stiffness, culminating in a diagnosis of Chiari Malformation Type II. Her condition reached a critical point as she required resuscitation after an agonizing 23 minutes. Undeterred by the frightening odds stacked against her, Carla embarked on a grueling five-month hospitalization. Her resilience continued to shine brightly.

During the pandemic, Carla's homecoming was both bitter and sweet, supported by her dedicated grandparents and sister who underwent rigorous training to care for her. Despite the challenges associated with a tracheostomy tube, ventilator, feeding tube, spinal cord injury, quadriplegia, and the need for full assistance, Carla remained determined, surpassing her condition's limitations and striving for progress.

Upon returning home, Carla set three ambitious goals: to speak again, breathe independently, and regain hand mobility. With relentless determination, she underwent intensive therapy and personal training, meticulously documenting her progress. Remarkably, within six months, Carla made significant strides, reducing reliance on ventilation support and intensifying focus on speech and eating assessments.

In early 2021, Carla passed her eating assessment, a remarkable achievement given her spinal cord injury, allowing her to eat orally. She began sleep studies to reduce ventilator support, coached by her sister Cassidy. Gradually downsizing her tracheostomy tube, Carla's voice resurfaced, marking another milestone in her journey. Undeterred by challenges, she persisted, investing nearly a year in preparation for subsequent sleep studies.

By 2022, Carla completed her second sleep study, no longer needing respiratory support during the day. On her birthday in March, she lifted her head unassisted for the first time, inspiring others with her determination to surpass expectations. Despite skepticism, Carla defied doubts, showcasing her unwavering strength and resilience with each determined movement.

In 2023, Carla sustained holding her head up for over two minutes, showcasing her perseverance. She completed her final sleep study on her birthday in March and astounded everyone in July by spontaneously rising to a standing position while working on sitting at the edge of a mat table.

In September 2023, Carla peacefully earned her angel wings. Her legacy of boundless strength and determination continues to illuminate the lives of all who were privileged to know her.

Community Networks: Parent Meet-Ups

We don't want you to miss out on support opportunities that are important to you! Register for the group that best meets your needs.

Parents of Middle School Aged Children

Held the 2nd Tuesday of the month

(Runs only during the academic school year, September- May)

Is your child starting or continuing in middle school? This can be a challenging time for both parents and kids alike. Join other parents to exchange experiences about entering and navigating this especially awkward time of life.

Contact: Susan Fiorella and Jessica Abercrombie
Email: info@hydroassoc.org

L1CAM Family and Relatives Meet-Up

Held the 3rd Tuesday of the month, Quarterly

This group is designed to be a source of encouragement, support, and share helpful resources as we find our way with L1CAM. Join our space to learn more about the impacts of the L1CAM syndrome on families within our community.

Contact: Alison Kandrovy
Email: info@hydroassoc.org

Supportive Families Embracing Disability Journeys

Held every 3rd Thursday of the month

Open to parents of young adult and adult children ages 19 and above living with hydrocephalus and any type of disability.

Welcome to a supportive haven for parents! We embrace all parents navigating the complexities of hydrocephalus and intellectual and developmental disabilities in their adult children. Our inclusive community recognizes the diverse ways hydrocephalus affects our loved ones. If you're supporting an adult children with intellectual disability/ learning challenges, autism, and/or physical disability, you're not alone. Join fellow parents on a shared journey to connect, discuss, and find solace in understanding each other's experiences as caregivers, advocates, and individuals.

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

Building Bonds:- Parents of Young Adults Living with Hydrocephalus

Held every 4th Sunday of the month

This parent-to-parent group is designed to provide a safe and welcoming space for parents with children ages 19- 29 transitioning into the adult world. We will gather together to share ideas, celebrate successes, and navigate the challenges of hydrocephalus in a supportive environment.

Contact: Tiffany Everett and June Moser
Email: southfloridacommunity@hydroassoc.org

PRESENTADO

Grupo de habla hispana

Held every 3 months on the 4th Tuesday

La asociación está aquí para apoyar a todos los afectados por la hidrocefalia, incluyendo nuestra comunidad que habla español! Unámonos para construir un círculo de apoyo para nuestras familias. Las Redes Comunitarias de la Asociación de Hidrocefalia están diseñadas para unirnos, conectarnos entre nosotros y crear un espacio seguro donde podamos hacer preguntas y encontrar apoyo de otros que han caminado o están caminando por un camino similar.

Contact: **Mario Acosta**
Email: info@hydroassoc.org

Find a Community Network

hydroassoc.org/find-a-community-network

Community Network Leader Spotlight

Mallory Bauman

Mallory Bauman's journey with hydrocephalus began unexpectedly when her daughter, Carson, was diagnosed at 20 weeks gestation. Determined to educate herself and support her daughter, Mallory embarked on a path filled with challenges and triumphs.

Carson's journey included a successful ETV procedure shortly after birth, followed by the placement of a programmable shunt. Despite initial setbacks, Carson has thrived since October 2021, thanks to the interventions available for her condition.

In June 2023, Mallory began volunteering for the Hydrocephalus Association (HA), driven by a desire to raise awareness and support others facing similar challenges.

Inspired by the significant needs in her home state of New Mexico, Mallory assumed the role of Community Network Leader (CNL) to educate her community and advocate for those affected by hydrocephalus.

Outside of her advocacy work, Mallory enjoys spending time with her family in La Plata, NM. Together with her husband, three children, and a few furry companions, Mallory embraces outdoor activities, family outings, and pursuing her master's degree in physical education.

For Mallory, supporting the mission of HA is deeply personal. She is committed to contributing to efforts aimed at finding a cure and improving the lives of those affected by hydrocephalus within her community and beyond. Through her dedication and resilience, Mallory Bauman continues to be a beacon of hope for the hydrocephalus community.

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New Members Join Congressional Hydrocephalus Caucus

The Congressional Pediatric and Adult Hydrocephalus Caucus has welcomed seven new member of Congress in 2024, bringing total membership to 28. The new members include **Gabe Amo (RI-01), Yadira Caraveo (CO-08), Morgan McGarvey (KY-03), Seth Magaziner (RI-02), Jerry Nadler (NY-12), Derrick Van Orden (WI-03), Bill Posey (FL-08), and Marc Veasey (TX-33).**

The additions to the Caucus would have not been possible without our passionate advocates from around the country. Much of this success was a direct result of advocates meeting in the district with their elected Representatives and staff. Members of the Hydrocephalus Action Network shared their stories and explained the importance of the Hydrocephalus Caucus.


Gabe Amo (RI-01


Yadira Caraveo (CO-08)


Morgan McGarvey (KY-03)


Seth Magaziner (RI-02)


Jerry Nadler (NY-12)


Derrick Van Orden (WI-03)


Bill Posey (FL-08)

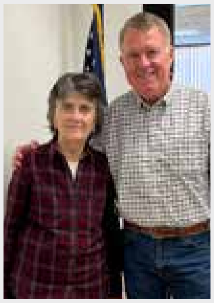

Marc Veasey (TX-33

Scan for the latest list of congressional offices that are on the Caucus, or visit hydroassoc.org/congressional-pediatric-and-adult-hydrocephalus-caucus/

ADVOCATE SPOTLIGHT

Nikki Batsford

Nikki Batsford, from Johnston, Rhode Island, met with two lawmakers in one week to discuss issues surrounding the hydrocephalus community. Nikki shared her story growing up with hydrocephalus in a state with insufficient medical resources. Her motivational testimony inspired Congressman Amo to be the first member from Rhode Island to join the Hydrocephalus Caucus. There may be a second member from Rhode Island on the Caucus very soon. Shortly after she met with Rep. Amo, Nikki had a successful meeting with Congressman Magaziner.



Dorothy Sorlie
Toni Travline

Dorothy Sorlie and Toni Travline worked tirelessly in Wisconsin to spread awareness about the challenges individuals with hydrocephalus face. Both were able to meet with the district offices of Representative Van Orden to share their inspirational stories with his staff. Their testimony and renewed efforts demonstrated the need and importance of Congressman Van Orden's membership on the Hydrocephalus Caucus.

This could be you!

If you're interested in making a difference in your local community, please contact our Advocacy Manager, Davis Kaderli at Davis@hydroassoc.org.

Congressional Briefing

The Hydrocephalus Association recently partnered with the Defense Health Research Consortium (DHRC) to host a research-centered Congressional Briefing on Capitol Hill.

The briefing, which took place on Friday, March 15th, brought in a variety of speakers to educate congressional staffers on the importance of the Congressionally Directed Medical Research Program (CDMRP), showcasing hydrocephalus to demonstrate the life-changing impact of the funding.

The CDMRP, which is under the Department of Defense, funds high-impact, high-risk, and high-gain projects with the goal of improving patient care and treatment. Hydrocephalus has been eligible within the program since 2015 and it has been a critical source of funding. Hydrocephalus research received $15.3 million during the Fiscal Year (FY) 2022 grant process and $11.7 million during the FY 2023 grant cycle. Part of this funding went into the creation of the first Hydrocephalus Research Center at the Indiana University–Purdue University Indianapolis (IUPUI) School of Science and funded the first human clinical trial of a drug combination to protect the brain after a brain bleed and potentially prevent the development of hydrocephalus at Johns Hopkins.

The event underscored the need for increased federal funding for the program in FY 2025. The topline funding number of the CDMRP ($1.651 billion) has not changed since 2021, leaving many scientists unfunded. In 2023, only four out of the 12 hydrocephalus research proposals submitted to the PRMRP review board were chosen to receive funding.

Diana Gray, HA's President and CEO, opened the briefing with an overview of hydrocephalus and the number of individuals impacted in the U.S. Natasha Buchanan, a Navy spouse and mom to Zander, 6, who has hydrocephalus, personalized the condition for the audience by sharing her family's journey from diagnosis to today, highlighting the unique challenges faced by military families with children who have complex medical conditions.

With the stage set regarding the challenges of treating and living with hydrocephalus, the briefing turned to the incredible success of CDMRP-funded research. Mark Vieth, lead of the Defense Health Research Consortium (DHRC), provided the historical context of the program and how it differentiates itself from the National Institutes of Health (NIH). He also provided the challenges associated with the program's lack of funding increases and its impact on the research workforce in the United States.

Dr. David Limbrick, a CDMRP-grantee and Chair of the Virginia Commonwealth University (VCU) Department of Neurosurgery, spoke on the evolution of hydrocephalus research over the last 20 years and how the infusion of CDMRP funds has allowed for the discovery of potential cellular and genetic targets for drug therapies and the development of two new devices to treat hydrocephalus. The two scientists spearheading the device development joined Dr. Limbrick for an open discussion on the significance of the CDMRP funding. They emphasized that without it, the process of developing and bringing their impactful technology to market could have been significantly delayed, especially considering the sharp decline in overall funding from private investors for medical device companies in 2023, with a decrease of over 50% from the sector's peak in 2021. Sascha Lee, CEO of Senseer Health, elaborated on how the grant is facilitating the finalization of an internal monitor. This monitor is built on a proprietary microsensor that integrates with commercial shunts, allowing doctors and patients to wirelessly monitor shunt status based on cerebrospinal fluid (CSF) flow rate through the device. Lora Allemeier, CEO of Cerulean Scientific, hopes to have a new shunt to market by the end of 2025 that will use a material that prevents the adherence

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of cells on the tubing in the brain, ultimately resulting in fewer shunt revisions. The funding is allowing Cerulean Scientific to complete product testing and move their device through the final process with the FDA.

These briefings play a crucial role in filling knowledge gaps for staff on Capitol Hill, many of whom are new to the Hill due to high turnover and who are managing multiple topic areas. We are grateful for the support of John McDonogh, Legislative Director for Congressman Chris Smith (R-NJ) and Afton Cissell, Legislative Director for Congressman Lloyd Doggett (D-TX), the two chairs of the Congressional Pediatric and Adult Hydrocephalus Caucus, for their support of this educational event.

Rare Disease Week

Members from the Hydrocephalus Association Action Network (HAN) came to Washington, DC, to participate in Rare Disease Week, Feb. 25-28, 2024.

The annual event, sponsored by Everylife Foundation for Rare Diseases, the annual event brings together advocates from across the country to lobby on Capitol Hill for the needs of the Rare Disease Community. HA first participated in the event in 2016, uniting our hydrocephalus voice with the larger rare disease community.

Although hydrocephalus as a whole is not considered a rare disease due to the over 1 million individuals who have the condition, the various medical classifications (etiologies) of hydrocephalus are considered rare. This rare disease characterization allows hydrocephalus to be eligible for federal funding within the rare disease space and pathways that provide special considerations or incentives that allow drugs and devices to reach patients faster.

The 2024 Rare Disease Week included four days of events for advocates to take part in. The Legislative Conference and day of meetings on Capitol Hill are at the heart of the events, having taken place on Monday and Tuesday. The Legislative Conference brought in a variety of speakers from the disability and health policy space to talk about the current legislative issues affecting the rare disease community. Some of the topics included step therapy protocol, pediatric out-of-state medical licensing, and Rare Disease Priority Review Voucher Reauthorization. These educational lessons provided advocates with the resources and knowledge to effectively lobby their members of Congress the next day.

The next morning, advocates headed to Capitol Hill for congressional meetings with their state Representatives. During the meetings, they were able to share the connection between the legislative issues and their healthcare journey. Our hydrocephalus advocates were Jonathan Moe (Washington), Kevin Flynn (Tennessee), Elana Schwartz and Yehuda Gelman (New York), Amanda Garzon (Maryland), Lakisha Harris (representing Louisiana), and Davis Kaderli (representing California).

“Coming to Rare Disease Week with the Hydrocephalus Association was pivotal for me in embracing who I am as a hydrocephalus survivor. Advocating on Capitol Hill empowers me to remember that despite my challenges through 15 brain surgeries, I can help fight to make change, to make life easier for people with hydrocephalus and the community around them,” shared Kevin. Kevin had the opportunity to meet directly with Senators Marsha Blackburn and Bill Hagerty from his home state.

These lobbying efforts had a significant impact, resulting in the addition of two new members to the Congressional Pediatric and Adult Hydrocephalus Caucus. The addition of these new members shows the impact of continued advocacy from individuals within the hydrocephalus community.

Congressional Meetings

Leading up to the Congressional Briefing, members of HA's staff and hydrocephalus researchers met with congressional offices to talk about HA's policy priorities and the importance of increased funding for the Congressionally Directed Medical Research Program (CDMRP) in FY 2025. The schedule included meetings with the offices of Senator Hassan (NH), Senator Kelly (AZ), Senator Capito (WV), Senator Van Hollen (MD), Senator Murray (WA) and Congresswoman McClellan (VA-04). The researchers were able to directly share the science that was funded by the CDMRP in FY2023. Staffers were especially interested in how new technology funded by the CDMRP could reduce shunt failures and overall spending within the healthcare system. They were also impressed to learn that the CDMRP funding may result in a drug that could prevent the development of hydrocephalus after a brain bleed. The CDMRP is showing real impact, which lends motivation to Senator Murray who puts forth hydrocephalus each year as an eligible condition for funding under the CDMRP. We are so grateful for her steadfast commitment to making a better future for our community.


Team with Olivia from Senator Murray's office


The HA delegation pictured with Senator Maggie Hassan.

The Senator's son, Ben, was born with hydrocephalus and cerebral palsy. Her transition to public service was fueled by her motivation to address the gaps in the healthcare systems that were experienced by her family. She was especially interested to hear about the recent technological developments, given her personal connection with the condition. She left wearing one of HA's shunt pins.

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

SEPTEMBER 20TH

World Hydrocephalus Day

World Hydrocephalus Day aims to shed light on this often-misunderstood condition and promote worldwide unity among patients, caregivers, healthcare professionals, and advocacy organizations. By fostering understanding and compassion, the day seeks to improve the lives of those affected by hydrocephalus.

WAYS TO GET INVOLVED

Wear Blue: Show your support by wearing blue clothing or accessories on September 20th.

Social Media Campaign: Share your hydrocephalus story, facts, and resources using the hashtag #WorldHydrocephalusDay to raise awareness.

Local Events: Organize local events such as awareness walks, seminars, or support group meetings to bring the community together.

Educational Initiatives: Partner with schools and colleges to conduct educational sessions about hydrocephalus.

Fundraising: Support hydrocephalus research and patient advocacy groups by organizing fundraising activities.

Join Us and Spread Awareness on World Hydrocephalus Day!

worldhydrocephalusday.org

Hydrocephalus
Association

4340 East West Highway, Suite 905
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