

VOLUME
37
EDITION 2

Registration for HA CONNECT Now Open!

Join us in Houston, TX
June 25-27 for
HA CONNECT, our
National Conference
on Hydrocephalus.

5

Celebrating 10 Years of Discovery

Families and researchers from
across the U.S. came together
on Nov. 3 in St. Louis to
celebrate the 10th Anniversary
of HA's Research Initiative.

8

HA Scholarship Recipients Announced

12 amazing young people who
are living with hydrocephalus
were awarded scholarships
from HA to pursue their
academic dreams!

13

Read About Our Incredible WALK Season!

We had an incredible 2019 WALK to
End Hydrocephalus season, with over
15,000 people participating. And for
the first time, our WALKs raised over
\$2M to support HA's mission.

MESSAGE FROM THE PRESIDENT & CEO



Dear friends,

I cannot believe 2019 is already coming to an end – and what a whirlwind it's been!

This year was exciting for the Hydrocephalus Association because we celebrated the 10th anniversary of our Research Initiative. Ten years ago, we began investing in high-impact research because we

wanted a different future for people living with hydrocephalus. Now, we're proud to say we are the largest, private funder of hydrocephalus research in the country, investing nearly \$10 million in research and awarding 40 grants to brilliant scientists. As you'll see on pg. 5, in November we held a 10th Anniversary Research Dinner in St. Louis. The event gave us a chance to celebrate our research accomplishments and honor the trailblazers who started it all.

That same week, we hosted an amazing two-day Research Workshop, which brought together 37 scientists from various disciplines to explore areas of potential collaboration. The goal was to bring these great minds together so they could learn from each other and discover areas that hold the most promise for new therapy development and better outcomes for hydrocephalus patients (learn more on pg. 6).

One of the ways that we raise money to fund our Research Initiative is through our WALKs to End Hydrocephalus. For the first time in the history of our WALK program, we raised over \$2 million for HA's mission! That's a wonderful accomplishment that we could NOT have done without YOU! Thanks to everyone who participated in a local WALK to End Hydrocephalus and donated to a WALK team. And a special thanks to the 1,700 volunteers who helped make each WALK a success. Your support is what enables us to continue helping

families impacted by hydrocephalus and funding research for a cure! Read more about our WALK season on pg. 13.

In this issue of *Pathways*, you'll also learn about our Hydrocephalus Caucus Briefing that we held on Capitol Hill on Oct. 17th. The briefing educated lawmakers about hydrocephalus and its impact on patients and families. The meeting was a great way to introduce hydrocephalus to members of Congress and to hopefully engage them on the bipartisan Congressional Pediatric and Adult Hydrocephalus Caucus (read more on pg. 11).

Another major milestone we achieved here at HA is developing a new three-year Strategic Plan. Our plan was developed with significant input from our Board of Directors, program committees, and from the hydrocephalus community.

Last year, we sent out a survey asking for your feedback on what focus areas you valued the most. Your responses helped us develop this new and very ambitious plan. We consider this our roadmap for helping us achieve our mission of finding a cure and improving the lives of those impacted by this condition (see pg. 4 for details).

So as you can see, we've been busy! But we're not complaining. It's what we LOVE to do! Thank you for your support and I hope to see you next June in Houston at HA CONNECT, our National Conference on Hydrocephalus!

“Ten years ago, we began investing in high-impact research because we wanted a different future for people living with hydrocephalus. Now, we're proud to say we are the largest private funder of hydrocephalus research in the country.”

Sincerely,

Diana Gray, MA
President and Chief Executive Officer

To learn about the various ways you can get involved with HA, visit www.hydroassoc.org/get-involved.

FEATURED ARTICLES

Register for HA's National Conference on Hydrocephalus!



**16TH NATIONAL CONFERENCE
ON HYDROCEPHALUS**

June 25-27, 2020

The Westin Houston, Memorial City
Houston, Texas

Start packing your bags! Our 2020 National Conference on Hydrocephalus, HA CONNECT, will be held next June in Houston, TX! Our conference offers resources and connections that address the medical, educational and social complexities of living with hydrocephalus. HA CONNECT attracts participants from all over the world, including physicians, researchers, individuals with hydrocephalus, caregivers and others. This extensive three-day program will cover topics of interest to all members in the hydrocephalus community through interactive sessions, research updates, and educational seminars.

Presentations will be offered through large plenary sessions, panels, workshops with open discussion, and small round tables to allow for intimate learning opportunities on topics such as diagnosis, treatment, and living with hydrocephalus.

Registration is now open!

Visit www.hydrocephalusconference.org to register and to learn more about the sessions and speakers.

Drink Cider and Support the Hydrocephalus Association!

If you like cider and want to support hydrocephalus research, support and education, buy Locust Cider! The company donates a portion of their proceeds, and \$25 from each club membership, to the Hydrocephalus Association!

Visit one of their taprooms in:

Seattle, WA | Spokane, WA | Tacoma, WA | Walla Walla, WA
Woodinville, WA | Fort Worth, TX | Boulder, CO



**Visit www.locustcider.com
to learn more.**

Forging Ahead with a New Strategic Plan

Earlier this year, the Hydrocephalus Association launched a new three-year Strategic Plan. The new plan was developed with input from YOU, as well as members of our Board of Directors. The 2019-2021 plan better reflects our mission — to find a cure for hydrocephalus and improve the lives of those impacted by the condition. Here's a summary of our plan:

Pillar 1: Find And Engage the Hydrocephalus Community

The Hydrocephalus Association still remains relatively unknown by the majority of individuals in this country living with hydrocephalus. It is estimated that there are approximately 1 million Americans living with hydrocephalus, yet we are reaching a very small portion of that number. Increasing the number of patients and families connected with the association will increase our ability to serve patients' needs, as well as our capacity to grow our overall mission. Increased engagement with media, medical professionals, and volunteers are key channels for this effort.

Strategies:

- Increasing Awareness of HA by the Patient Community.
- Increasing Engagement of the Patient Community with HA.

Pillar 2: Fund And Promote High Impact Research to Advance Care, Treatments, Prevention, and Ultimately a Cure for Hydrocephalus

Research offers hope for present and future generations of patients, and underlies the association's vision of a world without hydrocephalus. Since its inception in 2009, HA's research program has been highly successful not only in generating research findings, but also in growing the research community and building infrastructure for that community. The task is to continue funding, and promoting the funding of high impact research, while further strengthening the infrastructure and helping guide the research community toward areas with maximum benefit for patients.

Strategies:

- Leveraging and Coordinating the Research Networks.
- Incorporating the Patient Voice.
- Growing the Research Community.
- Advocating for Outside Research Funding.

Pillar 3: Improve the Lives of Those Impacted by Hydrocephalus at Every Age and Every Stage of Life

The provision of services to those impacted by hydrocephalus is a critical part of HA's mission, and does much to connect the patient community to the association (Pillar 1). These services include acting as a source of information as well as providing social and emotional support, and working with the medical community and other stakeholders to improve care. We would like to better understand our community's needs and ensure we are providing services to support the hydrocephalus community at all ages and stages of life.

Strategies:

- Improving the Care of Adults with Hydrocephalus.
- Improving Access to Information.
- Supporting Personal Connections.
- Improving the Legislative Framework.

More details about our new Strategic Plan are available at:
www.hydroassoc.org/2019-2021-Strategic-Plan/.

St. Louis Event Celebrates 10th Anniversary of HA's Research Initiative

Families and researchers from across the country came together on Nov. 3 in St. Louis, MO to celebrate the 10th Anniversary of HA's Research Initiative. The event highlighted the successes of our research investments and honored the trailblazers who started it all.

"Since the start of our research initiative in 2009, we have worked diligently to build a comprehensive research program. Today, our program spans basic, translational, and clinical research and funds efforts to find

Dr. David Limbrick, MD, PhD, with St. Louis Children's Hospital and Washington University School of Medicine, gave the keynote address about what the future holds for hydrocephalus research. He urged the audience to believe that it is possible to find ways to prevent and cure hydrocephalus.

"It's doable through team-based science and really probing these common pathways, enabling us to make transformative advances



Dr. Carolyn Harris (on the right) accepting her Research Innovation Award. Also pictured: Tessa van der Willigen, Vice Chair of HA's Board of Directors



HA's Amanda Garzon and Diana Gray with Paul Gross, who received the Visionary Leader Award



Vicki and Craig Brown with Pam Finlayson



Stephanie Buffa Vogt accepting her award from Brett Weitz

a cure and improve the lives of those living with the condition, from the smallest preemies to seniors with Normal Pressure Hydrocephalus," said Diana Gray, HA's President and CEO, as she welcomed guests.

At the event, Paul Gross, past HA Board Chair and co-founder of the Hydrocephalus Clinical Research Network (HCRN) and the Adult Hydrocephalus Clinical Research Network (AHCNRN), was presented with the Visionary Leader Award for his efforts to help launch and shape HA's Research Initiative. He shared stories of how HA's research ecosystem began and highlighted the individuals who helped make it successful.

Dr. Carolyn Harris, PhD, from Wayne State University, was honored with the Research Innovation Award. Dr. Harris, the recipient of HA's 2018 Innovator Award, is testing a new shunt coating that stops cells from attaching to the shunt. Her goal is to create a shunt catheter that does not block, which would be a game changer for hydrocephalus patients.

"Shunt failure is a solvable problem. Better treatments for hydrocephalus are on the horizon. We need good mentors, we need support, we need encouragement and we need collaboration. Collaboration is a necessity in order to really make progress and the Hydrocephalus Association is really working hard in trying to help researchers toward that goal," she said after accepting her award.

towards precision medicine for hydrocephalus... the need is urgent and significant and they're counting on us," he said.

HA Board Chair Brett Weitz presented Stephanie Buffa Vogt with the 2019 Vicki Brown Volunteer of the Year Award. Stephanie has been living with hydrocephalus since she was 6 weeks old. She has attended almost every Hydrocephalus Association conference over the past 20 years and is a longtime HA peer support volunteer. Since 2008, she has been Chair and Co-Chair of the St. Louis WALK to End Hydrocephalus, which has raised over \$500,000 for HA's support, education and research programs.

"I've been very lucky to not have to worry too much about having hydrocephalus – it's just a blessing. That's truly why I chair the walk every year and love meeting families because I want to see how I can help them and see what I can do. Thank you to all the scientists, all the doctors and everyone at the Hydrocephalus Association who works tirelessly to make sure that we figure out a cure for hydrocephalus," she said.

For the first time, we live streamed the Research Dinner onto our Facebook page. To view a recording of the live stream, visit HA's Facebook page, click on videos and select "A Celebration of 10 Years of Discovery": www.facebook.com/HydroAssoc/.

HA Research Workshop Hosts Scientists from Around the World



In November, scientists from across the United States, and five countries, convened at Washington University in St. Louis for the Hydrocephalus Association's Driving Common Pathways Workshop. The workshop delved deeper into the research around posthemorrhagic hydrocephalus (PHH) and explored the overlap between the mechanisms implicated in PHH and other forms of hydrocephalus.

development and microglia, the role of ependyma, and opportunities in cell therapies. Researchers came from as far as Norway and Greece to participate in the workshop.

"The goal of the two-day workshop was for researchers to explore areas of overlap to determine which hold the most promise for new therapy development and improved outcomes for hydrocephalus patients," explained Diana Gray, HA President and CEO. "We were excited to see a lot of active discussion among the scientists and hopefully many will collaborate in the near future."

The workshop featured 23 presentations and panel discussions with scientists from various disciplines. Topics included the role of the choroid plexus in the development of hydrocephalus, the role of cilia, brain

The workshop was funded through a \$3 million Vision Dinner PHH Campaign led by Vicki and Craig Brown, longtime HA benefactors.

Join us in congratulating Diana Gray, HA President and CEO, for being named Vice Chairperson of the National Health Council (NHC) 2020 Board of Directors!

The announcement was made at NHC's Annual Meeting on December 10, 2019. The NHC convenes more than 100 health-related nonprofit organizations and businesses committed to better health outcomes for patients.



HA represents the hydrocephalus patient community at key professional meetings. Here are meetings we have recently attended:

Hydrocephalus Clinical Research Network Meeting

Oct 3-4 | Deer Valley, UT

Neurological Conditions Surveillance Summit

November 5 | Atlanta, GA

Adult Hydrocephalus Clinical Research Network Meeting

Nov 15-16 | Salt Lake City, UT

American Association of Neurological Surgeons/ CNS Section on Pediatric Neurological Surgery 4th Annual Meeting

December 5-8 | Scottsdale, AZ

Technology Update: Moving Towards a Self-Sensing Shunt



The Hydrocephalus Association submits letters of support for grant applications and other activities that have the potential to benefit the hydrocephalus patient community.

Earlier this year, we submitted

a letter of support for Senseer, a Los Angeles-based medical device company, which applied for funding to support the development of a “smart shunt.” We are happy to report that the National Science Foundation (NSF) responded by granting Senseer with the Small Business Innovation Research (SBIR) Phase I grant, totaling \$225,000 for a period of six months.

The Goal of the Project:

Senseer is developing a wirelessly operated multi-sensor module that can be integrated into current standard shunt therapies, allowing for remote monitoring of shunt status, therapeutic efficacy, and patient health. This means that a doctor would be able to monitor a patient’s shunt status in real-time in an outpatient setting.

What the Microsensors Will Measure:

- (1) level of shunt obstruction (patency),**
- (2) cerebrospinal fluid flow rate,**
- (3) intracranial pressure,**
- (4) intracranial temperature, and**
- (5) cerebrospinal fluid pulse waveforms.**

To date, pre-existing sensor technologies measure only a single parameter, which is insufficient to provide reliable and clinically actionable data. Senseer’s approach uses multiple sensors to ensure greater accuracy.

“Remote monitoring for chronic disease treatment is a rapidly growing field which will have a huge impact on clinical practice in the U.S. Our team’s goal of developing a wireless, passive sensor module, which can be chronically implanted in the human body, shows great promise for improving the treatment of hydrocephalus and other chronic conditions. As hydrocephalus is a particularly underserved condition that could see huge benefit from remote monitoring, our team is extremely enthusiastic about serving this patient population as the primary market for our technology,” said Sascha Lee, Senseer’s CEO.



HAPPIER

Join the first Hydrocephalus Patient Powered Registry! Be a part of research!

www.hydroassoc.org/HAPPIER

Whether you are living with hydrocephalus or provide care for someone with hydrocephalus, we welcome you to join our quickly growing community and share your experiences in our Hydrocephalus Patient Registry! Your experiences are crucial to helping scientists better understand the full impact of hydrocephalus and where to focus their research. Together, we will move hydrocephalus research forward as well as improve support services and resources for our community!

Joining takes just 3 easy steps!

Congratulations to the 2019 Hydrocephalus Association Scholarship Recipients!

The Hydrocephalus Association is pleased to announce our 2019 Scholarship Award Recipients. We would like to thank everyone who applied for a scholarship and congratulate those of you who were selected this year.

HA's scholarship program was established in 1994 to provide financial assistance to capable and promising teens, young adults and adults who live with the ongoing challenges and complexities of hydrocephalus. Since the scholarship program was established, HA has awarded 203 scholarships to 203 deserving future leaders of our community. We are proud to honor these remarkable young adults. In addition to successfully managing their hydrocephalus, these students continue to excel in the classroom, volunteer and give back to help their local communities. They

are an inspiration to us all, demonstrating that hydrocephalus does not stand in the way of pursuing one's goals.

These twelve scholarships are funded by the: Gerard Swartz Fudge Memorial Scholarship Fund, Morris L. and Rebecca Ziskind Memorial Scholarship Fund, Anthony Abbene Scholarship Fund, Justin Scot Alston Memorial Scholarship Fund, Mario J. Tocco Hydrocephalus Foundation Scholarship Fund, Baldus Family Scholarship in Memory of Gerard Swartz Fudge, Kate Finlayson Memorial Scholarship, and the Hydrocephalus Association Scholarship, which is provided by Erik and Lisa Chamberlain.

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

**To learn more about our Scholarship Program, visit: <https://www.hydroassoc.org/scholarships/>.
The cycle for the 2020 Scholarship Program opens in January.**



Anh Bui

Anh is currently in her third year of medical school at the University of Florida. As a healthcare provider she wants to reach out to children and adults diagnosed with hydrocephalus in developing countries and help them obtain treatment without cost or minimal cost.



Colin Holt

Colin is a freshman at Whitworth University where he is majoring in biochemistry, with a minor in psychology. Colin has a strong desire to help others overcome medical challenges. He plans to accomplish this by becoming a doctor, specializing in the field of oncology.



Robert Donahue

Robert is in his first semester at the University of Pittsburgh where he plans to major in bioengineering. After receiving his degree in bioengineering he hopes to continue onto graduate school to earn a Master's degree, if not a doctorate. Robert is passionate about science and its importance on society as well as the applied nature of engineering.



Matthew Jameson

Matthew recently earned a Bachelor of Arts degree in Psychology at the University of Massachusetts Dartmouth and is currently studying to receive a Master of Arts Degree in Global Inclusion and Social Development at the University of Massachusetts Boston.



Oliver Lee

Oliver is a sophomore at California Lutheran University where he is on a five-year track to obtain an undergraduate degree in Spanish, with a minor in biology. Oliver's dream is to become a paramedic and to attend medical school.



Aaron Miller

Aaron is a student at Virginia Tech and he is studying to earn a Bachelor's Degree in Mechanical Engineering. He desires to have a career where he can use his imagination and make new innovations in the future.



Nicole Ohr

Nicole is well on her way to fulfilling her dream of becoming a professional performer and artist, having already graduated with honors from Hofstra University with a Bachelor's of Arts Degree in Dance and Psychology. She is continuing her education at Hunter College's Dance Education program to receive a Master's Degree in Dance Education.



Alison Puckett

Alison is a freshman at Walton Honors College of Business at the University of Arkansas, where she is majoring in marketing, with a minor in biology. Diagnosed with hydrocephalus at the age of one, she has developed a deep personal passion to help others. Her firsthand experiences are her motivation for pursuing a degree in healthcare law and a career path in pharmaceutical or medical sales.



Alex Rodger

Alex is a freshman at the University of Florida and plays the trumpet for the University of Florida's Fightin' Gator Marching Band. After graduation, he plans to pursue a Master's or Doctorate's degree that will allow him to work in the field of sports medicine and orthopedic medicine.



Amanda Schumacher

Amanda is studying at Northwest Arkansas Community College (NWACC) where she is beginning her culinary training at Brightwater, a culinary school affiliated with NWACC. Then she will transfer to the University of Arkansas to obtain a Bachelor's Degree in Food and Culinary Science to pursue a career in product development with an emphasis on creating healthy, yet tasty, foods for individuals with restricted diets.



Caleb Wolf

Caleb is a student at Missouri Southern State University where he is studying to receive his Bachelor of Science and Nursing (BSN) degree. His dream to pursue a career path in nursing directly comes from the hardships he has faced throughout his life.



Abigail Wood

Abby is attending Central New Mexico Community College to earn a degree in Associate of Arts in Psychology and a certificate in American Sign Language. After graduation she plans to transfer to New Mexico State University to receive her Bachelor of Arts in Family and Child Science to pursue a career path as a Child Life Specialist.

Medical Experts and Patients Help Educate New Jersey Families About Hydrocephalus

On Nov. 9, the Hydrocephalus Association participated in an Education Day hosted by Hackensack Meridian Health at Jersey Shore University Medical Center in Neptune, NJ. The event, “Living with Hydrocephalus: Symptoms, Treatments & Beyond,” included presentations by doctors, clinicians and patients who are living with hydrocephalus.

Carly Weisman, who acquired hydrocephalus as a baby, shared her story of living with this condition in the morning workshop focused on pediatric hydrocephalus. She has endured 12 brain surgeries due to her hydrocephalus and volunteers with HA as our New Jersey Community Network leader and Co-Chair of our Jersey Shore WALK to End Hydrocephalus. Trish Bogucki, who was diagnosed with Normal Pressure Hydrocephalus (NPH) in 2015, spoke in the afternoon workshop focused on adult hydrocephalus and NPH. She shared her story in the hopes of helping other older Americans who may be living with debilitating symptoms, when they could actually be enjoying their retirement.

Dr. Lawrence Daniels, a neurosurgeon from Jersey Shore University Medical Center, was one of the medical experts who participated. He explained

what hydrocephalus is, common symptoms and treatment options. He was joined by colleagues who covered fetal diagnosis of hydrocephalus, outcomes for infants with infant hydrocephalus, adult forms of hydrocephalus, and the challenges of diagnosis and new treatment trends for NPH. The Hydrocephalus

Association is grateful for the opportunity to support Hackensack Meridian Jersey Shore Hospital and Dr. Daniels in this event bringing together our hydrocephalus community in New Jersey.



New Ask the Expert Video Series for Adults Living with Hydrocephalus



Are patients with hydrocephalus predisposed to having more headaches? Is it safe for women with hydrocephalus to get pregnant? If you haven't had any problems with your shunt or ETV for many years,

is it necessary to see a medical professional? These are a few of the questions we address in our new Ask the Expert Video Series for Adults Living with Hydrocephalus.

The new series features two experts from Johns Hopkins Cerebral Fluid Center: Dr. Mark Luciano, a neurosurgeon, and Abhay Moghekar, a neurologist. Together with Amanda Garzon, HA's National Director of Program Services and Communications, and Jennifer Bechard, HA's

Education Manager, they tackle some of the most common questions the Hydrocephalus Association receives to its support line and on social media.

Videos include:

Episode 1: Slit Ventricles vs. Slit Ventricle Syndrome

Episode 2: Headaches and Hydrocephalus

Episode 3: Pregnancy and Hydrocephalus, Is It Safe?

Episode 4: With No Problems Should You See a Neurosurgeon?

Episode 5: Intracranial Pressure in Hydrocephalus Patients

Episode 6: Transitioning to Adult Healthcare

To view these helpful videos, visit HA's YouTube channel: www.youtube.com/hydroassoc and click on the Ask the Expert – Adults Living with Hydrocephalus playlist.

Connect with Local Families through Our Community Network!

The Hydrocephalus Association has over 40 Community Networks across the country. Community Networks are a great way to connect with individuals and families in your local area who are impacted by hydrocephalus. They host educational events, support group meetings, and other fun gatherings. Visit HA's website to find and join your local Community Network's online private Facebook group and to stay updated on local events. Don't see one in your area? Start one! Contact info@hydroassoc.org or call (888) 598-3789 for details!

AK Anchorage	NY Western NY
AZ Phoenix	Long Island
CA Los Angeles	New York City
Ventura	OH Cleveland
CO Denver	OK Oklahoma City
CT Hartford	OR Portland
DC Washington	PA Eastern PA
DE Middletown	RI Providence <i>online only</i>
FL Central FL	SC Charleston NEW!
Miami NEW!	SD Sioux Falls
GA Atlanta	TN Chattanooga
IL Chicago	TX Dallas
IN Indianapolis	Houston <i>peds/adolescent</i>
MA Boston	UT Salt Lake City
MD Baltimore	VA Richmond
ME Portland	WA Seattle <i>pediatric</i>
MI Detroit	Eastern WA
MN Minneapolis <i>peds/adolescent</i>	Vancouver
MO St. Louis	WI La Crosse <i>online only</i>
NC Charlotte	Military Members <i>online only</i>
ND Fargo & Morehead, MN	Nigeria Lagos <i>children/families</i>
NJ Jersey Shore	Spanish-Language Network
Northern NJ <i>NPH</i>	(Red de Apoyo Para la Hidrocefalia)
	<i>online only</i>

 Search Hydrocephalus Association Community Network on Facebook to find your local online Community Network

Support the Hydrocephalus Association by Donating your Change!

Did you know that the Hydrocephalus Association is now on the RoundUp app for smartphones?

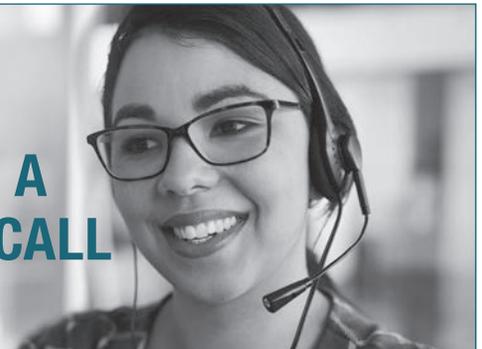
It's a cool app that lets you automatically donate the change from your credit or debit card transactions to support our work!

It's small change for you, but a game changer for us!

ROUNDUP APP



HELP IS A PHONE CALL AWAY!



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

The helpline is available via phone and email.



Call (888) 598-3789 to speak to a support staff member.



Email info@hydroassoc.org for support, resources and answers to your questions.

Caucus Briefing Educates Members of Congress About Hydrocephalus



Staffers from over 60 Congressional offices attended the briefing.

A packed room of more than 60 staff members from Congressional offices, and members of the hydrocephalus patient community, took part in the Hydrocephalus Caucus Briefing on Oct. 17th.

The briefing, hosted by the Hydrocephalus Association and the Pediatric Hydrocephalus Foundation (PHF), explored the impact hydrocephalus has on patients, caregivers, and members of the military, and how members of Congress can support families impacted by this condition. The briefing was supported by Congressmen Christopher H. Smith and Lloyd Doggett, Co-Chairs of the Congressional Pediatric and Adult Hydrocephalus Caucus.

Michael Illions, PHF Vice President, shared the story of his 14-year-old son Cole, who is living with hydrocephalus and has endured 14 brain surgeries to manage his condition. Amanda Garzon, HA's National Director of Program Services and Communications, who is also a parent to a teen living with hydrocephalus and a former Navy spouse, shared the story of

James Spence, a retired Army veteran who developed hydrocephalus after a traumatic brain injury while serving in the military.

Dr. Mark Luciano, neurosurgeon and Director of the Cerebral Fluid Center at John Hopkins Medicine, discussed the challenges and opportunities faced by researchers to find treatment alternatives and cures. He shared the story of a hydrocephalus patient who has endured over 200 brain surgeries and the impact of her repeated surgical procedures.

Diana Gray, HA's President and CEO, urged Members of Congress to support increased research funding from federal agencies, such as the National Institutes of Health, the Department of Defense, and the Patient-Centered Outcomes Research Institute. She also stressed the importance of expanding access to affordable healthcare for patients.

"Of utmost importance is the ability of our patient population to have access to affordable healthcare that will provide the care and services that our patients need to stay in good health through their entire lifespan, including individuals with pre-existing conditions. This not only impacts the quality of life for individuals with hydrocephalus, including the parents of babies born with the condition, it also helps reduce healthcare costs for our entire system," Diana said.

Congressman TJ Cox Joins Congressional Hydrocephalus Caucus



HA's Amanda Garzon had the opportunity to meet with Congressman TJ Cox at his Washington, DC office.

In November, Congressman TJ Cox (D-CA) announced that he joined the bipartisan Congressional Pediatric and Adult Hydrocephalus Caucus. The Hydrocephalus Association applauds Representative Cox's support for our community. His action reflects a

welcome commitment to working with his colleagues in Congress to find practical, bipartisan solutions for the over one million Americans living with this condition.

"We appreciate Representative Cox's leadership in joining this critical caucus. Through this action he has become a vital Congressional champion for our community. We look forward to working with him and

other members of the Caucus to identify policies and programs that will improve quality of life, identify better treatments, and possibly find a cure," said Diana Gray, President and CEO of the Hydrocephalus Association.

The Congressional Pediatric and Adult Hydrocephalus Caucus serves to inform the congressional community about the needs of those living with hydrocephalus, their families and caregivers, including funding for research from the National Institutes of Health and Department of Defense, health policy including the access to affordable healthcare, Medicare and Medicaid, special education and rehabilitation services.

"I'm proud to stand up for families like Judy Ames' from Hanford whose son, Holden, was diagnosed with hydrocephalus at only five days old," Said Rep. TJ Cox. "Current treatments for hydrocephalus tend to fail and require multiple surgeries, so increases in research will go a long way for families like Judy's. This effort will require all hands-on deck and I'm ready to work with anyone and everyone so we can make breakthroughs for people living with hydrocephalus in the Central Valley and across the nation."

HA WALKS

WALKs to End Hydrocephalus Help Raise Over \$2 Million for Key Programs

Over 15,000 individuals and families participated in a WALK to End Hydrocephalus this year, raising over \$2 million to support HA's mission!

WALKs to End Hydrocephalus were held in 44 locations across the country. The WALKs are an opportunity to meet others impacted by hydrocephalus and to raise critical funds for the Hydrocephalus Association's education, support, and research efforts. All 44 HA WALKs are 100 percent volunteer-led by dedicated members of the hydrocephalus community.

"We, for the first time in our history, have exceeded \$2 million in our WALK program. We could not do this without the wonderful members of the hydrocephalus community and the passionate volunteers who helped make each walk successful," said Diana Gray, HA President and CEO.

WALK participants are encouraged to form a team and to raise funds for their teams. This year, there were 1,290 teams participating in the WALKs. Teams varied in sizes — from two people to over 100.

THANK YOU TO OUR NATIONAL WALK SPONSOR

PERMANENTE MEDICINE
Mid-Atlantic Permanente Medical Group

THANK YOU TO OUR INDUSTRY PARTNERS



Codman **AESCULAP**
SPECIALTY SURGICAL
AN INTEGRAL LIFESCIENCES COMPANY

Together we are making a difference!



Team Alex, from the South Florida WALK to End Hydrocephalus, was among the top 10 WALK teams.



Huntington Beach was the location for the first-ever Orange County WALK to End Hydrocephalus.

TOP 5 WALK SITES (based on funds raised):

Orange County WALK to End Hydrocephalus:	\$148,341
Los Angeles WALK to End Hydrocephalus:	\$124,585
National Capital WALK to End Hydrocephalus:	\$120,166
Seattle WALK to End Hydrocephalus:	\$114,065
Long Island WALK to End Hydrocephalus:	\$101,457

TOP 10 WALK TEAMS (based on funds raised)

Team Alex (South Florida WALK)	\$44,120
Surf 4 Shea (Orange County WALK)	\$39,105
Team Rain (Los Angeles WALK)	\$34,161
UCSF Hydro Warriors (San Francisco WALK)	\$24,075
Team Spenser (South Florida WALK)	\$21,429
Charlie's Angels (Los Angeles WALK)	\$20,735
Team Jacob (National Capital WALK)	\$20,711
Hydro Cure (NYC WALK)	\$20,324
Tyler's Warriors (Long Island WALK)	\$19,825
Dr Muhonen and his CHOCalongs (Orange County WALK)	\$19,345

No WALK to End Hydrocephalus in your community? **START ONE!**
Contact Randi Corey at 240-483-4605 to discuss how you can start a WALK in your area.

Hydro Mom Organizes Successful Golf Fundraiser for HA



(From L to R) Kasey Andrew, Kathy Andrew, Spenser and her twin sister Skyler.

Over 100 golfers in the South Florida area came together on July 20th for an important cause — to raise funds for a cure for hydrocephalus. The Jacaranda Summer Series Tournament held at the Jacaranda Golf Club in Plantation, FL, raised over \$17,000 for the Hydrocephalus Association.

The tournament was organized by Kasey Andrew, who is Chief Financial Officer and Director of Membership for the Jacaranda Golf Club. She is also a passionate hydro mom, whose 3-year-old daughter Spenser was diagnosed with hydrocephalus when Kasey was 32 weeks pregnant.

“Spenser is my feisty little hydro warrior who’s been fighting since she was born due to this condition. She had four brain surgeries before she was 3 years old and fights hard to do things that come so easily to other people,” Kasey explained. “Raising awareness in the community and even among people that I know is very important to me. That’s how I fight and advocate for her.”

The event, which attracted around 170 people, included golf, other fun activities, and a variety of ways to donate to the Hydrocephalus Association. The club partnered with a local company that allowed participants to shoot their golf ball out of a canon if they donated \$20. There were also contests for long drive and closest to the pin on two separate holes. Golfers and guests also had the opportunity to meet the Florida Panthers NHL hockey team mascot.

The event’s success surprised even Kasey.

“When I started planning the tournament I was hoping to make \$5000. When I saw the final number, I was honestly in disbelief. I never could

have imagined raising that much money in the 1st year of the event and I was completely overwhelmed emotionally and so humbled by the support we received,” she said.

The tournament was also an opportunity to educate the local community about hydrocephalus and to encourage them to get involved with the Hydrocephalus Association.

THANK YOU Kasey and the Jacaranda Golf Club for putting this event together!

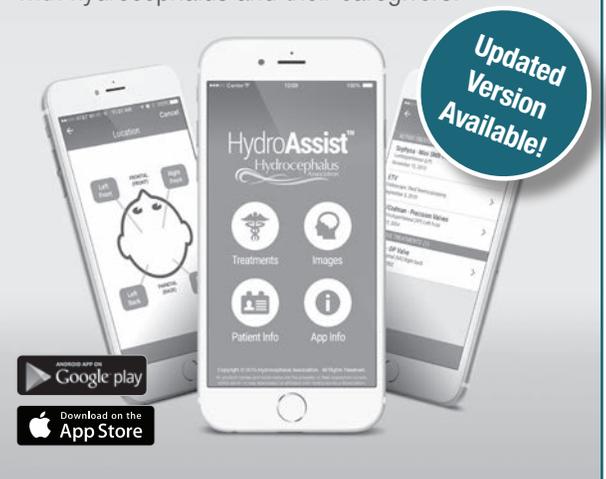
“I think sometimes people see Spenser and think nothing is wrong. They just don’t have any concept of what it means to have hydrocephalus. So I think this event allowed people who had never heard of hydrocephalus to receive some exposure as well as enlighten people who knew what it was but didn’t realize what that actually entails or how it impacts our lives and the lives of so many other people.”

— Kasey Andrew
Chief Financial Officer and Director of Membership, Jacaranda Golf Club

HydroAssist™

Updated version allows you to share your hydrocephalus treatment history with your loved ones.

HydroAssist™ is the first mobile app that allows you to record and store your hydrocephalus treatment history and access it when you need it from your mobile device or through your computer or laptop. Perfect for individuals living with hydrocephalus and their caregivers.



Why I Joined the Hydrocephalus Association's Fudge Solomon Legacy Society

By Sally Baldus



I have been involved with the Hydrocephalus Association (HA) for 30 years, most recently as a member of the Board of Directors. I have seen great growth within the organization as the Hydrocephalus Association has worked to both find a cure for hydrocephalus and improve the lives of those impacted by the condition.

I try to help where I can, both by volunteering and by providing annual financial support. But I also wanted to support HA's future efforts as well. This is why I have included the Hydrocephalus Association in my estate plan, by making the organization a beneficiary in my will.

I ask that any of you who value HA's work as I do, consider joining me and becoming a member of the Hydrocephalus Association's Fudge Solomon Legacy Society.

Contact giftplanning@hydroassoc.org for more information.

High School Student Educates Others about Hydrocephalus



In September, Mauryce Thomas, II, a 17-year-old from Mobile, AL, organized an event at USA Children's and Women's Hospital to educate

his local community about hydrocephalus. The event not only raised awareness about the condition, it also raised \$1,320 to support the Hydrocephalus Association's mission!

Mauryce was born with hydrocephalus and had a shunt placed to manage his condition when he was six months old. He's had two brain surgeries due to his hydrocephalus.

"I think it's important to raise money for hydrocephalus because nobody really knows about this condition and it's not really published widely like other conditions or diseases," Mauryce said.

The event even garnered attention from a local TV news station, NBC/WPMI 15, who came to interview Mauryce.

The presentation was attended by 30 friends, family and church members. Dr. Anthony Martino, who is Mauryce's neurosurgeon, also spoke at the meeting.

In addition to this event, Mauryce was able to get the city of Mobile to pass a proclamation naming September as Hydrocephalus Awareness Month.

Way to go, Mauryce!



4340 East West Highway, Suite 905
Bethesda, Maryland 20814-4447



LEAVE YOUR LEGACY

The Fudge Solomon Legacy Society

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

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

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

