



VOLUME  
**36**  
EDITION 2

## Join the Nation's First Hydrocephalus Patient Registry!

Help scientists prevent and cure hydrocephalus by signing up for the first ever Hydrocephalus Patient Registry!

6

### Raising Money for Critical Research

Our 2018 Vision Dinner raised \$3 million for Posthemorrhagic Hydrocephalus research!

12

### Helpful Tips for People Living with NPH

Is your balance off?  
Learn how to improve  
symptoms.

13

### Our 2018 WALK season was a success!

14,000 people  
participated in a WALK  
to End Hydrocephalus  
this year in 43 locations.

## MESSAGE FROM THE CEO



Education, Research, and Hope. If I had to give 2018 a headline, it would be that! As we near the end of 2018, it's exciting to reflect on all we've accomplished at the Hydrocephalus Association, starting with HACONNECT, our National Conference on Hydrocephalus. The 2018

conference was our biggest ever, with over 700 people participating in-person and online, and more than half of our participants were first-time attendees. I was thrilled to see people from across the country attend our event – some came from as far as Nigeria and Canada to take part in this rich learning opportunity. I got the chance to speak to many individuals and families directly impacted by hydrocephalus. The experiences they shared with me re-energized me and reminded me why events like HACONNECT are so important. Not only does the conference offer the latest research and information on a variety of relevant topics, but it also enables people to connect with others facing similar challenges and learn from each other. (Read more about HACONNECT 2018 on page 14)

2018 was also a big year for our Research Initiative, because we completed our three-year effort to raise \$3 million for research into posthemorrhagic hydrocephalus (PHH). This critical funding will go toward research into how to prevent the development of PHH and how to prevent brain damage caused by PHH. PHH remains one of the most insidious forms of hydrocephalus and will continue to be a major focus of our research going forward. Of course, none of this would have been possible without our generous benefactors, Craig and Vicki Brown, who launched HA's Vision Dinner six years ago as a way to raise funds for our Research Initiative. PHH has been a major focus of the Vision Dinner for the past three years. This year, our Vision Dinner brought together families, researchers, philanthropists, business leaders and advocates

to learn about promising research we're funding and to provide the opportunity to celebrate community members helping to make a difference. (Read more on page 6)

As you may know, we launched our Research Initiative in 2009. Since then, we've invested over \$7.8 million toward hydrocephalus research. We are proud to say that our researchers have gone on to secure over \$19 million in additional funding to continue their innovative work! (Read more about our research programs on page 4)

To help accelerate hydrocephalus research, this year we launched the first-ever hydrocephalus patient registry, also known as HAPPIER. THIS IS BIG! Thanks to HAPPIER, people living with hydrocephalus and their caregivers can share their experiences with us – both medical and social. This data will help inform the work scientists are doing and will hopefully lead to major discoveries and breakthroughs!

"I got the chance to speak to many individuals and families directly impacted by hydrocephalus. The experiences they shared with me reenergized me and reminded me why events like HACONNECT are so important."

Throughout this issue of *Pathways*, you'll see that we are hopeful for the future. We believe that one day we will find a cure for hydrocephalus and a way to prevent hydrocephalus, and we know that soon, brain surgery will not be the only treatment option for the 1 million Americans living with hydrocephalus. And that's because of YOU!

Many of you have generously donated to HA, whether it was to a WALK to End Hydrocephalus, a donation on our website, or a Facebook birthday fundraiser, and we can't thank you enough for your support! With your help, we know we can change the future of hydrocephalus!

Sincerely,

Diana Gray, MA  
Chief Executive Officer

**To learn about the various ways you can get involved with HA, visit [www.hydroassoc.org/get-involved](http://www.hydroassoc.org/get-involved).**

## BOARD UPDATES

### Brett Weitz Named New Board Chair

We're excited to announce that Brett Weitz has been named Chair of our Board of Directors. He will begin his term in January, at the completion of Aseem Chandra's term as Board Chair.



Outgoing Board Chair Aseem Chandra congratulates Brett in his new role.

Brett is the Executive Vice President of Original Programming at TBS and has been a member of the Hydrocephalus Association Board of Directors since 2016. He previously served as Vice Chair of HA's Board and was a member of the Communications and Executive Board Committees.

As Executive Vice President of Original Programming for TBS, Brett Weitz is spearheading the new direction of the network into younger and more relevant comedy, moving towards a bolder, more diverse, and millennial

voice. His prior work experience includes executive work at 20th Century Fox Television where he helped develop the popular series "Prison Break" and "Sons of Anarchy". Prior to his current position at TBS, Weitz was the Senior Vice President of Scripted Development for TNT and TBS, where he developed the dramas "The Last Ship" from Michael Bay and "Legends" from Howard Gordon, as well as the comedies "Ground Floor" from Bill Lawrence and Jeff Astrof and "Clipped" from "Will and Grace's" David Kohan and Max Mutchnick.

In 2013 his youngest daughter, Emerson Rain, was born on her due date, "healthy as a horse, and deliciously cute." Three weeks later their lives changed when they discovered that she had a brain bleed and would require brain surgery. Six months and four brain surgeries later she was on her way to recovering and could begin the joy of being a free spirited child.

Brett was instrumental in the creation of the #NOMOREBS campaign and secured celebrity Max Greenfield (The Neighborhood on CBS) for our PSA. He also helped organize a comedy show, "In Stitches," featuring Tracy Morgan and friends, to raise funds for hydrocephalus research and programs. Brett and his family take part in the Los Angeles WALK to End Hydrocephalus each year, and have had the highest grossing WALK team in the country for at least three years.

### Farewell and Thank You

Join us in thanking these three outgoing board members who have been major assets for the Hydrocephalus Association.



**Craig Brown**

Craig Brown has served as a member of HA's Board of Directors since 2009. He, along with his wife Vicki, have been HA's biggest benefactors, devoting a substantial amount of time and expertise to raise critical funding for the Hydrocephalus Association's research and awareness initiatives.



**Dr. Marion "Jack" Walker**

Dr. Walker has served as a member of HA's Board of Directors since 2008 and on the Medical Advisory Board, where he is completing his chairmanship. He played an integral role in the design and development of HA's Research Initiative, and helped facilitate the first National Institutes of Health sponsored workshop on hydrocephalus. Beloved by the patient community, Dr. Walker is known for his compassionate support of our patients, and most publicly known as the chair and co-chair of our biennial National Conference on Hydrocephalus.



**Mike Schwab**

Mike Schwab has served as a member of HA's Board of Directors since 2009 and has supported efforts to grow HA's budget. He and his wife Tara hosted fundraising events for HA and helped raised awareness and funds for the Portland WALK to End Hydrocephalus. He also played a major role in HA's Scholarship Committee, dedicating a significant amount of time to reviewing and ranking over 100 applications annually from young people across the country.



### HA-Funded Researcher Awarded \$1.8M NIH Grant



Kristopher Kahle, MD, PhD, one of the many researchers HA has funded, was recently awarded a National Institutes of Health (NIH) grant worth \$1.8 million over five years. This funding will allow Dr. Kahle and his research team to dig deeper into new theories on why posthemorrhagic and post-

infectious hydrocephalus develop and test drugs to prevent or minimize hydrocephalus after a brain bleed or infection.

In 2017, with HA support, Dr. Kahle and medical student Jason Karimy published a seminal paper on cerebrospinal fluid (CSF) production after a brain bleed. Using an animal model, this paper showed that the choroid plexus produced too much CSF in the days after a brain bleed – three times more than normal! When they stopped this overproduction of CSF, the animals did not develop hydrocephalus. They believe this same overproduction of CSF is happening after a brain infection, causing post-infectious hydrocephalus.

The NIH funding will allow Dr. Kahle and his team to understand exactly why the CSF is being overproduced and if the reasons are the same in posthemorrhagic and post-infectious hydrocephalus. They will then test drugs that target the molecular pathways involved to stop the CSF overproduction and development of hydrocephalus.

What is even more exciting is that the lab is testing drugs already approved for other conditions by the Food and Drug Administration (FDA). If successful, it is possible to get these drugs to the clinic and into patients faster than drugs that are not already FDA approved.

Dr. Kahle, Assistant Professor of Neurosurgery and Pediatrics at Yale School of Medicine, and Director of Neonatal and Congenital Anomaly Neurosurgery in the Division of Pediatric Neurosurgery, received HA's Innovator Award for Posthemorrhagic Hydrocephalus (PHH) in 2016 and our Innovator Award for Post-infectious Hydrocephalus (PIH) in 2017.

### NIH Awards Prestigious \$8.1M Grant to Dr. Steven Schiff That Could Reduce Incidence of Hydrocephalus Worldwide



Congratulations to Penn State researcher Steven Schiff, MD, PhD, for receiving an \$8.1 million NIH Transformative Research Award. This is the second largest NIH grant ever awarded related to hydrocephalus and demonstrates that hydrocephalus is gaining major attention within the research community.

His research will focus on predicting infectious disease outbreaks in the developing world and allowing real-time preventive treatment at the point of care, instead of relying on standard diagnostic approaches. The goal is to reduce the incidence of post-infectious hydrocephalus, the leading cause of hydrocephalus in developing countries. Dr. Schiff is a member of the Hydrocephalus Association Network for Discovery Science (HANDS).



### Calling all Hydrocephalus Researchers!

Join the HA Network for Discovery Science (HANDS) to connect with other researchers, gain access to our databases and CSF Biobank, and apply for HA Grants!

Visit [www.hands.hydroassoc.org](http://www.hands.hydroassoc.org)

# HA Launches Nation's First Hydrocephalus Patient Registry

The Hydrocephalus Association is excited to announce the launch of the HA Patient Powered Interactive Engagement Registry, also known as HAPPIER. HAPPIER is the first-ever hydrocephalus patient registry and will help accelerate hydrocephalus research!

The Patient Registry is an online database created for our community to share your experience living with hydrocephalus. By sharing your experience, you're giving researchers access to important data that can lead to discoveries in underlying causes of the condition, intervention strategies for preventing the condition, improvements in diagnosis, and/or alternative treatments. You're also informing the work of the Hydrocephalus Association in developing programs and resources to support you with living daily with hydrocephalus. Discoveries in any of these areas ultimately leads to improved outcomes for patients. It's important to note that your personal identifying information is not shared with researchers.

Your experiences matter! So, 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.

Together, we will move hydrocephalus research forward as well as improve support services and resources for our community.

**Join the Patient Registry by visiting**  
**[www.hydroassoc.org/happier](http://www.hydroassoc.org/happier)**

"Information about the prevalence and incidence of hydrocephalus does not exist at either the regional or national level. We have only guesstimates. Support is needed for research initiatives that aim to better understand the distribution and determinants of this condition and to develop new therapies and other interventions."

— Dr. Abhay Moghekar

Research Director of the Cerebral Fluid Center,  
Department of Neurology, Johns Hopkins Medicine  
Member, Hydrocephalus Association Medical Advisory Board  
Investigator, Adult Hydrocephalus Clinical Research Center

## 3 Steps to Completing the Patient Registry:

- 1 Create Your HA User Profile.
- 2 View & Accept the Registry Consent Letter.
- 3 Complete the First HAPPIER Survey!

After you've completed the Registry, don't forget to stay engaged through your HA Dashboard.

## Your data will be used by researchers in three ways:

- 1 To help HA better understand the condition and improve our research, advocacy, support and education efforts.
- 2 To provide researchers with data to conduct research projects.
- 3 To identify patients who are eligible to participate in future clinical trials.



## Find a Doctor Who Understands Using HA's Physicians Directory!

The Hydrocephalus Association Physicians Directory is an interactive online tool that helps you find the specialists you need to manage your hydrocephalus. The directory includes neurosurgeons, neurologists, and neuropsychologists for all ages.

**Search by location, specialty and age range!**

**[www.hydroassoc.org/physicians-directory](http://www.hydroassoc.org/physicians-directory)**

# \$3 Million Raised for Posthemorrhagic Hydrocephalus Research!



Thanks to Craig and Vicki Brown, the Vision Dinner helped raise critical funding for hydrocephalus research.

The 6th annual Vision Dinner was held on Friday, November 2, 2018, at the Mandarin Oriental in New York City. Generously underwritten by Craig and Vicki Brown, benefactors of the Hydrocephalus Association, the evening seeks to raise national attention about hydrocephalus and raise funds to advance hydrocephalus research.

Chart a course for the future, it has. Since the first Vision Dinner in 2013, the initiative has played a critical role in growing investments into the Hydrocephalus Association's Research program. This year's Vision Dinner served as a celebration of the successful completion of

"Vicki and I launched the Vision Dinner initiative in 2013 to raise awareness of hydrocephalus and its impact on patients and families while we work to improve treatments and ultimately find a cure to end the suffering caused by the condition. The Vision Dinners represent a campaign designed to bring together the hydrocephalus community to share information, spotlight progress and chart a course for the future," shared Craig Brown in his welcoming remarks.



Drs. June Goto, her husband Mark Andermann, and Maria Lehtinen were among the scientists who showcased their innovative hydrocephalus research.

a 3-year campaign launched at the 2016 Vision Dinner to raise \$3 million to support a focused research initiative into Posthemorrhagic Hydrocephalus (PHH), the development of hydrocephalus after a brain bleed. PHH is the leading cause of hydrocephalus in children, but investments into preventing the development of hydrocephalus after a brain bleed benefit individuals of all ages who acquire hydrocephalus from a traumatic brain injury.



Actress Phylicia Rashad attended the Vision Dinner in support of her brother Hugh Allen (pictured L) and nephew Andrew (pictured R).

The evening honored three individuals for their impact on and service to the hydrocephalus community. Annie Mason received the 2018 Vicki Brown Volunteer of the Year Award for her one-on-one support to hydrocephalus families in her hometown of Richmond, Virginia, and as a peer support volunteer to individuals across the country. Dr. Jill Morris, Program Director, Division of Neuroscience, National Institute of Neurological Disorders and Stroke, National Institutes of Health, received the Hydrocephalus Association's 2018 Award for Service for championing hydrocephalus research at the NIH. We also honored Dr. Jerold Chun, Sanford Burnham Prebys Medical Discovery Institute, with our 2018 Award for Leadership. Dr. Chun, who previously received a seed grant from the Hydrocephalus Association, is conducting innovative research testing drugs that target a molecular pathway involved in the development of PHH.

The Hydrocephalus Association would like to thank the Brown's for their unwavering commitment to creating a better future for those living with hydrocephalus, and to our Partners in Research for their steadfast support of our vision. We look forward to continuing to celebrate the accomplishments of the hydrocephalus research community at next year's, and future, Vision Dinners.

**To view more pictures from the 2018 Vision Dinner, visit [www.hydroassoc.org/3-million-raised-for-posthemorrhagic-hydrocephalus](http://www.hydroassoc.org/3-million-raised-for-posthemorrhagic-hydrocephalus).**



# Announcing the 2018 Discovery Science Award Grantees

Dr. Maria Lehtinen, Boston Children's Hospital; Dr. David Limbrick, Washington University in St. Louis; and Dr. Yun Yung, Scintillon Institute; have been named recipients of the Hydrocephalus Association 2018 Discovery Science Awards. The award allows these scientists to expand their research on posthemorrhagic hydrocephalus (PHH).

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**Dr. Maria Lehtinen**

Boston Children's Hospital

Dr. Lehtinen's research will determine how blood changes the makeup of cerebrospinal fluid (CSF) after a brain bleed and how these changes affect brain development. Her work will also test how drugs currently given to preterm infants change the choroid plexus' response to blood and if these changes lead to better brain development.



**Dr. David Limbrick**

Washington University  
in St. Louis

Dr. Limbrick, a principal investigator for the HA-funded Hydrocephalus Clinical Research Network, will explore how blood damages the cells that line the ventricles and test if a specific drug can stop this damage and prevent hydrocephalus. In 2017, Dr. Limbrick received HA's Innovator Award for Posthemorrhagic Hydrocephalus.



**Dr. Yun Yung**

Scintillon Institute

Dr. Yung will investigate how lipids (fats) present in blood interact with other factors in blood, such as iron, to cause hydrocephalus after a brain bleed. The study will also focus on getting drugs into the brain through non-invasive techniques. In 2011, Dr. Yung received HA's Mentored Young Investigator Award.

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HA's Discovery Science Awards provide sustained support for high quality, innovative, and timely research projects. The goals are to expand the scope of promising research studies, increase a lab's focus on hydrocephalus, and involve junior investigators in conducting the research through a substantial multi-year commitment.

Each awardee will receive \$300,000 over a three year period. These projects were supported through HA's PHH Campaign and with funding from Team Hydro.

# New Paper on Transitioning to Adult Care Published in Journal of Neurosurgery



A new paper summarizing the findings from the Hydrocephalus Association's first-ever Transition Summit was published in the prestigious Journal of Neurosurgery (JNS). This marks the first time a major paper was published in an academic journal comprehensively highlighting the challenges faced

by teens and young adults with hydrocephalus when transitioning from pediatric to adult care. Being published in JNS, the world's leading journal in neurosurgery, is a big win for the hydrocephalus community and will go a long way towards educating medical providers about this important issue. The JNS reaches both pediatric and adult providers, all of whom will have crucial roles to play in improving transition.

HA's Transition Summit, held in 2017, brought together adult and pediatric neurosurgeons, neurologists, pediatricians and other medical professionals, health system administrators, patients, and parents to discuss solutions to improve transitional and longitudinal care for adolescents and young adults with hydrocephalus. The Summit produced a set of consensus recommendations for improving care, which are

outlined in the Transition Initiative Action Plan. The Action Plan includes recommendations for hospitals, health systems, practices, professional societies, and HA itself. Recommendations aim to improve processes and infrastructure for transition and adult care; to improve training in both transition services and the medical and surgical management of hydrocephalus; to disseminate helpful information to patients and families; and to promote research that would demonstrate the effectiveness of systematic transition planning and longitudinal care. The JNS paper will help disseminate relevant recommendations to neurosurgeons and neurologists, hospitals, health systems, and medical societies, so as to ensure that our young adult patient population receives the longitudinal care they need to lead healthy and supported lives.

**The paper, "Improving Health Care Transition and Longitudinal Care for Adolescents and Young Adults with Hydrocephalus: Report from the Hydrocephalus Association Transition Summit," is available at [www.thejns.org](http://www.thejns.org).**

## Connect with Local Families through Our Community Network!

Did you know that the Hydrocephalus Association has 41 Community Networks in locations across the country? Community Networks allow you to connect with individuals and families in your area who are impacted by hydrocephalus. They host educational events, support group meetings and other gatherings. Visit our website to join your Community Network's online private Facebook group. Don't see a Community Network in your area? Start one! Email [support@hydroassoc.org](mailto:support@hydroassoc.org) or call (888) 598-3789 to launch one near you.

**AK** Anchorage  
**AZ** Phoenix  
**CA** Orange County NPH **NEW!**  
 Los Angeles  
 Ventura  
**CO** Loveland  
**CT** Hartford online only  
**DC** Washington  
**DE** Middletown  
**FL** Central  
**GA** Atlanta

**IL** Metropolis **NEW!**  
 Chicago  
**IN** Indianapolis  
**MA** Boston  
**MD** Baltimore  
**ME** Portland  
**MI** Detroit  
**MN** Minneapolis peds/adolescent  
 Moorhead  
**MO** St. Louis  
**NC** Charlotte

**ND** Fargo  
**NJ** Northern NPH **NEW!**  
 Jersey Shore  
**NY** Western  
 Long Island  
 New York City  
**OH** Cleveland  
**OK** Oklahoma City  
**PA** Eastern  
**RI** Providence online only  
**TN** Chattanooga

**TX** Dallas  
 Houston peds/adolescent  
**UT** Salt Lake City  
**VA** Richmond  
**WA** Seattle pediatric  
 Eastern WA  
**WI** La Crosse online only  
 Military Members online only **NEW!**  
**NI** Lagos children/families



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



# Raising Our Voice During Hydrocephalus Awareness Month

Throughout the month of September, social media sites were flooded with messages, pictures, and videos in recognition of Hydrocephalus Awareness Month (HAM). That, combined with HAM proclamations issued by 25 cities and states, made 2018 one of our most successful years for raising awareness about hydrocephalus.



Jessica Caulder, a longtime HA volunteer, worked with her local mayor's office to get a Hydrocephalus Awareness Month proclamation passed in Columbia, S.C.

Arizona; Arkansas; Colorado; Loveland, CO; Fort Collins, CO; Connecticut; Indiana; Indianapolis, IN; Iowa; Kansas; Louisiana; Massachusetts; Missouri; New Jersey; New York; North Carolina; Pennsylvania; South Carolina; Columbia, SC; Tennessee; Chattanooga, TN; Utah; Virginia; Washington; and West Virginia issued HAM proclamations.

Local volunteers around the country worked with their local elected representatives to make the Hydrocephalus Awareness Month proclamations a reality. At the national level, the unwavering support of U.S. Congressman Leonard Lance (R-NJ) and U.S. Congressman Andre Carson (D-IN), Co-Chairs of the Congressional Pediatric and Adult Hydrocephalus Caucus, have allowed the hydrocephalus community to advocate for substantive changes for patients, opening doors to new research opportunities that could result in alternative treatment options, forms of prevention, and a cure.

To encourage the hydrocephalus community to join our awareness efforts on social media, the Hydrocephalus Association launched a #HAM2018 Social Media Challenge. More than 45 people posted videos on social media about their hydrocephalus-related brain surgeries, calling for #NOMOREBS (No More Brain Surgeries) and more treatment options for the 1 million Americans living with hydrocephalus. Others shared their hydrocephalus stories via pictures and social media messages, and hundreds changed their profile images on Facebook and Twitter to Hydrocephalus Awareness Month frames. Of those who posted #NOMOREBS videos, three were selected at random to win #NOMOREBS merchandise.

## Drink Cider and Support Hydrocephalus!

If you like cider and want to support hydrocephalus research, support and education, buy Locust Cider! The company donates a portion of their proceeds to the Hydrocephalus Association!



### Woodinville Cidery and Taproom

19151 144th Avenue NE, Unit B/C  
Woodinville, WA 98072  
(206) 494-5968

### Ballard Taproom New!

5309 22nd Ave NW, Suite D  
Seattle, WA 98107  
(206) 494-5968

### Tacoma Taproom

2805 6th Ave  
Tacoma, WA 98406  
(206) 494-5968

### Ft. Worth Cidery and Taproom

710 S. Main  
Ft. Worth, TX 7610  
(817) 344-7035



Can't visit a taproom? Consider a club membership for doorstep delivery of their various ciders! A portion of the proceeds from each sale, as well as \$25 from each club membership, goes directly to the Hydrocephalus Association.

**Visit [www.locustcider.com](http://www.locustcider.com) to learn more.**

"It was exciting to see so many people help educate the public about hydrocephalus on social media. The videos people posted and stories they shared touched us all and helped amplify our collective voice. Thanks to these efforts, hopefully more people understand what hydrocephalus is and why we need to invest in research into new treatment options and ultimately a cure for hydrocephalus," said Amanda Garzon, HA's National Director of Program Services and Communications.

In addition, HA volunteers across the country held Hydrocephalus Awareness Month activities in their communities – everything from turning monuments and neighborhoods blue to commemorate HAM to holding HA WALKs to End Hydrocephalus.

## Camp Head Strong: A Sleep Away Camp for Kids with Hydrocephalus!

Do you have a teen or preteen living with hydrocephalus? Consider signing them up for Camp Head Strong, where they can meet other young people living with hydrocephalus and learn new skills in a fun and supportive environment.

Camp Head Strong, developed by Brainy Camps in conjunction with the Hydrocephalus Association and Children's National, offers children and teens with hydrocephalus (ages 10-17) five days and three nights of summer fun, education, and social connections. Children learn from peers and adult volunteers who live effectively with the same health conditions and are offered hope for the future. In addition to fun, the goal of Camp Head Strong is to reduce the social isolation often associated with this condition and increase each camper's knowledge and understanding of hydrocephalus.

Medical staff, including physicians, nurses, social workers, a physical therapist and psychologist, are on-site 24 hours a day and counselors are trained to deal with issues related to hydrocephalus.

"In August 2018, I was as a counselor at Camp Head Strong. From my perspective as a camp counselor, I could tell that the kids all formed great friendships. The kids were always having fun – even the ones who were shy at first. By end of the week, it was as if the campers had known each other for years," said David Walters, a Camp Head Strong counselor.

The 2019 Camp Head Strong will take place July 7-11. To learn more, visit [www.brainycamps.com/camps/hydrocephalus.html](http://www.brainycamps.com/camps/hydrocephalus.html) or contact Brainy Camps at [njosey@childrensnational.org](mailto:njosey@childrensnational.org).

## HA in Attendance

*HA represents the hydrocephalus patient community at key professional meetings, keeping our agenda on the table. Between April and December 2018, we participated in the following meetings:*

### Hydrocephalus Clinical Research Network

April 17, 2018, Bethesda, MD

### NIH Hydrocephalus Workshop

April 18-19, 2017, Bethesda, MD

### Adult Hydrocephalus Clinical Research Network

May 4-5, 2018, Seattle, WA

### National Health Council

October 15-16, 2018, Washington, DC

### Hydrocephalus Society

October 19-22, 2018, Bologna, Italy

### AANS/CNS Section on Pediatric Neurological Surgery

December 6-8, 2018, Nashville, TN

## HydroAssist™

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.



# HA Awards Scholarships to 11 Remarkable Young People



This year, the Hydrocephalus Association awarded scholarships to 11 remarkable young people living with hydrocephalus.

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 191 scholarships to 191 deserving future leaders of our community.

"I want to change the lives of children who have had to endure numerous surgeries like I have, and I want the future generations of children with hydrocephalus to grow up healthy," said **Kaitlyn O'Bryne**, one of the scholarship recipients. Kaitlyn is a biology major at the University of Florida and volunteers as a swim instructor for Special Olympics Maryland.

Kaitlyn was diagnosed with hydrocephalus at six months of age and has endured numerous shunt revisions. Following a surgery in her sophomore year of high school, she enrolled in an independent study class to further learn about anti-siphon valves. This led to writing a research paper on the technology and influenced her decision to pursue medical school and become a doctor.



Another scholarship recipient, **Ellie Chaffin**, hopes to further her education to help children with medical conditions learn to cope with the challenges they face. She has been accepted to the Central Washington University, the University of Montana and Carroll College. Although she has not determined which school she will attend, Ellie plans to obtain a major in psychology, early childhood

education, or child life. Ellie's dream is to become a Certified Child Life Specialist, but she isn't stopping there.

"I will volunteer at hospitals in underprivileged areas of the world and show the staff how helping children understand what is happening to

them and teaching them coping skills actually makes treatment easier for medical professionals and children," Ellie said.

"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," said Diana Grey, HA's President and CEO.

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

**Thank you to our funders for their generosity and the Scholarship Committee for all their support and dedication!**

Other recipients include:



**Delia Fleming**



**Emily Braden**



**Nicholas Jenkins**



**Kaylie Yuill**



**Lauren Eng**



**Maggie Newman**



**Molly McEnroe**



**Nicholas Griffin**



**Sarah Nohr**

**To read more about our scholarship winners, visit [www.hydroassoc.org/scholarships/](http://www.hydroassoc.org/scholarships/) and click on Scholarship Recipients.**



## View our Webinar Recordings

Have you missed our latest webinars? Our interactive, free webinars are designed to educate our community on a variety of topics and are led by medical professionals or experts in their respective fields. Our most recent webinars include:

**Planning for the Road Ahead Part 1: Legal Planning, part of our Living with NPH Series, Dec. 13**

**Drug Development for the Management of Hydrocephalus, Nov. 14**

All webinars are recorded and available on our website. Watch, listen and learn from the comfort of your home by visiting our Webinars page under Knowledge on our website: [www.hydroassoc.org/webinars](http://www.hydroassoc.org/webinars).

## Donate to HA Through the 2018 Combined Federal Campaign (CFC)



Do you work for the federal government? Serve in the military? A lasting gift this holiday season can be made through your workplace! Designate the Hydrocephalus Association with code #10066 through the CFC Campaign, the

federal government's workplace giving program, and help us change the future of hydrocephalus!

## CAN A DRUG CURE HYDROCEPHALUS?

Hopefully, with your help, we will soon be able to say YES!

Every year, about 36,000 children and adults—one every 15 minutes—undergo brain surgery to treat hydrocephalus. But shunts are not a cure and they often fail. We need a better way. That's why, since 2009 the Hydrocephalus Association has invested nearly \$8 million in innovative science that is leading to breakthroughs large and small, including seven funded scientists who are testing drug therapies as alternative treatments to brain surgery for hydrocephalus! Please support this vital work! Donate to the Hydrocephalus Association's Research Initiative and help us find a cure and expand treatment options for the 1 million Americans living with hydrocephalus.

**Join us on the Roadmap to a Cure!**  
Visit [support.hydroassoc.org/findacure](http://support.hydroassoc.org/findacure)

## Our Advocacy Efforts on Capitol Hill Worked!



We did it! On September 28th, President Trump signed a major budget bill that protects and increases funding for several crucial hydrocephalus-related research programs. This bill included \$761 million for the Congressionally Directed Medical Research Programs (CDMRP) at the Department of Defense, as well as nearly \$39.1 billion for the National Institutes of Health (NIH), a 5.4 percent increase from the last fiscal year. It includes funding for critical research programs, including:

- The National Neurological Conditions Surveillance System: \$5 million
- National Institute for Neurological Disorders and Stroke (NINDS): \$57.5 million
- Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative: \$57.5 million

**Thanks to the many hydrocephalus patients, caregivers and medical personnel who helped make this happen!**

# Balance Therapy Tips for NPH Patients

By Trish Bogucki, Peer Support Volunteer and Chair of HA's New Jersey NPH Community Network



A few months ago, I noticed that my balance was deteriorating so I mentioned it to my GP at my annual physical. He immediately ordered a CT scan and more Physical Therapy. The CT scan showed nothing was amiss with my shunt but the new round of PT made a big improvement in my life. Below are some tips I'd like to share from this part of my NPH journey:

## Speak Up and Seek Help

One of the classic symptoms of NPH is a loss of balance. That was very much the case with me three years ago, and though my balance improved after shunt surgery and my initial round of Physical Therapy, it was never really strong again. And it was not what I needed it to be to pursue one of my new hobbies – line dancing -which challenges both my memory and balance. Line dancing involves a lot of turns, and I just couldn't manage them. I also noticed occasional loss of balance while taking a walk or doing routine chores around the house – especially anything that changed the level of my head or line of sight. I mentioned all of this at my annual physical, and my GP prescribed more Physical Therapy and gave me a list of recommended therapy centers.

## Be as Detailed as Possible in Describing Your Problems

When I was evaluated at the new PT place I stressed how much I wanted to focus on balance and not spend time on general strength exercises that I could do at the gym. I was fortunate to find a very creative and accommodating physical therapist – Katie Finn of Excel Physical Therapy in Mahwah, NJ. Katie asked me to give her as much detail as I could describing the circumstances where I had balance problems. I was happy to spend some time coming up with a list of those, and I also included some of the therapies that helped in the past. Based on this information Katie designed a program of balance exercises that worked on my problem areas.

## Try Lots of Things

Some of the exercises were relatively easy and comfortable – e.g. chin tucks while seated on an inflated ball – and some were very challenging

– e.g. standing in tandem position on a foam pad with my eyes shut. A few didn't seem to help much, so after some tries they were replaced. I always greeted Katie's announcement that she had something new for me with a mixture of joy and trepidation. New moves frequently were difficult, but we both noticed that my brain seemed to adapt – most of the hardest exercises got easier after just a few sessions (but that tandem stand with eyes shut still needs more work.

## Up the Ante

One exercise that seemed like a keeper was a little too easy – standing toe taps on a cone – so we thought of a way to make it tougher – doing the taps while moving in a circle around the cone, changing direction once in a while. Another favorite exercise that I had learned at my earlier therapy was what I irreverently called Old Lady Dodge Ball – I jogged around cones while an aide tossed a ball at me. Katie upped the ante on this one by having two people throwing a ball from different positions and angles as I jogged around the cones. We dubbed this one Double Dodge Ball. We even tried Triple Dodge Ball a few times but it was too much for my always-weak catching skills.

## Prepare for PT to End

After a month of appointments three times a week I started seeing significant improvement in all the problem situations I had identified but thought I needed a bit more work. Katie and my doctor agreed, so my PT was extended for another month during which the improvements continued and became the norm. I agreed that we could stop after the second month but wanted a list of the exercises so I could continue the work at home and at the gym. I had been doing a few at home for in between sessions, but now I am doing 20-30 minutes of balance exercises 5 times a week. And my goal of being able to do all the turns at line dancing has been achieved. I feel like I am finally back to normal and it feels great!

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Have you joined us on **Social Media?**



# HACONNECT Offers Hope and Connections to Patients and Families

Learn, connect, and repeat. That's what 700 people did at HACONNECT, the Hydrocephalus Association's 15th National Conference on Hydrocephalus, held in June in Orange County, CA. HA's biennial conference offered helpful tools and personal connections to address the medical, educational and social challenges of living with hydrocephalus. People came from as far as Nigeria and Canada to take part in this rich learning opportunity – and some watched our live streamed sessions from the comfort of their own home!

HACONNECT featured more than 70 sessions with some of the nation's leading experts in neuroscience, dementia, mental health, and brain disorders. In addition to networking and supporting each other, participants spent three days attending sessions on a variety of topics – everything from learning challenges posed by hydrocephalus and transition planning to shunt systems and nutrition and lifestyle techniques. They also heard scientists discuss current research efforts focused on preventing the development of hydrocephalus and identifying alternative treatment options.

Actress, producer, and recording artist Becky Baeling Lythgoe, energized the crowd during her keynote address, offering words of encouragement and singing “This Is Me” from The Greatest Showman soundtrack. “It

“Our family has attended almost every HA Conference over the last two decades. We started coming when our son David, who has hydrocephalus, was two years old! At every Conference we've found there is useful information to learn, both because there is new science and because our family is at a different stage in life. And every time we feel the support of the community and how great it is to know we are not alone on this journey.”

— Tessa Van der Willigen

“What a blessing! There was so much we didn't know! We met others walking similar, yet different roads and made invaluable, life-long friendships, which we will treasure always. We have honestly learned something new and have developed new friendships at every Hydrocephalus Association conference.”

— Marnie Wood



**HACONNECT**<sup>20</sup>  
NATIONAL CONFERENCE ON HYDROCEPHALUS

**SAVE THE DATE**

for the 16th National Conference on Hydrocephalus  
which will take place in Houston, TX

**June 25-27, 2020**



[hydrocephalus] doesn't define us. It's something we should be proud of. We are warriors for what we've been through," said Lythgoe, whose son was born with hydrocephalus. "Through community, we can have courage to face any fears."

Another memorable moment for attendees was during the conference welcome when we did a live count of the total number of brain surgeries people in the room had endured. 1,056 total brain surgeries! The point was to highlight HA's NOMOREBS (No More Brain Surgeries) campaign, explained Diana Gray, HA's President and CEO. "The campaign is about building hope. It speaks to our desire to minimize the number of brain surgeries our community must endure," she said.

The event also included Healthcare Professional Day, a one-day symposium geared toward medical professionals.

Recordings of the 19 live stream sessions from HACONNECT 2018 are available to all paid registrants! People who did not register for HACONNECT can also access the live streamed sessions for a small fee. Visit [www.hydroassoc.org/watch-recorded-sessions-from-ha-connect-2018](http://www.hydroassoc.org/watch-recorded-sessions-from-ha-connect-2018) for details.



"I hoped HA's conference would be an educational experience and it was, but it was also much more! HA led the charge, but everyone at the conference seemed very supportive of our community. It felt great to be with 600 other people whose lives have been forever changed by hydrocephalus and to feel the fellowship. I enjoyed hearing the many scientists and researchers, like Carolyn Harris who is looking for what causes shunt obstructions and gave very honest answers to our questions, and Yale's Kris Kahle who is looking for genetic clues to who gets hydrocephalus and who has recently expanded his research to include NPH patients. "

— Trish Bogucki



## WALKs to End Hydrocephalus Help Raise Nearly \$2 Million

The 2018 WALK to End Hydrocephalus season is in the books! And what a year it was. Thanks to HA's wonderful volunteers, 43 WALKS were held across the U.S., with more than 14,000 participants representing over 1,200 teams. The WALKs are projected to raise nearly \$2 million for HA's research, education and support programs!

### Some of the WALK sites that posted increases in funds raised include:

**Atlanta** – Ashley Magg, Larissa Olivieri, Karla Webber (Co-Chairs) – raised \$32,600 – a 157% increase over prior year

**Baltimore** – David Brucker, Sara Curran-Kellogg, Dave Kellogg (Co-Chairs) with Jodi Heston and Gina Moorhead (committee members) raising \$50,000 – a 32% increase over prior year

**Cincinnati** – Molly Kirstein, Eric Blom (Co-Chairs) – post a \$58,000 total – a 66% increase over prior year

**Dallas/Fort Worth** – Megan Redfearn Williams, Ryan Williams (Co-Chairs) – raised \$45,000 – a 19% increase over prior year

**Northwest Arkansas** – Kipp Coco, Jana Crouch (Co-Chairs) – \$32,000 – a 42% increase over prior year

**Twin Cities** – Michelle Egertson, Ashley Helberg, Tonja Niema, Dylan Johnson (Co-Chairs) \$59,200 – a 32% increase over prior year (Note: at the time of this writing all WALKS sites have not been held or post-event data entry completed – so there may be more sites with amazing results!)

### Our Newest Six Figure WALK Site

Now in its fifteenth year, the Denver WALK is expected to join the very exclusive list of WALK sites raising over \$100,000! Special thanks and congratulations to Phyllis Rogers and Tiffany Meguire (Denver's new Co-Chair!).



Once again, the L.A. Kings helped make the Los Angeles WALK to End Hydrocephalus the highest-grossing WALK.

### Congrats to Our Newest WALK Site!

HA's newest WALK site, Des Moines, IA (Dhuha Tawil, Jacy Cowan and Katalina Kutsch – Co-Chairs) broke all records for new HA WALKS in markets of that size – with over 340 registered participants, raising more than \$33,000! Congratulations to Iowa for this incredible inaugural WALK!

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



Families in Cincinnati WALK to find a cure for hydrocephalus.



AVA's Army from Denver was one of 1,200 teams that took part in a WALK to End Hydrocephalus, raising critical funds for hydrocephalus research, support and education programs.

## VOLUNTEERS MAKING AN IMPACT

### NYC Dad Builds Race Car to Help Find a Cure for Son's Hydrocephalus

"Your son has a life-threatening condition and is going to need emergency brain surgery to manage it." Those words will be forever etched into Bennett Wilson's memory. It was the moment he was told his six-month-old son Dean had hydrocephalus, an incurable neurological condition that can only be treated with brain surgery. After learning that Dean would need multiple brain surgeries to manage his condition, Bennett decided to turn his son's love of race cars into a hydrocephalus fundraising endeavor. So, with the help of his friends, the New York-based dad converted his family's minivan into an endurance race car dubbed "Dean the Machine". The car will take part in endurance races around the country to raise awareness and funds for the Hydrocephalus Association. So far, "Dean the Machine" has participated in two 24 Hours of LeMons races in Connecticut and New Hampshire.



"We wanted to do everything we could to help not just Dean, but others who are battling this condition every day, and after meeting the folks at the Hydrocephalus Association, we knew we had found a group where we could make an impact. So we figured a unique way to raise awareness was to build a race car, plaster the Hydrocephalus Association logo all over it, and take it around race tracks as fast as we could for incredibly long periods of time," Bennett says. "Each race, we are going to look to individuals and companies to sponsor us per lap, with 100 percent of those donations going directly to the Hydrocephalus Association!"

The race car, branded with Hydrocephalus Association and #NOMOREBS logos, is also helping to bring attention to the limited treatment options available to the 1 million Americans living with hydrocephalus through the #NOMOREBS – No More Brain Surgeries – campaign.

**To make a donation to HA in honor of "Dean the Machine" race car, visit [www.hydrocephalusracingteam.com](http://www.hydrocephalusracingteam.com).**

## BE A PART OF OUR **#NOMOREBS** CAMPAIGN

So many of you have asked to be a part of our **#NOMOREBS (No More Brain Surgeries) multimedia campaign.**

### NOW IS YOUR CHANCE!

We want to celebrate everyone - all of us - that make up our hydrocephalus community. Let's show the world who we are and why we deserve a world where brain surgery is not our only treatment option.

Send us a **1** pic of yourself or your loved one, **2** the person's name and **3** the number of brain surgeries you or they have endured. **4** Email it to [natalia@hydroassoc.org](mailto:natalia@hydroassoc.org).

**THE ONLY TREATMENT FOR  
HYDROCEPHALUS IS  
BRAIN SURGERY.**

**#NOMOREBS**



**OLIVIA. 21 YEARS OLD. 140 BRAIN SURGERIES.**

[NOMOREBRAINSURGERIES.ORG](http://NOMOREBRAINSURGERIES.ORG)

**Help us make 2019 another great year  
for our #NOMOREBS campaign!**



## VOLUNTEER SPOTLIGHT:

### Annie Mason



In addition to being an artist, Annie Mason, the mother of a daughter with hydrocephalus, is the founder and former leader of the Hydrocephalus Association Community Network in Richmond, VA.

She continues to help HA today by serving as a community network leader mentor and as a HydrocephalusCONNECT Peer Support Volunteer. She is also a Boozle Bear Lead Sewer. This year, Annie received the 2018 Vicki Brown Volunteer of the Year Award. Congratulations Annie!

## 12-Year-old Raises Over \$5K for HA!



Hunter Aamot from Minnesota achieved two major milestones in October. He ran in his first marathon, the Medtronic Twin Cities Marathon, and raised over \$5,000 for the Hydrocephalus Association! Hunter launched a fundraiser for his marathon race in honor of his brother who has hydrocephalus. Not only did he finish the marathon, but he exceeded his \$5K fundraising goal! Congrats and thank you Hunter!

FACEBOOK  
FUNDRAISER



**Launch a fundraiser for the Hydrocephalus Association on Facebook!**

Facebook fundraisers are a great way to support HA's mission and get us closer to finding a cure! They are also an excellent way to raise awareness about hydrocephalus among your friends and family. You can launch a Facebook fundraiser for your birthday, the holidays, or any occasion! Because don't we all have one too many sweaters?! Let your friends and family gift you something that can make a huge difference!

**Remember to share your fundraiser on Facebook and ask your friends and family to donate.**

## Making Our Voices Heard at the Rally for Medical Research



A small but mighty team of advocates from DC, Maryland, and Virginia joined the Hydrocephalus Association on Capitol Hill in September for the Rally for Medical Research. Advocates held meetings with members of Congress,

where they shared their personal stories and requested more funding for the National Institutes of Health (NIH).

The Rally for Medical Research is the one day where we unite with 300 other health organizations to support sustained funding for NIH.

**THANK YOU CORPORATE SPONSORS! Together we are making a difference!**



# SHARE YOUR STORY: Gabrielle Wolf



My story really only began a few years ago. I lived a healthy, seemingly normal life up until the age of 23. I was a dancer since the age of two and a half, competing on my studio's dance team, as well as being a member of my high school's team and university's team. I had no real medical issues during this time. I began experiencing constant dull headaches, pain, and pressure behind my eyes beginning during the summer of 2013, before my senior year of college. The pain was pretty faint, so I didn't think too much of it. I went on to graduate college enrolling in mortuary school to follow my passion of becoming a funeral director. While I excelled in school, my symptoms worsened with no answer from my doctor. I simply went on and pushed through.

In October of 2016, my symptoms were progressing and I pushed for an appointment to see a neurologist. He sent me for an MRI, downplaying my symptoms. He said, "These headaches are the

most common thing I treat women for of your age" and simply prescribed me medication that "should help." Well it did not help and my symptoms, which now included intense vertigo and lack of coordination, were worsening. In one of my prior appointments, he stated that while I did have a small amount of visible hydrocephalus, I shouldn't be concerned at all because it must just be part of my normal anatomy. That did not sit well with me. I pushed and pushed back at him, advocating for myself that something was not right here. Finally, he ordered a new MRI. His tune quickly changed. He was now talking spinal taps and neurosurgery immediately.

Eventually I was finally properly diagnosed with Obstructive Hydrocephalus. There are a few rarities in my case. My obstruction is located in the fourth ventricle, when normally it is seen in the third ventricle. My age at diagnosis makes my case rare, as well. Usually this is seen in babies or elderly patients, but here I was an otherwise healthy 23-year-old young woman. The doctors have never been able to pin point when or how my Hydrocephalus originated, but they believe it had been developing for years.

After my first Endoscopic Third Ventriculostomy (ETV) in April of 2016, my symptoms came creeping right back just before my one-year surgery anniversary. I underwent my second ETV in May 2017 but my symptoms came roaring right back – this time only six months after surgery. The next step which we had tried to avoid, was the placement of a Ventriculoperitoneal Shunt in December 2017.

I have learned so much about myself through this journey over the past couple of years. This past brain surgery has by far been the hardest recovery both physically and mentally, but through sharing my journey I have gained such a community of fellow "Hydrowarriors" which has been the light in a dark room. My story could have ended short so many times, and though I may not know how many more brain surgeries lie ahead of me, here I am, family at my side, still standing strong, ready to take on whatever comes my way!

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## DON'T MISS AN OPPORTUNITY TO SHARE YOUR STORY!

Interested in sharing your loved one's journey with hydrocephalus or your own?  
We love highlighting individuals in our community in our publications and on the HA website.  
**To submit your story, visit: [support.hydroassoc.org/shareyourstory](https://support.hydroassoc.org/shareyourstory).**



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](mailto:giftplanning@hydroassoc.org)**

