

**SPECIAL SECTION:** *Normal Pressure Hydrocephalus*



VOLUME  
**35**  
EDITION 1

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## MESSAGE FROM THE CEO



Daily we are each bombarded by messages ranging from retailers to political activists asking us to take action to achieve an outcome that will most certainly make our lives more fulfilling than what the other guy is asking us to do. Retailers have

turned this into an artform — buy this car because it has a special rebate and it has the latest, greatest technology to make your driving experience more exceptional than the competitors. Likewise, the Hydrocephalus Association is asking for you to take action, whether it be to join a Community Network, call your Member of Congress or give a financial contribution to support our mission. Put simply, without you, we cannot move the needle towards achieving our mission.

I decided to use my editorial space to invite you to learn why we should warrant a top spot on your list of requested activations. We don't have a multi-million dollar marketing budget designed to influence you with subliminal messages or a 50% off teaser. We are, however, on a the road to finding a cure for hydrocephalus and improving the lives of those living with the condition. Becoming an active and engaged participant with HA means understanding our roadmap and how it will help further critical outcomes that directly relate to our mission. This goal is important to you or you wouldn't be reading this newsletter.

Here are just a few of the reasons to activate with us:

- You may learn something new about the care and treatment of hydrocephalus that could change the life of you or someone you love.
- As the largest private funder of hydrocephalus research, we directly fund scientists who have conducted trials resulting

in proven protocols to improve the care of individuals with hydrocephalus. Further, we support science studying the causes of hydrocephalus to one day prevent its occurrence.

- We are actively monitoring proposed legislation to try to curb any new bills that are brought forward that could be harmful to individuals living with hydrocephalus.
- We are supplying hospitals with comprehensive patient kits to provide information and a connection to our services that may be a lifeline for someone who is newly diagnosed.
- We are continuously sharing messages on all media fronts to try to bring this condition out of the darkness.
- We are creating best practices to solve the enormous challenges of transition from pediatric to adult care to combat the fear and lack of reliable and competent providers available to care for adults with hydrocephalus.

Whether you get involved as an advocate, a volunteer or a donor, you can have an impact. Nike tells us to “just do it.” I am asking you to “please do it.” Learn about our Roadmap to a Cure and walk with us. We need everyone if we are to tackle the significant goals before us.

Sincerely,

Diana Gray, MA  
Chief Executive Officer

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

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



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# HA CONNECT<sup>18</sup>

NATIONAL CONFERENCE ON HYDROCEPHALUS

**JUNE 28-30, 2018**

**ORANGE COUNTY, CA**

15th National Conference on Hydrocephalus

Irvine Marriott | 18000 Von Karman Avenue | Irvine, CA 92612-1004

Our National Conference provides individuals living with hydrocephalus and their families, an opportunity to learn from leading medical experts and from each other through an extensive three-day program comprised of interactive sessions, research updates, and educational seminars. **We invite you to join us!**

- Expand your awareness about hydrocephalus from leading medical professionals and researchers.
- Gain the necessary resources and tools needed for navigating the medical, educational, professional and social challenges of living with hydrocephalus.
- Connect with, be understood by, and learn from people living positively with hydrocephalus.

Book your hotel today! Special group room rate of \$169/night plus tax.\* To reserve your room, call the hotel directly at (949) 553-0100 or the Marriott Reservations office 24 hours a day, 7 days a week at (800) 228-9290. Please be sure to mention the 15th National Conference on Hydrocephalus or just the Hydrocephalus Conference.

\*Room rates are subject to applicable state and local taxes (currently 10%) and CA Tourism \$0.85. Taxes will be billed at the time of check-out.

**Learn more about conference! Visit [www.hydrocephalusconference.org](http://www.hydrocephalusconference.org)**

## 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)**



# Department of Defense Funds Two Research Studies on Hydrocephalus



Two hydrocephalus researchers have been awarded funding through the Department of Defense Congressionally Directed Medical Research Program (CDMRP).

Dr. Bonnie Blazer-Yost, Professor of

Biology at Indiana University-Purdue University Indianapolis, and Dr. Jerold Chung, Professor in the Degenerative Disease Program at Sanford Burnham Prebys Medical Discovery Institute, have been awarded grants totalling over \$2,000,000 through the Fiscal Year 2016 (FY16) Peer Reviewed Medical Research Program (PRMRP) Investigator-Initiated Research Award.

## The Research

The lab of Dr. Bonnie Blazer-Yost is testing drug candidates that could improve brain function in hydrocephalus patients. With funding through the Hydrocephalus Association 2015 Innovator Award generously supported by Team Hydro, Dr. Blazer-Yost has shown that a specific class of drugs can decrease cerebrospinal fluid production (CSF) and reduce the severity of the hydrocephalus in an animal model. The study entitled, "Development of Pharmacotherapies for the Treatment of Hydrocephalus," will continue under her grant through the PRMRP. While initially focused on early interventions to minimize the severity of hydrocephalus in infants born with enlarged ventricles, the research could have applications in the continued treatment of hydrocephalus in all ages as well. In the future, this line of research could help patients manage CSF production. This could be particularly helpful if a person's shunt is not draining enough CSF. Decreasing CSF production in this situation could help patients avoid emergency surgery and potentially decrease brain damage. Dr. Blazer-Yost has now established a team of experts to advise on the direct applicability of these drug candidates to hydrocephalus patients.

The prevention of posthemorrhagic hydrocephalus (PHH) may be on the horizon. At Sanford Burnham Prebys Medical Discovery Institute, Dr. Jerold Chun and Dr. Yun Yung (HA Mentored Young Investigator (MYI), 2010) are now testing drugs that target a molecular pathway involved in the development of PHH. By blocking the activity of a specific compound found in blood, Dr. Chun and Dr. Yung hope to stop the downstream effects of a brain bleed and prevent PHH. The goal is to develop a drug

intervention that can be administered to any patient who has a brain bleed in order to prevent the development of hydrocephalus. The HA MYI Award provided Dr. Yung with the initial funding for this project. Dr. Chung and Dr. Yung's research went on to be funded by a large National Institutes of Health (NIH) grant. This award through the PRMRP will allow the team to continue their groundbreaking work.

## Research and Advocacy Wins

Funding of these two scientists reflects the success the Hydrocephalus Association has had with both its Research and Advocacy

Initiatives. HA's initial funding of both of these projects supported the collection of critical preliminary data needed to pursue larger grants through

government funding mechanisms like NIH and

DoD. DoD dollars were not available to our

scientific community until December 19,

2014, when President Obama signed into

law H.R. 83, the Omnibus and Continuing

Resolution Appropriations Act of 2015,

which, for the first time, made hydrocephalus

a condition eligible to receive funding through

the Congressionally Directed Medical Research

Programs. The inclusion of hydrocephalus on the

list of eligible conditions was a direct result of a small

dedicated group of Hydrocephalus Association advocates

working in conjunction with our allies on Capitol Hill.

Established in 1999, the PRMRP is committed to funding research with the potential to profoundly impact the development and implementation of medical devices, drugs, and clinical practice guidelines that will enhance the precision and efficacy of diagnosis and treatment across the spectrum of health care settings. The groundbreaking research of both Dr. Blazer-Yost and Dr. Chun could lead to significant changes in treatment and outcome for patients that are born with hydrocephalus or develop hydrocephalus as the result of a brain bleed. More significant, while these studies are still in their early phases, the prevention of hydrocephalus may now be a realistic expectation.

We encourage you to visit our website to learn more about our Research Initiative as well as our Advocacy program. If you are interested in becoming an advocate for hydrocephalus through our Hydrocephalus Action Network, please email [advocacy@hydroassoc.org](mailto:advocacy@hydroassoc.org). More information about the Department of Defense Peer Reviewed Medical Research Program is available on their website: <http://cdmnp.army.mil>.

Funding of these two scientists reflects the success the Hydrocephalus Association has had with both its Research and Advocacy Initiatives.

# Tackling the Challenges of Transitioning from Pediatric to Adult Medical Care

By Tessa van der Willigen  
Board Member, HA Co-Chair, Transition Summit



The weather in Seattle in mid-February was unusually mild and sunny, but the 60 or so participants in the Hydrocephalus Association's Transition Summit didn't notice. They were huddled together in a conference room surveying the disappointing state of care for young adults with hydrocephalus, discussing where the obstacles are, and looking for solutions.

The agenda for the meeting was ambitious: no less than laying the basis for transforming the ecosystem for transitional care for young adults with hydrocephalus in the United States and Canada. For this purpose, the event brought together the whole range of stakeholders: adult and pediatric neurosurgeons and neurologists, neuropsychologists, pediatricians, family physicians, internal medicine specialists, physiatrists, nurses, social workers, federal administrators, state health administrators, health system administrators, neuroscientists, as well as patients and parents. All these people not only made time in their busy schedules to attend, but were fully engaged in the debate: over two days, there was hardly an empty seat or a cell phone in sight!

The summit began by hearing from patients and parents, both directly and by way of a report on some focus groups held last summer. The

overall message was clear: we are terrible at transition, and patients and families feel abandoned. Patients talked about the difficulty of finding adult hydrocephalus care; about the challenges of adapting to a very different culture in adult care (challenges often compounded by learning disabilities and cognitive impairments); about inadequate transfer of information to adult health care providers; and about the difficulty of securing adequate insurance.

The first takeaway that imposed itself was that the summit was not really looking at one issue but at two. Transition involves both a journey and a destination. Over and over, participants heard that patients could not find a destination—that is, a team willing and able to provide care for their hydrocephalus in adulthood. Patients who are lucky enough to find a neurosurgeon who will see them will often hear, "You look fine to me; I'll see you in the ER if anything goes wrong." Yet, as our patients well know, hydrocephalus is not a cookie-cutter condition, and all indications are that an ongoing relationship between physician and patient improves the odds of successful treatment.

Transition, then, is part of a larger problem of longitudinal care for hydrocephalus. That adequate adult care is scarce is hardly surprising.

After all, a few decades ago there were virtually no adults with hydrocephalus, as the condition was typically fatal. Now, the time has come for the adult neurosurgical and neurological communities to “own” hydrocephalus, and to ramp up the relevant professional training. Primary care providers will also need to become more familiar with the condition. Moreover, payment disparities will need to be addressed. The summit heard that payment rates in fee-for-service models value hydrocephalus surgery far less than other types of neurosurgery—but also that the health sector’s move towards other payment models (like accountable care) will create opportunities to have hydrocephalus care valued more fairly.

But even with adequate adult care in place, there will still be significant challenges in the journey of transition. Some pediatric systems have special clinics to help patients with transition, and some have clinics that continue to care for complex patients indefinitely. These clinics are extremely helpful where they exist, and should surely be encouraged. But they pose financial and administrative challenges and are unlikely to become the norm, at least in the immediate future.

Fortunately, the experts at the summit emphasized that good transition can happen even without such structures, as long as providers follow the right processes. The summit heard about the identified best practices in the areas of preparing the youth and family for transition, handing over care, and integrating the young adult into the adult system. Many resources for transition were shared also, and it was clear that it would be helpful to customize and/or disseminate some

of these. For instance, if there was a template for a summary medical record for hydrocephalus cases, it would be easier for pediatric physicians to transfer information to adult providers, and they would not need to resort so often to sending an unmanageable mass of documents and scans.

We went into the Transition Summit knowing we were tackling a big issue. We came out slightly daunted by the magnitude and importance of the task, but mostly elated at the prospect of making a real difference — a difference that will be all the greater because the issue of “transition” turned out to encompass many issues relevant to adult care in general. We are extremely grateful to the Theodore W. Batterman Foundation for its foresight in making the summit possible.

We are well aware, however, that this is only the beginning. We are currently engaged in writing a white paper summarizing the learnings from the summit and putting forward a 5-10 year action plan. There will be actions for HA to take directly, but there will also be a need for action by other stakeholders: by professional societies, by healthcare professionals who can “champion” different models of transition and care, by researchers who can help establish the cost-effectiveness of different approaches, by advocates who can spread awareness of insurance and payment issues. None of this will be easy, but we are encouraged by the passion of all the summit participants and their interest in working with us to move this agenda forward. Together, we will transform transitional and longitudinal care for hydrocephalus.

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## RESEARCH

### HA Presents at the National Institutes of Health



The National Institutes of Health (NIH) National Institute of Neurological Disorders and Stroke (NINDS) hosted their annual 2016 Nonprofit Forum last September. The Progress through

Partnership Forum provided an opportunity for nonprofit leaders to network with colleagues and to engage in discussions with NINDS staff. The forum also promotes the role nonprofits play in linking scientists at NINDS with the patient community for better research outcomes.

The agenda featured panel discussions on natural history databases, biomarker identification, data integration and management, clinical outcome measures, and success stories. Dr. Jenna Koschnitzky, the Hydrocephalus Association Director of Research Programs, served as a panelist for *Cultivating Collaborations on a Shoestring and Investing in*

*the Intellectual Pipeline*. The panel focused on how to build a network comprised of many different interests as well as finding and funding the researchers. Paul Gross, former HA Board Chairman and interim CEO, moderated a panel that looked at the challenges and opportunities of data integration and management for shared data repositories.

“HA is honored to play a role in the Nonprofit Forum where NINDS staff garners feedback from the patient advocacy community,” shared Dr. Koschnitzky. “We have developed deep and meaningful relationships with the NINDS staff and leadership and continue to be considered a respected voice among the not-for-profit advocacy organizations.”

This year’s agenda featured panel discussions on strategies for biomarker identification used to find targets for interventions that could lead to cures or preventions for conditions, to integrating patient-reported outcomes and wearable technologies to develop better clinical outcome measures for studies with patients.

## 2016 Innovator Award Announcement

The Hydrocephalus Association is pleased to announce the funding of three hydrocephalus researchers through the HA Network for Discovery Science (HANDS) Innovator Award.

The Innovator Award is designed to provide seed funding for bold and innovative research with the potential to transform hydrocephalus research. In this cycle, the Award focused on Posthemorrhagic Hydrocephalus (PHH) research with emphasis on understanding the disease mechanisms and the development of novel therapies and treatment approaches. Innovator Awards are for one year of support at a \$25,000 or \$50,000 level. These awards further the Hydrocephalus Association mission to promote a cure for hydrocephalus and improve the lives of those affected by the condition.

Funding for the 2016 Innovator Award was made possible through the support of the Grant and Pam Finlayson family and the dedicated efforts of Craig and Vicki Brown, hosts of the 2016 Vision Dinner.

In 2016, the Hydrocephalus Association spent over \$800,000 directly on clinical and basic science grants. This brings our total research spending to over \$6,000,000 since the start of the research initiative in 2009. In 2017, the Hydrocephalus Association will continue pushing hydrocephalus research forward through continued support of the Hydrocephalus Clinical Research Network, the Adult Hydrocephalus Clinical Research Network, and by providing more research opportunities through the HA Network for Discovery Science.



**Kristopher Kahle, MD, PhD,**  
*from the Yale School of Medicine*  
will evaluate how intraventricular hemorrhage impacts choroid plexus CSF production.



**Shenandoah Robinson, MD,**  
*from Johns Hopkins University,*  
will test clinically available drugs to enhance natural repair processes in the brain in hopes of reversing the damage caused by intraventricular hemorrhage and hydrocephalus.



**Jennifer Strahle, MD,**  
*from Washington University,*  
will determine how iron gets into and damages the cells lining the ventricles and how this contributes to the development of hydrocephalus.

## HA in Attendance

*HA represents the hydrocephalus patient community at key professional meetings, keeping our agenda on the table.*

### **NINDS Nonprofit Forum**

September 13-14 | Bethesda, MD

### **Health Research Alliance**

September 27-28 | Washington, DC

### **Hydrocephalus Clinical Research Network**

September 29-30 | Deer Valley, UT

### **National Health Council**

October 27-October 28 | Baltimore, MD

### **Adult Hydrocephalus Clinical Research Network**

November 4-5 | Salt Lake City, MD

### **Health Research Alliance**

March 23-24 | Los Angeles, CA

### **Adult Hydrocephalus Clinical Research Network**

March 31 - April 1 | Vancouver, BC

### **Hydrocephalus Clinical Research Network**

April 6-7 | St. Louis, MO

### **American Association of Neuroscience Nurses**

April 20-23 | Boston, MA

### **Experimental Biology**

April 22-26 | Chicago, IL

### **American Association of Neurological Surgeons**

April 23-26 | Los Angeles, CA



## Florida Grandparents Helps Raise Awareness and Funding for Pediatric Research

The future of HA's research is driven by members who volunteer to help increase awareness about hydrocephalus at every opportunity. In January 2017, Iris and Nat Adler hosted a luncheon and card party at their Country Club in Boca Raton to educate over 200 members about hydrocephalus and to raise funds for research.

The Adler's granddaughter, Charlotte, was born with Dandy Walker, a malformation of the cerebellum, which led to hydrocephalus. She had her first shunt placed at three months of age and has undergone multiple brain surgeries. The family established the Cure Charlotte's Hydrocephalus Fund to help find alternative ways to treat and prevent hydrocephalus. As part of the event, attendees enjoyed an afternoon of social bridge, canasta and Mahjong. In addition, the Adlers organized a silent auction, shop for a cause boutique, and a raffle.

As Iris shared, "Our goal is to make possible the necessary research so that children will never need shunt revisions or, even better, discover a way to eliminate shunts completely without consequence and cure this horrible condition."

The HA is so very grateful to have Iris and Nate as new partners on this journey to find a cure for hydrocephalus and improve the lives of those affected.

## Calling all Hydrocephalus Researchers!



# HANDS

Hydrocephalus Association  
Network for Discovery Science

Collaboration • Innovation • Impact

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)

# Aging Out of Pediatric Care: A Cautionary Tale

By Dan Kricke, living with hydrocephalus



### Four.

That is how many different hospitals I visited trying to transition from a pediatric neurosurgery program to an adult neurosurgery program in the midst of a shunt malfunction.

I was as scared, frustrated and upset as I've ever been as a hospital patient.

It hardly made any sense at all. It wasn't as if I developed hydrocephalus on the cusp of adulthood and then quickly had to transition from pediatric to adult doctors. I had been with the same neurosurgeon and hospital system for two decades. The second of those two decades was a quiet one as far as my hydrocephalus was concerned. A revision of my malfunctioning shunt around age 12 with another around age 14, and then nothing.

From age 14 to 26, I would head in to see my neurosurgeon for routine check-ups every few years and little else. I'd have a few pressure headaches and migraines here or there, but they'd fade away well before anyone thought it was time for me to head to the hospital.

But then for a few weeks in the middle of winter, I couldn't shake out of... something. I didn't even know what it was. My head didn't hurt that bad. But I felt so lethargic. Suddenly, there was a constant pressure in my head. Not nearly as bad as some migraines I've had in the past, but it just wouldn't go away.

I discussed it with my mom and we called the office of the neurosurgeon I've seen since I was a kid. They said because I was 25 I should see an adult neurosurgeon, but didn't recommend anyone in particular. So my mom, the advocate that she has always been, went about searching for someone familiar with hydrocephalus that could help.

I wound up at a different hospital speaking with a neurosurgeon who explained that although he treated adults with hydrocephalus, he didn't have the right equipment to treat me because I had "Slit Ventricle Syndrome," and he suggested I go back to the hospital that placed the shunt.

So we called the first hospital back up and explained the situation. They told me to come in and I transitioned from an ER waiting room to an exam room where I waited for a long time, only to be told by the neurosurgeon on call that I was too old to be treated at the hospital. As I looked on, transformed from a 26 year-old adult to a helpless patient in pain trying to keep my headache under control with little more than hope, my mom sprang into action. She demanded to know why we were being treated this way. She spoke with hospital officials at length who apologized for telling her to come in and told us to go to their affiliate hospital that treats adults.

Now, suddenly,  
I was visiting three  
hospitals in a day and  
trying to figure out how  
to keep from falling apart  
emotionally.

At the third hospital, we again explained my situation and I was examined by an on-call neurosurgeon who, I think, may have never heard of hydrocephalus. I will never forget when the surgeon said, "Well, I've Googled your symptoms..." This is a major hospital in a metropolitan city and they're Googling hydrocephalus symptoms?

They gave me something in an IV to help with my headache and relax me. Whatever they put in my IV made my skin crawl. I was hot and cold and hot again. My heart was racing. It was the worst I had felt throughout the entire ordeal. As I waited for this terrible medicine's effects to pass, that was the last straw for my mom.

She called the pediatric neurosurgeon's office and explained our journey and demanded an actual referral from my long-time neurosurgeon so we could get out of the hospital we were sitting in.

I'd like to emphasize again how scared I was at this point. I've never particularly liked being in the hospital but I've never felt like the treatment I was getting would be detrimental to my recovery. Now, suddenly, I was visiting three hospitals in a day and trying to figure out how to keep from falling apart emotionally. This all started with me feeling a little tired and suddenly I didn't know who was going to help me.

My mom's call generated results this time, as we wound up in the office of a neurosurgeon who, long story short, booked me for a shunt revision surgery in short order. He replaced the old shunt valve I had been using since I was a child with a newer adjustable model. I was out of the hospital and feeling like my old self in a matter of days.

Ultimately, I wound up needing a few more revisions a few years later, but if I hadn't gotten to the neurosurgeon I wound up with, I don't know that I would have been around to get those additional revisions and meet and marry the love of my life.

My current neurosurgeon has remarked how strange he thinks it is that there isn't a better transition system for children seeing neurosurgeons as they grow into adulthood. And I suppose I shoulder part of the blame

in waiting until a time of medical crisis to transition, but there has to be a better way.

I'm sharing this story both as a cautionary tale, to encourage anyone with a child who is going to age out of their pediatric hospital, to work on finding an adult neurosurgeon equivalent as soon as possible, and also to spotlight a way in which a system that should have been protecting its patients, did such a lousy job with one in particular.

## Hydrocephalus Education Days Provide Connections

Complementing our National Conference on Hydrocephalus, the Hydrocephalus Association (HA) is proud to host Hydrocephalus Education Days in select cities across the United States for individuals living with hydrocephalus and their caregivers. In partnership with the expertise of national and regionally located medical professionals and institutions, these free, one-day events are designed to deliver education, support and networking opportunities for the hydrocephalus community.

Four successful Education Days have already taken place this year. The first was held on Saturday, February 25, 2017, in partnership with Children's National Health System in Washington, D.C. The event drew 125 attendees and included presentations from Suresh Magge, MD, Taeun Chang, MD, Yael Granader, PhD, and Justin Burton, MD, four clinical experts in neurosurgery, neurology, neuropsychology and rehabilitation, respectively. The second took place on Saturday, March 11, 2017, in partnership with Barrow Neurological Institute. Nearly 100 participants gathered to learn more about normal pressure hydrocephalus (NPH). Presentations were hosted by Maggie Bobrowitz, RN, MBA, David Barranco, MD, Krista Hanson, PhD, Sharon



Hayden, PT, Kamala Saha, MD, Jiong Shi, MD, and Joseph Zabramski, MD. Welcoming a new partnership for our Education Day program, Johns Hopkins All Children's Hospital in St. Petersburg, Florida, held their first Education Day on Saturday, April 29, 2017. Presentations diagnosis,

treatment, and living with hydrocephalus were given by

two pediatric neurosurgeons, George Jallo, MD, and

Gerald Tuite, MD, followed by a presentation on

learning and neuropsychological function by

Jennifer Katzenstein, PhD, ABPP-CN. The day

also featured and intergenerational panel.

In another new partnership, we hosted an

Education Day in New York City with New

York University Langone Medical Center

on Saturday, June 3, 2017. Long-time HA

supporters, Drs. Jeffrey Wissoff and Rick Abbott,

were joined by colleagues offering sessions for the

entire patient age spectrum, including sessions in

Spanish and for those living with NPH.

"The [Children's National] event was thorough and on point. Speakers went to great lengths to present in lay terms. Overall, it was useful, informative, comforting, and detailed... Looking forward to the next one and beyond!" shared one D.C. participant.

### LEARN MORE

about our upcoming Education Days scheduled in 2017

- **Miami, FL** July 29th
- **Houston, TX** August 19th
- **Los Angeles, CA** September TBD

Check [www.hydroassoc.org/get-involved](http://www.hydroassoc.org/get-involved) for details and for new dates and locations being added in cities across the country.

## Our Community Networks

We hope you can join us online or at a local get-together this year! Visit our website to find your Community Network's online closed Facebook group and for upcoming events. If you'd like to start a network in your area, email [support@hydroassoc.org](mailto:support@hydroassoc.org) or call (888) 598-3789.

<b>AK</b> Anchorage	<b>FL</b> Central	<b>NC</b> Charlotte	<b>SC</b>
<b>AL</b>	<b>GA</b> Atlanta	<b>ND</b> Fargo(and Moorhead)	<b>TN</b> Chattanooga
<b>AR</b>	<b>IL</b> Chicago	<b>NY</b> Buffalo	<b>TX</b> Dallas
<b>AZ</b> Phoenix	<b>IN</b> Indianapolis	Long Island	Houston
Phoenix (NPH)	<b>KS</b>	New York City	<b>UT</b> Salt Lake City
<b>CA</b> Los Angeles	<b>KY</b>	<b>OH</b> Cleveland	<b>VA</b> Richmond
San Diego	<b>MA</b> Boston	<b>OK</b> Oklahoma City	<b>WA</b> Seattle
<b>CO</b>	<b>MD</b> Baltimore	<b>OR</b> Portland/Vancouver	Eastern WA
<b>CT</b> Hartford	<b>MI</b> Detroit	<b>PA</b> Northeast	<b>WI</b>
<b>DC</b> Washington	<b>MN</b> Minneapolis	Pittsburgh	<b>Nigeria</b> Lagos
<b>DE</b> Middletown	<b>MO</b> St. Louis	<b>RI</b> Providence	



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

## SHARE YOUR STORY: Jordan Weaver



I was born prematurely at twenty-six weeks in 1997, and developed hydrocephalus because of a bilateral intraventricular hemorrhage. This caused a clot that prevented my cerebral spinal fluid from flowing to the rest of my body. I had my first shunt inserted when I was 10 months old. I have been immensely lucky to have only needed one shunt revision when I was 12.

I am one of the many faces of hydrocephalus, but you would not be able to tell that just by looking at me. The condition has not placed any limitations on what I have been able to do and, at present, does not greatly affect how I live my day-to-day life. I am currently a rising sophomore Medieval Studies major at St. Olaf College in Northfield, MN, and am applying to study abroad during the January term of my sophomore year. I have also parasailed, rock climbed, downhill skied, and traveled abroad multiple times with my family.

Though I understand that hydrocephalus comes in many different forms, I hope that my story provides hope and comfort to people affected by hydrocephalus.

*The Weaver family have been members of the Hydrocephalus Association since 1998, participating in the Chicago WALK to End Hydrocephalus and supporting key growth initiatives of the organization over the years. We are extremely grateful to loyal members who help move HA one step closer to fulfilling our mission of finding a cure for hydrocephalus.*

## Hydrocephalus and Disability Benefits



Daily life with hydrocephalus can be a challenge to successfully performing everyday activities, including professional duties. Adults with hydrocephalus may develop symptoms indicating a problem with their current treatment slowly over

time or they may have a rapid onset of symptoms, which can include headaches, vision issues, vomiting, a loss of coordination and balance, fatigue, and problems with speech, memory, and thinking, as well as personality changes and impulse control issues.

For some individuals, symptoms often diminish or disappear entirely once a successful treatment intervention, like a shunt revision, takes place.

### Matching a Blue Book Listing with Hydrocephalus

The SSA's Blue Book is a manual of recognized disabilities. While there is no dedicated listing for hydrocephalus, you may qualify by showing through medical records that your symptoms are equal in severity to one of the following listed impairments:

- Stroke or Traumatic Brain Injury – Section 11.04
- Traumatic Brain Injury – Section 11.18
- Epilepsy – Sections 11.02 and 11.03
- Tumors of the head and neck – Section 13.02
- Organic Mental Disorders – Section 12.02

This is not a complete list. Qualifying for benefits will hinge on finding a listing that you can meet in the Blue Book based on your own symptoms from hydrocephalus. To meet the SSA's medical eligibility requirements, you must have:

- a thorough medical history,
- a formal diagnosis,
- and detailed documentation of how your symptoms affect your daily life and abilities.

Your doctor is an invaluable resource. He or she can help you understand the Blue Book medical stipulations and can assist you in compiling required medical records.

Medically qualifying for children is different than qualifying for adults. Hydrocephalus in children is listed in the Blue Book, in Section 111.00. Your child will be able to qualify if he or she has non-compensated hydrocephalus. The hydrocephalus must also cause intellectual or motor delays.

However, in many individuals symptoms can persist at varying degrees and intensities, and, in some cases, may be permanent. If your symptoms continue to prevent you from working, then you have a strong disability application, provided you have appropriate medical evidence to back up your claim.

### Disability Benefit Programs

The Social Security Administration (SSA) provides support to disabled individuals through two separate programs:

Supplemental Security Income (SSI) benefits are available to disabled persons of any age. This program does not require you have a work record at all but it does have "financial-need" standards you must meet.

Social Security Disability Insurance (SSDI) benefits are paid to disabled workers that meet work history or work record requirements. To qualify you must have contributed to the Social Security fund through Social Security taxes during your employment history and, dependent upon your age, you typically must have worked between 5 and 10 years. Younger applicants with hydrocephalus will not be expected to have worked as long as a 60-year-old applicant.

### Qualifying Under a Medical Vocational Allowance

If you're unable to match a listed condition, then you must be able to show your everyday abilities are severely compromised by your symptoms, including things like cooking, cleaning, shopping, communicating with others, or interacting socially. The SSA will conduct a "residual functional capacity" or RFC evaluation that looks at your physical and mental limitations.

If the RFC shows:

- you are not able to work in any job for which you already possess the training and skills necessary, AND
- you cannot reasonably be trained for a new job, given your education level, training, work history, and your physical and mental limitations, then you will be granted disability benefits through a medical vocational allowance. Your doctor can download an RFC evaluation online and fill it out for you.

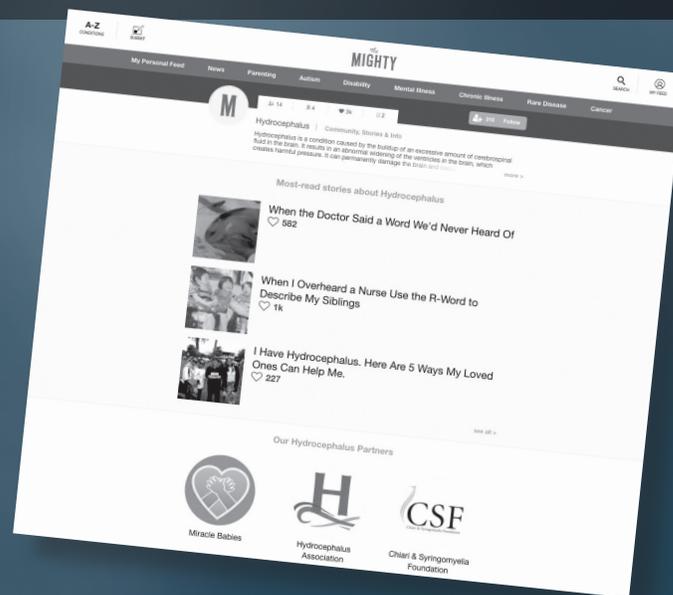
### Applying for Benefits

The SSI and SSDI programs require separate applications. The SSDI application can be completed online, but the SSI application must be filled out for you by an SSA representative, using the details you provide during your application interview. Visit the SSA's website to start your online application, or call 1-800-772-1213 to schedule an appointment at the closest SSA office.

This article was provided by Social Security Disability Help. For any additional information, please feel free to email them at [help@disability-benefits-help.org](mailto:help@disability-benefits-help.org).

# We're Partnering with THE MIGHTY!

We're thrilled to announce a new partnership that brings our hydrocephalus stories and resources in front of The Mighty's wide-reaching readership. We now have a growing home page on The Mighty and appear on many stories throughout the site. We encourage you to submit a story to The Mighty and make your voice heard.



## Let's get our community connected!

## Whole Foods Features Cider With A Purpose

Jason Spears and his brother, Patrick, founded Locust Cider in March of 2015, inspired by real, tough people, aka children with hydrocephalus. With them in mind, their mission is to make outstanding hard cider... and they have been doing just that. Whole Foods featured the new "Hootenanny" series in stores across Washington and Oregon. They will soon be adding stores across Texas to the list.

Locust Cider is a company with a mission. Locust Cider educates about hydrocephalus on each bottle and on their website. In addition, a portion of the proceeds of each sale as well as \$25 from each of their club memberships (The Club) goes directly to the Hydrocephalus Association. Jason's daughter, Lucy, is their inspiration.

In early 2015, Jason's daughter (born in February 2015) was diagnosed with hydrocephalus, along with craniosynostosis. By the age of one, Lucy

had already undergone 4 brain surgeries and 7 hospital stays.

"Children with hydrocephalus are the toughest people we have found so far, and we have made it our mission to use this cider company as a vehicle to improve their lives," stated Spears.

The Spears brothers want a better future for Lucy and for all the children with hydrocephalus.

Learn more about Locust Cider and find out if there is a local distributor near you! If you are a cider aficionado but are unable to buy locally, check out The Club for doorstep delivery of their various ciders.



Learn more about Locust Cider and find out if there is a local distributor near you! If you are a cider aficionado but are unable to buy locally, check out The Club for doorstep delivery of their various ciders. Visit their website to learn more: [www.locustcider.com](http://www.locustcider.com)

## TEENS TAKE CHARGE

### Hydrocephalus Shunt featured on Nike's Air Max Zero

*Chase designed a hydrocephalus shoe for Nike... and it's cool.*

Photo courtesy of Doernbecher Children's Hospital



Chase lives with both hydrocephalus and seizures. He is a patient of Dr. Nathan Selden, a pediatric neurosurgeon with Doernbecher Children's Hospital and Chair of the Oregon Health & Science University (OHSU) Department of Neurological Surgery in Portland, Oregon, and the medical chair of the Hydrocephalus Association National Conference on Hydrocephalus that took place in Portland in 2014. As is the case with so many of our pediatric neurosurgeons, Chase and Dr. Selden have developed a close relationship over the

years. So this year when there was a call for nominations for children to design Nike shoes in the annual Doernbecher Freestyle fundraiser supporting Doernbecher Children's Hospital, Dr. Selden submitted Chase's name. Annually 20 children are nominated and 6 are ultimately selected.

Tami, Chase's mom, remembers receiving the call in January. Over many visits to the hospital, Chase would see Nike shoes on display that were designed each year by patients like himself. Every year there would be a new set of shoes, and Chase loved looking at the display to see the unique designs. The family was ecstatic when Chase was selected. He began thinking about what his shoe design would incorporate.

The process was exciting. Chase received a call from Nike, headquartered in Portland, telling him which Nike model he would be designing – the

Nike Air Max Zero. They gave him an outline of the shoe and said he could put anything on it he wanted. At home he worked on his design and then he sent it in to the team of designers. Chase met with one of the Nike design teams who reviewed his design with him to make sure they got it exactly to his specifications. His design incorporated two things that are very important to Chase. Living with hydrocephalus and lighthouses. On the tongue of his shoe he put a shunt valve, the tubing running on the outside of the shoe and "draining" into the sock liner. The inside of his shoe looks like a brain. There is a lighthouse where the Nike swoosh typically is placed that has a beam of light that glows in the dark. The design team worked with Chase to refine the design and choose the colors and materials before sending it to production.

Once all of the shoes were designed, they were readied for auction at an evening gala benefiting Doernbecher Children's Hospital on October 28, 2016, that had over 650 people in attendance. Chase got to see his shoe completed for the first time. To his surprise, Russell Wilson, Quarterback of the Seattle Seahawks, signed the shoe. Chase spent the evening answering questions from guests about the design and about what it is like to live with hydrocephalus. The shoe was auctioned for \$21,000 to Nike's COO, Erik Sprunk.

Chase is grateful for the opportunity to participate in this experience. As if designing a shoe for Nike isn't cool enough, he also got to meet the original designer of the Air Max Zero, Tinker Hatfield (who also designed the Air Jordan). They hung out for an hour, during which time Chase got to try on the Back to the Future self-lacing shoes.

## SLEEP AWAY CAMP JUST FOR KIDS WITH HYDROCEPHALUS!

4-day, 3-night camp for 10-17 year olds diagnosed with hydrocephalus. Typical camp experience with trained medical professionals on-site.



Brainy Camps  
ASSOCIATION



Children's National

August 6-9, 2017

High View, West Virginia

(Buses from the Washington, D.C. area to camp)

Learn more and register! [www.brainycamps.com](http://www.brainycamps.com)

## Like Father, Like Son: An NPH Journey

By Bob Neely, Guest Blogger and HA Volunteer

Most people who have heard of hydrocephalus think of the congenital version, afflicting newborns and young children, and are not aware there is a separate, equally devastating version reserved for us old folks and our families named Normal Pressure Hydrocephalus (NPH).

The story below is a very accurate description of NPH. I know, because it is my story. I had a shunt implanted in my head on October 8, 2014, and recovered most of my faculties over 10 months.

My father also was a victim of NPH, which went misdiagnosed for over 8 years.

Instead of sharing his retirement and senior years with his wife (my mother), Genevieve, our family watched him slowly deteriorate from a sharp, friendly, loving southern gentleman to a shuffling recluse who had to wear Depends. His mental and physical condition required constant supervision from Genevieve or a health-care worker.

History would have repeated itself had I not witnessed the slow but ruthless degeneration caused by untreated NPH gone misdiagnosed in my father...

Like Father, Like Son.

My mother and father started a small family business in 1944, in Laurel, Mississippi, when I was three years old. For 40 years they worked hard, long hours together building the company into an industry success and a small business success story. They looked forward to really enjoying their retirement years traveling, golfing, and spending time with their many friends, once I took over the reins. They had earned it.

In 1972, when my dad was 62 years old, I noticed a change in his behavior. He had lost all motivation to continue leading Neely Blue Print. His usual creativeness, enthusiasm, problem-solving skills, and concentration were disappearing. He was unable to remember names, numbers, and sometimes entire conversations. He was easily distracted and would change the subject to something totally

unrelated to the current conversation. Something had changed. I did not realize at the time it was his mental state, an indicator of what was to come.

He retired from Neely's in 1978. His energy level was down, and it took him longer to perform the same tasks he had performed automatically all his career. He had to quit driving his car. He loved to play golf, bridge or poker with his buddies, but had to stop because he couldn't remember the rules, keep score or track of

whose turn it was. He could no longer stand over a golf ball and hit it with any accuracy, nor could he remember

where it landed on the fairway... if it landed on

the fairway. He was unable to travel, play

games, or read (he had always been an

avid reader to compensate for his lack

of formal education). He had been

diagnosed with type 2 diabetes in

1962, and was supposed to exercise

by walking every other day, but he

could not maintain his balance and

had to stop. He kept stubbing his feet

on the asphalt bumps and ridges on the

street in front of his house.

His physician was also a close family friend and tried to diagnose the problem, but could not find what was causing such a swift decline into senility.

Remember, in the 1970's little was known about neurological problems like "adult onset" hydrocephalus. Even Alzheimer's and Parkinson's disease were largely unknown. There was no CT-scan or MRI imaging; no internet or Google search, medical search databases or web-sites for easy sharing of medical or diagnostic information. His physician told him he was just getting old and senile.

Around 1982 his doctor attended a medical convention where one of the speakers made a presentation on "adult onset hydrocephalus." As soon as he returned to Jackson he reexamined dad's condition and realized it fit the description he had just heard described at the conference.

A shunt was implanted in my dad's skull. It resembled the bulb gas-line primer on a power lawn mower or chainsaw. My mom had to press it several times a day to flush the cerebral spinal fluid



(CSF) out of the ventricles in his brain. While it stopped the rapid degeneration, it was too late for any improvement or recovery. He was unable to take care of himself. My mom, who was battling breast cancer, also had to take care of my dad.

My dad passed away March 30, 1994. He was 83 years old when he died. My mom passed away in September that same year. She had fought the breast cancer since 1981 and was determined to take care of her husband and life-long business partner, and never let him be placed in an assisted living facility (nursing home). Once he was gone, she had about 4 months to visit and renew old friendships before she joined him. Now they both enjoy each others company in heaven, eternally.

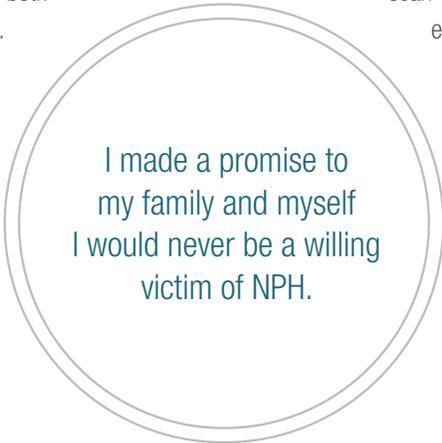
I made a promise to my family and myself I would never be a willing victim of NPH. My father and I were almost identical in body shape and type, give or take 32 years. He and I both were diagnosed with type 2 diabetes the same year of our lives. We worked together, ate together, shared the same environment for most of our lives. I had a premonition that I would one day fight NPH. I had a CT scan performed in 2006 in Clearwater, Florida which showed no signs of enlarged ventricles. At the time I did not know the “signs” to look for.

In late 2011, I noticed some deterioration in my balance, and began having problems performing tasks, particularly planning or analysis. I was actively involved in a local volunteer ministry that specializes in building and installing disability ramps for families with beloved members who are wheelchair bound. It took me a lot longer to complete an application, or draft a plan for a disability ramp and prepare a materials purchase order. I also developed a hand/eye coordination problem; typing on a keyboard without wearing out the backspace and delete keys, being unable to remember a measurement long enough to record it on a ramp plan or mark the board for cutting.

During my 2014 six-month physical with my primary care physician (PCP), I mentioned some of my problems and raised the possibility that I might be in the early stages of “adult onset hydrocephalus.” He said maybe I was developing Alzheimer’s or maybe Parkinson’s but not to worry unless it got worse. I mentioned my father suffered from misdiagnosed hydrocephalus and it turned him into a zombie the last 10 years of his life, and I was not going to let it happen to me without a fight. My PCP did not know what I was talking about!

When I got home following the exam, I started researching the Internet for information of Adult Onset Hydrocephalus. I found articles from teaching hospitals like John Hopkins, the National Institute of Health, neurology and neurosurgery clinics, and finally the Hydrocephalus Association.

When I returned, for my second semi-annual exam, I came prepared. I had a diary of specific symptoms and a record of continuing deterioration of memory and lack of motivation. When presented with this information and my insistence on checking for swollen ventricles, my PCP reluctantly ordered a CT scan which was performed the next day. Sure enough the ventricles were swollen and I was scheduled to see a neurologist.



I made a promise to my family and myself I would never be a willing victim of NPH.

I was dismayed to learn the first open appointment date was two months away, which meant my condition would have progressed eight months from the first doctor visit. I got on the cancellation list and was thrilled to see the neurologist the very next day. Things were moving along after all and I felt blessed. Even better, he had just recently graduated and begun practicing in Chattanooga, Tennessee. He was very familiar with NPH, it’s symptoms, diagnosis and treatment. He performed a comprehensive examination testing my mental condition, medical history and observing my gait. Based on the exam, he ordered an MRI which confirmed the CT-scan diagnosis: swollen ventricles. He then ordered a lumbar puncture, or spinal tap, which removes a certain amount of cerebral spinal fluid, reducing the CSF pressure in the brain. Once removed, fluid pressure was reduced and my symptoms immediately disappeared for 3 days! This improvement indicated that NPH was present, and confirmed my candidacy for a shunt implant.

I am happy to report that I had successful shunt implant surgery in October 2014. The surgery lasted 45 minutes and I stayed in the hospital overnight. My symptoms have either disappeared or are slowly decreasing.

I am now a volunteer with the Chattanooga Hydrocephalus Association Community Network and WALK to End Hydrocephalus and hope to help create awareness of NPH in our senior population, their health-care providers, and Primary Care physicians. Most of the active volunteers consist of mothers of infants and children born with pediatric hydrocephalus. It is a joy and inspiration to work with them.

I cannot ignore the fact that neither myself nor my PCP would have been aware of why my balance, short-term memory, cognizance, and energy level were going south if it had not been for my journey. My father, "The Boss," mentored me right up to the end, even though he wasn't aware of it. His leadership style always was "lead by example."

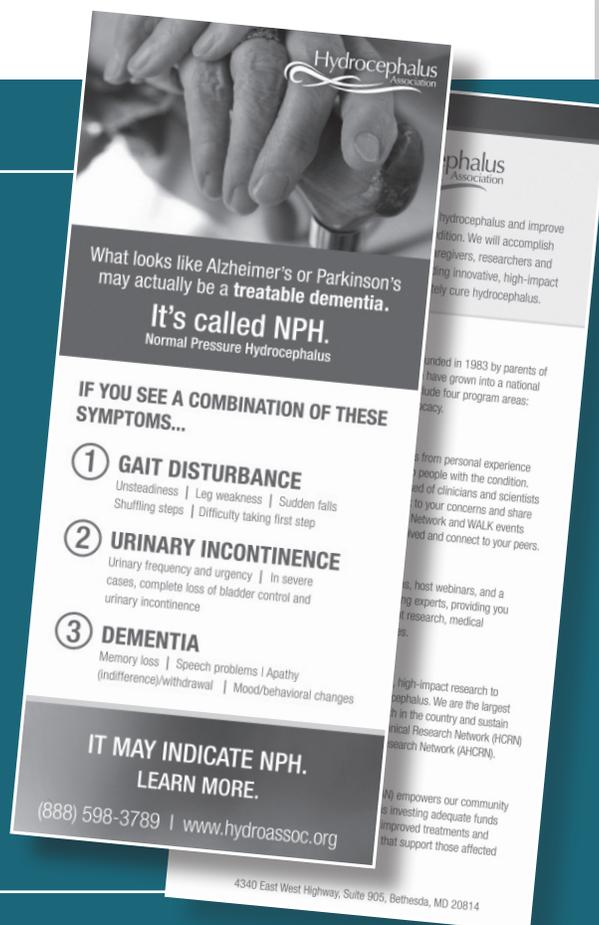
God truly blessed me to be his son. If sharing our experience will prevent you and/or your family and friends from the suffering, frustration, lost opportunity, and/or loss of quality of life caused by Normal Pressure Hydrocephalus, it will enhance his legacy. Below are the lessons I learned:

- You are responsible for your own health. You are responsible for learning what your symptoms are, and how best to accurately describe them to your Primary Care Physician. You cannot expect him or her to automatically think "NPH!"
- Learn the "Triad of Symptoms" for NPH. They are very similar to the symptoms of Alzheimer's or Parkinson's, but there are subtle differences that will help your medical team members properly diagnose and treat your illness. Visit the NPH area of this website to learn more.
- NPH is sneaky. The changes can be so slow you don't realize they're happening (i.e. the frog on the stove analogy). It disguises itself as "just old age" or one of the better known senior diseases like Alzheimer's or Parkinson's.

- The kink in the hose blocking a patient's access to neurologists and neurosurgeons seems to be your Primary Care Physician. For many of us, you cannot go directly to a neurologist... you have to be "referred". If your referrer does not know what NPH is, you are stymied. Statistical studies estimate 80% of the 700,000 older (60 yrs) Americans with NPH are not aware of it.
- NPH is controllable, particularly if diagnosed early. Alzheimer's and Parkinson's is not. Treatments for Alzheimer's or Parkinson's will not help NPH!
- Stay Healthy! Don't mask, accelerate, or exacerbate health problems with untreated diabetes, smoking, excess alcohol consumption, poor health habits, and not exercising.
- Information and Support is Available. Thanks to modern medical science diagnostics and technology, the growing amount of information available over the Internet, and support groups like the Hydrocephalus Association, which has Community Networks around the country and a national headquarters in Bethesda, Maryland, can provide the Baby Boomer Generation with good information. Baby Boomers are reaching the age when NPH usually occurs (60 years).

# HELP SPREAD AWARENESS about the symptoms of NPH

These cards are available for download on our website or by order through mail. Consider distributing them at a local community center, doctor's office, assisted living facility, or other location serving individuals over 55 years of age. Email [info@hydroassoc.org](mailto:info@hydroassoc.org) for inquiries.



4340 East West Highway, Suite 905, Bethesda, MD 20814



## Hydrocephalus Advocates Join Rare Disease Week

Rare Disease Week 2017 took place on February 27 through March 2 in the Nation's capital. Hundreds of patients, caretakers, and rare disease organizations gathered on Capitol Hill to advocate on behalf of the rare disease community. HA staff were joined by members of our Hydrocephalus Action Network (HAN) to represent our hydrocephalus community in the week of activities.

The week kicked off at the National Institutes of Health (NIH) where each year the National Center for Advancing Translational Science (NCATS) and the NIH Clinical Center sponsor Rare Disease Day. This year's theme was Research, using the slogan, "Research brings hope to people living with a rare disease." Key experts in their field delivered presentations on rare diseases, ranging from Aids to Zika.

The next two days were dedicated to understanding current policy issues that impact the rare disease community and then taking our message to Capitol Hill. A Legislative Conference hosted by RDLA in partnership with the EveryLife Foundation for Rare Diseases prepared all the participants for their Hill visits. On Wednesday's Lobby Day, rare disease advocates urged members to increase NIH funding by \$2 billion for more medical research, to sign-on and support the OPEN Act, and to join the bipartisan and bicameral Rare Disease Caucus. In addition, HA advocates urged our representatives to assure that hydrocephalus, along with other neurological conditions, is included under the 21st Century Cures' National Neurological Conditions Surveillance Systems. The week's events came to a close with a Rare Disease Congressional Caucus briefing focusing on what the rare disease community should expect and prepare for in Fiscal Year 2017 with the pending healthcare reform.

We want to thank the advocates who joined us in Washington, D.C. for Rare Disease Week. If you want to become an advocate for the hydrocephalus community, join our Hydrocephalus Action Network! Email [tenasha@hydroassoc.org](mailto:tenasha@hydroassoc.org) to sign up.

## ADVOCACY

### Where we Stand on the Issues: Advocacy Position Statements

The Hydrocephalus Association's Advocacy Program is charged with the responsibility to advocate on the behalf of the hydrocephalus community; on behalf of increased funding for research into hydrocephalus causes, treatments, and cures; and to address public policies and legislation that will impact the lives of people living with the daily challenges of hydrocephalus. On April 10, 2017, the Board of Directors approved our position statements on key legislative issues. **This is how we stand.**

## HEALTHCARE

The Hydrocephalus Association will urge legislators to preserve and/or amend healthcare policies that:

1. Assure access to affordable health insurance coverage 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.
2. Maintain the prohibition on annual and lifetime limits on health insurance.
3. Maintain out-of-pocket spending limits for patients.
4. Provide affordable health coverage options that enhance the value and control the cost of health insurance and insurance premium increases.
5. Enhance healthcare coverage for children with disabilities, children of low-income families, and economically disadvantaged families.
6. Maintain eligibility for individuals and children to remain on their parent's insurance until the age of 26.



Join our Hydrocephalus Action Network (HAN) to become an advocate for the hydrocephalus community! Email [advocacy@hydroassoc.org](mailto:advocacy@hydroassoc.org) for more information.

## EDUCATION

The Hydrocephalus Association will urge legislators to support educational policies that:

1. Increase and preserve investment in education at all levels for children and young adults with special needs, including preserving Part B of the Individuals with Disabilities Education Act (IDEA) that guarantees children with disabilities a free public education appropriate to their needs.
2. Oppose any initiatives that would reduce the existing educational rights of children with special needs under such bipartisan laws as the Every Student Succeeds Act (ESSA) and the Individuals with Disabilities Education Act (IDEA).
3. Preserve Early-Intervention and Head Start programs for at-risk infants and toddlers.
4. Oppose any change to existing federal law or regulations that would (a) permit the expenditure of federal funds in any school or educational setting which fails to comply with federal education laws regarding children with special needs, or (b) reduce the availability of funds that support Free Appropriate Public Education (FAPE) and special education services and programs that comply with federal educational laws, including ESSA and IDEA.

## LABOR

The Hydrocephalus Association will urge legislators to preserve and protect labor policies that:

1. Prohibit discrimination based on disability in the workforce, including accessibility and reasonable accommodations to employees with disabilities.
2. Preserve the Workforce Innovation and Opportunity Act and Americans with Disabilities Act to protect the employment rights of people with disabilities in the workforce.

## SCIENCE and RESEARCH

The Hydrocephalus Association will urge legislators to develop research policies that:

1. Support increased funding for science and health research, including allocations that reflect the prevalence of hydrocephalus in the population.
2. Support hydrocephalus research as a condition to be tracked under the National Neurological Diseases Surveillance System.
3. Support the continued inclusion of Hydrocephalus as a condition eligible for funding through the CDMRP.
4. Support increased funding for NIH, NINDS, the BRAIN Initiative, and the Precision Medicine Initiative.

## WALKS AND SPECIAL EVENTS

### Top 2016 WALK Teams

Congratulations to our Top WALK to End Hydrocephalus™ Teams throughout the country. They are ranked from among the 1,020 Teams representing more than 8,300 participants who participated in 2016 WALK events! The teams are ranked by amount raised — some of which are very close. Who will be in this year's Top 20?



Team Rain, Los Angeles WALK

### 2016 WALK – National Top Teams

Nat'l Rank	Team Name	Team Captain	WALK Site	# of Team Members	Amount Raised
1	<b>TEAM RAIN</b>	Farrah Weitz	Los Angeles WALK	43	<b>\$ 67,901</b>
2	<b>TEAM ALEX</b>	Alex Rodger	South Florida WALK	94	<b>\$ 49,667</b>
3	<b>CHARLIE'S ANGELS</b>	Jennifer Pope	Los Angeles WALK	68	<b>\$ 35,140</b>
4	<b>KYLE'S KREW</b>	Veronica McGee	Central Alabama WALK	1	<b>\$ 34,035</b>
5	<b>TEAM WILLIAM</b>	Lori Poliski	Seattle WALK	47	<b>\$ 24,123</b>
6	<b>TEAM HARRIS</b>	Joey Harris	Chicago WALK	42	<b>\$ 18,120</b>
7	<b>TYLER'S WARRIORS</b>	Tyler Padron	Long Island WALK	40	<b>\$ 15,580</b>
8	<b>CONOR'S CREW</b>	Katie Cook	Chicago WALK	32	<b>\$ 14,689</b>
9	<b>TEAM DAVID</b>	Tessa van der Willigen	National Capital WALK	19	<b>\$ 12,258</b>
10	<b>TEAM GOLDMAN</b>	Julie Goldman	New York City WALK	17	<b>\$ 11,667</b>
11	<b>TEAM JACOB DENNIS</b>	Susan Fiorella	National Capital WALK	36	<b>\$ 11,335</b>
12	<b>TEAM MAX</b>	Cortney Pellettieri	Los Angeles WALK	12	<b>\$ 11,240</b>
13	<b>WILL'S WARRIORS</b>	Heather Rader	Central PA WALK	84	<b>\$ 11,125</b>
14	<b>AMELIA STRONG</b>	Claire Holley	Atlanta WALK	8	<b>\$ 10,955</b>
15	<b>ASHLEY AND THE ROCKIN' RUTHS</b>	Christy Ruth	Greater Charlotte WALK	19	<b>\$ 10,943</b>
16	<b>TEAM EMA'S HOPE</b>	Chara McLaughen	Chattanooga WALK	34	<b>\$ 10,712</b>
17	<b>TEAM LILLY</b>	Anna Beck	Atlanta WALK	19	<b>\$ 10,211</b>
18	<b>MYLES NINJA WARRIORS</b>	Erik Chamberlain	Chicago WALK	8	<b>\$ 9,845</b>
19	<b>TEAM LILY</b>	Kristen Woodruff	St. Louis WALK	9	<b>\$ 9,821</b>
20	<b>TEAM ABAGAIL: THOUGH SHE BE BUT LITTLE, SHE IS FIERCE</b>	Matt McCall	National Capital WALK	45	<b>\$ 9,754</b>

# INTRODUCING OUR NEW ONLINE SYSTEM

## for the WALK to End Hydrocephalus™

HA is pleased to announce a change in software for the 2017 WALK to End Hydrocephalus™! Switching to the latest software for WALK fundraising, Team Raiser, will make all online aspects of HA's WALK program easier to navigate.

### What does this mean for previous WALK participants?

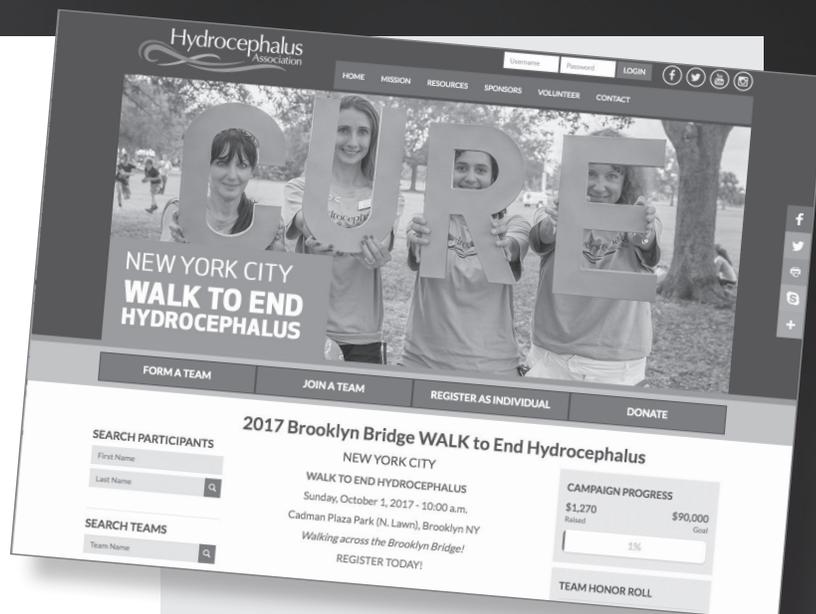
All Teams, Team Captains, and Participants will need to re-register in the new system.

Access your local WALK to End Hydrocephalus web page at HA's web site. Go to [www.hydroassoc.org](http://www.hydroassoc.org), select Get Involved, select WALK Schedule and choose your local WALK site.

**Questions?** If you have any questions or experience any difficulties in registering your Team, yourself, team members, or donating to a WALK to End Hydrocephalus participant, please contact the WALK/Special Events Department at 888-598-3789 or [walk@hydroassoc.org](mailto:walk@hydroassoc.org).

Did you notice the "™" designation included with the name of the event — the WALK to End Hydrocephalus? The WALK'S new name — the WALK to End Hydrocephalus — has been trademarked by the Hydrocephalus Association!

Have you joined us on Social Media?



### FORM A TEAM

If you are, or were, a Team Captain, select *Form a Team* and follow the prompts.

### JOIN A TEAM

If you are, or were, on a WALK Team previously, select *Join a Team* and search to see if your Team web page has been launched. (If it has not, contact your Team Captain) Then, follow the prompts.

### REGISTER AS INDIVIDUAL

If you are, or have participated in the WALK, but not as part of a team, select *Register As Individual* and follow the prompts.

### DONATE

**Donate** to support someone's participation in the WALK to End Hydrocephalus!

**Important Note: it is not necessary** to register as a WALK participant to donate to one — just select the *Donate* button on the WALK web page, search for the participant you're supporting with a contribution, and follow the prompts.

## Why we WALK

### Melenie Dailey, Charlotte WALK to End Hydrocephalus Co-Chair



Just over 16 years ago, my husband Tim and I were blessed with our 25 week, 1 pound, 8 ounce, 11 inch long, micro-preemie baby girl. From birth, Olivia defied the odds, born breathing and loudly voicing her protests. She was beautiful in that little, red, naked bird, kind of way, and appeared so healthy. Our level III NICU could not

believe how very healthy she was. 48 hours after birth, on morning rounds, they mentioned that she was showing a Grade 1 intraventricular hemorrhage (IVH). The consulting Neurosurgeon, upon speaking with us, said, "Nothing to worry about. Grade I's always resolve and never need intervention. We'll keep an eye on her, but this is nothing!"

Three days later, they placed a temporary Rickham Reservoir and, once she hit 2 lbs, she received not 1, but 2 ventriculopleural (VPLS) shunts. The same day they placed the Rickham, was the first day that they mentioned the word hydrocephalus. Our beautiful, perfect girl was determined to have congenital and acquired hydrocephalus. What??? I knew what hydrocephalus was, but I didn't know anyone who had it. We had concerns ranging from survival to intellect to life expectancy. I hit the internet and found extremely limited information, but did find the phone number for the Hydrocephalus Association and made a call. That call lasted more than 2 hours, began our education on hydrocephalus, and gave us hope.

Fast forward 16 years. Olivia is not developmentally disabled. In fact, she has ranked top of her class each year, and has taken advanced classes. She is funny and compassionate, fierce and sweet. She's also had 34 brain surgeries (in 3 different states), 3 lesser shunt infections and a vicious battle less than one year ago of Bacterial Meningitis that almost took her from us, kept her in the hospital 87 days, and that she is still recovering from. A recovery full of side effects and short term memory loss, a seemingly endless round of PT, OT and Memory Therapy, and an entire year of school and life missed.

So... we WALK. I may be a WALK Co-Chair, but this is a family (and friends) affair. My husband fully supports, contributing labor for the WALK and encouragement to other parents, spouses and those with hydrocephalus. Close friends who are generous with their time and talents. Olivia, who has helped with WALKs for many years.

We WALK because there is still a lack of funding and a large gap in research and awareness. We WALK because better protocols are needed. We WALK to provide a sense of community and support. We WALK because there is no guarantee that Olivia won't face another infection. We WALK because the only treatment is BRAIN SURGERY. We WALK because there are so many with hydrocephalus who still receive inadequate or second class care. We WALK for awareness and advocacy. We WALK in hopes that one day, no other parent, spouse or loved one has to face losing someone they love. We WALK for a cure. We WALK for Olivia. We will not stop WALKing until there is no longer a reason to WALK.

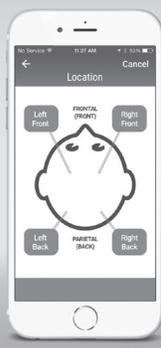
# HydroAssist™



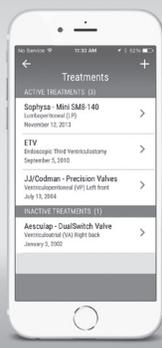
HydroAssist™ is the first mobile app that allows you to record and store your hydrocephalus treatment history and access it when you need it from your mobile device.



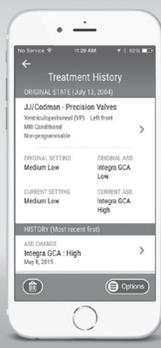
Use the first hydrocephalus app created by medical experts and patients.



Enter information quickly and easily.



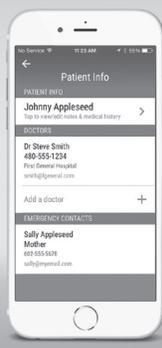
Get a clear and complete view of all active and inactive treatments.



Access a comprehensive treatment history documenting all procedures.



Store images of your recent scans.



Save information about yourself, doctors, and emergency contacts.

## Accept the Personal Challenge. Share the Victory!

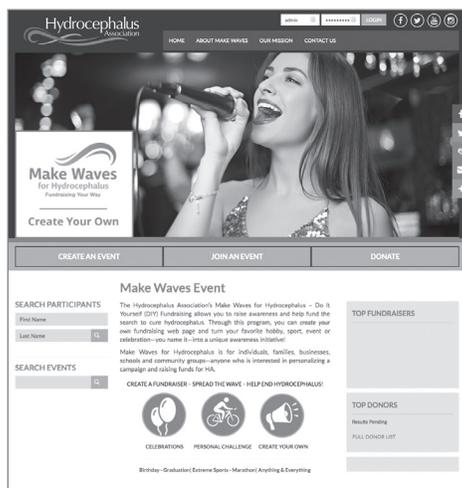


Calling all marathoners! Or iron man/woman competitors! Or competitive bicyclists! Did you know you could use your participation in a marathon, triathlon, Ironman/Ironwoman competition, or bicycle race to raise money for HA and its mission?

It's simple — register for the marathon or other competition in which you've chosen to participate.\* Then go to HA's web page ([www.hydroassoc.org](http://www.hydroassoc.org)), select **"Get Involved > Make Waves for Hydrocephalus."** On the Make Waves event page select **"Create an Event."** Instructions on the Personal Challenge section of Make Waves will help you setup your own web page. Edit your page to tell people what you're doing. Then tell your story and why HA's mission is important to you. Include a photo of yourself training for or a photo of your inspiration. Email everyone you know, asking them to make donations in honor of your participation in this grueling challenge.

You don't need to be a competitive runner or cyclist to use **"Make Waves- Personal Challenges"** to raise money for HA's mission. A personal challenge can be whatever you choose. HA's staff will be happy to help you with meeting your own personal challenge and using it to raise money to support the cause. **Accept the Challenge — Share the Victory!**

*\*HA does not manage marathon or other competition registrations. Nor does it cover any expenses associated with participation. This is solely a method to use your participation in a "challenge" to raise money for HA. Over the years, dozens of athletes have used their marathon, half-marathon or triathlon participation as a way to raise money for HA, totaling tens of thousands of dollars. Join this elite group and make a difference. For more information or assistance contact HA's WALK/Special Events team at (888) 598-3789 or [info@hydroassoc.org](mailto:info@hydroassoc.org).*



## 2017 WALK to End Hydrocephalus Sites

Atlanta, GA	9/16/17
Baltimore, MD	10/7/17
Basking Ridge (Morristown area), NJ	9/24/16
Central AL (Birmingham), AL, 10th Aniv.	10/29/17
Central PA (Hershey/Harrisburg), PA	9/16/17
Charlotte, NC	10/28/17
Chattanooga, TN	10/21/17
Chicago, IL	8/26/17
Cleveland, OH	10/8/17
Columbia, SC: 9/30/17	
Connecticut (Middlebury), CT	9/24/17
Dallas/Fort Worth, TX	10/14/17
Denver, CO	9/3/17
Detroit, MI	8/27/17
Eastern Carolina (Greenville area), NC	10/14/17
Greater New England, MA, 10th Aniv.	10/1/17
Houston, TX	10/28/17
Indianapolis, IN	9/30/17
Los Angeles (Redondo Beach), CA	9/9/17
Louisville, KY	9/24/17
New York City, NY	10/1/17
National Capital, Washington, DC	9/16/17
Northwest Arkansas (Rogers), AR	9/2/17
Orlando, FL	10/28/17
Portland, OR (Already Passed)	6/10/17
Salt Lake City-10th Annual!, UT	9/16/17
San Francisco, CA	9/23/17
Seattle, WA	8/12/17
South Florida (Deerfield Beach), FL	10/21/17
St. Louis, MO	10/21/17
Twin Cities (Mall of America), MN	9/10/17
Western NY (Buffalo area), NY	9/9/17
Western PA (Pittsburgh area), PA	9/23/17
Wichita, KS	10/14/17



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# BE A SUSTAINER

## Join Our Monthly Giving Program

What started as a small network of concerned parents in 1983 has blossomed into the nation's largest and most widely respected health advocacy organization devoted to meeting the needs of those affected by hydrocephalus. Today — with your support — we are the fastest growing hydrocephalus movement, representing over one million people and counting.

You can help us continue our work by becoming a Sustaining member through our Monthly Giving Program. Gifts of just \$20 a month will make a huge difference! Knowing we can count on you for 2017, we promise to continue to devote every dollar to further critical research and support services to our growing community.

**To find out how you can join our Monthly Giving Program, please contact the Hydrocephalus Association at (888) 598-3789 or choose the “Monthly Giving” option on [www.hydroassoc.org](http://www.hydroassoc.org)**

