



VOLUME
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EDITION 1

New Website, New Resources!

We've launched a new website! Our new site is filled with resources and tips to help you manage your day-to-day life of living, or caring for someone, with hydrocephalus.

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Meet Our Latest Research Grantees

Each year we award grants to brilliant scientists to fund their high-impact research projects. Learn about our latest grantees!

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One Woman's Struggle to Get Diagnosed

Merlin Bott spent 29 harrowing days in the hospital getting poked and prodded before finally being diagnosed with NPH. Read her inspiring story!

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Our WALKs Are Back!

We're excited to welcome you back in person to a WALK to End Hydrocephalus near you! Join us as we raise awareness and funds for a cure.

MESSAGE FROM THE PRESIDENT AND CEO



2020 was a year like no other, challenging all of us in ways we could never have imagined. We know the stress many of you felt this past year because we felt it, too.

The pandemic forced us to think outside the box, making us pivot all of our events to virtual. Like many nonprofit organizations, we were impacted financially, but it was wonderful to see how our community helped us weather the storm.

You made it possible for us to maintain operations and continue to fund important programs and research through your support of the Resilience Fund and all of our fundraising efforts. For that, I can't thank you enough!

Now, with the COVID-19 vaccine making its way across the country and a new year upon us, I'm feeling hopeful about the future.

That's why we've decided to return to hosting in-person WALK to End Hydrocephalus events in over 40 cities. We can't wait to come together as a community once again! We've missed your smiling faces and energy! As you may know, our WALK to End Hydrocephalus program is not only a great way to connect with others impacted by this condition, it's also one of our largest fundraisers – helping us raise critical funds to support our free education and support programs, and research. See page 16 to learn more.

The other big news to share is that we launched a new website filled with new resources and tips to help you manage your day-to-day life of living, or caring for someone, with hydrocephalus. Revamping our website on a small team like ours was no easy feat. We first surveyed some of our key stakeholders to find out what topics and sections they felt were most important. Using that feedback, we worked with

our Medical Advisory Board and other partners to develop new content. I hope you can agree that our new website will help you learn, connect, and get inspired!

Helping to educate and inform you is one of our top priorities. That's why this year we're hosting free webinars every month on topics you've told us are important. Be sure to check out page 9 to read about our upcoming webinars. We've also developed virtual meet ups through Facebook to help you connect with your peers around the country. You can learn about those on page 10.

There is so much going on and every day we strive to help you on your journey with hydrocephalus. One of the ways we're doing that is through our Research Program. We continue to fund high-impact research and this year, with generous support from Team Hydro and the Rudi Schulte Research Institute, we awarded four brilliant scientists with our Innovator Award. The Innovator Award provides seed funding for bold and innovative work with the potential to transform hydrocephalus research. Check out page 6 to read about our latest grantees! They are doing truly exciting research that could be a game changer for our community.

Of course, none of our research would be possible without YOU. So, on behalf of all of us at HA, thank you so much for your support -- whether you made a donation or volunteered your time, we couldn't do it without you!

Sincerely,

A handwritten signature in black ink that reads "Diana Gray". The signature is fluid and cursive.

Diana Gray, MA
President and Chief Executive Officer

VISIT
hydroassoc.org/get-involved
to learn about the various ways
you can get involved with HA

Introducing Our New Website!

With new resources to help you on your journey with hydrocephalus

Have you heard the news? We've launched a new website! The new hydroassoc.org not only looks different, it's filled with new resources and tips to help you manage your day-to-day life of living, or caring for someone, with hydrocephalus. Whether you are newly diagnosed or have been on this journey for a long time, our new website has something for everyone. Here are a few of the new sections we hope you'll check out:

NEWLY DIAGNOSED

Have you or a loved one recently been diagnosed with hydrocephalus? Whether you are living with hydrocephalus or are a caregiver – we're here to help you on this journey. We developed guides and next steps tailored to specific age groups and life stages.

DAILY LIFE

Hydrocephalus can affect your life in many ways but the degree of impact can vary. Learn how to manage the day to day symptoms and associated problems you might encounter so you can make informed decisions regarding your lifestyle and medical care.

CARING FOR YOUR CHILD

It's common to have countless questions about the condition and how to help your child live the best life possible. Here you will find essential tools and resources to help you advocate for your child, make informed decisions, and manage your child's daily needs.

LIFE WITH NPH

A diagnosis of Normal Pressure Hydrocephalus (NPH) is complex and frustrating. Staying informed about the condition is essential to managing care. Here you'll find resources, tips, and real-life stories, that will enable you to make smart choices about your care so you can learn to thrive with this condition.



LIFE TRANSITIONS

There are many milestones where hydrocephalus will play a role in your planning and the decisions you make. Learn how to navigate and embrace these milestones fully informed and with confidence.

PREPARING FOR SURGERY

The thought of having to undergo brain surgery is frightening and can be physically and emotionally taxing. That's why preparing is essential. This section will help you learn about shunt and ETV procedures and what to expect post-surgery.

This is just the tip of the iceberg! Be sure to visit the Research section to learn more about our research program, the progress we've made and the scientists we fund. We've also expanded our Help & Support section, with more information about the various ways HA can help you on your journey with hydrocephalus. Visit our Get Involved section to learn more about our WALK to End Hydrocephalus, our Advocacy efforts, and to find new tools to help you raise awareness about hydrocephalus!

We hope our new site will help you connect, learn and get inspired! Let us know of any suggestions for how we can improve the site. As always, we value your input!

Congressmen Lloyd Doggett and Chris Smith Join Forces to Raise Awareness About Hydrocephalus



Representatives Lloyd Doggett (D-TX) and Chris Smith (R-NJ) have joined forces to champion two critical Hydrocephalus Association priorities for the 117th Congress. Specifically, they've introduced H. Res. 20, a bipartisan resolution supporting September as Hydrocephalus Awareness Month. They also reconstituted the bipartisan Congressional Pediatric and Adult Hydrocephalus Caucus, which plays a critical role in raising awareness of the condition on Capitol Hill. Both actions reflect their deep and abiding understanding of the needs and interests of hydrocephalus patients, families, and caregivers.

H. Res. 20 points to the many challenges this condition poses for patients, their families, and the country as a whole. Among other things, the resolution references the following facts: over one million Americans live with the condition; one in 770 babies develop hydrocephalus each year; up to two-thirds of service members with traumatic brain injuries may develop hydrocephalus; and, the only treatment for the condition is brain surgery. The Congressional Hydrocephalus Caucus serves to raise awareness of these devastating problems, along with the need for concrete solutions.

"In support of the over one million people living with hydrocephalus in the U.S., we are deeply grateful to Representatives Doggett and Smith for their support of Hydrocephalus Awareness Month and in reinstating the Congressional Pediatric and Adult Hydrocephalus Caucus. Their actions demonstrate their commitment to raising awareness about this condition in Washington, D.C. and beyond. We at the Hydrocephalus Association appreciate their willingness to embrace the needs of patients and families around the country as we seek to find better treatments and possibly a cure. They are essential partners

in these efforts," said Diana Gray, President and CEO of the Hydrocephalus Association.

Anyone can develop hydrocephalus, an abnormal accumulation of cerebrospinal fluid in the brain, at any time. This can include premature babies, active duty service members, veterans, and seniors. Individuals can also be born with it, develop it as part of the aging process, or acquire it as a result of infections, brain tumors or traumatic brain injuries, among other causes. Unfortunately, the overall population affected by hydrocephalus is growing, but the public and many policymakers are still unaware of the condition and the needs of those it affects. The Congressional Hydrocephalus Caucus works toward increasing understanding of the condition, as well as developing policy solutions designed to improve quality of life for those impacted.

WANT TO HELP OUR ADVOCACY EFFORTS? JOIN US!

MAY 25

Congressional Fireside Chat about the Congressional Hydrocephalus Caucus featuring Kelsey A. Griswold, Legislative Director, Congressman Christopher H. Smith (NJ-04); and Benjamin Faiz, Legislative Fellow, Congressman Lloyd Doggett (TX-35)

JULY

Congressional Virtual Fly-In to meet with our elected members of Congress

Check out our Advocacy Center on our website for dates of upcoming events and information about our Advocacy Initiative

hydroassoc.org/advocate

HA In The News!

The Hydrocephalus Association has been appearing in the media lately!



Did you catch us in *Reader's Digest The Healthy* publication? They published a series on Normal Pressure Hydrocephalus (NPH) and featured two of our peer support volunteers, highlighting their inspiring stories about their NPH diagnosis and what happened after they received treatment. The articles also featured comments from a member of our Medical Advisory Board,

Dr. Abhay Moghekar with John Hopkins University, and Dr. Guy McKhann with Columbia University, who is part of HA's Adult Hydrocephalus Clinical Research Network (AHCN). In addition, HA was profiled on Research!America's blog.

Here are some of the headlines we've made recently:

How a Reversible Type of Dementia Can be Mistaken for Alzheimer's Disease

Reporter Russell McLendon wrote an in-depth piece about Normal Pressure Hydrocephalus (NPH), a treatable form of dementia that targets more than 700,000 Americans, yet about 80 percent of cases are undiagnosed. The article highlighted the typical symptoms of NPH, why it can be hard to diagnose, how its treated and what happens after treatment.

www.thehealthy.com/alzheimers/normal-pressure-hydrocephalus

Women's "Dementia" Turned Out to Be a Treatable Brain Condition

This piece highlighted the story of Dorothy Sorlie, an HA Peer Support Volunteer. It took years for doctors to discover that Dorothy's walking, incontinence, and cognitive problems were due to NPH. After finally getting diagnosed and treated, Dorothy's debilitating symptoms disappeared and she is now thriving.

www.thehealthy.com/alzheimers/normal-pressure-hydrocephalus-diagnosis

This Man Battled Dementia for 20 Years Before Finding a Solution

This article shares the story of Stanley White, an HA Peer Support Volunteer. For two decades, Stanley battled mental fog, falls, and urinary incontinence. Finally, after doing his own research and seeing several medical professionals, he received a diagnosis of NPH.

www.thehealthy.com/alzheimers/undiagnosed-normal-pressure-hydrocephalus

Great.com Interviews Diana Gray About Promising Search for New Treatments

Spirit Rosenberg from Great.com interviewed Diana Gray, HA President and CEO, as part of their 'Great.com Talks With...' podcast. This series is an antidote to negative news stories that aims to shed light on organizations and experts whose work is making a positive impact on the world. The interview focused on HA's Research Program and the work HA is doing to accelerate hydrocephalus research.

www.hydroassoc.org/great-com-interviews-hydrocephalus-association-about-the-promising-search-for-treatment

Tune In May 26 for a Special Podcast



HA's Amanda Garzon will be a guest host on the **Advocate Like a Mother™** pocast series. The podcast, titled "Advocating for our Medically Complex Children," will feature Melenie Dailey and HA

Board Member Eileen Rodger, both hydromoms of young-adult children living with hydrocephalus. They will share stories and lessons learned on advocating effectively with doctors and in the hospital setting. The podcast will be available on the Advocate Like a Mother™ page and through Apple Podcast, Spotify, Google Podcasts and Anchor.

Meet Our Newest Innovator Award Grantees

Every year, the Hydrocephalus Association awards grants to brilliant scientists to fund their high-impact research projects. We're pleased to announce our latest Innovator Award grantees! These researchers are examining everything from why some people experience shunt blockages to new techniques to treat congenital hydrocephalus.



Carolyn Harris, PhD

Wayne State University
Supported by Team Hydro

Preventing shunt occlusion

Dr. Harris is focused on understanding the differences in how immune cells in the brain react after a shunt is placed. This information will shed light on why some people are more likely to experience shunt blockages than others and direct new therapies to prevent shunt blockages.



Jose Peiro, MD, PhD

University of Cincinnati
Funded by RSRI

Treating congenital hydrocephalus prior to birth

Dr. Peiro is developing a technique to treat congenital hydrocephalus by performing an endoscopic third ventriculostomy (ETV) in utero. Early treatment may improve cognitive outcomes and negate the need of a shunt.



Aditya Pandey, MD

University of Michigan

Preventing hydrocephalus after a stroke

Dr. Pandey aims to test if acetazolamide (Diamox), when put directly into the ventricles, can block the activity of a protein in blood and prevent hydrocephalus after a stroke. Although acetazolamide has been tested before, this is the first time intraventricular administration will be attempted.



Stavros Taraviras, PhD

University of Patras
Supported by Team Hydro

Turning scar tissue into functioning cells

Dr. Taraviras is working to reprogram scar tissue into functioning ependyma, the cells that line the ventricles. In many forms of hydrocephalus, ependyma are damaged and fall into the cerebrospinal fluid (CSF). Scar tissue replaces the ependyma. This treatment could reduce ventricle size and improve CSF movement, brain development, and brain health.



Make an Impact by Joining our Monthly Giving Club!

By giving every month, you help to ensure that the work of the Hydrocephalus Association continues, as we get closer to a cure for hydrocephalus, and provide programming that improves the lives of those impacted by the condition.

hydroassoc.org/impactpartners

HA in Attendance

HA represents the hydrocephalus patient community at key scientific and professional meetings. Here are meetings we have attended over the last six months:

**Research America Alliance
Member Meeting**
October 28

**Milken Institute 2020 Future
of Health Summit**
December 7-9

Society for Neuroscience
January 11-13

**NHC Virtual Health
Leadership Conference**
February 10-11

**Health Research Alliance Spring
Membership Meeting**
March 22-23,25



How Can You Make the Difference?

Join HAPPIER!

The Hydrocephalus Patient Registry!

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

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

JOIN NOW!

hydroassoc.org/happier

Introducing our Inaugural Scientific Advisory Board

We're excited to introduce our new Scientific Advisory Board (SAB). The SAB will help shape HA's research agenda, providing scientific leadership and guidance, and input into the development of our scientific programming and alliances.



Guy Fish, MD (Chair)

HA Board Member, former CEO, Cellanox

Expertise in life sciences and health care innovation, development, and commercialization



Jill Morris, PhD

National Institutes of Health

Expertise in neurological disorders, glial biology, neural crest cells, and genetics



Richard Keep, PhD (Vice Chair)

University of Michigan

Expertise in blood-brain and blood-CSF barriers, hemorrhage, and inflammation



Mike Siegel, PhD

Pediatric Dermatology Research Alliance

Expertise in scientific programs and bioengineering, living with hydrocephalus



Issac (Zak) Kohane, MD, PhD

Harvard Medical School

Expertise in genomics, precision diagnoses, technology, and big data



Mark Wallace, PhD

Vanderbilt University

Expertise in sensory motor integration, developmental conditions, and electrophysiology

NEW AND IMPROVED HYDROASSIST | COMING SOON!

Hydro Assist[®]

- ✓ Symptom journal
- ✓ Headache tracker
- ✓ Physician finder based on location

Hydro Assist[®] is a mobile app that allows you to record and store your hydrocephalus treatment history and access it when you need it from your mobile device or through your computer or laptop. Perfect for individuals living with hydrocephalus and their caregivers. Based on feedback from YOU, we made several improvements! New features available later this year!



SUPPORT AND EDUCATION

Register for One of Our Free Webinars!

This year, we're hosting one new webinar every month. Be sure to take advantage of these FREE educational opportunities from the comfort of your own home!

Role of the Ventricular Lining in the Development of Hydrocephalus and Potential Drug Targets

JUNE 8, 2021, 7:00 PM ET

Join Dr. David Limbrick from Washington University in St. Louis to learn more about his research on how the cells that line the ventricles may contribute to multiple types of hydrocephalus, including congenital hydrocephalus and posthemorrhagic hydrocephalus. Dr. Limbrick's research has led to the discovery of a new drug target that his lab is currently testing.



David D. Limbrick Jr., MD, PhD

Executive Vice-Chair, Department of Neurosurgery Chief, Division of Pediatric Neurosurgery T.S. Park, MD Chair of Pediatric Neurosurgery, Professor of Neurological Surgery and Pediatrics, Neurosurgeon-in-Chief, St. Louis Children's Hospital, Member of HA's Medical Advisory Board

Do You Know Your Rights?

JULY 15, 2021, 7:00 PM ET

Living with a chronic medical condition like hydrocephalus can also mean living with a number of other health conditions, including mild to severe physical, cognitive, and/or mental health challenges. As adults (or children growing into adults) living with differing abilities, what protections do we have under federal law? How is disability defined in the U.S.? How can this definition both define and confine us, as individuals?

Join Betty Siegel, a nationally recognized leader in disability, human and civil rights, for an engaging presentation on the history and evolution of federal laws and legislation for individuals with disabilities, the protections they provide, and how they relate to individuals living with hydrocephalus. If you've heard of an IEP or a 504 plan, have felt that you were treated differently or that you had to hide your hydrocephalus, or any other differing abilities, this webinar is for you!



Betty Siegel, JD

Director of VSA and Accessibility, The John F. Kennedy Center for the Performing Arts

[Visit hydroassoc.org/webinars](https://hydroassoc.org/webinars)

to register, to see a full list of upcoming webinars and to view recordings from previous webinars.

Join Us For Our First Spanish-Language Webinar

Offering an Overview on Hydrocephalus

Únase a los Dres. Michael G. Muhonen y Joffre E. Olaya para aprender más sobre la hidrocefalia. Obtenga información sobre las causas de la hidrocefalia, cómo se diagnostica, las diferentes opciones de tratamiento que hay disponibles, las posibles complicaciones y cómo controlar la salud de su hijo.

Visit hydroassoc.org/webinars for the date and time, and to register!

Join Us Online for These Fun and Interactive Events!

In response to the current COVID-19 pandemic and the social distancing guidelines, many of our community networks are hosting meetings virtually. Here are some of the events taking place this year! Join your local community network to participate and learn more.

Discovering Your Strength with Lian

MAY 17 AND MAY 24, 2 PM EST

Hosted by community networks in the Northeast and Southeast regions

Lian will discuss overcoming anxiety by cultivating your resilience and well-being through the practice of yoga.

Sibling Panel for Parents

JUNE 11, 7 PM EST

Hosted by community networks in the Southeast and Northeast regions

An open and honest Q&A with siblings of individuals living with hydrocephalus. This session is intended for parents and caregivers.

PARENTS: Planning for the Future for our Kids with Eric Jorgensen, Special Needs Navigator

JUNE 16, 8 PM EST

Hosted by community networks in the Midwest, Southwest, and Western regions

There are so many services, programs, legal and financial advice given to parents to help with the transition into independence - college, work, life - yet it seems like no one is connecting the dots about how they all work together.

Sibling Panel for Parents

AUGUST 13, 9 PM EST

Hosted by community networks in the Midwest, Southwest, and Western regions

An open and honest Q&A with siblings of individuals living with hydrocephalus. This session is intended for parents.

PARENTS: Your Child's Journey with Hydrocephalus

SEPTEMBER 14, 7:30 PM EST

Hosted by community networks in the Southeast and Northeast regions

A conversation with a panel of young adults reflecting back on growing up with hydrocephalus.

We also have support networks who meet regularly:

Adults with Hydrocephalus

(DC, MD, VA, PA, DE, NJ)

MEET ONCE A WEEK ON SATURDAYS AT 3 PM EST

Young Adults in their 20s

MEET ONCE A WEEK ON SATURDAYS AT 7 PM EST

Teens

MEET THE FIRST SUNDAY OF THE MONTH AT 6 PM EST



Visit HA's Facebook page (@HydroAssoc) to join these regular group meetings.

Join Your Local HA Community Network

You are not alone! The Hydrocephalus Association has over 40 Community Networks across the country. Community Networks are a great way to connect with individuals and families in your local area who are impacted by hydrocephalus. In response to the current COVID-19 pandemic and the social distancing guidelines, many are hosting meetings virtually. Visit HA's website to find and join your local Community Network's online private Facebook group and to stay updated on local events. Don't see one in your area? Start one! Contact info@hydroassoc.org or call (888) 598-3789 for details!

AK	Anchorage	OH	Cleveland
AZ	Phoenix	OK	Oklahoma City
CA	Los Angeles Ventura	OR	Portland
CO	Denver	PA	Eastern PA Central PA <i>NEW!</i>
CT	Hartford	RI	Providence <i>online only</i>
DC	Washington	SC	Charleston
DE	Middletown	SD	Sioux Falls
FL	Miami South Florida (St. Port Lucie) <i>NEW!</i>	TN	Chattanooga
GA	Atlanta	TX	Dallas Houston <i>peds/adolescent</i>
IL	Chicago	UT	Salt Lake City
IN	Indianapolis	VA	Richmond
MA	Boston	WA	Seattle <i>pediatric</i> Eastern WA Vancouver
MD	Baltimore	WI	La Crosse <i>online only</i>
ME	Portland	Military Members	<i>online only</i>
MI	Detroit	Nigeria	Lagos <i>children/families</i>
MN	Minneapolis <i>peds/adolescent</i>	Spanish-Language Network	(Red de Apoyo Para la Hidrocefalia) <i>online only</i>
MO	St. Louis	Young Adults 20s Group	<i>national - online only</i>
NC	Charlotte		
ND	Fargo & Morehead, MN		
NJ	Jersey Shore Northern NJ <i>NPH</i>		
NY	Western NY Long Island New York City		

HELP IS A PHONE CALL AWAY!

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

The helpline is available via phone and email.



(888) 598-3789

to speak to a support staff member.



info@hydroassoc.org

for support, resources and answers to your questions.

Visit hydroassoc.org/communitynetworks to learn more!

Stories from Our Community

We invite the hydrocephalus community to share their hydrocephalus journey with us so we can highlight stories of resilience! Stories are posted on HA's website, featured in our print and electronic newsletters, and shared on our social media channels.



Inspired by the many nurses who cared for her over the years, Brianna recently graduated from nursing school to fulfill her lifelong dream of becoming a nurse.

BRIANNA, 23

Over the years, hospitals have become my "home away from home." My life started in the operating room at Stony Brook Hospital, and I spent the first year of my life in the Pediatric Intensive Care Unit. CT scans, IVs, and surgeries marked the beginning of my life.

Just when my parents thought they were to give birth to a baby girl, their whole world came crumbling down. When I was only three and a half weeks old, I was diagnosed with bacterial

meningitis. My parents were distraught, especially when the doctor told them I was not going to make it. Tears rolled down my dad's face as he held me. My aunt Angela was there through thick and thin giving my family the best support. As she saw my dad crying, she said, "Don't worry she's going to be okay. You will be walking her down the aisle for her wedding."

I was hospitalized for months at a time having many antibiotic treatments to treat this deadly disease. The doctors informed my parents that I most likely would have permanent damage, such as being blind or deaf, and may not be able to lead a normal life. I am not blind or deaf, but meningitis led me to develop hydrocephalus.

After I was discharged from the hospital, my parents looked at my head and I had a huge lump on the back of my head. So,

I had emergency surgery done to have my first shunt placed. I ended up having 10 brain surgeries before the age of 1! But by the time I turned 2, I was surgery free for over a decade.

That all changed when I turned 13 and began experiencing awful headaches, neck pain, and no appetite. I had doctor visits day after day, but they told me it was just a virus. This continued for three weeks until one day I couldn't function in school and went to the nurse pale as a ghost. My mom picked me up and brought me home where I vomited. She called my neurosurgeon who told her to rush me to the ER. When I got there, I was informed that my whole shunt had detached from my head. The doctor was surprised I was still smiling and laughing.

I had ten more surgeries that year due to an infection in my spinal fluid. In total, I have had over 40 brain surgeries.

I presently have three shunts in my head and suffer daily from severe right eye pain, headaches, stomach pain along the tract of my shunts, and dizziness. ***Through my journey though, I have learned to stay strong and never give up. I do not give up hope that one day I will feel better and be able to live my normal life again.***

Dealing with hydrocephalus takes an emotional toll on me but I am blessed to have the support system that I do. I do not let my condition stop me. I am now pursuing my childhood dream to become a nurse. While in nursing school at Adelphi, I was told by the dean that I didn't have what it took to be a nurse. After hearing this, I was distraught and asked to leave Adelphi. I transferred to Suffolk County Community College and it has been the best decision of my life. I recently graduated nursing school and am currently applying to jobs. The care that I have received throughout my life from the amazing nurses have inspired me to pursue this career.



MORGAN, 36

In May of 2019, I became extremely ill. For days I had extreme nausea, debilitating headaches, body aches, dizziness, and neck stiffness. My belief was that I had the worst kind of flu, but not being able to turn my head or see clearly gave me the urgency to go to the ER.

My last visit to the ER I was put in the hallway for 4 hours, given a Tylenol, and sent home. So my outlook on this visit wasn't much

"As a woman of color, our grievances are usually overlooked and we tend to fade into the background suffering in silence. My vow is to not let this illness get the best of me or others."

different or with any positivity. Thank God I met with a doctor who was genuinely concerned as my symptoms presented as meningitis. After multiple tests and my opening pressure from the spinal tap, he then diagnosed me with pseudotumor cerebri and hydrocephalus.

I broke down and cried. Not from fear or even pain at that point, but to have an answer. The years of migraines were REAL. The ringing in my ears was REAL. The increased depression was REAL. From there I was put on Diamox for about a year but with no real relief. After reaching the maximum dosage (2,000mg/day), it was then I saw an Ophthalmologist and was informed how inflamed my optic nerves were. I had suffered some vision loss which turned out to be because of my hydrocephalus. That didn't sit well with me.

My follow up was with my current neurosurgeon who advised me that I have extremely narrow ventricles in my brain and that a VP shunt would be the best solution. Then in October 2020, my shunt was placed. Recovery has been a battle since.

My symptoms of seizures, memory loss and severe residual pain were dismissed or medication was thrown at me to soothe my fears. I have seen just about every scope of doctor under the sun to find answers to my extreme pain, but only

my own research and relentless questions were able to give me the answers I need.

I am still battling through this rough recovery every day, and now feel back to where I began. However, I will NOT give up. As a woman of color, our grievances are usually overlooked and we tend to fade into the background suffering in silence. **My vow is to not let this illness get the best of me or others.** With the help of the Hydrocephalus Association and its community, I will gladly help in being a voice for the class of people that go unheard and need healing.

TELL US ABOUT YOUR JOURNEY WITH HYDROCEPHALUS!

Hydrocephalus affects each of us differently. Share your story of hope and perseverance with us!

We will feature the amazing individuals in our community who are living life to the fullest regardless of their condition!

Visit [hydroassoc.org/
shareyourstory](https://hydroassoc.org/shareyourstory)
to submit your story!

A Mystery Disease: One Woman's Struggle to Get Diagnosed



Merlin Bott remembers the day she first started feeling sick. She woke up one morning in October 2013 with a severe case of vertigo. It quickly got worse and over the next few days she couldn't keep anything down, kept falling over and

started having problems with her short-term memory.

She consulted her ear, nose and throat doctor, who ended up performing a balloon sinuplasty procedure, thinking she had a terrible ear and sinus infection. Unfortunately, her symptoms only continued to worsen. Soon, she became so dehydrated that she had to be hospitalized.

"At the hospital, they thought I had h pylori because I kept throwing up and they also thought I might have lung cancer so they ran several tests. They even thought I might have some type of dementia since my memory was so bad at that point. Then, since I was a flight attendant they thought I caught a rare disease overseas like SARS or TB. So I was quarantined for 48 hours. They called in the CDC to come in and do independent tests on me. The tests came back negative for everything," Merlin explained.

Finally, doctors performed a lumbar puncture and discovered that she had excessive fluid in the brain. She was told she likely had hydrocephalus but not to worry about it and was told she could go home. Wanting to seek a second opinion, Merlin and her husband Chris sought out a neurosurgeon at the Cleveland Clinic. The neurosurgeon performed an MRI and gave them bittersweet news.

"He said she needs brain surgery and she needs it now. I was hesitant and thought, 'isn't there a pill that can help her get better?' The doctor said there wasn't and the next day she had surgery to have a shunt placed," said Chris, who has been with Merlin every step of the way throughout her journey. "It was a horrible feeling. When you're told your loved one need brain surgery you just think, 'oh my god will our lives ever be the same?'"

It turns out that Merlin had **Normal Pressure Hydrocephalus (NPH)**, a type of hydrocephalus most commonly seen in older adults. People with NPH typically

have difficulty walking, cognitive impairment, and impaired bladder control. Merlin had all of those symptoms.

Since NPH symptoms often mirror those of other diseases that affect people over 60, like Alzheimer's, Parkinson's or other neurodegenerative conditions, many people with NPH struggle to be diagnosed correctly. **In fact, it's estimated that 1 in 10 dementia patients actually have NPH but may never be diagnosed.**

In total, Merlin spent 29 harrowing days in and out of the hospital.

Since her shunt surgery, life for Merlin changed for the better. While her recovery wasn't easy, she slowly regained her ability to walk. The vertigo disappeared and her memory improved. Today, Merlin is 66 years old and is enjoying her recent retirement from over 35 years as a flight attendant.

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"I don't know how I got NPH. We need to know more about hydrocephalus and we need more treatments other than brain surgery. If we can keep doing research and find other treatments and a cure, I would love to see that in my lifetime."

.....

She considers herself one of the lucky ones.

"I came close to dying and was down to 85 pounds. But I'm a strong person and fought hard to come out of this, with Chris' help. I always say, I have hydrocephalus but it doesn't have me," Merlin said.

A big part of her recovery was finding the Hydrocephalus Association, which helped her connect with other individuals who are living with NPH.

"I started participating in the Hydrocephalus Association WALK to End Hydrocephalus and met others who have NPH. Connecting with others who have what I have was so important because I didn't know what hydrocephalus or NPH was and had never met anyone with this condition," Merlin said.

She hopes HA's research efforts will help identify more ways to treat hydrocephalus and lead to a better understanding of why NPH develops.

NEW STUDY

The Use of Lumboperitoneal Shunts in iNPH Patients

By Noriana Jakopin



In the United States, the standard treatment for idiopathic Normal Pressure Hydrocephalus (iNPH) patients is a ventriculoperitoneal shunt (VPS). However, lumboperitoneal shunts (LPS) have also been shown to improve iNPH symptoms and are widely used in Japan. VPS treatment diverts CSF from the brain ventricle to the peritoneal (abdominal) cavity while LPS treatment diverts cerebrospinal fluid (CSF) from the spinal canal to the peritoneal cavity. Each treatment has its own set of advantages and disadvantages as detailed in the medical literature.

A study recently published by lead author Dr. Massimiliano Todisco in the *Journal of Neurology* aimed to investigate the efficacy of LPS in treating iNPH. This prospective study recruited 78 iNPH patients, 44 of which received an LPS while the remainder elected to forgo any surgical intervention and served as the control group. The patients underwent clinical and neuropsychological evaluations at 6 and a 12-month follow-ups.

At 6 months, patients who had an LPS had improved gait and balance. Urinary incontinence also improved in these patients, though to a lesser extent. However, there were no significant cognitive changes. At 12 months, the LPS patients still had better gait and balance than they had before surgery, however they showed a slight decline from the 6-month follow-up. The improved urinary incontinence from the 6-month follow-up remained. However, there was still no significant changes to cognition. Control patients, who received no treatment, had a worsening of gait disturbances and urinary incontinence at the 12-month follow-up, though there was no significant change in balance and cognitive function.

At the 12-month follow up visit, patients also underwent repeat MRI scans. The imaging showed improvements in the LPS group related to the subarachnoid space. They also looked at white matter hyperintensities on the MRI. A white matter hyperintensity is a bright spot on an MRI scan which indicates changes or irregularities to the white matter structure in that region. They looked at both periventricular white matter (PWM) hyperintensities, which is the white matter surrounding the ventricles, as well as deep white matter (DWM) hyperintensities.

The study found that patients who responded well to the LPS also had a reduction of PWM hyperintensities after their surgery but no significant change of DWM hyperintensities. As a high number of PWM hyperintensities at baseline was associated with more gait and balance disturbances, the authors believe the reduction of the PWM hyperintensities may help explain the post-operative improvement to gait and balance. Urinary incontinence and cognitive function had no correlation to PWM hyperintensities at baseline, which may explain why less improvement was shown in these areas after LPS. In contrast, control patients had an increase in PWM hyperintensities at the 12 month follow up.

The authors conclude that LPS can improve symptoms in iNPH patients and is a safe option that surgeons may want to consider for patients who may be unable to undergo an intracranial operation. They also note that PWM hyperintensities may be a good marker for the clinical effectiveness of LPS.

However, at the beginning of the study (baseline), the control and LPS groups had different clinical presentations which limits the ability to directly compare the two groups. In addition, this study did not compare LPS to VPS treatment for iNPH. Therefore, no comparisons can be made between the two treatment methods.

Register for a WALK to End Hydrocephalus Near You!

We are excited to announce that our 2021 WALK to End Hydrocephalus events will go back to conventional and in person. We may have to make some accommodations for safety reasons, but we can't wait to come together as a community once again!

AL Central Alabama WALK.....	October 16	NJ Jersey Shore	September 12
AR Northwest Arkansas WALK.....	September 4	NC Charlotte.....	September 25
AZ Phoenix WALK.....	November 6	NC Eastern Carolina	TBD
CA San Francisco WALK.....	TBD	OH Greater Cincinnati	October 3
CA Los Angeles WALK	TBD	OH Cleveland.....	October 16
CA Fresno WALK.....	TBD	OH Columbus	September 26
CA Sacramento WALK.....	TBD	OR Portland.....	TBD
CA Orange County WALK	October 16	PA Philadelphia	September 19
CO Denver	September 5	PA Central PA.....	TBD
CT Connecticut	TBD	PA Western PA.....	October 2
DC National Capital	October 9	SC Columbia	September 11
FL South Florida.....	TBD	TX Greater Dallas/Ft. Worth	September 25
FL St. Petersburg/Tampa Bay	TBD	TX Houston.....	November 6
GA Atlanta.....	TBD	UT Salt Lake City.....	September 18
IA Des Moines.....	October 3	WA Seattle	October 2
IL Chicago	TBD		
IL Decatur	September 18		
IN Indianapolis.....	October 2		
LA New Orleans	September 25		
KS Wichita	September 25		
KY Louisville.....	September 25		
MD Baltimore.....	TBD		
MA Greater New England.....	TBD		
MA Fitchburg Thanks for Running	November 25		
MI Detroit.....	TBD		
MN Twin Cities-Minneapolis/St. Paul	TBD		
MO St. Louis	October 23		
NE Omaha	September 19		
NY Capital District.....	TBD		
NY Long Island.....	October 16		
NY New York City.....	September 26		
NY Western NY	September 11		



Visit hydroassoc.org/walk
to register for a WALK in your area.

Our Community in Action



HydroWarrior Jessica Moser Awarded Prestigious Scholarship

Jessica Moser, a college student living with hydrocephalus, was recently awarded a Barry Goldwater Scholarship, a prestigious national award that annually recognizes the brightest

mathematics, science and engineering college sophomores and juniors across the country.

Jessica is a sophomore at Florida State University majoring in behavioral neuroscience. Her current research focuses on the location of dopamine receptors in the olfactory bulb but her long-term goal is to research a cure for hydrocephalus.

"I'm hoping to study Normal Pressure Hydrocephalus (NPH) because that's the fastest-growing population that's getting hydrocephalus so I was thinking that would be a good potential area of research. My goal is to find a cure for hydrocephalus or at least better treatments," she explained.

Jessica is passionate about hydrocephalus, which she developed shortly after birth. She has endured four brain surgeries to treat her condition. Her family has been a part of the HA community for many years and her dad, Raymond Moser, has served on HA's Board of Directors since 2017.

Congratulations Jessica!!



Gaming to Raise Funds for a Cure

Jaime Louise Neal has been playing video games for as long as she can remember. But it wasn't until a couple years ago that she decided to take her gaming to the next level. She hosted a charity stream on her

gaming channel to raise funds to support HA's mission!

Jaime, who goes by FaultyCodeGamer on Twitch, was born with hydrocephalus. She's had three brain surgeries and after the last one she wanted to do something to raise awareness and funds to find a cure for hydrocephalus.

"As a person living with hydrocephalus and having a platform to be able to spread awareness; let alone host charity campaigns, I would almost be remiss not to use those opportunities to try to raise awareness; and if we raise money in the process, even better," she said.

So for the past two years she's hosted a charity stream on Twitch during the month of December, raising around \$400 for HA. She also recently added a permanent donation link on her channel, hoping to encourage donations throughout the year. Jaime is so passionate about this cause that she also got a tattoo featuring the blue hydrocephalus ribbon!

"It's so important to raise awareness. I've had people that also have hydrocephalus message me on Twitter thanking me for the charity events I run. I'm not striving to be the face of the hydrocephalus community; but if I can be a role model for just one person; I'll have considered my work a success," Jaime said.

Thank you Jaime!

Get to Know Our Support Volunteers



MIRIAM VELADI

Q. Tell us a little bit about you and your journey with hydrocephalus. When were you diagnosed with hydrocephalus and how many brain surgeries have you had?

A. I was diagnosed with hydrocephalus at birth. I received my shunt, a VP shunt, when I was 12 days old. To date, I have had three brain surgeries with my most recent surgery in 2017.

Q. When did you start volunteering for the Hydrocephalus Association?

A. Dr. Muhonen, my neurosurgeon, introduced me to the Hydrocephalus Association and encouraged me to attend the 2018 annual conference in Orange County. The timing and location were perfect as I had recently become more aware of my condition because of my recent surgery and the location was only a few minutes away. My mom, sister and I attended the event and were amazed by the

warm tight-knit community. I have had the pleasure of volunteering for the Hydrocephalus Association for 2 years as a Peer Support Volunteer and a committee member of the Orange County WALK to End Hydrocephalus.

Q. What made you want to be a Peer Support Volunteer?

A. In March of 2019, I had the pleasure of meeting Diana Gray, HA's President and CEO, at a hydrocephalus networking event. During the event I met numerous members of hydrocephalus community that reside in LA and Orange County. I spoke with Diana and loved her passion for the association and her commitment for helping individuals like myself. Diana and I exchanged contact information and I reached out to her a week later and was introduced to the Peer Support Volunteers programs. This sparked my interest and the next day I reached out to Lakisha Harris, Support Programs Manager, to join the program.

Q. What do you like most about being an HA Peer Support Volunteer?

A. I enjoy connecting with individuals with hydrocephalus to share my experience and learn from one another.

Q. What do you like to do in your spare time when you're not serving the hydrocephalus community?

A. I like to go for long walks and spend time with my friends and their children. I also enjoy attending the theater and travels.

Q. Why is it important to you to support HA's mission?

A. HA's mission is important to me because hydrocephalus is something I deal with on a daily basis. I am thankful for the community that has embraced me and enabled me to help make a difference for those on the same journey as I am.

High School Basketball Team Raises \$2K for HA!



In February, the Vikings basketball team at Francis Howell High School in St. Charles, MO, raised nearly \$2,000 for the Hydrocephalus Association! The team did it in honor of Garrett Puckett (pictured in the white shorts), who plays on the team, and his sister, Aly, who has hydrocephalus.

Join us in thanking the Vikings team and the Puckett family for supporting our mission!

HA Volunteer Partners with Local Boutique to Raise Awareness



Longtime HA volunteer Annie Mason, whose daughter has hydrocephalus, sells her hand-painted greeting cards at Heather Boutique in Fredericksburg, VA. The store, however, does more than sell Annie's beautiful cards – they also help raise awareness about hydrocephalus and donate to HA. Visit them online: heatherboutique.com.

Thank you Annie and Heather Boutique!



Drink Cider while Supporting HA's Efforts to Find a Cure

Do you love cider? Want to support hydrocephalus research, support and education? Buy Locust Cider! The company donates a portion of their proceeds, and \$25 from each club membership, to the Hydrocephalus Association!

Visit www.locustcider.com

VISIT ONE OF THEIR TAPROOMS IN:

Redman, WA | Seattle, WA | Spokane, WA | Tacoma, WA
Vancouver, WA | Walla Walla, WA | Woodinville, WA
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NEWSLETTER
VOLUME
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EDITION 1



The Fudge Solomon
LEGACY SOCIETY

Leave Your Legacy

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](tel:8885983789) or development@hydroassoc.org

