



Hydrocephalus Association Newsletter Volume 38, Edition 1, 2020



This Year We WALK Your Way!

This year we've expanded our WALK to End Hydrocephalus into a virtual movement that lets you turn your passion into a way to raise awareness and funds for a cure!

9 New Study Compares Treatments

Which hydrocephalus treatment required fewer repeat surgeries — shunts, an ETV or an ETV-CPC? That's what a new study aimed to find out. 10

Over 2,000 Registered for Our Virtual Conference

Our first virtual National Conference on Hydrocephalus was a success, with people from 72 countries participating and connecting!

17 An NPH Story About Perseverance

Dorothy spent months suffering with debilitating symptoms until finally being diagnosed with NPH. Now she educates others about this condition.

Helping You Through the COVID-19 Pandemic



Dear friends,

around

us, the

We find ourselves living in an unprecedented time of uncertainty. The COVID-19 pandemic has changed our world. I want to assure you that regardless of what is happening in our country and the world

Hydrocephalus Association is here to help you and your loved ones with support, trusted resources and educational programs. Our mission has not changed and we will continue to serve our community.

Many questions have arisen throughout our community regarding COVID-19 as we learn more about the virus and how it impacts "Regardless of what is happening in our country and the world, the Hydrocephalus Association is here to help you and your loved ones with support, trusted resources and educational programs."

individuals. To directly address the COVID-19 pandemic, we have developed a robust **COVID-19 Resource Center** on our website (www.hydroassoc.org/COVID-19), which I hope you've had a chance to visit. You will find guidance from our Medical Advisory Board for people living with hydrocephalus and their caregivers. You will also find the video recordings of a special two-part virtual Q&A event we held on March 20 to address concerns from the hydrocephalus community related to COVID-19. Part I was a webinar with neurologists and neurosurgeons from our Medical Advisory Board who offered an overview of COVID-19 in relation to hydrocephalus, guided by some of the questions we received from all of you on social media. Part II followed where we hosted a live Q&A with our experts to answer questions directly from our viewers.

> Like many organizations around the world, COVID-19 has had a major impact on everything we do at the Hydrocephalus Association – but especially on our ability to fund the support, education and research programs you care deeply about. That's why now, more than ever, we need YOUR help. Help

During the webinars, our experts stressed the following key points:

- Hydrocephalus by itself is not a risk factor for contracting COVID-19 or developing severe COVID-19 disease.
- Hydrocephalus treatment (shunt or ETV) does not increase a person's risk for contracting COVID-19 or developing severe COVID-19 disease.
- COVID-19 does not increase a person's risk of developing a shunt infection.
- People with hydrocephalus who have coexisting health conditions, such as heart disease, diabetes, immune suppression, or lung disease, should consider themselves in the higher-risk population, as described by the CDC.
- Persons with Normal Pressure
 Hydrocephalus (NPH) should consider
 themselves at high risk for severe
 COVID-19, but not because they have NPH.
 Persons with NPH are at risk because they
 are over the age of 60, and many have
 coexisting conditions, such as hypertension,
 diabetes, cardiovascular disease, and other
 conditions that can make it more difficult
 to survive the viral pneumonia, ARDS, and
 complications of critical illness that are
 seen in severe COVID-19 disease.
- Nobody is immune from COVID-19. Persons of all ages, including infants, children, teens, young and middle-aged adults, and the elderly, are at risk for contracting COVID-19, including a risk for developing severe COVID-19 disease.

- Fear of COVID-19 should not stop you from seeking necessary medical care, but call your physician's office first so that they can recommend how and where to be treated.
- If you are experiencing symptoms that are concerning for shunt malfunction or another issue that could be harmful to you if not addressed promptly, please contact your physician's office, or, if there is an emergency, call 911 or the number for emergency services in your community.
- Everyone should continue to follow CDC guidance, as well as federal, state, and local governmental guidance to prevent the spread of COVID-19.

us raise critical funds to support our work by registering for a WALK to End Hydrocephalus. This year, we've expanded our WALK to End Hydrocephalus into a national movement that lets you turn your passion into a way to raise awareness and funds for a cure! With most WALKs going virtual, anyone can participate by walking, rolling, jogging, dancing, baking – whatever moves you! Visit www.hydroassoc.org/walk to find and register for a WALK near you. **Because hydrocephalus doesn't stop, so neither are we.**

We know this is a stressful time. Rest assured that you and your loved ones can always reach us for support through our free Helpline (888-598-3789 or info@hydroassoc.org). I also invite you to join one of our local Community Networks, which are hosting virtual meet-ups and other events. Visit www.hydroassoc.org/communitynetworks to join one in your area.

While this is a difficult time for all of us, I'm confident that with your help we will get through this. Thank you for your continued support and trust in us! Be safe and stay healthy.

Sincerely,

Duna Aray

Diana Gray, MA President and Chief Executive Officer

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



HELP IS A PHONE CALL AWAY!

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

The helpline is available via phone and email.



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



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



See What We Accomplished in 2019!

You – everyone in the hydrocephalus community – were our inspiration for our 2019 Annual Report! That's because while we accomplished so much last year, none of it would have been possible without YOU! Our 2019 Annual Report is available to view online at: https://annualreport.hydroassoc.org. You may even see yourself in our Photo Gallery!

WALK TO END HYDROCEPHALUS

Find a Walk Near You and Join Our #HydroStrong Movement!

What would YOU do to end hydrocephalus? This year we've expanded our WALK to End Hydrocephalus into a virtual movement that encourages you use any activity as a way to raise awareness and funds for your local WALK. And it starts NOW wherever you are! Whether you go for family walks around your neighborhood, a short jog, host a hula hoop competition in your backyard or virtual happy hours with friends, turn your passion into a way to raise funds for a cure!

Here's how you join our movement:

- 1. Visit www.hydroassoc.org/walk to find and register for a WALK to End Hydrocephalus near you or in your state. No WALK? Register for our Virtual ANYWHERE WALK to End Hydrocephalus. After you register and set up your fundraising page, you'll have access to tools and ideas to get you started!
- Ask your family and friends to support you for a cause that means 2. so much to you. KICK IT UP A NOTCH by launching a fun challenge you can do from your own home. For example, set a goal to walk or ride 100 miles before a certain date, commit to doing 20 jumping jacks each day until the day of your local WALK, or host a Netflix watch party and encourage your friends to donate what they would usually spend at the movies! ANYTHING YOU WANT!
- Using the hashtag #HydroStrong, post photos and/or videos 3. of yourself on social media letting people know what you're doing and include a link to your individual or team WALK to End Hydrocephalus page, encouraging people to support you by making a donation.
- Join us online on September 26th, for our Live National WALK 4. to End Hydrocephalus Celebration, where we will celebrate our journey together and highlight the fun challenges people did across the country.

The idea is to show our resiliency while we are social distancing to spread awareness about hydrocephalus and to raise much-needed funds to help HA survive this pandemic. Because, now more than ever, WE NEED YOUR HELP so we can continue to support YOU and the over 1 million Americans living with hydrocephalus and to fund research that is already yielding results! (8 drugs in testing!) Let's show the world what it means to be #HydroStrong.



Top Photo: Julie Shannon is doing a headstand every day for 25 days to raise funds for her WALK team!

Bottom Photo: People across the country are turning their passion into a fundraising activity for their WALK! Jayne Crouthamel launched a challenge to swim 1000 laps by the end of the summer.



THANK YOU TO OUR NATIONAL WALK SPONSORS **& INDUSTRY PARTNERS**

Together we are making a difference!



THIS YEAR WE WAALK YOUR WAALS



₩ALK (ROLL...DANCE...JOG...) TO END HYDROCEPHALUS™

Hydrocephalus doesn't stop for COVID-19 and neither can we! So, while many of our WALKs to End Hydrocephalus will look different this year, we're still raising awareness and funds to end hydrocephalus. Register now and participate in our virtual movement: www.hydroassoc.org/walk



Be one of the first to use our new WALK to End Hydrocephalus mobile app, where you can update your fundraising page, send emails to your contacts, start a Facebook fundraiser AND MORE!



Don't miss out on our new t-shirt, which celebrates the resiliency of the hydrocephalus community. Raise \$75 or more for your WALK to End Hydrocephalus to qualify for the shirt!

Four Scientists Awarded HA Grants to Deepen Our Understanding about Hydrocephalus

There is a lot we do not know about how hydrocephalus develops and how to best treat the condition across our many communities. Our 2019 Innovator Award recipients are looking to change that by exploring new ideas about why hydrocephalus develops and testing new treatments to improve long term outcomes



Dr. Engin Deniz, Assistant Professor in the Division of Critical Care Medicine at Yale University, will determine how cilia, small hair like structures that move cerebrospinal fluid (CSF), contribute to post-traumatic hydrocephalus. This study will use an innovative tadpole model that allows the entire CSF system to be imaged in a living animal.



Dr. Joel Geerling, Assistant Professor at the Carver College of Medicine at the University of Iowa, will focus on linking changes in the brain with symptoms experienced by those with Normal Pressure Hydrocephalus (NPH). The goal is to better understand the neural networks affected by NPH in order to develop symptom-specific treatments.



Dr. Bernadette Holdener, Associate Professor in the Department of Biochemistry and Cell Biology at Stony Brook University, will work on understanding how changes in the way the brain produces and uses energy are related to the development of hydrocephalus in both children and adults.



Dr. Brandon A. Miller, Assistant Professor in the Division of Neurosurgery at the University of Kentucky, will conduct preclinical tests of an antioxidant drug therapy that could reduce nerve injury caused by a brain bleed. The drug is already FDA approved for other uses and could improve brain function for premature babies who are at risk of developing posthemorrhagic hydrocephalus.

These scientists are expanding our knowledge about the causes of hydrocephalus and working to develop new treatments that could impact our entire community, from infants with posthemorrhagic hydrocephalus to older adults with NPH. The Innovator Award is designed to provide seed funding for bold and innovative research with the potential to transform hydrocephalus research. Emphasis is placed on innovation and potential impact of the project on hydrocephalus research and clinical outcomes. Innovator Awards are for one year of support at a \$25,000 or \$50,000 level. These awards further the Hydrocephalus Association mission to find a cure for hydrocephalus and improve the lives of those impacted by the condition.

Funding for the 2019 Innovator Awards was made possible through the support of the Posthemorrhagic Hydrocephalus Campaign and individual donations.

Hydro Assist

Updated version allows your loved ones to access your hydrocephalus treatment history.

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



Innovator Award Grantee Highlight

Dr. Joel Geerling Explores Symptom-Specific Treatments for NPH



Dr. Joel Geerling is an Assistant Professor of Neurology at the Carver College of Medicine at the University of Iowa. We interviewed Dr. Geerling to learn more about his research. Maggie Tish, a Graduate Student who works in Dr. Geerling's lab, also participated in the interview. Their research will focus on linking changes in the brain with symptoms experienced by adults with Normal Pressure Hydrocephalus (NPH). The goal is to better understand the neural networks affected by NPH in order to develop symptom-specific treatments.

What sparked your interest in hydrocephalus research?

As a cognitive neurologist, I see a lot of patients who have bladder problems with a variety of neurologic diseases. Even in the case of hydrocephalus, some patients will have incontinence problems and some won't. It's hard to predict. Neurosurgeons can put a shunt in patients with hydrocephalus and a minority of them will regain some bladder function, but most do not. Beyond shunting, we have no ability to treat bladder symptoms caused by neurologic diseases affecting the brain. We have no way of predicting which patients will or won't lose continence and no effective ways of treating those that do. What specifically cause these symptoms – and conversely, what neural circuits normally maintain continence – seemed like a big missing piece of basic scientific research and an important thing to investigate.

What do you find most interesting about hydrocephalus research?

The ventricular system is such a simple-sounding part of the brain. It is covered quickly and almost dismissively in most neuroscience courses, and students including my former self can get the impression that the study of cerebrospinal fluid circulation through the ventricles and related diseases is a mature science. I think maybe for that reason it has been a little understudied. Adults with hydrocephalus have been somewhat left behind by the neuroscience community. Clinically, most of the task of helping these patients has fallen on neurosurgeons. Our neurosurgeons here at UIHC, led by Dr. Matt Howard, are among the best in the world at caring for these patients and guiding them through the decision and process of shunt placement. But we have virtually no understanding of the cell and molecular changes that link enlarged cerebral ventricles to neural circuit dysfunction that underlies the symptoms of NPH (urinary incontinence, gait problems, and cognitive impairment). It's important to gain an understanding of why these symptoms occur, as well as why hydrocephalus occurs in each patient.

What do you hope to learn from your research funded by the Innovator Award Grant?

We are working to identify the neuroanatomical and functional basis of specific symptoms. Once we accomplish this, we can adapt neural circuit tools to treat specific neurologic symptoms of chronic idiopathic, communicating hydrocephalus. The first part of our plan involves seeing if we could generate an animal model for chronic hydrocephalus in adult mice. Having an animal model would allow us to perform controlled scientific experiments to make rapid progress in this line of investigation. Having a mouse model, in particular, is important because we have an unprecedented level of genetic access to specific cell types and neural circuit tools in this species. We adapted a well-established technique that was used in the past to produce acute, severe hydrocephalus, and Maggie is using it to produce varying degrees of mild to moderate, chronic hydrocephalus in adult mice, which then, over several weeks to months, develop neurologic symptoms that are similar to human patients with NPH. In every experimental and control mouse, we get one "before" and several "after" MRIs and analyze serial, 3D images of the brain to monitor the pattern and progression of cerebral ventricular enlargement. Across the same months before and after, Maggie is monitoring their urinary continence, gait, and cognitive function. We are seeing bladder problems develop in one-third to one-half of the mice, but interestingly - and similar to human patients - this doesn't have a simple correlation with the severity of hydrocephalus. Our initial goal is to analyze the individual, neuroanatomical changes in the brain along with individual symptom patterns to understand how different hydrocephalic symptoms result from changes in specific neural pathways and not others. We are starting with bladder control and trying to locate which brain region(s) exhibit a change that correlates specifically with incontinence, first at the millimeter level of regions and fiber tracts and, ultimately, at the level of specific neurons and the synaptic connections that control continence.



YOUR EXPERIENCE MATTERS!

Join HAPPIER: Our Hydrocephalus Patient Registry!

Whether you are living with hydrocephalus or provide care for someone with hydrocephalus, we welcome you to join our quickly growing community and share your experiences in our Hydrocephalus Patient Registry!

Your experiences are crucial to helping scientists better understand the full impact of hydrocephalus and where to focus their research. Together, we will move hydrocephalus research forward as well as improve support services and resources for our community! Joining takes just 3 easy steps!

Join now: www.hydroassoc.org/happier

We hope and expect to learn in mice, and then in the human brain, which changes predict bladder problems compared to the ones that don't. At the same time, we are measuring how the mice walk and balance, and we are assessing their cognitive function, and hope to make similar progress in these more complex symptoms.

What makes your project unique?

It's our focus on neural circuits that are responsible for normal function, and how hydrocephalus intersects with normal function and damages it. Our project is also unique because it focuses on adults with chronic, communicating hydrocephalus. Our number one focus right now is looking at the neural circuits controlling the bladder. Along the way, however, we hope to make a dent on cognition and gait, but those are secondary to our primary focus on the bladder. My scientific background is in neuroanatomy, specifically in the neural circuit control of micturition, appetite, and other basic neural circuits. When the need for more and better work on the neural circuits controlling the bladder became apparent roughly five years ago, we developed a technique to non-invasively measure the timing and amount of mouse voiding by using a thermal camera. Maggie is a co-first-author on this work, along with a collaborator from Beth Israel-Deaconess Medical Center, and it was just published last month in the Journal of Neuroscience Methods. This technique allows us to monitor bladder function as often and for as long as we like, making a chronic set of experiments in mice, like ours, practical for the first time.

How important is HA's Innovator Award grant for your project?

Very important. The funding gives us breathing room to run more experiments and therefore make more rapid progress on this project. As importantly, having funding from an esteemed organization adds gravity and signals the seriousness and importance of this line of investigation, which will help our momentum going forward. Some of the things that we're doing, like getting serial MRIs on the mice, are really powerful in that they help accelerate the experiments and allow us to design and target our experimental assays better, but they're expensive and we wouldn't be able to afford as many without the HA award. Hopefully within a year or so, depending on what we find in our data, we can apply for an NIH grant to continue and expand this research.

What is the long-term plan for the project?

At this stage of the project, it's really about building a foundation with a highly reliable model, plus a rigorous set of tests with results that can be replicated by others, so we can move forward on our neural circuits focus. Eventually, we hope to be able to treat specific neurologic symptoms in hydrocephalic mice by activating or inhibiting specific subtype of neurons in specific locations. These results would pave the way for a more targeted, symptom-specific approach in NPH patients. My patients who complain of bladder systems with hydrocephalus tell me that at first they felt a sensation we call urgency, where it's uncomfortable, but they can control it and not leak. Then, as it progresses, distractions like a phone ringing will steal their focus and they begin losing control intermittently. Finally, they progress to a stage with no control at all, for which our only treatment is adult diapers – I should add that within a year or a few years, adult diapers are poised to begin out-selling baby diapers in the U.S., and already do in a couple of other countries. Ultimately, it would be nice if we had some type of neural circuit therapy to treat that. This therapy may require injecting a "chemogenetic" vector or implanting an electrode or light fiber targeting one or more specific brain regions. However, neurons in the brain are the most diverse cell type in the body, so it's theoretically possible that there could be a drug that could target the neurons of interest and address bladder symptoms without causing too many other side effects. Overall, this is a very complex, difficult problem, but our patients deserve the best that we can do to better understand it and then to design and test therapies that could relieve their neurologic symptoms.

Staying out of the Hospital: Comparing Hydrocephalus Treatments in Children



A Hydrocephalus Clinical Research Network (HCRN) study with lead author Dr. Jonathan Pindrik was recently published in the *Journal of Neurosurgery: Pediatrics*. The study looked at differences in the number of subsequent surgeries a child had to undergo after the initial treatment of

hydrocephalus. Each child was treated with a shunt, an endoscopic third ventriculostomy (ETV), or an ETV with choroid plexus cauterization (ETV-CPC). Choroid plexus is a type of tissue that produces cerebrospinal fluid (CSF). Cauterizing the choroid plexus reduces the production of CSF in the ventricular system.

What They Did

This study, published in June of 2020, used data collected from the HCRN's database to determine which treatment for hydrocephalus had the least amount of subsequent surgeries and hospital admission days related to surgery. Patients had to receive treatment before reaching 24 months of age. Data were collected on what caused the hydrocephalus, age, ethnicity, and clinical outcomes following the surgery after one, three, and five years. The follow-up data included the number of hydrocephalus surgeries and hydrocephalus-related hospital admission days.

What They Found

1,090 patients were included in this study. 83.5 percent of them received shunts, 10 percent an ETV with CPC, and 6.5 percent an ETV alone. Over 50 percent of the patients were less than one month old at the initial treatment, and 90 percent of the patients were less than a year old. The cause of hydrocephalus was primarily posthemorrhagic hydrocephalus (PHH) (26 percent) and myelomeningocele (23 percent).

Patients who had an ETV-CPC had to undergo more surgeries, on average, than either shunted patients or those who had an ETV alone within the first year. The number of days spent in the hospital was not significantly different between the three groups. Shunt revisions and insertions accounted for over 75 percent of surgeries performed in the

HA in Attendance

HA represents the hydrocephalus patient community at key scientific and professional meetings. Here are meetings we have attended this year:

National Health Council Health Leadership Conference February 12-14

Health Research Alliance Virtual Meeting March 30-31

AHCRN Virtual Meeting May 1

NINDS Virtual Nonprofit Forum June 29-30

first year after the initial treatment. This includes shunt revisions, shunt insertion following a shunt infection, and first shunt placement after a failed ETV or ETV-CPC.

Within three years of the initial surgery, the ETV group had fewer hospital admission days than the CSF shunt group. Although not statistically significant, patients with an ETV alone experienced fewer revisions than shunted patients at the three and five year follow ups as well. ETV-CPC was not included in the three and five-year follow-up analysis due to inadequate duration of follow up.

This study indicates that there may be a time-dependent benefit of ETV, and potentially ETV-CPC (in future long-term studies), procedures over shunt insertion which is consistent with previously published studies. However, if these treatment types fail, shunt placement remains the alternative treatment option. In addition, the authors note that, the ETV-CPC data (higher surgical utilization at 1 year) may not reflect current practices as ETV-CPC is now performed on a more narrowly defined patient population who tend to have better outcomes.

The full study can be found at: https://pubmed.ncbi.nlm.nih.gov/32559741/

About the HCRN

The HCRN is a network of fourteen children's hospitals that conduct clinical research to improve the lives of children suffering from hydrocephalus. The HCRN has published 23 studies since its inception in 2005. The Hydrocephalus Association has provided over \$2 million to support the HCRN since 2009.

SUPPORT AND EDUCATION

HA's First-Ever Virtual Conference Attracts Over 2,000 People



Speakers share their experiences during our "Looking Back...Moving Forward: A Conversations for Teens with Young Adults" session.

For the first time ever, our National Conference on Hydrocephalus, HA CONNECT, was held entirely online. Over 2,000 people from 72 countries registered for our virtual event and connected through our HA CONNECT mobile app, proving that not even COVID-19 can dampen the spirts and enthusiasm of the hydrocephalus community!

We made the decision to go virtual in early April, due to the COVID-19 pandemic. Thanks to our conference sponsors, we were able to make HA CONNECT free of charge! This, plus the fact that it was held virtually, allowed more people to participate and enabled our U.S community to meet others impacted by hydrocephalus from all parts of the world!

"We were initially very disappointed about not being able to connect in a live space ... then we realized we could have these amazing connections with individuals from all corners of the world," said Diana Gray, HA's President and CEO, during the opening session. "By having a virtual conference we are able to bring this exciting content to many who would not have otherwise been able to attend."

HA CONNECT, held June 26-27, offered a wide range of sessions featuring over 25 speakers including world-renowned medical professionals, scientists, and other experts. Participants learned about the latest research on hydrocephalus, received helpful tools to navigate the daily challenges of the condition, and formed lasting connections with others through the official HA CONNECT app.

Whether it was an introduction to mindfulness techniques or an overview of medical care transition for teens, HA CONNECT featured a session for everyone, with tracks for adults living with hydrocephalus or Normal Pressure Hydrocephalus, parents, and teens. The Robert Pudenz Lectureship featuring new research by Young Investigators, hosted by Dr. J. Gordon McComb, stood out as a highlight of the first day. The session showcased exciting hydrocephalus research being conducted by the brightest emerging scientists in the field. Other highly-attended sessions of the first day included the session on "Chronic Headaches and Hydrocephalus: When it's Not the Shunt," and "Brain Matters: Hydrocephalus 101," where Drs. James McAllister and Marion (Jack) Walker, from HA's Medical Advisory Board, took participants on a journey through the brain.

One of the high points of the second day was a panel of young adults answering questions from teenagers about living with hydrocephalus. The wonderful young adult panelists spoke from their own teenage experiences with hydrocephalus and advised teenagers to "Be an advocate for yourself, lean on your support team, and live life to the fullest!"

The conversations and connections made through the HA CONNECT app were exciting to see. Many people reconnected with old friends or made new ones through the app's various "community walls."

"It is the first time I have heard from others the emotions and experiences we have felt and had – validating that what we are going through is real. We don't have these resources in our country, but you have inspired and fueled me to become an advocate for Hydro and my beautiful daughter," said participant Vicky Blanford.

On behalf of all of us at the Hydrocephalus Association, THANK YOU for making the 2020 conference amazing and we look forward to seeing everyone in Houston in 2022!





SESSION RECORDINGS NOW AVAILABLE!

Purchase session recordings from HA CONNECT. Recordings are bundled into tracks: All Ages, Adults Living With Hydrocephalus, NPH, and Parents. Each track is only \$20.20 or you can purchase all of the conference sessions for \$59.99.

www.hydroassoc.org/recordings

"This conference was so helpful to me. There is an acceptance, hope, and an abundance of people living productive lives with an abundance of resources out there. Thank you for the complete wholistic, comprehensive, educational and hopeful conference. It is life changing!"

— Diane Chamiso

Donate To HA Through The 2019 Combined Federal Campaign (CFC)

Do you work for the federal government? Serve in the military?

Help the Hydrocephalus Association find a cure by making a donation to HA through your workplace giving program! Designate the Hydrocephalus Association with code #10066 through the CFC Campaign, the federal government's workplace giving program, and *help us change the future of hydrocephalus*!

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, we 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!

AN	Anchorage
AZ	Phoenix
CA	Los Angeles
	Ventura
CO	Denver
CT	Hartford
DC	Washington
DE	Middletown
FL	Miami new!
GA	Atlanta
IL	Chicago
IN	Indianapolis
MA	Boston
MD	Baltimore
ME	Portland
MI	Detroit
MN	Minneapolis peds/adoles
MO	St. Louis
NC	Charlotte
ND	Fargo & Morehead, MI
NJ	Jersey Shore
	Northern NJ NPH

NY	Western NY Long Island New York City
OH	Cleveland
OK	Oklahoma City
OR	Portland
PA	Eastern PA
RI	Providence online only
SC	Charleston NEW!
SD	Sioux Falls
TN	Chattanooga
ТХ	Dallas Houston <i>peds/adolescent</i>
UT	Salt Lake City
VA	Richmond
WA	Seattle <i>pediatric</i> Eastern WA Vancouver
WI	La Crosse online only
Milit	ary Members online only
Nige	ria Lagos children/families
Spar (Red online	hish-Language Network de Apoyo Para la Hidrocefalia) • <i>only</i>

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Visit www.hydroassoc.org/communitynetworks to find your local CN!

A Conversation with Aesculap About the New M.blue[™] Valve



Earlier this year, Aesculap Inc., in partnership with MIETHKE, announced the launch of a new valve for hydrocephalus patients called the M.blue valve. HA spoke with Odra Anderson, Aesculap Product Manager; Steve Owens, Aesculap Clinical Manager; and Christoph Miethke, Original Engineer and Founder of the Christoph Miethke

Company in Potsdam, Germany; about their new valve and what it means for children and adults living with hydrocephalus.

How long has this been in use in Europe?

Odra Anderson: First of all, thank you for the opportunity to share with you and our hydrocephalus community this great news. We are excited to finally have the M.blue Valve in the U.S. The M.blue Valve received its CE mark and the first valve was implanted in Europe in 2018. Since then, hundreds of hydrocephalus patients have been implanted with this 2-in-1 valve. We call it a 2-in-1 valve because the M.blue Valve is the only programmable gravitational valve in the market with an integrated fixed pressure differential pressure (DP) unit. It provides customization of the opening pressure during the most active time of the day, which is the upright body position but also works to relieve the pressure in the lying down position. The M.blue Valve represents over 26 years of hydrocephalus valve experience. We launched the M.blue Valve in the U.S. just a few weeks ago and have already seen a lot of interest from the hydrocephalus community. The new M.blue Valve has already been implanted in patients from California and Texas and we are looking forward to hearing about the positive outcomes similar to our other gravitational systems.

How does it work in laymen's terms?

Steve Owens: First, let me say that the new M.blue Valve is the first programmable gravitational valve with an integrated fixed DP unit. Let's talk about each part of the valve and how it works. The fixed DP unit integrated in the M.blue Valve is basically your "Iying down" valve. This relatively low-pressure resistance will facilitate optimal drainage while you sleep. We believe that when someone is lying down there is really no other external influences on a shunt system, such as gravity. With this being said, we can use a fixed or non-programming valve. The unknown or the inconsistent pressure happens once someone sits or stands. Now we have to take into account and adjust for height and in some cases abdominal back pressure and the adaptability of ventricles to large pressure changes. The M.blue Valve can provide both by using an adjustable, 0-40 cm/H2O, gravity device that only adds resistance upon sitting or standing and a low consistent DP valve.

Odra Anderson: The M.blue Valve, with its 2-in-1 design, addresses the "lying down" and the "sitting/standing up" different pressures that a patient encounters.

Anti-siphon and anti-gravitational valves have been around for a while. How is this shunt different?

Steve Owens: The M.blue Valve and our gravitational systems provide an uncompromising pressure adaptation to optimize individual patient needs. The M.blue Valve is the only valve that allows you to adjust the gravity device (activated when you are standing or moving around) independently of the DP unit. Most valves require the clinician to increase or decrease the entire shunt resistance to correct a specific symptom. In many cases, this

(continued on page 19)

Drink Cider and Support the Hydrocephalus Association!

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

Visit one of their taprooms in:

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



A TRIBUTE TO Dr. James T. Goodrich

The Hydrocephalus Association and many in the hydrocephalus community were deeply saddened to learn of the passing of Dr. James Goodrich on March 30, 2020. Dr. Goodrich was a pediatric neurosurgeon and longtime friend and supporter of HA, presenting at our educational events and serving as a compassionate physician to many in the hydrocephalus community, particularly New York City, where he practiced. He will be deeply missed. He was the director of the Division of Pediatric Neurosurgery and Professor of Clinical Neurological Surgery, Pediatrics, Plastic and Reconstructive Surgery at the Albert Einstein College of Medicine in New York City.

James Tait Goodrich (April 16, 1946 – March 30, 2020), MD, PhD, born in Oregon, received his undergraduate degree from the University of California (Irvine) and masters, Ph.D. and M.D. from Columbia University. He completed his residency training at New York – Presbyterian Hospital and the NY Neurological Institute. He also served as a Marine during in the Vietnam War.

Best known for his 2004 and 2016 separations of conjoined twins, he developed a multi-stage approach to separate craniopagus twins. In 2004, he operated on Carl and Clarence Aguirre, conjoined twins who shared brain tissue. During a 27-hour procedure, Dr. Goodrich led a 40 doctor team to separate them when they were 13 months old.

Dr. Goodrich also held the rank of Professor Contralto of Neurological Surgery at the University of Palermo in Palermo, Italy. He authored numerous book chapters and articles in neurosurgery and the history of medicine and was known internationally as a lecturer.

Goodrich was truly a renaissance man with diverse interests; a wine connoisseur, a historian of medicine and collector of antiquarian medical and scientific books, as well as a collector of pre-Colombian art focused on medicine conditions. In 1982, he was elected to the American Osler Society, an organization of physicians and historians dedicated to perpetuating the life, teachings and ethical example of Sir William Osler (1849-1919), the Canadian physician, educator, bibliophile, historian, author and a co-founder of Johns Hopkins Hospital. Goodrich considered Osler his role model and his interests and achievements paralleled those of Dr. Osler. In 2018, Dr. Goodrich was awarded the prestigious Marquis Who's Who Lifetime Achievement Award.

He was named one of the Best Doctors in America and was listed in the Guide to America's Top Surgeons by the Consumers Council of America and *New York Magazine*. He received the New York City Mayor's Award in Science and Technology. He was the recipient of many awards, including



Quotes From The Hydrocephalus Community:

"Saved my life. Will forever be grateful. Amazing doctor and person."

– Ginaa Marie Teresa

"He was an amazing doctor, human being and my son's first neurosurgeon. RIP."

– Marcia Benjamin

"Amazing Dr. Sleep in peace sir, you will be remembered."

– Chels Alli

"He was an amazing neurosurgeon and human being. I'm heartbroken and we will miss him as our doctor." "My wonderful doctor. He will be missed so much!! Like she said, never will be another Dr. Goodrich."

@Emmasumoza

"Dr. Goodrich was a legend in his own time. He was a healer, an intellect, and a friend to everyone. Wonderful memories of him will be in the minds and hearts of many for a long time to come."

@Llintula

"I have been in complete shock since I found out. He was my neurosurgeon since I was 14 and he will be missed."

@Marin1704

@Prnygurl

an honorary Doctor of Science (D.Sc.) from the Burdenro Neurological Institute (Moscow), the Bronze Medal from the Alumni Association of the College of Physicians and Surgeons, the Mead-Johnson Award, the Roche Laboratories Award in Neuroscience and the Sir William Osler Medal.

The James T. Goodrich Award for Excellence in Neurobiology was established in 2018 by Dr. Goodrich and his wife, Judy L. Goodrich, to honor Dr. James McGaugh. The award recognizes an undergraduate student completing his/her 3rd year, for outstanding achievement in neurobiology.

Dr. Goodrich died in New York on March 30, 2020, of complications from COVID-19. He is survived by his wife, Judy Loudin, and three sisters. The Hydrocephalus Association extends its deepest sympathies to his family and the patients he served.

STORIES FROM OUR COMMUNITY

We invite the hydrocephalus community to share 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.



"My hope is that in sharing a snippet of my journey with hydrocephalus, you are able to focus on the good days and not the bad days of your journey with this condition. Celebrate the good moments and remember them when challenges come up so that you can be a Hydro Warrior, too!"

Lola Bolaji, 30

I was diagnosed with hydrocephalus at the age of 6. Up until then, I was a healthy child with no known illnesses or conditions. From the age of 6 to 22, I lived symptom free and would have to show my friends the scars on my belly to prove that I had an internal medical device. Around the age of 22, when I had just completed my undergraduate degree, I started to experience really bad headaches, double vision and a loss of balance. After a few months of doctor visits and diagnostic tests, I had my first shunt revision. Over the next 5 years, I went on to have 5 more revisions with the final surgery occurring in January 2017.

After my last surgery, I began focusing on how I could better manage this life-long condition with the assistance of my wonderful doctors, family and friends. While I'd love to say I've found a recipe for success, that couldn't be any further from the truth! Hydrocephalus is a condition that wears many hats and the impact it has on you and I can vary, A LOT! For instance, I have a programmable VP shunt. I also have nystagmus and suffer from migraines and year-round allergies. So, on any given day I could have a sinus headache, shunt headache and mild migraine and it can be hard to distinguish what type of

headache I'm having at a given time. This level of complexity requires patience and time. Two things that don't come naturally as a young professional, but are a must have for a Hydro Warrior in order to have some quality of life.

Today I'm happy that the good days still outnumber the bad days. I hope that will be the case for a long time. I celebrate major milestones and accomplishments, such as traveling internationally without any family members for the first time, which is huge! My hope is that in sharing a snippet of my journey with hydrocephalus, you are able to focus on the good days and not the bad days of your journey with this condition. Celebrate the good moments and remember them when challenges come up so that you can be a Hydro Warrior too! Your doctors, family and friends are all rooting for you along with the great folks at the Hydrocephalus Association.

Eric Rhee, 23

I was born premature at 26 weeks, weighing just three pounds, and developed hydrocephalus as the result of a level 3 intraventricular hemorrhage (IVH). I remained in the NICU separated from my parents for nearly 2 months before they could finally hold me, but their resilience shone throughout my hospitalization. I received a VP shunt from Dr. Michael Muhonen at Children's Hospital of Orange County and had only one revision during my childhood years. Growing up, the left side of my body was particularly weak, which initially resulted in my parents enrolling me in several occupational therapy, physical therapy and speech therapies as a toddler. However, at four years of age, I started playing recreational soccer and basketball and grew stronger both physically and mentally.

I was valedictorian of my high school class and matriculated to UC Berkeley to study biology. My time in college was difficult, particularly the initial adjustment to the surrounding competition and feelings of being different. Many of my peers didn't know anything about hydrocephalus or the experiences surrounding it. These feelings only intensified when my shunt from infancy failed during my second year of college (on the first day of finals week!) after eighteen years of good health. Following the hospitalization, my experience brought me a very limiting perspective. I feared for what



"My perception of hydrocephalus has changed. I no longer view it as a limitation nor a difference to be scared of, but a unique quality that brings out my greatest strengths while nurturing my weaknesses. I hope others can find hope and opportunity through their diagnosis like I did."

came next — the next shunt failure, the stigma surrounding illness, a deeper sense of unrelatability to my peers, and shame for placing my loved ones in a position of worry. However, I found solace in the deep conversations I had with my closest friends and Dr. Muhonen over the course of the next few years. I found strength in what I initially perceived to be a failing limitation.

I'm now a graduate setting my sights on medical school. I'm using my gap year to work as a scribe and research assistant for Dr. Muhonen in Neurosurgery. I'm currently working on a study evaluating two different surgical incision approaches for pediatric patients who received a VP shunt.

My perception of hydrocephalus has changed. I no longer view it as a limitation nor a difference to be scared of, but a unique quality that brings out my greatest strengths while nurturing my weaknesses. I hope others can find hope and opportunity through their diagnosis like I did. I understand that not everyone can relate to my experience nor can I provide regimented advice. But I know that there are people working tirelessly to advance treatment for this condition. I was blessed to find amazing opportunities and mentors, and I hope to offer the same opportunities to someone as a practicing physician in the future. Your experiences will only make you stronger and more grounded. Take pride in all that you have overcome.

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 http://www.hydroassoc.org/shareyourstory to submit your story!**

Individuals Diagnosed with Idiopathic Normal Pressure Hydrocephalus Show Improved Quality of Life after Shunting



There are many studies that compare the symptomatic outcomes of individuals with idiopathic Normal Pressure Hydrocephalus, or iNPH, a type of hydrocephalus that typically affects older adults. Idiopathic NPH is typically characterized by several symptoms such as gait changes, dementia, and incontinence. In a 2019 Swedish study titled "Cerebrospinal Fluid Shunting Improves Long-Term Quality of Life in Idiopathic Normal Pressure Hydrocephalus" by Hanna Israelsson MD, PhD, from the Congress of Neurological Surgeons, 176 individuals with iNPH and 368 people without iNPH were asked about their quality of life through self-report questionnaires. For those diagnosed, particular attention was paid to their quality of life (QoL) before and after shunting.

What They Did

The patients in the study were between 60-85 years old and scored highly on a questionnaire that determined cognitive functioning, as those patients with low cognitive functioning could not give reliable answers about their QoL. When patients visited their physicians, they were given a survey to determine their QoL currently, and they were asked to rate their perceived QoL one year prior to shunting. The surveys were given an average of 21 months after being shunted. The patients ranked five aspects of their life: mobility, self-care, usual activities, anxiety/depression, and pain/discomfort. For a control group, the study chose four people that matched closest in age and sex to each patient in the study from the Swedish population register.

What They Found

Prior to being shunted, patients reported a lowered QoL than the control group. After being shunted, patients reported an increase in their overall QoL. The data shows that 72 to 75 percent of iNPH patients saw improved QoL after shunting. These findings were not dependent on when the surveys were administered after the procedure.

However, QoL for iNPH patients still ranked worse than the control groups in all but the pain/discomfort category of the given survey. They also were significantly more likely to need assistance at home compared to the control group.

Symptoms of depression were the main predictors of lower QoL in patients with iNPH. This is not unexpected as depression has also been found to predict low QoL in other similarly aged populations. How severe the gait problems were and whether a person can live independently also greatly affected their QoL ratings.

What Do Other Studies Say?

Numerous studies have been conducted about the overall change in QoL a person experiences after being diagnosed with iNPH, including whether receiving a shunt improves their QoL. Many report improvements in gait and physical functioning, but there are mixed results regarding other factors such as independence and cognitive functioning. A 2015 study from the *European Journal of Neurology* has data that agrees with this more recent study, that although people with iNPH have lower QoL scores than those without iNPH, they still show marked improvement from those who have the condition and aren't shunted.

On the other hand, a 2011 study from the *Journal of Clinical Neuroscience* found that after shunting, many patients showed more favorable results and were able to get back to their regular activities such as driving and working. It also reported that 81 percent of people surveyed had improved gait. Another study from the *Oxford Academic Neurosurgery Journal* from 2011 reported better QoL for both the patient and the caregiver after being shunted. Overall, most studies report improvements in at least physical functioning after a person with iNPH has been shunted.



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

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

Search by location, specialty and age range!

www.hydroassoc.org/physicians-directory

Dorothy Sorlie: A Teacher's Unbreakable Spirit



Dorothy Sorlie has always been a passionate teacher, writer, and reader. However, at age 74, she found it more and more difficult to do the things she had loved her whole life.

"I thought 'where are the good authors these days.' Well it wasn't the authors, it was me," she said. Her problems

began with difficulty reading and concentrating. Then she started experiencing decreased mobility and urinary incontinence, making her think she might have early dementia.

This kicked off a lengthy search for answers.

Sorlie tried everything. She visited numerous physicians, an acupuncture specialist, a chiropractor, an Eastern medicine doctor and others. She even traveled as far as Alabama from her home in Eau Claire, Wisconsin but nothing could relieve her symptoms.

Fortunately, she never gave up hope and kept looking for answers and eventually she was referred to neurosurgeon Dr. Jonathan Bledsoe who conducted a CT scan and diagnosed her with Normal Pressure Hydrocephalus (NPH), a type of hydrocephalus that most commonly affects older adults. Sorlie underwent brain surgery to have a shunt placed almost immediately. Her surgery was successful and she checked into a rehab center for recovery.

Sorlie's recovery was a yearlong grind filled with occupational, speech, and physical therapies. However, she showed the same

grit and unbreakable spirit in her battle to recover as she did when searching for a diagnosis.

"I didn't give up then either. I worked like a trooper and I still do," she recalled.

Sorlie slowly but surely improved, eventually recovering completely from her debilitating symptoms. She relied heavily on her support system. "My husband was a rock. And so were my friends and my kids. They were right there," she said.

Now she is back to doing all that she loves: reading, writing, walking and spending time with her family. Her husband, Jim Urness, even describes her as being "back to 120%"

As a former English professor at Chippewa Valley Technical College, Sorlie sees her story as a chance to teach others about NPH in order to help them avoid her experience. She has advertised her story in a local newspaper, given presentations to seniors at the Learning and Retired Group and even informed medical professionals about her experience. She is now an Outreach Volunteer for the Hydrocephalus Association and is raising much needed NPH awareness among both doctors and patients.

"My message is to get out there and help other people to become aware. It's not about me. It's about them trying to escape what I've endured," Sorlie explained.

More than 700,000 Americans are estimated to have NPH, but less than 20 percent receive the proper diagnosis, with many misdiagnosed as having Alzheimer's or Parkinson's disease.

Learn more at: https://www.hydroassoc.org/nph

ADVOCACY

An Update on What's Going on in the Nation's Capital



As of the end of May, Congress has passed four bills related to coronavirus relief. These bills focused on better access to testing, paid family leave and helping individuals and small businesses with cash—for example, a \$1,200 stipend, increased

unemployment benefits and small business loans. In addition, because small businesses raised concerns about the requirements for their loans, Congress passed a "technical correction" bill to give small businesses more flexibility. All these bills have been bipartisan.

Congress is now considering another coronavirus relief bill.

Advocating for you...

In May, we joined hundreds of patient advocacy groups in sending a letter to Congress asking that patients with chronic conditions like hydrocephalus be eligible for the coronavirus paid family and medical leave program. We also joined the Consumers for Quality Care in asking the Department of Health to protect consumers from Short-Term Limited Duration Insurance (inexpensive high-deductible insurance that often does not cover many health problems).

Would you like to help?

We're still looking for members of Congress to join the Congressional Hydrocephalus Caucus—and those requests carry far more weight when they come from constituents! All you need to do is find your representative at www.house.gov/representatives/find-your-representative. Then either call their office or find them on social media and send a message that you'd like the representative to join the Congressional Pediatric and Adult Hydrocephalus Caucus. It's that easy! Visit our website for a list of our current Caucus members, as well as those members that served last year who need to be asked to continue serving: www.hydroassoc.org/congressionalcaucus.

HA Joins the Consumers for Quality Care Coalition

The Hydrocephalus Association has joined the Consumers for Quality Care (CQC), a coalition of advocates and former policy makers working to provide a voice for patients in the health care debate. This will expand HA's ability to advocate for higher quality, affordable health care for people with chronic medical conditions.

The CQC coalition is comprised of 21 leading advocacy organizations that are passionate about highlighting the needs and rights of health care consumers.

"Since our establishment in 1983, the Hydrocephalus Association has championed the rights of individuals with hydrocephalus in health care, education, labor, and scientific research," said Amanda Garzon, National Director of Program Services and Communications. "Uniting our voice with other CQC Partners allows us to advocate more loudly and effectively for the quality health care and services individuals typically left out of the healthcare debate deserve, namely those with chronic medical conditions and in underserved populations."

DEDICATE YOUR BIRTHDAY

to the hydrocephalus association!

Celebrating a birthday this Fall? Help us raise much-needed funds for hydrocephalus research, education & support programs by launching a birthday fundraiser for the Hydrocephalus Association on Facebook! Your fundraiser will go a long way toward helping us find a cure!

https://www.facebook.com/fund/HydroAssoc/

A Conversation with Aesculap About the New M.blue Valve (continued from page 12)

one-sided approach only trades one symptom for another. I heard a surgeon ask a patient once, "When do you want your headaches, AM or PM?" My interpretation was that the patient had to choose between over or under draining. That is not the case for our valves, we can address both.

Does this valve change under an MRI or any other magnets?

Odra Anderson: The active-lock mechanism protects our programmable valves against reprogramming by magnetic fields up to 3 Tesla. It is protected from unintentional adjustment by everyday magnets such as smartphones, toys, hearing devices, induction cookers and safety barriers at airports. To put that in perspective, 1 Tesla is equal to 10,000 gauss. Gauss is how you measure magnetic induction and a typical fridge magnet is approximately 100 gauss. We tested the brake safety and effects of exposure to MRI conditions up to 3 Teslas and verified that the MRI exposure had no effect on the valve function and adjustability. The active-lock protects against inadvertent re-adjustment by external magnetic field and it can only be changed by the physician with a special tool to mechanically unlock the brake. The M.blue Valve is MR Conditional up to 3 Tesla.

How did you come up with the new valve?

Christoph Miethke: Around the same time we developed the proGAV[®] 2.0 Valve, it became clear to us that the same improved features can

be extended to our programmable gravitational valve. For the patient, the upright position is more variable, in terms of height, conditions/ circumstances and even the BMI factors just like Steve said. The need to have variability and choice to adjust this aspect is key.

Over-drainage is a dangerous complication that happens in the upright position. Our programmable gravitational valve, the proSA® Valve addresses that need. Looking at the improvements that we were applying to the original proGAV Valve, we wanted to do the same to the proSA Valve. This thought led to the improvement project and the decision to integrate a DP unit to the adjustable gravitational valve. By adding the DP unit, this allowed for a 2-in-1 design. To take it a step further, using both programmable valves, the proGAV 2.0 Valve and the M.blue Valve, offer the best of both worlds. These valves are designed to be used for all patients (pediatric and adults). For particularly challenging forms of hydrocephalus that require an even greater flexibility in treatment, this could be a great solution.

In line with all of our actions and innovation is the direct line to collaboration with neurosurgeons and patients. We often sought the feedback of those within the hydrocephalus community. A lot of requirements, wishes and feedback have been incorporated directly into this product. That is why we say that the M.blue Valve is inspired by you.

Sophia Gigante: Finding Strength from Within



Sophia Gigante was tired of hearing people tell her no. Born with hydrocephalus and then later developing hypotonia, she was tired of sitting on the sidelines during P.E. class in school, tired of not participating in any sports, tired of not being able to

walk correctly. But at age 16, a trip to the gym helped her realize that she was stronger than any of her health conditions.

Gigante had her first brain surgery at just three weeks old to have a shunt placed to manage her hydrocephalus. A few years later, she was fitted with a leg brace to help her walk since she lacked physical strength on the right side of her body due to the hypotonia. Then, at 9 years old, she developed a seizure disorder and also had her second brain surgery to have her shunt replaced.

"My life was a series of doctor visits, MRIs, and physical therapy," she recalled. "I spent years struggling with anxiety and PTSD due to my childhood and was never confident or courageous enough to speak out about my experiences. It felt like no one around me knew what hydrocephalus was and I didn't like having to explain it to people," she said.

After going to the gym with her mom, Gigante began working out and

realized that her body was stronger than she thought. Slowly, physical fitness transformed not just her body – but also her mind. Now, the 22-year-old owns her own fitness company called SRG Fitness, where she provides personal training, health coaching and nutrition counseling. She especially loves training people with hydrocephalus and special needs.

"I want to show the world that you can overcome anything and you shouldn't let challenges and your own negative thoughts stop you from achieving your goals. 'I'm in control' is what I say to myself all the time. By strengthening my body, my hypotonia improved. I definitely still have imbalances and am misaligned but it doesn't stop me. I try my hardest and get through it," she said.

Gigante's clients are often surprised to learn that she has hydrocephalus and hypotonia because she seems so fearless and strong. That's why she is coming out with a book about her life, called "Strength, Resilience, Growth: How I Defied Physical and Mental Limitations and Took Control of My Future." Through her book she hopes to inspire others living with a neurological disorder, or other conditions, so they can learn to find the strength within them and live life to the fullest. Gigante's book will be available on Amazon in September.



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Hydrocephalus

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

