

SPECIAL NPH SECTION: *From Aerospace Engineer to NPH Advocate*



VOLUME
36
EDITION 1

15th National Conference on Hydrocephalus

June 28-30, 2018,
at the Renaissance Newport
Beach in Orange County, CA

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Join a WALK to End Hydrocephalus near you!

Help raise funds for
hydrocephalus research
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MESSAGE FROM THE CEO



"The farther backward you can look, the farther forward you are likely to see." This poignant quote from Winston Churchill reminds us that our past quite often forges the path for our future. At the Hydrocephalus Association, much of our success today has been built upon the efforts of historic thought leaders in our community. For example, we owe

our commitment to improving the lives of patients to HA's founding mothers Emily Fudge, Cynthia Solomon and Pip Marks. Our current research program and related successes are directly tied to the forethought and vision of Paul Gross who advocated vehemently for this expansion of our mission. There are many stories of impact I could share about those who have shaped our current priorities. Each critical juncture in which a key strategic pathway was selected launched us forward to our present results. In December, I had the privilege of sharing lunch with two previous chief executives of HA, Dory Kranz and Dawn Mancuso, and was able to thank them for their contributions to HA. It is gratifying for me to be a part of their legacy as we drive forward towards aggressive, high impact goals. As I reflect upon 2017, I feel a great sense of pride in highlighting just a few of our accomplishments:

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

- After successfully advocating in 2015 to have hydrocephalus added to the list of conditions eligible to receive DoD Congressionally Directed Medical Research Program (CDMRP) funding, in 2017 we witnessed our first big successes with two HA-funded scientists receiving significant awards. Dr. Bonnie Blazer-Yost and Dr. Jerald Chun each received \$1.2 million in grants to further their research. Both of these scientists received critical funding from HA that enabled them to complete preliminary data necessary to apply for these highly competitive DoD awards.
- We launched our No More Brain Surgeries, #NoMoreBS, awareness campaign which was well-received from individuals with hydrocephalus, families, healthcare providers, scientists and industry. It was validating to experience how this message resonated with so many who rallied with us around the call for additional treatments. We are grateful for the passionate dedication of neurosurgeons who perform life-saving brain surgeries every day and for our industry partners who are diligently working to advance their shunt systems. For many patients, a life filled with multiple brain surgeries is not an acceptable long-term solution for hydrocephalus.

Through awareness of this condition we hope to bring forward more support of our efforts.

- On the heels of our awareness campaign we publicly launched our Roadmap to a Cure campaign with a goal of raising \$20 million by 2020 for life-saving hydrocephalus research and support programs. We are well on our way. Please check out the campaign on our website to learn more about all of the important initiatives these dollars will fund and how you can help.
- On October 6, 2017, we held our fifth annual Vision Dinner, which brought us even closer to our goal of raising \$3M to fund critical research to solve the challenges of Post Hemorrhagic Hydrocephalus (PHH), the leading cause of pediatric hydrocephalus. This incredible event was underwritten by our generous benefactors Craig and Vicki Brown to ensure that every dollar donated goes toward advancing hydrocephalus research. We are so thankful to the Browns and all of the other individuals and companies who supported the Vision Dinner. Please mark your calendar for the 2018 Vision Dinner to be held at the Mandarin Oriental hotel in NYC on November 2nd.

As we dive into 2018, we invite you to join us June 28-30 in Orange County, CA, at HA CONNECT, our 15th National Conference on Hydrocephalus. With an expert cast of presenters, this three-day event offers you a unique opportunity to expand your knowledge on hydrocephalus. You'll meet the experts in hydrocephalus care, learn new tools for navigating the complex challenges of living with the condition, and interact with people living positively with hydrocephalus.

Let me close by thanking our many generous HA supporters – we would not be successful in moving our mission forward without your help! With your support, we look forward to an impactful 2018!

Sincerely,

A handwritten signature in dark ink, appearing to read "Diana Gray". The signature is fluid and cursive, with a large, stylized "D" and "G".

Diana Gray, MA
Chief Executive Officer

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

FEATURED ARTICLES

HA CONNECT¹⁸

NATIONAL CONFERENCE ON HYDROCEPHALUS

JUNE 28-30, 2018

ORANGE COUNTY, CA

15th National Conference on Hydrocephalus

Renaissance Newport Beach | 4500 MacArthur Boulevard | Newport Beach, CA 92660

Come Together and Connect at HA's 15th National Conference on Hydrocephalus

Don't miss your chance to dramatically expand your knowledge on hydrocephalus at HA CONNECT, our 15th National Conference on Hydrocephalus, held June 28-30, 2018, at the Renaissance Newport Beach in Orange County, CA. During this three-day event, you'll hear from more than 60 world-renowned medical professionals, researchers, life management professionals and individuals living with hydrocephalus. You'll walk away with new tools and connections to help you address the medical, educational and social complexities of living with hydrocephalus.

Why You Should Attend

- More than 70 interactive sessions with leading experts and researchers
- 500+ participants from all over the world, including patients, caregivers, medical professionals, scientists, medical device representatives and other organizations
- Round table learning opportunities covering diagnosis, treatment, living with hydrocephalus, life skills and the latest research

NEW Hotel Location!

Just two miles from our old location, the new venue is serviced by the same airport and has access to all the great entertainment and natural attractions of the area. For those who have already secured hotel rooms, the transfer of rooms will be seamless. We can't wait to see you in June!

GET TO KNOW SUNNY ORANGE COUNTY!

Whether you like pristine beaches, theme parks or cultural exploration, there is no shortage of activities in the "OC." The conference hotel is just a short drive to the world-famous Disneyland Park, Disney's California Adventure and the always-thrilling Knott's Berry Farm. Often featured in movies and TV shows, Newport Beach has that sun-bleached SoCal aesthetic that makes it a magnet for beach bums and travelers alike. It's not hard to see why, with near constant pristine weather and an abundance of things to do. Go hiking, trail running or exploring with the kids at a wilderness park or nature preserve. Laugh, cry or sigh at the

on-stage artistry at the world-renowned South Coast Repertory Theatre or Segerstrom Center for the Arts. Sample exotic eats and diverse cultures in The OC's ethnic enclaves. Live like a local by checking out one of the many Farmer's Markets taking place throughout the week, or attend a game at Angel Stadium of Anaheim. Wherever you turn, the OC beckons with a playful spirit and unlimited possibilities. Visit the conference website for more tips on fun activities: <http://hydrocephalusconference.org/travel/things-to-do/>.



Highlighted Sessions

Regaining Balance and Your Life: Role of Physical Therapy in Normal Pressure Hydrocephalus

Sharon Hayden, PT, Barrow Neurological Institute

Ms. Hayden will discuss the gait and balance impairments seen in the diagnosis of Normal Pressure Hydrocephalus and obtaining an extensive physical therapy evaluation to identify the impairments. She will compare and contrast pre and post large volume spinal tap assessments used to determine if a shunt will be effective. Her didactic presentation will include video analysis, and emphasis will be placed on the importance of physical therapy after undergoing a shunt placement.

How do you Prepare your Child for Independence?

Alexander van Speybroeck, MD, MPH, Children's Hospital Los Angeles

At what age should our children begin to prepare for living independently? And what does the transition process entail? You might be surprised at how early that process should begin! This session will explore when and how to prepare teens to take over their medical care as well as their daily routines, whether that be a new college schedule or a new job.

SSI, Social Security Survivor Benefits and Medicaid/Medicare

Andre Sam, CRPC®, APMA®

What is SSI? Is it the same as Social Security Disability or is it different? How do I know if my child or loved one is eligible for SSI or other Social Security benefits? What is Medicaid and what is the difference between Medicaid and Medicare? In this session, we will discuss these sometimes confusing and frustrating topics in disability and special needs planning. Amongst many other questions, topics will include clarity on the different types of social security cash benefits and medical benefits, how Medicaid is different from Medicare, how these cash and medical benefits will integrate with other Disability and Special Needs Planning financial and legal tools that will affect your future planning for your loved one.

#BRAINmatters

Ramin Eskandari, MS, MD; Carolyn Harris, PhD; James P. (Pat) McAllister, II, PhD

What does a brain look like? Feel like? Our teen conference attendees will journey through the brain with a pediatric neurosurgeon and neuroscientists. Teens will get to learn about the basic structure and functions of the brain (where do those thoughts come from?) and the special nature of their brains with hydrocephalus. Through hands-on activities, the teens will understand their shunts and even get to place a shunt into the brain.

Relationships and Hydrocephalus

Amy Thomas; Greg Tocco; Georgana Tocco; SarahAnn Whitbeck, MBA, CHCP

Relationships are complex - and even more so when complicated by hydrocephalus, headaches, shunts, revisions, and more. Join us for an interactive discussion about tips and tricks for managing relationships with family members, friends, colleagues, and significant others. Our panel of discussants will reflect on and share strategies for success they have identified from their experiences. You won't want to miss it!

Research Update – Health Risks of Radiation from Medical Imaging

Diane Armao, MD, UNC Healthcare System/Elon University; Carolyn Quinsey, MD, UNC School of Medicine

During the session, Drs. Armao and Quinsey will review the risks of repeated radiation exposure and offer ways to decrease the radiation exposure when imaging is necessary. They will also discuss their efforts to develop hands-on tools for patients, families, and doctors to talk about radiation exposure and the health risks. The session will also serve as an opportunity for Drs. Armao and Quinsey to hear from the audience about their experiences with radiation exposure, their interactions with medical professionals, and what tools they would find most useful.



LIVE STREAM SESSIONS

This year, HA will be live streaming 17 sessions, allowing more people to attend the conference virtually.

Register online today!

Kids Camp

Parents attending HA CONNECT can sign their children up for HA's Kids Camp, which is offered to all children with or without hydrocephalus between the ages of 3 and 11 years old. Kids Camp allows parents or guardians to attend the conference sessions and socialize with other adults while their child is having a wonderful experience with kids who may become lifelong friends.

Learning Challenges Posed by Hydrocephalus: Maximizing Your Child's Learning Potential in the Classroom

T. Andrew Zabel, PhD, ABPP, Kennedy Krieger Institute

This presentation will explore how hydrocephalus impacts the brain and its ability to process and hold information. Dr. Zabel will identify the learning challenges most commonly confronted by children with hydrocephalus at various ages and stages of their education.

HA CONNECT¹⁸

NATIONAL CONFERENCE ON HYDROCEPHALUS

To register, learn more about the
conference speakers and sessions,
and to book your hotel room,
visit: www.hydrocephalusconference.org

Special Invitation for Our Medical Professionals

Healthcare Professionals Day Symposium | Thursday, June 28

CME/CEU credit eligible for In-person or Virtual attendees

The symposium will cover all aspects of hydrocephalus: from the basics of anatomy and physiology to identifying the condition, treatment options, long-term management and other disorders associated with hydrocephalus. The goal is to provide healthcare professionals with the tools they need to help patients with hydrocephalus improve their quality of life. This symposium will be a live-lecture format showcasing presentations from a diverse faculty. Attend in person or virtually!

NIH Announces Funding Opportunities for Hydrocephalus Research

The National Institutes of Health (NIH) has released two Program Announcements (PAs) specifically for hydrocephalus. PAs are NIH's signal to the research world that NIH is interested in a specific topic or condition. Historically, funding for that topic or condition increases when PAs are announced.

"The release of these two PAs has been years in the making through our advocacy efforts and through our connections with NIH," explained Dr. Jenna Koschnitzky, HA's National Director of Research Programs. "Dr. Jill Morris, who spoke at the June HA Board meeting, was critical in developing and advocating for these PAs to the NIH."

The PAs also reflect the HA Research Program's focus on the development of new, non-surgical therapies and specifically call out research in both posthemorrhagic hydrocephalus and postinfectious hydrocephalus.

Disease Mechanisms of Prenatal and Pediatric Hydrocephalus (R01 Clinical Trial Not Allowed)

R01 Research Project Grant

The purpose of this funding opportunity announcement (FOA) is to support hypothesis-driven research of prenatal and pediatric hydrocephalus. This FOA intends to support hydrocephalus research projects that examine the developmental etiology (intrinsic factors including genetics) and acquired etiology (extrinsic factors including

hemorrhage and infection) of prenatal and/or pediatric hydrocephalus. Studies should focus on understanding the molecular, cellular and developmental mechanisms involved in the pathogenesis of prenatal and/or pediatric hydrocephalus.

For more information, visit:

<https://grants.nih.gov/grants/guide/pa-files/PA-18-622.html>

Tools to Enhance the Study of Prenatal and Pediatric Hydrocephalus (R21 Clinical Trial Not Allowed)

R21 Exploratory/Developmental Research Grant

The purpose of this FOA is to encourage research grant applications that propose to develop or substantially modify existing cutting-edge tools that will advance prenatal and/or pediatric hydrocephalus research. The primary objective of this FOA is to remove barriers to hydrocephalus research that are due to scarcity of tools to investigate both the disease mechanisms and alternative therapies (non-shunt) in a rigorous manner. Applications should aim to transform the field of prenatal and/or pediatric hydrocephalus research by generating tools including animal and cell models, novel methods and innovative technologies that will be widely used throughout the neuroscience community to understand disease mechanisms and/or developing therapeutics.

For more information, visit:

<https://grants.nih.gov/grants/guide/pa-files/PA-18-623.html>

Meet the 2017 Innovator Award Investigators

The Hydrocephalus Association is the leading nonprofit funder of hydrocephalus research in America. To date, we have invested over \$7M in promising research to prevent, cure, and treat hydrocephalus and to improve the lives of those living with the condition.

We are pleased to announce eight 2017 Innovator Award recipients. The Innovator Awards fund early stage, innovative, cure-focused research. This year, the awards were targeted to Posthemorrhagic Hydrocephalus

(PHH) and Postinfectious Hydrocephalus (PIH). PHH is the most prevalent form of pediatric hydrocephalus in the United States, and PIH is the most prevalent form in many developing countries.

Funding for the 2017 Innovator Awards was made possible through the support of Team Hydro and the dedicated efforts of Craig and Vicki Brown, hosts of the annual Vision Dinner.



Joane Conner, PhD,
Associate Professor, University of Connecticut

Goal: Investigate the Disease Progression of Post-Infectious Hydrocephalus

Study Title: *Post-infectious hydrocephalus: Developmental sensitivities based on stem cell niche and ependymal lining status*



Yan Ding, PhD,
Research Associate, Loma Linda University

Goal: Understand how the Germinal Matrix Hemorrhage (GMH) Interferes with the CSF Reabsorption Process

Study Title: *The Impact of germinal matrix hemorrhage on the cerebrospinal fluid reabsorption through the glymphatic system*



Aristotelis Filippidis, MD, PhD,
Neurosurgery Resident,
Beth Israel Deaconess Medical Center

Goal: Identify Markers of Delayed Hydrocephalus Following Subarachnoid Hemorrhage (SAH)

Study Title: *Prediction of delayed hydrocephalus with MRI and CSF analysis of iron levels in patients with subarachnoid hemorrhage*



June Goto, PhD,
Research Instructor,
Cincinnati Children's Medical Center

Goal: Understanding the Mechanisms of CSF Accumulation in Posthemorrhagic Hydrocephalus (PHH)

Study Title: *Investigation of motile cilia functions in posthemorrhagic hydrocephalus*



Kristopher Kahle, MD, PhD,
Assistant Professor of Neurosurgery,
Pediatrics, and Cellular & Molecular
Physiology, Yale School of Medicine

Goal: Understanding the Role of the Choroid Plexus Epithelium (CPE) in Postinfectious Hydrocephalus (PHH)

Study Title: *Innate immunity and CSF production in post-infectious hydrocephalus*



David Limbrick, MD, PhD,
Chief of Pediatric Neurological Surgery,
Washington University

Goal: Identify the Causative Organisms of Postinfectious Hydrocephalus (PIH) and the Patient's Immune Response to those Organisms.

Study Title: *Pathogens and host immune response in post-infectious hydrocephalus*



Jennifer Strahle, MD,
Assistant Professor of Neurological
Surgery, Washington University

Goal: Understanding How Blood is Cleared from the Ventricles Following IVH

Study Title: *Intraventricular hemorrhage clearance markers in human neonatal CSF*



Hannah Tully, MD, MSc,
Assistant Professor, University of Washington

Goal: Identify Markers for Infants at Risk for Posthemorrhagic Hydrocephalus (PHH)

Study Title: *Early identification of ventriculitis and structural imaging markers for posthemorrhagic hydrocephalus*

AHCRN Making Strides to Improve Care for Adult Patients

The Adult Hydrocephalus Clinical Research Network (AHCRN) has expanded its network, paving the way for greater data collection and research. The group added three new sites, including the first European site. The new sites are the University of Bristol headed by Dr. Richard Edwards, Columbia University Medical Center headed by Dr. Guy McKhann, and NYU Langone Medical Center headed by Dr. Jeffrey Wisoff. With the addition of these three sites, the AHCRN now has eight clinical sites and a data coordinating center.

In November, AHCRN met in Salt Lake City, Utah, to discuss the progress and next steps for the network. This meeting was focused on analysis of the first 500 people in the registry including comparisons between patient care groups. These groups are adults who were diagnosed and treated as children (transition), adults with congenital hydrocephalus who were not treated as children (congenital), adults who acquired hydrocephalus and were treated as adults (acquired), and adults suspected of having idiopathic Normal Pressure Hydrocephalus (iNPH). HA will share the results of this analysis once they are published.

The group also discussed ongoing studies focused on the causes of shunt failure in adults and also the effectiveness of endoscopic third ventriculostomy (ETV) treatment in adults. The second day of the meeting was focused on training for an upcoming randomized controlled trial which will determine the effectiveness of shunting for iNPH patients.

The AHCRN is chaired by Dr. Mark Hamilton, Director of the Adult Hydrocephalus Program at the University of Calgary, and comprised of neurosurgeons, neurologists, a neuropsychologist, philanthropists, and business and nonprofit leaders. The group shares data and partners on investigations into improved treatment for the adult forms of hydrocephalus.

Visit <http://www.ahcrn.org/> for more information.



Calling all Hydrocephalus Researchers!



HANDS
Hydrocephalus Association
Network for Discovery Science
Collaboration • Innovation • Impact

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

Visit www.hands.hydroassoc.org

HA in Attendance

HA represents the hydrocephalus patient community at key professional meetings, keeping our agenda on the table. Between September 2017 and March 2018, HA participated in the following meetings:

NIH NINDS NonProfit Forum

September 5-6, 2017
Bethesda, MD

NIH NINDS Council Meeting

September 7-8, 2017
Bethesda, MD

American Academy of Pediatrics

September 16-19, 2017
Chicago, IL

Health Research Alliance

September 17-18, 2017
Chicago, IL

Hydrocephalus Clinical Research Network

September 28-29, 2017
Deer Valley, UT

Congress of Neurological Surgeons

October 7-11, 2017
Boston, MA

Adult Hydrocephalus Clinical Research Network

November 10-11, 2017
Salt Lake City, UT

AANS/CNS Section on Pediatric Neurological Surgery Meeting

November 27-December 1, 2017

American Association of Neuroscience Nurses Annual Meeting

March 17-18, 2018

HA Announces the Launch of New Physicians Directory

The Hydrocephalus Association (HA) is excited to announce the launch of our new Physicians Directory. The Directory was made possible through HA's longstanding relationships with the medical community since the founding of the association. Our Medical Advisory Board (MAB) plays an active role in assisting us in supporting our population as well as providing oversight on all of our written resources that go out to ensure accuracy of the information we provide.

This new interactive tool, which was previously a PDF on our website, can help you find the leading specialists you need to manage your condition. The directory includes neurosurgeons, neurologists, and neuropsychologists for all ages. You can search by location, specialty and age range.

On the Directory, you'll find other resources and tips, questions to ask your doctor, and a full list of professional societies if you cannot find a doctor in your area.



Locust Cider Adds New Locations!

Cider aficionados who want to support hydrocephalus research now have more ways to buy Locust Cider!



Woodinville Cidery and Taproom

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

Ballard Taproom *New!*

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

Tacoma Taproom

Opening Spring 2018
2805 6th Ave.
Tacoma, WA 98406

Ft. Worth Cidery and Taproom

Opening Spring 2018
710 S. Main
Ft. Worth, TX 76104



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

Visit www.locustcider.com to learn more.

Get Involved with Your Local Community Network!

Did you know that the HA Community Network hosts educational events, support group meetings and other gatherings around the country that enable individuals and families to connect? We hope you can join us online or at a local get-together this year! Visit our website to join your Community Network's online closed Facebook group and to see upcoming events. Don't see a Community Network in your area? Start one! Email support@hydroassoc.org or call (888) 598-3789 to launch one near you.

AK	Anchorage
AL	Birmingham
AZ	Phoenix
CA	Los Angeles Ventura
CO	Loveland
CT	Hartford
DC	Washington
DE	Middletown
FL	Central

GA	Atlanta
IL	Chicago
IN	Indianapolis
MA	Boston
MD	Baltimore
ME	Portland
MI	Detroit
MN	Minneapolis
MO	St. Louis
NC	Charlotte

ND	Fargo and Moorhead, MN
NJ	Jersey Shore North NJ
NY	Western Long Island New York City
OH	Cleveland
OK	Oklahoma City
PA	Eastern

RI	Providence
TN	Chattanooga
TX	Dallas Houston
UT	Salt Lake City
VA	Richmond
WA	Seattle Eastern WA
WI	La Crosse
Nigeria	Lagos



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

HydroAssist™

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



Sleep Away Camp Just for Kids with Hydrocephalus!

Six days and five nights of summer fun, education, and social connections just for children and teens with hydrocephalus (ages 10-17). Typical camp experience with trained medical professionals on site.

July 29-August 3, 2018

St. George, VA

Learn more and register!

www.brainycamps.com



Brainy Camps
Association



Children's National

SHARE YOUR STORY: Sarah Churchill Kell



Sarah Churchill Kell, who was born with hydrocephalus and shunted at the age of two days, married Ben Merriman on the dock of her parents' home, just off the South River in Annapolis, MD, on September 9, 2017. Ben is a British citizen and the couple resides in London, where they met.

A lifelong adventurer, Sarah says she never lets hydrocephalus, "stop me from doing anything major," though she endures frequent headaches and related symptoms. She is an avid runner and swimmer, has completed two Masters degrees abroad, and loves to travel.

Sarah and Ben met through a mutual friend at a pub in London. Their friend realized that the two had hit it off and insisted they go on a date, though Sarah would soon have to move back to the United States because her student visa was set to expire.

Their first date proved to be a magical marathon. They arrived at the Shard (the tallest building in Western

Europe) at 3 pm and were told the building would close at 10:30 pm. "We scoffed at that, thinking we wouldn't stay nearly as long as we did but, sure enough, we sat on the floor chatting and looking down at London until closing. I think that night, when we lost track of time and then continued to another venue to keep talking, I knew he was something special," Sarah said.

Sarah's sister officiated at their wedding. Just the couple's parents, siblings and nieces attended the ceremony, but they live streamed the whole event, so their family and friends around the world could tune in.

Sarah and Ben have yet to go on a honeymoon because the UK Home Office is processing her spousal visa, but Sarah says they plan to go to Switzerland, because they prefer cooler weather. "We read something about a hotel with an infinity pool overlooking the Alps, and I am all about that!"

Sarah was an active member of Teens Take Charge as a teen and young adult. She also interned at the Hydrocephalus Association for a summer and developed resources for teachers to help them understand the complexities of educating children with hydrocephalus. The staff of the Hydrocephalus Association wish Sarah and Ben a lifetime of happiness and adventure that matches their intrepid spirits.

DON'T MISS AN OPPORTUNITY TO SHARE YOUR STORY!

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

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



R S R I



Rudi Schulte
Research Institute



The Surgical Complication No One Talks About

By Jamie Mae Wright, MD/PhD Student and HA Volunteer



You are on the road to recovery after yet another surgery but suddenly you find yourself unable to focus. You go back to school or work but have to escape to the bathroom throughout the day to cry. One minute you are sitting at your computer working and the next thing you know you are thinking back to being in the

hospital — the pain, the fear, the unknowns about the future — and suddenly you are overwhelmed by emotion.

You lay in bed thinking back to the surgery, was there something I could have done differently? Will it happen again — or in the case of hydrocephalus, when will it happen again? You get to sleep and then you wake up before your alarm for no apparent reason just to be hit with emotion all over again. And at the worst moments, you wonder if hydrocephalus and the surgeries will make your dreams impossible. You start to lose hope.

Those of us with hydrocephalus are often all too familiar with the risks of surgery. But there is one surgical complication that is seldom, if ever, mentioned before or after surgery - post-surgical depression.

It is not surprising that major illness, hospitalization and surgery can trigger depression in someone with a history of the illness, but it can even trigger depression in someone with no prior history of it. It can strike even weeks after the surgery, when you think you are finally getting back to “normal.” Many factors about surgeries can cause depression. They are often a harsh reminder of how fragile life is and can seem overwhelming, especially for those of us with hydrocephalus, who rely on brain surgeries and medical devices. Disrupted sleep while in the hospital; having to be away from home, school and work; and the stress of impending medical bills can also add to the stress.

However, studies have found that there may be more to post-surgical depression than just a normal reaction to stress. It is important to recognize post-surgical depression and treat it quickly. Depression has been associated with a poorer outcome after surgery. While we know that hydrocephalus and brain injury can affect cognitive function, depression can also impair your ability to think, remember information, focus on a task and learn new things. Research has shown that depression can even make you more

susceptible to infection. Pain and headaches, a common problem with hydrocephalus, can also be made worse by depression.

With all the potential negative effects of post-surgical depression, it is important to recognize the symptoms and seek treatment quickly just like you would for any other postoperative complication.

The signs and symptoms of post-surgical depression include:

- Difficulty getting or staying asleep, or waking up early
- Poor appetite or eating more than you usually would
- Not being able to concentrate or focus your attention on even simple tasks, such as watching TV or reading a news article
- Not wanting to participate in activities you used to enjoy, such as being with friends and family
- Lack of energy or interest in things
- Feeling hopeless and helpless
- Feeling like your family or friends would be better off without you

If you recognize these symptoms in yourself or a loved one after surgery, it is important to talk to someone about it and get help. This can be your primary care physician, your neurosurgeon or neurologist, your minister, priest, imam or rabbi, or if you already have one, a psychiatrist or psychologist. In addition, most colleges and universities have Counseling Centers that offer mental health services. There are also hotlines and online services available if you need to talk to someone immediately (see links below).

Here are things you can do at home to help prevent post-surgical depression or lessen the symptoms:

- Try to keep a normal sleep schedule and routine.
- Eat a healthy diet.
- Take a walk.
- Call a friend.
- Write down three things each day that you are grateful for.

Online Resources:

National Suicide Prevention Lifeline
<https://suicidepreventionlifeline.org/>

American Foundation for Suicide Prevention: <https://afsp.org/>

Anxiety and Depression Association of America
<https://adaa.org/>

MentalHealth.gov: <https://mentalhealth.gov/>

Stanley White: From Aerospace Engineer to NPH Advocate



Dr. Stanley White delivers an NPH lecture at Mission Hospital

Dr. Stanley White is no stranger to research. First as a PhD student at Purdue University, then throughout his more than 50-year career as an aerospace engineer and scientist. So it's no surprise that when he started experiencing difficulty walking, poor coordination, and some troubling cognitive problems, he approached it like any other research project.

After a string of misdiagnoses by neurologists and other medical professionals, he took matters into his own hands and began researching his symptoms online and in the medical literature. As a result of his thorough research, he self-diagnosed himself as having normal pressure hydrocephalus (NPH).

"I'd seen several internists and neurologists who provided a variety of opinions, everything from Alzheimer's and vascular dementia to Parkinson's, MS and old age, none of which were NPH. But one day I found a notation on a radiologist's report that mentioned NPH. The neurologist discounted it. I didn't and I continued digging deeper," White explained.

That digging helped save him years of pain and discomfort. After his eureka moment, he contacted neurosurgeon Dr. Marvin Bergsneider, who heads the NPH Research Group at the University of California Los Angeles (UCLA.) White volunteered to participate in a clinical trial and in a 40-minute surgical procedure, Dr. Bergsneider and his team installed a ventriculoatrial (VA) shunt with a magnetically programmable 20-200 mm Hakim-Codman shunt in July 2007. Shortly after, he required a revision to address deflating issues, so a 70mm regulator valve was added. Since then, White has remained largely symptom-free.

Sadly, White's experience is not uncommon. Today, more than 700,000 Americans are estimated to have NPH, but fewer than 20 percent receive an appropriate diagnosis; consequently, the condition often goes undiagnosed and untreated. Without appropriate diagnostic testing, NPH is often misdiagnosed as Alzheimer's disease or Parkinson's disease, or the symptoms are attributed to the aging process. In fact, of the estimated 5.2 million individuals diagnosed with dementia, 10-15 percent are believed to actually have NPH, which is treatable.

"At the hospital where I volunteer, I was unable to find anyone with knowledge of NPH, other than what one might glean from a news article. We really have a lot of educating to do," White said. "The lack of awareness of NPH is having a terrible impact on families because it's hard for people to find someone knowledgeable to talk to and ask for advice."

That's why the 87-year-old retiree now dedicates much of his time to raising awareness about NPH, particularly among medical providers.

White began his career at the Atlantic Missile Range where he was assigned by the U.S. Air Force to test and evaluate captured German WWII missiles. He then held several positions at major companies in the engineering and aerospace field, most notably he spent 31 years at North American Aviation/North American Rockwell/Rockwell International developing guidance, navigation and control and communications systems for aircraft, missile and space systems. He has also served as an engineering professor, an inventor (82 U.S. patents) and is the co-author of three engineering textbooks and dozens of research articles.

Currently, he is a Clinical Volunteer for Mission Hospital Medical Center in southern California where he assists nurses, trains and supervises more than 30 volunteers, and serves as a VA "Vet-2-Vet Weekly in-Home Visitor" who checks on and reports on patients' wellbeing to their families. He is also a HydrocephalusCONNECT Peer Support Volunteer for the Hydrocephalus Association where he shares his experience and offers advice to patients recently diagnosed with NPH.

White gives presentations on NPH and will speak to whomever will listen. His most recent endeavor is trying to educate staff at senior centers since they are often the first ones to notice the telltale signs of NPH.

"It isn't just members of the medical community who need more education on NPH, the general public needs more awareness too," White said. "When I'm giving a talk, I discovered that the most attention-grabbing statement is when I say to people that NPH is a condition that comes late in life and can steal your brain, but if caught early the symptoms are reversible! That usually gets people's attention."

Stanley White will be speaking at HA CONNECT, the 15th National Conference on Hydrocephalus, which takes place June 28-30, 2018, in Orange County, CA. For details, visit <http://hydrocephalusconference.org/>.

Monitoring Capitol Hill

The Hydrocephalus Association is actively monitoring and engaging in legislation that has a direct impact to our hydrocephalus community. Hydrocephalus advocates across the country helped us raise our voices to our elected officials, and these efforts paid off. Here are highlights of some key wins and where we are currently turning our attention with Congress.

What's Next

Department of Defense Congressionally Directed Medical

Research Program (CDMRP): Hydrocephalus is once again included on the list of eligible conditions to receive funding for the 2018 grant cycle. We also feel we are in good standing for inclusion in 2019, with the support of Senator Patty Murray (D-WA), Senator Lindsey Graham (R-SC), and Senator Dick Durbin (D-IL). However, the future of the entire CDMRP is currently at risk. Senator John McCain (R-AZ) has moved to defund the program in 2019 and reallocate those dollars to programs for necessary Department of Defense functions. Senator McCain has expressed two concerns. First, that CDMRP research efforts are duplicative of the type of research done at the National Institutes of Health (NIH); and second, that the research is not limited to conditions that are military-specific. HA has joined the Defense Health Research Consortium (DHRC) as part of a larger strategy to keep the CDMRP.

HR 620: ADA Education and Reform Act: The House passed HR 620 by a vote of 225-192. The concern with the bill is that it shifts the burden of protecting the right to equal access to (or work in) a public place to the person with the disability, making it less likely that businesses will proactively comply. The person with the disability first has to be denied access; then must determine that violations of the law have occurred and file a written technical notice (usually requiring a lawyer); the aggrieved person with the disability must wait up to 60 days to receive a response; and finally, they must afford the business 120 days to make substantial progress on the problem before the issue can be brought to court. For some individuals dealing with their work place (as opposed to a retail business), this can mean a period of time without wages. The final bill holds the defendant liable if they fail to make substantial progress on ADA compliance complaints. The bill has now moved on to the Senate for a vote.

Transition Initiative: The HA Transition Initiative will focus on paving the way for a smooth entry for our teens and young adults into adult medical care. Advocacy will play a substantial role in creating this

reality. The most pressing issues center around medical providers willingly serving adult patients and around the need for value-based care and reimbursement models, particularly as a vehicle to incentivize providers not currently willing to take on transitioning adult patients. The CDC wants to pull together groups like ours around transition issues. This is an opportunity for us to be an active leader on this topic.

Telehealth: We are currently following two pieces of legislation that support telemedicine and telehealth initiatives. The first is the Vets Act, which passed the Senate on January 3rd. The bill allows the Department of Veterans Affairs providers in any state to provide care via telemedicine to patients in any state. The second are policy changes in MEDPac Policy. The Medicare Payment Advisory Commission voted unanimously to expand Medicare's telehealth reimbursement. The Commission presented to Congress a report mandated by the 21st Century Cures Act. The report notes increasing use of telemedicine, but suggests some caution is needed on reimbursement.

Advocacy Wins!

NIH Program Announcements: Addressed in detail in the Research Update, we are very excited to announce that the NIH has just released two Program Announcements (PAs) specifically for hydrocephalus. PAs are NIH's signal to the research world that NIH is interested in a specific topic or condition, and, historically, funding increases when PAs are announced. The release of these two PAs has been years in the making through our advocacy efforts and through our connections with NIH.

Health Provisions in the recent Continuing Resolution: The 2-year budget deal passed by Congress has a number of health provisions for which we had active engagement with our legislators via members of our community:

- The Continuing Resolution permanently ends the previous therapy cap policy that placed a hard \$1,980 limit on access to physical therapy and speech pathology services for those enrolled in Medicare. Our #StoptheCap efforts paid off!
- Gives NIH \$2 billion in funding through FY2019.
- Increases access to telemedicine services for Medicare Advantage enrollees, and encourages care providers to expand use of telemedicine.
- Funds Children's Health Insurance Program (CHIP) for 4 more years, community health centers for 2 years, and includes 5 years of funding for home visiting programs.
- Imposes a 2-year delay of the implementation of 2.3% excise tax on medical devices.

WALKS AND SPECIAL EVENTS

Top 2017 WALK Teams

Congratulations to all of our WALK to End Hydrocephalus Teams throughout the country. More than 1,200 teams participated in the 2017 WALKS. Thanks to their hard work, nearly \$2 million was raised in 2017 to help fund hydrocephalus research. Below is a list of the top 20 teams, ranked by amount raised. Who will be this year's Top 20?



Team Alex, South Florida WALK

2017 WALK – National Top Teams

Nat'l Rank	Team Name	Team Captain	TOTAL Raised	Walk Site
1.	TEAM RAIN	Farrah Weitz	\$ 82,257	Los Angeles
2.	TEAM ALEX	Alex Rodger	\$ 46,864	South Florida
3.	CHARLIE'S ANGELS	Jennifer Pope	\$ 32,371	Los Angeles
4.	TEAM MEREDITH	Sharilyn Green	\$ 22,628	National Capital
5.	HYDRO CURE NYC	Julie Matos	\$ 20,300	New York City
6.	TEAM EMA'S HOPE	Chara McLaughen	\$ 18,120	Chattanooga
7.	TEAM WILLIAM	William Gross	\$ 18,635	Seattle
8.	TEAM JOSHASAURUS REX	Emily Sajor	\$ 16,653	Detroit
9.	TYLER'S WARRIORS	Tyler Padron	\$ 16,560	Long Island
10.	WILL'S WARRIORS	Heather Rader	\$ 14,226	Central Pennsylvania
11.	TEAM MAX	Cortney Pellettieri	\$ 11,335	Los Angeles
12.	VIOLET FEMMES	Colleen Richardson	\$ 11,240	Chicago
13.	CONOR'S CREW	Katie Cook	\$ 13,040	Chicago
14.	TEAM GRANT	Jerrod Miller	\$ 12,462	Portland
15.	TEAM IAN	Gerri Keating	\$ 12,324	Jersey Shore
16.	TEAM RAIN-NYC	Allison Fox-Collis	\$ 10,712	New York City
17.	TEAM JACOB	Susan Fiorella	\$ 10,380	National Capital
18.	ASHLEY & THE ROCKIN' RUTHS	Christy Ruth	\$ 10,366	Charlotte
19.	TEAM LAWRENCE	John Lawrence	\$ 9,660	National Capital
20.	TEAM MARY	Mary Conyard	\$ 9,627	Seattle

Create Your Own Fundraiser with the Do It Yourself Tool!

The Hydrocephalus Association's Make Waves for Hydrocephalus – Do It Yourself (DIY) Fundraising allows you to raise awareness and help fund the search to cure hydrocephalus. Through this program, you can create your own fundraising web page and turn your favorite hobby, sport, event or celebration—you name it—into a unique awareness initiative! Make Waves for Hydrocephalus is for individuals, families, businesses, schools and community groups—anyone who is interested in personalizing a campaign and raising funds for HA.

DIY Fundraiser: Reason for Hope Holiday Concert



Stephanie Oltean, a vocalist from Kansas, gave a beautiful performance on December 4, in Lucas, KS, to raise money for HA. The event was a DIY fundraiser. Stephanie is committed to doing DIY events. As a mom of a son with hydrocephalus, she understands the need to raise funds to support our mission. Thank you Stephanie for a very successful event!

Help Laura Raise Funds for Hydrocephalus Research



Daniel Nelson has been battling hydrocephalus since he was very young. As the majority of the people with this condition Daniel has gone through so many setbacks, pain and long hospital stays. Recently Daniel had surgery again. He went back to college only days later. An uninformed and unkind person suggested that he cover up that scar. This put Laura Reeb,

KEEP Collective Designer, into action. She is donating her commission on her jewelry sales to the Hydrocephalus Association! Daniel is fundraising for this event as well. Shop for jewelry with Laura at <https://www.keepcollective.com/with/laurareeb>.

Have you joined us on Social Media?



2018 WALK to End Hydrocephalus Sites

Join a WALK near you!

Atlanta, GA	September 22
Baltimore, MD	September 22
Central Alabama, AL	November 11
Central Pennsylvania (Hershey, PA)	September 15
Charlotte, NC	October 20
Chattanooga, TN	October 20
Chicago, IL	August 18
Cleveland, OH	October 7
Columbia, SC	September 22
Dallas/Ft. Worth, TX	September 29
Denver, CO	September 2
Des Moines, IA	September 30
Detroit, MI	August 26
Eastern Carolina, NC	October 27
Fresno, CA	October 7
Greater Cincinnati, OH	October 14
Greater New England, MA	September 30
Houston, TX	October 20
Indianapolis, IN	September 29
Jersey Shore, NJ	September 16
Long Island, NY	September 30
Los Angeles, CA	September 8
Louisville, KY	September 29
Middlebury, CT	September 16
New York, NY	October 7
Northwest Arkansas, AR	September 1
Orlando, FL	September 29
Philadelphia, PA	September 9
Phoenix, AZ	November 3
Portland, OR	June 9
Salt Lake City, UT	September 22
San Francisco, CA	September 22
Seattle, WA	August 11
South Florida (Deerfield Beach), FL	October 13
St. Louis, MO	October 20
St. Petersburg/Tampa Bay	November 3
Twin Cities, MN	September 22
Washington, DC (National Capital)	September 15
Western New York, NY	September 8
Western Pennsylvania, PA	September 29
Wichita, KS	October 13



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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

