



In Stitches with Conan O'Brien Raises \$300K for HA's Mission

Our second annual comedy fundraiser delivered laughs and raised much-needed funds for our mission!

6

Join our Hydrocephalus Patient Registry!

Join HAPPIER, the first Hydrocephalus Patient-Powered Registry, and help scientists understand the complexities of living with hydrocephalus.

8

New Ask the Expert NPH Video Series!

Our new Ask the Expert video series answers your questions about NPH diagnosis, treatment, symptoms and more!

11

Find a WALK to End Hydrocephalus Near You!

There are 46 hydrocephalus WALKs taking place across the country. Register for a WALK in your area or donate to a WALK team or participant.

MESSAGE FROM THE PRESIDENT & CEO



Inspired. That's how I feel every day as the President and CEO of the Hydrocephalus Association. Inspired by the community we serve, the many people who support our work, and the researchers who are getting us closer to a cure. Over the past six months, I've had the chance to meet so many wonderful people who remind me why our mission is so important.

As you'll read in this issue of *Pathways*, we've been busy traveling to different parts of the country raising awareness about hydrocephalus and meeting parents and others impacted by this condition. Whether it was in Los Angeles in April, where we hosted our 2nd Annual "In Stitches" comedy fundraiser with Conan O'Brien, or Washington, D.C. and Seattle in June where we brought local members of the hydrocephalus community together to learn about our research progress, we highlighted how HA is working to find a cure and improve the lives of those living with the condition.

I was especially touched to be able to meet some of you at a networking event in Chicago. I value the opportunity to hear from you and find out how we can work together to make an even greater impact.

In this issue, you'll also learn about some of the great work HA and our Medical Advisory Board is doing to help those living with Normal Pressure Hydrocephalus (NPH). This Spring, we were thrilled to launch a new Ask the Expert video series on NPH with our friends at Johns Hopkins Medicine. The series is available on our YouTube channel: www.youtube.com/user/hydroassoc. We know that NPH is still relatively unknown and many of you have requested more resources on NPH. We hope this series answers your questions and I encourage you to share the videos on your social media channels. If you're not already subscribed to HA's YouTube channel, please do so!

Whether you have NPH, have congenital hydrocephalus or you developed hydrocephalus after a brain bleed, I hope you will join

HAPPIER, our Hydrocephalus Patient-Powered Registry! HAPPIER is an online database created for our community to share your experience living with hydrocephalus or caring for someone with hydrocephalus. It's important that everyone is represented in the Registry, whether you've had one brain surgery or 100. By sharing your experiences in the Registry, you are helping scientists understand the complexities of living with this condition and where to focus their research. Join now at www.hydroassoc.org/HAPPIER.

As you know, research is a top priority at the Hydrocephalus Association. That's why we've invested over \$9.6 million in research since 2009, funding the best and the brightest scientists who are changing the hydrocephalus research landscape. On pg. 5, you'll read about our latest grantees, who are doing really innovative work to identify new ways to prevent or stop the development of hydrocephalus, and to develop a shunt that doesn't get blocked. We're so proud of this work and we hope you are too!

You can help boost our research efforts by signing up to participate in a WALK to End Hydrocephalus near you. We have HA WALKs in 46 locations this year (learn more on pg. 11). The WALKs are a great way to connect with others impacted by hydrocephalus and to raise funds to support our mission. Start a team or donate to an existing team, and know that your support is making a huge difference!

I hope this newsletter inspires you to get more involved with HA, whether it's by participating in a WALK, joining our Hydrocephalus Patient Registry, or by making a donation. Together, I know we will find a cure!

Sincerely,

A handwritten signature in dark ink, reading "Diana Gray".

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.

In Stitches with Conan O'Brien Raises \$300K for HA's Mission



The Hydrocephalus Association's mission to find a cure and improve lives got a major boost on April 11 when comedy powerhouse Conan O'Brien headlined our 2nd Annual "In Stitches: A Night of Laughs" comedy event. Four hundred people attended the sold out show, held at the Avalon Hollywood in Los Angeles, raising \$300,000 for hydrocephalus research, support and education programs.



Dr. McComb accepting his award.

Guests were treated to a performance by Conan, joined by Moses Storm and Taylor Tomlinson, stand-up comedians who have appeared on the CONAN show. Actor Max Greenfield, who stars in the CBS comedy *The Neighborhood* and appeared in a PSA for HA's #NOMOREBS campaign, also took the stage to share his personal connection to hydrocephalus

through the diagnosis of his close friend's daughter. He also introduced Olivia Maccoux, who co-starred in the PSA with him. Maccoux shared her

personal story of resilience after enduring 147 brain surgeries to manage hydrocephalus.

During the event, HA also honored Dr. J. Gordon McComb, Children's Hospital Los Angeles, with the inaugural Lifetime Achievement Award. Dr. McComb is a beloved neurosurgeon in the hydrocephalus community and has cared for patients for more than 50 years!

"Our 2nd annual In Stitches event was truly a magical night. Conan O'Brien and the other comedians were incredible and we are so grateful to them for helping us raise much-needed dollars for our cause," said Diana Gray, HA's President and CEO. "Of course, the evening would not have been possible without our incredible committee, co-chaired by board members Jennifer Pope and Sheryl Rosenberg, who were instrumental in organizing the event."

In addition to great comedy, the event included a Fund-a-Cure segment, where members of the audience could text in a donation, as well as an exciting silent auction organized by committee member Julie Jennison.

"In Stitches, a Night of Laughs" was sponsored by Hulu and TBS, who were platinum sponsors, as well as Awesomeness, CBS, Children's Hospital Los Angeles, The Gersh Agency, L.A. Kings, Sony and Southern Wine & Spirits. Special thanks to our In Stitches Committee members: Sheryl Rosenberg, Jennifer Pope, Julie Jennison, Becky Lythgoe, Kris Lythgoe, Cortney Pellettieri, Mike Pellettieri, Matt Pope, Billy Rosenberg, Farrah Weitz, and Brett Weitz.

Let's Make Our Voices Heard This September!

September is Hydrocephalus Awareness Month – our chance to bring national attention to the one million Americans living with hydrocephalus and the impact of this condition. The quickest way to reach thousands is through social media. That's why this year we're calling on YOU to help us educate the public about hydrocephalus.

Here's how you can join our #HAM2019 Challenge:

Step 1: Print out one of the signs we've created. You can find them all at www.hydroassoc.org/ham

Step 2: Snap a photo of yourself holding the sign.

Step 3: Post to your Facebook page and/or on Instagram using the hashtag #HAM2019 and remember to tag the Hydrocephalus Association (@hydroassoc) so we can like and share your post! Sample Post: *It's Hydrocephalus Awareness Month! So, today I'm joining @HydroAssoc in raising awareness about #hydrocephalus. Let's find a cure! #HAM2019 #NOMOREBS.*



And don't forget to like and share other #HAM2019 posts you see on social media. By working together, we can make hydrocephalus a household name!

Encouraging Medical Professionals to Get More Involved in Transition

This Spring, members of HA's Medical Advisory Board (MAB) were busy raising awareness about the challenges teens and young adults with hydrocephalus face when transitioning from pediatric to adult care.

In March, Cathy Cartwright, a neuroscience nurse at Children's Mercy Hospital in Kansas City, MO, and MAB member, encouraged her peers at the American Association of Neuroscience Nurses (AANN)'s Annual Meeting to take a more active role in helping hydrocephalus patients and families transition successfully to adult care.

Cathy led a session entitled, "The Role of the Neuroscience Nurse in Transitioning Youth to Adult Healthcare," at the AANN meeting in Denver. The goal was to raise awareness among AANN members about the difficulties facing young adults with hydrocephalus when seeking adult care, and to issue a call to action for AANN and neuroscience nurses to become more involved in transition of neuroscience youth.

"Neuroscience nurses play a key role in transition planning for patients and families by initiating early transition planning and educating patients about caring for their hydrocephalus," Cathy explained.

In addition to serving as a member of our MAB, Cathy was involved in HA's Transition Summit in 2017 and is helping HA implement its Transition Initiative Action Plan, a multifaceted effort aimed at improving transitional and longitudinal care for adolescents and young adults with hydrocephalus. The Action Plan includes recommendations for hospitals, health systems, practices, professional societies, and HA itself. One of the recommendations from the Summit was for professional organizations, like the AANN, to take an active role in the transition process.

In February, MAB Chair Dr. Mike Williams, a professor of neurology and neurological surgery at the University of Washington (UW) School of Medicine, was interviewed for a news article on transition published by the UW School of Medicine. The article highlighted a paper he was published in the *Journal of Neurosurgery* (JNS) in December 2018, which summarized the findings from HA's first-ever Transition Summit, and explained the important role neurologists and neurosurgeons play in helping youth transition to adult care.

To learn more about HA's Transition Initiative Action Plan, visit: www.hydroassoc.org/transition-initiative/.

Two Friends Run 200 Mile Race to Find a Cure for Hydrocephalus

When Brett Bauer decided that he wanted to raise awareness and funds to help find a cure for hydrocephalus, he knew it would involve the one thing he loves to do – ultrarunning. So he partnered with his friend and fellow ultrarunner, Matt Campbell, to run the Reebok Ragnar Northwest Passage, a 200-mile journey from the Canadian border to Langley, WA, on July 12-13, 2019.

That's right – between the two of them they ran 200 miles! The endeavor, which they're calling Project No Shunt, raises awareness and funds for hydrocephalus. Brett's motivation comes from his nephew, Max, who was born with hydrocephalus. The proceeds from the relay race will benefit Team Max's Peeps at the Seattle WALK to End Hydrocephalus.

"Ultrarunning is my passion and has given me unforgettable experiences and life lessons I wouldn't have otherwise. Having a platform like ultrarunning to bring awareness and raise funds for a cause near and dear to my heart is an opportunity not everyone has. Doing something for someone else who will never be able to repay you makes projects like this bigger than yourself. Like my nephew Max always says, 'Crazy uncle Brett!'" Brett said.



Three Scientists Awarded HA Grants for Their Bold and Innovative Work



What if you could prevent or stop the development of hydrocephalus after a brain bleed or develop a shunt that doesn't get clogged? That's what the 2018 Hydrocephalus

Association (HA) Innovator Award grantees are hoping to do through their research projects.

Dr. James M. Drake, Head of Neurosurgery, Chief of Perioperative Services, and Surgeon-in-Chief in the Department of Surgery at the Hospital for Sick Children, will test the use of focused ultrasound to dissolve blood clots in the brain of premature infants who have a brain bleed. The goal is to reduce the damage caused by blood in the ventricles and prevent hydrocephalus.

Dr. Carolyn Harris, Assistant Professor of Chemical Engineering and Materials Science at Wayne State University, will conduct research to understand the reasons shunt fail on a molecular level. Her goal is to create a shunt catheter that does not block.

Dr. Kathleen Millen, Professor of Pediatrics at the University of Washington School of Medicine and Principle Investigator at Seattle Children's Hospital Research Institute, will conduct preclinical research to test a new drug to stop the development of posthemorrhagic hydrocephalus.

These scientists are testing innovative techniques and drug therapies that could potentially change the future of hydrocephalus.

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's mission to promote a cure for hydrocephalus and improve the lives of those affected by the condition.

Funding for the 2018 Innovator Awards was made possible through the support of the Posthemorrhagic Hydrocephalus Campaign and individual donations.

HA in Attendance

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

American Association of Neuroscience Nurses (AANN) Annual Meeting

March 21-24, 2019 | Denver, CO

Health Research Alliance

March 28-29, 2019, Atlanta, GA

HA Medical Advisory Board Meeting

April 6, 2019, Chicago, IL

American Association of Neurological Surgeons (AANS) Annual Scientific Meeting

April 13-17, 2019 | San Diego, CA

Adult Hydrocephalus Clinical Research Network

April 26-27, 2019, Calgary, CAN

American Academy of Neurology (AAN) Annual Meeting

May 4-10, 2019 | Philadelphia, PA

Brain Health Fair - American Academy of Neurology (AAN)

May 9, 2019 | Philadelphia, PA

Hydrocephalus Clinical Research Network

May 9-10, 2019, Denver, CO

"HA has funded Innovator Awards annually since 2015, and the results have been amazing. From an investment of just over \$1 million, these HA-funded researchers have gone on to secure over \$8 million in additional funding to continue their research. Already we are seeing some of these projects move towards clinical trials, and the 2018 Innovator Award projects promise to be just as successful."

— Dr. Jenna Koschnitzky
HA's National Director of Research Programs

Hydrocephalus Patient Registry Continues to Grow

To date, over 400 individuals have joined HAPPIER, the first hydrocephalus patient-powered registry. HAPPIER was created for patients and caregivers to provide input to scientists about how hydrocephalus impacts their daily life. By joining our patient registry and adding your experience with hydrocephalus, you are helping scientists understand the complexities of living with this condition and where to focus their research.

"What does our hydrocephalus community look like? Never before have we been able to fully understand the diversity of our community and how hydrocephalus impacts the lives of both patients and caregivers.

Thanks to HAPPIER, we will now be able to!" said Dr. Jenna Koschnitzky, HA's National Director of Research Programs.

The registry includes questions about the patient, their medical history, their current health, and the daily challenges of living with hydrocephalus. The information submitted is secure and stripped of any identifying information, making records completely anonymous to researchers.

Joining HAPPIER is EASY!

- 1 Login to Our Website
- 2 View the Consent Letter
- 3 Complete the First Survey In Less Than 15 Minutes!
- 4 Stay Engaged through Your Personal Dashboard On Our Website



HAPPIER

Join the first Hydrocephalus Patient Powered Registry! Be a part of research!

www.hydroassoc.org/HAPPIER

VOLUNTEER SPOTLIGHT:

Taking a Pie in the Face for Hydrocephalus



Would you let kids throw a pie in the face for a good cause? That's exactly what Jason Plucker, an administrator at Varsity Lakes Middle School in Lehigh Acres, FL, did. In March, his school held a "Penny War" in which students donated pennies, dollars and other coins in order to pie one of their administrators. Jason

was the lucky administrator and he chose to donate the funds to the Hydrocephalus Association. Thanks and we hope the pie tasted great, Jason!

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!*

Hope in Progress Events in DC and Seattle Highlight Research Efforts



DC Hope in Progress Dinner



DC Hope in Progress Dinner



Seattle Hope in Progress Dinner

Board member Teresa Mastrangelo and her friend Hollin Dwiggins hosted an event on June 7th to raise awareness about the Hydrocephalus Association's research efforts. The DC Hope in Progress Dinner, held just outside of Washington, DC, brought together members of the DC area hydrocephalus community and featured a presentation by Dr. Shenandoah Robinson, a Professor of Neurosurgery at Johns Hopkins University. Dr. Robinson, who was awarded a 2016 Innovator Award grant from HA, highlighted her research on Posthemorrhagic Hydrocephalus of Prematurity (PHHP) and how HA funding has impacted her work.

"Thank you Teresa Mastrangelo and Hollin Dwiggins for hosting this special event! It was a perfect evening and we were thrilled to have the opportunity to share an update on HA and our research progress. Special thanks to Dr. Dody Robinson for sharing about her work on PHHP and the impact funding from HA has had on her lab. Because of you there is hope!" said Diana Gray, HA's President and CEO.

On June 15th, Dr. Michael Williams and Clifton Scott hosted our Seattle Hope in Progress Dinner. The event brought together the local hydrocephalus community and included a presentation by Dr. Williams about HA's incredible research progress and future plans. Dr. Williams serves on the HA Board of Directors and is a neurologist at UW Medical Center, where he directs the Adult and Transitional Hydrocephalus Program and the Intracranial Hypertension Program. He is also a member of the Adult Hydrocephalus Clinical Research Network (AHCN) and Chair of our Medical Advisory Board.



Calling all Hydrocephalus Researchers!

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

Visit www.hands.hydroassoc.org

Card Party Helps Raise Awareness and Funds for Hydrocephalus Research



In March, Iris and Nat Adler hosted their 10th Annual Charity Card Party at the Broken Sound Country Club in Boca Raton, FL. Participants played fun card games and Mahjong, shopped and enjoyed brunch. The event raised awareness and research funds for hydrocephalus and Charcot-Marie-Tooth (CMT) Disease by benefiting both the

Hydrocephalus Association and the Hereditary Neuropathy Foundation. Iris' granddaughter suffers from hydrocephalus and her grandson has CMT2A, a variant of CMT Disease.

New Ask the Expert NPH Video Series!



We're excited to announce our new Ask the Expert video series on Normal Pressure Hydrocephalus (NPH), available now on HA's YouTube channel! In the series, Dr. Abhay Moghekar, neurologist and

Research Director of the Cerebrospinal Fluid Center at Johns Hopkins Medicine; and Dr. Mark Luciano, neurosurgeon and Director of the Cerebrospinal Fluid Center at Johns Hopkins Medicine, answer questions about NPH diagnosis, treatment, symptoms and more!

The videos explore the proper way to diagnose someone with NPH, a type of hydrocephalus that is most commonly seen in older adults, the steps patients should take after diagnosis, what happens when NPH is untreated, symptom improvement after treatment, ETV as a treatment for NPH, and why symptoms sometimes return after treatment.

This series is sponsored by our industry partner Codman, a part of Integra Lifesciences. To watch our NPH Ask the Expert Series, visit HA's YouTube channel at www.youtube.com/user/hydroassoc/ and click on the Ask the Expert NPH Playlist.

Tips to Survive College While Living with Hydrocephalus

By Caitlin K. Maynard



College or graduate school is an exciting time in your life. You may have moved away from home for the first time, you are forming lifelong friendships, and gaining knowledge and skills that will help prepare you for your career. But what happens when hydrocephalus disrupts your studies?

Hydrocephalus is unpredictable. This means complications with your shunt or ETV can occur. When this happens it can be devastating as you were finally getting into a rhythm and enjoying your independence. After a revision (surgery), going back to school can be challenging. Below are several tips to help you overcome this difficult time:

- 1. First...Don't Panic!** Many people feel anxious about returning to school after an extended leave of absence. The comforting news is that colleges have procedures and processes in place that help make transitioning back into school as easy as possible. I encourage you to research the procedures at your school ahead of time.
- 2. Perseverance** to go back to school is something you need to find within yourself. Perseverance is the drive to keep going despite challenges, and the flexibility to adapt and change plans when necessary.
- 3. If you do not feel strong enough,** look to your support system for help. Reach out to your family or friends to help you find the strength to get back into a routine and return to school.

- 4. Be realistic** about what you can do. It's important to set reasonable goals and expectations for yourself. Start small and build-up as you are able.
- 5. Think "life success."** Success in life depends on things like a healthy sense of self, the willingness to ask for and accept help, and the determination to keep trying in spite of challenges.

You may encounter setbacks and delays but that doesn't mean you can't graduate! When I was in graduate school, I had to drop everything and go home because my shunt became infected. During treatment for the infection, my tubing slipped and I needed another surgery which resulted in my Endoscopic Third Ventriculostomy (ETV). As a result of these surgeries I was unable to complete the semester, which lengthened my graduate schooling by one year and I was unable to go on a planned Finland trip. I relied on my support system to help me go back to school. On the bright side of things, I developed new friendships, remained connected to my old friends, and went to Finland only a year later. It took strength, support and perseverance, but I finally received my Master's Degree in Social Work!

A wise person once told me, "Nobody will ever ask you how many years it took you to graduate. It only matters that you did." I have an undergraduate and a graduate degree and it is true, nobody asks me how long it took me to receive my degrees—it only matters that I have them!

Caitlin is a Social Worker from Massachusetts living with hydrocephalus. She has endured 48 hydrocephalus-related surgeries. Caitlin is a guest blogger and peer volunteer for the Hydrocephalus Association, and serves on the Hydrocephalus Association Scholarship Committee.

HA CONNECT²⁰

NATIONAL CONFERENCE ON HYDROCEPHALUS

SAVE THE DATE

for the 16th National Conference on Hydrocephalus
which will take place in Houston, TX
June 25-27, 2020

Get to Know Image Outfitters: A Company that Gives Back



Since 2015, the Hydrocephalus Association has been partnering with Image Outfitters for our promotional products and gear—everything from our WALK t-shirts and bandanas to drinkware. But the company does more than just create promotional products—they donate a portion of their profits to nonprofit organizations like the Hydrocephalus Association!

Image Outfitters is a promotional products supplier who uses business as a way to generate funds for charities across the nation, both big and small. Through their “iShare Charitable Donations Program,” they donate up to 10 percent of sales to a charity. By choosing Image Outfitters for your promotional product needs, you’re giving back to the Hydrocephalus Association!

“In the past few years, the Hydrocephalus Association has purchased promotional and apparel items from Image Outfitters, which we then donated right back to the Hydrocephalus Association, raising tens of thousands of dollars for their research to find a cure,” said Esbert Cardenas, Image Outfitters President.

To date, Image Outfitters has donated over \$35,000 to the Hydrocephalus Association.

To learn more, visit www.ishareworks.com

Connect with Local Families through Our Community Network!

The Hydrocephalus Association has over 40 Community Networks in locations across the United States. These Community Networks allow you to connect with individuals and families in your area who are impacted by hydrocephalus. They host educational events, support group meetings and other gatherings. Visit our website to join your 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 support@hydroassoc.org or call (888) 598-3789 to launch one near you.

AK Anchorage	NJ Jersey Shore
AZ Phoenix	Northern NJ <i>NPH</i>
CA Orange County <i>NPH NEW!</i>	NY Western
Los Angeles	Long Island
Ventura	New York City
CO Denver	OH Cleveland
CT Hartford	OK Oklahoma City
DC Washington	OR Portland
DE Middletown	PA Eastern PA
FL Central FL	RI Providence <i>online only</i>
GA Atlanta	SD Sioux Falls
IL Metropolis <i>NEW!</i>	TN Chattanooga
Chicago	TX Dallas
IN Indianapolis	Houston <i>peds/adolescent</i>
MA Boston	UT Salt Lake City
MD Baltimore	VA Richmond
ME Portland	WA Seattle <i>pediatric</i>
MI Detroit	Eastern WA
MN Minneapolis <i>peds/adolescent</i>	Vancouver
MO St. Louis	WI La Crosse <i>online only</i>
NC Charlotte	Military Members <i>online only NEW!</i>
ND Fargo & Morehead, MN	NI Lagos children/families



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

HA Volunteer Educates Senior Citizens About NPH



HA, along with its volunteers, are working hard to educate the public and doctors about Normal Pressure Hydrocephalus (NPH). In April, Trish Bogucki, a longtime peer support volunteer for HA and

NPH Community Network leader, conducted a presentation about NPH and cognitive therapy at a senior center in Midland Park, NJ.

Her presentation at the Northwest Bergen Senior Activity Center provided an in-depth overview on NPH, its symptoms and causes, treatments, resources provided by HA, and helpful therapies. Cognitive therapist, Olivia Bell of Valley Rehab, also presented along

with Trish. Olivia discussed how cognitive therapy can be helpful for NPH patients and explained how it works.

Trish began volunteering for HA after being diagnosed with NPH in 2015. "Initially I was terrified at the prospect of brain surgery but now feel very fortunate to be almost 100% back to normal and enjoying an active life. I want to help others get timely treatment by spreading the word about NPH; I also try to allay some of the fear by showing positive outcomes from both shunt surgery and the therapies that followed," Trish said.

Trish is one of our NPH Outreach Volunteers. If you're interested in learning how to help us raise awareness by becoming an NPH Outreach Volunteer, please email info@hydroassoc.org.

Developing New Guidelines for Diagnosing and Treating iNPH

How patients are diagnosed or treated with idiopathic Normal Pressure Hydrocephalus (iNPH), a form of hydrocephalus that typically affects people over 65, varies widely throughout the world and even in the United States. In some cases, doctors may not even consider iNPH as a possibility, diagnosing the patient with other conditions such as Parkinson's Disease or Alzheimer's Disease. That's why Dr. Mark Hamilton, Vice Chair of HA's Medical Advisory Board and Chair of the Adult Hydrocephalus Clinical Research Network (AHCN), has undertaken an effort to develop new international guidelines for diagnosing and treating iNPH.

iNPH is characterized by a classic triad of symptoms, including gait disturbance (walking and balance), cognitive deterioration (dementia), and impaired bladder control. It is estimated that more than 700,000 Americans may have iNPH, but less than 5 percent receive an appropriate diagnosis. iNPH is one of the few causes of dementia that can be controlled or reversed with treatment.

International guidelines to help doctors diagnose and treat patients who may have iNPH were last published in 2005 but a lot has changed since then, explained Dr. Hamilton.

"There's been a lot of additional research that now helps us better understand the specifics of how to approach diagnosis and treatment of patients with iNPH. While the basic approach for surgical treatment of patients with iNPH using shunts hasn't changed, there now are better approaches that help reduce shunt failure, shunt infection and other issues related to surgical care," he said.

To update the guidelines, Dr. Hamilton has assembled a multinational team of neurologists and neurosurgeons representing North America, Europe and Japan. Their first meeting was held during May, 2019 in Tokyo, Japan, where they began their initial review of the medical literature on iNPH and existing iNPH guidelines.

They will then present their findings at the annual Hydrocephalus Society Meeting to be held in Vancouver, Canada September 2019. The entire iNPH Guideline development process is projected to take up to two years. The finalized guidelines will be submitted for publication during 2021.

Despite the current evidence around iNPH, there are still medical professionals who don't believe iNPH is an actual diagnosis. Dr. Hamilton said he hopes the new guidelines will not only help manage any questions or doubts doctors have about iNPH but also help patients better understand the diagnosis process.

"We still get resistance from some neurologists and neurosurgeons about how important this is and if iNPH is even a real issue. That's a barrier we have to overcome, and we will do that by showing the evidence and providing clear evidence-based guidelines," he explained. "Hopefully, these guidelines will show physicians how to successfully approach the steps required to sort out a diagnosis of iNPH and increase the level of comfort for patients and families during this experience."

Dr. Hamilton is Director of the Adult Hydrocephalus Program (AHCN) and Professor of Neurosurgery at the University of Calgary.

WALK FOR A CURE

2019 WALK to End Hydrocephalus Sites: No One Walks Alone

Get excited! Our 2019 WALK to End Hydrocephalus season is HERE! This year, there are 46 WALKs taking place throughout the country, including six new WALK locations. Whether you're walking in Los Angeles, New Orleans or New York—you'll meet others impacted by the condition and help us raise much-needed funds for our research, education, support and advocacy programs. Where are you walking this year?

Visit www.hydroassoc.org/walk to find and register for a WALK near you!



Atlanta, GA	Sept. 21
Baltimore, MD	Sept. 21
Central Alabama	Oct. 6
Central Pennsylvania	Sept. 14
Charlotte, NC	Oct. 19
Chattanooga, TN	Oct. 19
Chicago, IL	Aug. 17
Cleveland, OH	Oct. 12
Columbia, SC	Sept. 21
Columbus, OH New!	Oct. 6
Connecticut	Sept. 22
Denver, CO	Sept. 1
Detroit, MI	Sept. 15
Des Moines, IA	Oct. 6
Eastern Carolina, NC	Oct. 19 (tentative)
Fresno, CA	Nov. 10
Greater Cincinnati, OH	Oct. 6
Greater Dallas/Fort Worth, TX	Sept. 28
Greater New England, MA	Oct. 6
Houston, TX	Sept. 21
Indianapolis, IN	Sept. 28
Jersey Shore, NJ	Sept. 15
Long Island, NY	Sept. 22
Los Angeles, CA	Sept. 7
Louisville, KY	Sept. 21
Memphis, TN New!	Sept. 28
National Capital, DC	Sept. 28
New Orleans, LA New!	Sept. 28
New York City, NY	Nov. 9
Northwest Arkansas	Aug. 31
Orange County, CA New!	Oct. 12

Philadelphia, PA	Sept. 21
Phoenix, AZ	Nov. 2
Portland, OR	June 8
Sacramento, CA New!	Sept. 14
Salt Lake City, UT	Sept. 14
San Francisco, CA	Sept. 28
Seattle, WA	Aug. 10
South Florida	Nov. 9
St. Louis, MO	Oct. 19
St. Petersburg/Tampa Bay, FL	Nov. 9
Twin Cities, MN	Sept. 21
Western Kansas New!	Oct. 5
Western New York	Sept. 7
Western Pennsylvania/Pittsburgh	Sept. 28
Wichita, KS	Oct. 12

**THANK YOU TO OUR
NATIONAL WALK SPONSORS**
Together we are making a difference!



Codman
SPECIALTY SURGICAL
AN INTEGRAL LIFE SCIENCES COMPANY

AESCU LAP



4340 East West Highway, Suite 905
Bethesda, Maryland 20814-4447



LEAVE YOUR LEGACY

The Fudge Solomon Legacy Society

Consider how you can help ensure future support of the Hydrocephalus Association by remembering HA in your long term estate plans. In doing so, you will **become a member of the Fudge Solomon Legacy Society**, established to honor HA's pioneering founders, Emily Fudge and Cynthia Solomon.

Making a bequest to HA is easy and the options are endless, including: bequests of cash, stock or other property, proceeds from a life insurance policy or retirement plan, to name a few. Giving can be customized to suit your specific situation and wishes.

To find out how you can include HA in your estate plan today, please contact the Hydrocephalus Association at (888) 598-3789 or giftplanning@hydroassoc.org

