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SPECIAL SECTION: Normal Pressure Hydrocephalus

This section features articles covering the difficulty diagnosing NPH, the looming financial crisis for long-term care, and one man's 9 year journey of misdiagnosis.

Diana Gray Announced as the New Chief Executive Officer



The Hydrocephalus Association (HA) is pleased to announce the appointment of Diana Gray as the new Chief Executive Officer (CEO).

"The Hydrocephalus Association's vision is to seek a cure for hydrocephalus and dramatically improve the lives of those living with the condition," stated Aseem Chandra, chairman of the Board of

Directors of the Hydrocephalus Association. "Diana's appointment as CEO of the Hydrocephalus Association represents the Board's commitment to that vision. We are delighted that Diana is bringing her 20 years of executive experience in fundraising, operations, new market development and volunteer management to lead the Hydrocephalus Association."

Building on the association's growth over the last five years, Diana joins HA at a pivotal time with the establishment of a five-year strategy to raise awareness of hydrocephalus and increase research funding to seek a cure. The strategy includes expanding educational and support services, influencing the health delivery system to improve diagnosis and treatments for patients, building key relationships with government officials and federal agencies, and pursuing high quality, high impact research in pursuit of a cure.

"I am honored to be joining the Hydrocephalus Association in support of its life-changing mission," shared Diana. "My hope is to provide strategic leadership and to add positive value as the organization seeks to expand its impact as outlined within its five-year strategic plan. Foremost, our collective goal is to move the needle in the landscape of hydrocephalus awareness, care, advocacy and research in order to improve the lives of those impacted by this condition. I enthusiastically embrace this challenge and look forward to creating new partnerships to strengthen our efforts."

Diana recently served as Vice President of two nationally-recognized organizations – the Lupus Foundation of America and the Juvenile Diabetes Research Foundation International (JDRF). Her tenure at both organizations involved overseeing field management and development while growing operational capabilities and expanding into new markets. Her efforts enabled programs to reach more communities, empowered more volunteers to become leaders, and delivered increased services to growing numbers of constituents. During her 12 years at JDRF she helped structure programs that continue to serve as models across the country. Prior to joining JDRF, Diana exemplified her commitment to members of patient organizations by providing outstanding service as CEO of the Damien Center. The governor of Indiana presented her with Indiana's highest civilian award, the *Sagamore of the Wabash*, in recognition of her distinguished service.

HAPPY NEW YEAR!

The Staff of the Hydrocephalus Association wishes everyone a Happy New Year! We look forward to working together toward our mission of promoting a cure for hydrocephalus and improving the lives of those affected by the condition.

HA Staff (from left to right.) Back row: Megeen White, Fernanda Brown, Amy Weist, Aisha Heath, Amanda Garzon, Jenna Koschnitzky. Front row: Diana Gray, Liz Trabucco, Marisol Ortiz, Jennifer Bechard, Randi Corey. Not pictured: Karima Roumila





JUNE 16-19, 2016

MINNEAPOLIS!

14th National Conference on Hydrocephalus

Marriott City Center | 30 S 7th Street | Minneapolis, MN 55402

The 14th National Conference on Hydrocephalus will be held **June 16 - 19, 2016**, at the Minneapolis Marriott City Center in Minneapolis, MN. Our National Conference provides individuals living with hydrocephalus and their families, an opportunity to learn from leading medical experts and from each other through an extensive four-day program comprised of interactive sessions, research updates, and educational seminars. **We invite you to join us!**

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

Book your hotel today! We have a special group room rate of \$159/night plus tax that includes complimentary internet. Reservations can be made online at the Minneapolis Marriott Center website or by phone at (612) 349-4000 through the Marriott Reservations office by calling (800) 228-9290. Please be sure to mention the 14th National Conference on Hydrocephalus or just the Hydrocephalus Conference.

Learn more about conference! Visit www.hydrocephalusconference.org

Vision Dinner Aims to Accelerate Hydrocephalus Research

The Hydrocephalus Association's Third Annual Vision Dinner was held on October 15, 2015, in New York City at the JW Marriott Essex House New York. The dinner is a five-year campaign launched in October 2013 to raise national awareness about hydrocephalus and, ultimately, find a cure for the condition. The campaign brings together existing and prospective members of the hydrocephalus community — patients and their families, clinicians, researchers, scientists, philanthropists, business leaders and advocates — to share information, spotlight progress and chart a course for the future.



new ideas and
execute innovative research.

The goal for this year's dinner was to raise of \$500,000 to support the launch of HANDS and we are proud to announce that we have exceeded this goal! We are thankful to our Partners in Research and donors who made this possible.

The focus of this year's Vision Dinner was the Hydrocephalus Association Network for Discovery Science (HANDS). HANDS is a dynamic virtual laboratory that connects scientists and clinicians with each other and with state-of-the-art resources and data from top institutions. HANDS is how modern science works best, facilitating collaboration among world class scientists and resources to rapidly tackle

Jerold Chun, MD, PhD, professor at Scripps Research Institute, served as the keynote speaker. He shared the current research being pursued to end hydrocephalus in babies that develop the condition as a result from a brain bleed. Dr. Chun reinforced the importance of and limitless possibilities now achievable through HANDS. The evening also featured the meritorious grants awarded to seven HANDS researchers who are dedicated to finding a cure and improving the lives of people who suffer





from hydrocephalus. Grant awardees had the opportunity to display their research at the Vision Dinner and engage directly with attendees.

Three individuals were honored for their tireless dedication to the elimination of the challenges of hydrocephalus through their affiliation with the Hydrocephalus Association. Kathryn "Kate" Finlayson posthumously received the Inspiration Award. Her mother, Pam Finlayson, accepted the award in her honor and shared her daughter's moving journey and passion for pursuing hydrocephalus research. James "Pat" McAllister, II, PhD, Professor, Department of Neurosurgery, Division of Pediatric Neurosurgery at Washington University and the Saint Louis Children's Hospital, received the Service Award, and Dr. Story Landis, PhD, former director of the National Institute of Neurological Disorders and Stroke (NINDS) of the National Institutes of Health (NIH), received the Leadership Award.

The Hydrocephalus Association would like to thank Craig and Vicki Brown for their leadership and generosity in hosting this extraordinary evening to raise the profile of hydrocephalus and the important work of the Hydrocephalus Association for our entire community. For more information on how you can support our new HANDS initiative please e-mail hope@hydroassoc.org.

Vision Dinner Partners in Research

FOUNDING PARTNER

TEAM HYDRO / KATE FINLAYSON FUND FOR HYDROCEPHALUS RESEARCH

The Grant and Pam Finlayson family, our Founding Partner in Research, has generously donated substantial funds through Team Hydro in support of four meritorious seed grant proposals that are part of the launch of the HANDS initiative. Team Hydro inspires thousands to get in the water and swim in support of hydrocephalus awareness and research. The Finlayson family's support is in loving memory of their daughter, Kate, who lost her life to hydrocephalus in 2010.

BENEFACTOR

\$25,000 and above

Roy and Merilee Bostock

Craig and Vicki Brown

Richard H. Goldman Foundation

Paul H. Gross and Lori Poliski

Jennifer and Jonathan Soros Foundation

PATRON

\$15,000 and above

Davis and Gilbert, LLC

Merrill Lynch

Morgan Stanley



Introducing HANDS

Hydrocephalus Association Network for Discovery Science (HANDS)



The Hydrocephalus Association (HA) is focused on creating a research ecosystem primed to find a cure for hydrocephalus. Through conferences and workshops, individual

grant awards, and the Mentored Young Investigator program, HA is supporting the research ecosystem and basic science efforts while the Hydrocephalus Clinical Research Network (HCRN) and Adult Hydrocephalus Clinical Research Network (AHCN) are providing the structure and expertise necessary to efficiently and thoroughly test new technology, therapies, and preventions with the highest clinical standards. What we are still missing is a unified basic research community committed to developing these breakthroughs. To fill this gap, HA created the Hydrocephalus Association Network for Discovery Science (HANDS).

Developed out of discussions from HA and National Institutes of Health (NIH) sponsored workshops, HANDS is a platform for both communication

and collaboration among hydrocephalus researchers with a focus on mentorship, innovation, and shared infrastructure to support high quality, high impact research. The HA Network for Discovery Science encompasses:

- Dynamic collaborations to tackle new ideas
- Central bio-repositories to accelerate experimentation
- Rapid animal model development to catalyze genetic discoveries
- High-powered imaging tools and image databases to visualize brain function and recovery
- Key scientific databases to engage and connect investigators
- Public and private funding opportunities to execute the research

By bringing together the brightest minds into a single virtual center, HANDS will centralize and solidify the field and forward-thinking researchers will be able to test their hypotheses at an accelerated pace, bringing us closer to the breakthroughs that will lead to preventions and cures.

New Discovery Makes Researchers Rethink CSF Absorption



The recent discovery of lymphatic vessels in the brain overturns decades of scientific dogma and provides a new target for scientific investigation. For hydrocephalus researchers, this discovery is extremely exciting because the lymphatic system represents an alternative route for cerebrospinal fluid (CSF) absorption.

The lymphatic system is a network of vessels, tissues, and organs that serves two key roles in the body. The lymphatic system plays a major role in fighting disease, producing white blood cells to fight inflammation or to fight a toxic or foreign substance. Has a doctor ever told you your lymph nodes are swollen? Lymph nodes swell when they are reacting to an infection or illness, trapping and destroying bacteria, viruses, and other harmful substances.

The lymphatic system is also responsible for maintaining fluid balance by draining excess fluid, called lymph, into the bloodstream. In doing so, the lymphatic system helps maintain appropriate fluid volumes and clears waste products from tissue.

Previously it was believed that the lymphatic system did not exist in the brain. One of the few known connections between the lymphatic system and the brain was through the cribriform plate. The cribriform plate is located at the junction of the nose and forehead. It is perforated, allowing direct connections between CSF and the lymphatic system. Past HA grantee, Miles Johnston, PhD, tested drugs administered via a nasal mist to modulate the absorption of CSF through this pathway. In his proof of concept paper, the nasal mist increased CSF absorption at elevated intracranial pressures.

Two new studies from Aspelund and colleagues, and Louveau and colleagues show that lymphatic vessels are in fact present in the brain. In addition, both studies show that these vessels are actively involved in CSF clearance. What we do not yet know is if these lymphatic vessels are a major player in CSF absorption, are involved in the development of hydrocephalus, or if they can be modulated to help improve CSF absorption and decrease intracranial pressure. The potential to increase fluid uptake into these vessels provides a new target for hydrocephalus researchers searching for non-invasive ways to increase CSF absorption.

Research into Shunt Obstruction Earns Award from SRHSB



The Society for Research into Hydrocephalus and Spina Bifida (SRHSB) hosted its annual conference in late June in Malaga, Spain, with special breakout sessions in folic acid, hydrocephalus, and spina bifida.

Founded in 1957, the society promotes research on prevention, cure, and management for patients of all ages. This society provides a friendly platform for scientists to share ideas and continue to advance clinical and basic research. In the experimental pre-meeting, new directions were discussed in promoting new growth and development of brain cells after the onset of hydrocephalus. The group also discussed how and why shunts obstruct, ideas for preventing shunt infection, and a new drug that may prevent hydrocephalus-related brain damage.

This year, the society introduced the first annual Gift of Knowledge Award honoring the pediatric neurosurgeon Norman Guthkelch. The award highlights the work of a young scientist, and encourages early stage investigators to focus their research efforts on hydrocephalus and spina bifida. Five finalists were invited to present their research and Dr. Carolyn Harris came away with the award with her presentation, "Investigating the mechanisms of shunt obstruction in hydrocephalus using human shunt explants." Dr. Harris is an Assistant Professor at Wayne State University in Detroit, MI, and has been a strong supporter of the Hydrocephalus Association throughout her career. In addition to her dedicated research focused on stopping shunt obstruction, Dr. Harris is a member of the HA Network for Discovery Science, has attended HA WALKS in Salt Lake City, UT, Seattle, WA, and Detroit, MI, and gave two presentations at HA's 13th National Conference on Hydrocephalus.

JOIN TODAY! The Professional Member Society

Join our team to promote a cure
and improve the lives of those affected.

Benefits include:

- Listing in the Hydrocephalus Physicians Directory.
- Opportunity to attend HA-sponsored Hydrocephalus Research Conferences.
- Opportunities to participate in our Scientific & Medical Review Board, our Medical Advisory Board, our Research Committee, and other volunteer roles.
- Opportunities to promote your medical and/or research work to colleagues, the hydrocephalus community, and the general public through the association's public relations department... and more!



Visit www.hydroassoc.org to learn more.

HA in Attendance

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

National Institute of Neurological Disorders and Stroke Nonprofit Forum

September 8-9, 2015 | Bethesda, MD

National Institute of Neurological Disorders and Stroke Advisory Council Meeting

September 10-11, 2015 | Bethesda, MD

Rally for Medical Research

September 17, 2015 | Washington, DC

International Society for Hydrocephalus and Cerebrospinal Fluid Disorders

September 17-21, 2015 | Banff, Ontario

Congress of Neurological Surgeons Annual Meeting

September 28-30 | New Orleans, LA

Health Research Alliance

October 8-9, 2015 | Cleveland, OH

Rare Disease and Orphan Products Breakthrough Summit

October 21-22, 2015 | Arlington, VA

Hydrocephalus Clinical Research Network

October 22-23, 2015 | Park City, UT

Adult Hydrocephalus Clinical Research Network

November 6-7, 2015 | Salt Lake City, UT

The Gerontological Society of America Annual Meeting

November 18-20 | Orlando, FL

44th Annual Meeting of the AANS/CNS Section on Pediatric Neurosurgical Surgery

December 9-11 | Seattle, WA

Education and Support

New HydroAssist Mobile App

We are proud to announce the launch of HydroAssist™, a mobile app that allows hydrocephalus patients to record and access their full hydrocephalus treatment history on their smartphones and tablets. It is available to download for free for both Apple iOS and Android mobile devices.

HydroAssist™ was created by Dr. Abhay Moghekar, an adult neurologist with the Johns Hopkins Hospital, Dr. Jesse Skoch, a pediatric neurosurgeon at Cincinnati Children's Hospital Medical Center, Peter Dziedzic, a developer specializing in telemedicine at the Johns Hopkins Hospital, and Amanda Garzon, representing the staff of HA and the patient community. In addition to the development team, patient representatives of all ages from around the country led by HA Education Manager Jennifer Bechard provided input and testing throughout the development of the app.

HydroAssist™ features easy data entry of treatments, organization of multiple treatments, and a complete history sorted by procedure date. This information is then easily accessible and able to be shared in the case of an emergency when a patient is not being seen by their doctor or in their usual facility. The first version of the app is akin to an electronic version of the shunt or ETV card. Future versions will include more functionality, taking advantage of features available on smartphones.



For those living with hydrocephalus, the app will help mitigate the fear of travelling far from their medical institutions for fear of an emergency and not having their medical history readily available in order to receive prompt care.

"I believe that by empowering patients to become managers of their own medical histories with a little help from their physicians and technology, better care can be achieved, even for patients that are not able to see the same provider every time," stated Dr. Skoch.

On launch day, HydroAssist™ debuted in the top percentage of all medical apps on the iTunes app store, ranking at #186. The app has been downloaded almost 800 times on iOS devices and 600 times on Android devices. To learn more, please visit our website. We look forward to ideas from our community to continue to enhance the app into the future.

An Evening Of Hope

2015 Hope in Progress Research Reception



The Hydrocephalus Association held its first Hope in Progress Research Reception in conjunction with the 2015 AANS meeting in Washington, DC. The event was generously hosted by Jan and Randy Kell to highlight the research

progress of HA and acknowledge three local champions for their service. The evening provided a wonderful opportunity to unite researchers, donors, congressional staffers and advocates to celebrate our community. Recipients of the 2015 Hope Awards are listed to your right.

The Hydrocephalus Association is grateful for the support of Randy and Jan Kell for opening their home to the community and to the Mid-Atlantic Permanente Medical Group for sponsoring the event.

Outstanding Advocate Award

Senator Patty Murray (D-WA)

United States Senate

Distinguished Provider Award

Michael A. Williams, MD, FAAN

Sandra and Malcolm Berman Brain & Spine Institute
Lifebridge Health and Sinai Hospital of Baltimore

Community Inspiration Award

Tanzanea Christian

High School Student

Hydrocephalus Awareness Month Wrap Up

September was buzzing with activity during Hydrocephalus Awareness Month (HAM). Individuals from across the country, and even the world, joined HA in raising awareness and educating the public about hydrocephalus.

Thanks to the work of our dedicated HA volunteers, this year seven new states joined the United States Congress in proclaiming September as Hydrocephalus Awareness Month. We are grateful to the Governors of Connecticut, New York, Virginia, Tennessee, South Carolina, Illinois and Colorado for working with our local community leaders to bring critical attention to this challenging neurological condition. A thank you goes out to Jenifer Jeans, Mary Wren, Mia Padron, Jackie Davidson, Annie Mason, Chara McLaughen, Jessica Caulder, Sherry Reising, and Shannon O'Connor. These states joined Indiana, Pennsylvania, West Virginia and Washington which already held proclamations for HAM. In addition, Chicago Mayor Rahm Emanuel and Chattanooga Mayor Andy Berke proclaimed September 9th as Hydrocephalus Awareness Day in their respective cities and the City Government of Grand Island, New York, proclaimed September 19th as Hydrocephalus Awareness Day.

"We are truly so humbled and impressed by how many states have taken the time to research what hydrocephalus is, then come together and stand by our community and recognize that hydrocephalus is an extremely serious condition that affects millions of individuals every day. It truly means the world to us to have so many states come together and support us as we continue to fight for a cure for those we love the most," affirmed Middlebury, Connecticut Hydrocephalus Association WALK event Co-Chairs Mary Wrenn and Jenifer Alex Jeans, who is also

an identical twin to Alexandria, 37, who acquired hydrocephalus 6 weeks after birth.



This year seven new states joined the United States Congress in proclaiming September as Hydrocephalus Awareness Month.

There were also a number of landmarks around the country illuminated a stunning hydrocephalus blue to commemorate HAM. The City of Wichita, Kansas, lit the pillars on their downtown area for the entire month. Thank you to Rachel Inskeep, our Wichita WALK Chair for working with the city government. In St. Louis, the James S. McDonnell Planetarium and Science Center shone like a blue beacon in the evenings, thanks to our St. Louis WALK Chairs Maggie O'Shaughnessy and Stephanie Vogt. In Chattanooga, Chara McLaughen facilitated the Liberty Building turning blue. And, most notably, Niagara Falls and the Peace Bridge, the largest major crossing into Canada in the North East, were illuminated blue. Thank you to Larry McKenzie, Kelly McKenzie, and Stacey Monaco.

For those not able to travel to see these amazing sites, we hope you were able to participate in our Turn the Country Hydrocephalus Blue challenge online. HA challenged everyone across the country to help spread awareness about hydrocephalus and educate the public on key facts about the condition by printing out informational signs, taking photos, and posting them to Facebook, Twitter or Instagram. We had over 2000 people participate in the challenge. Our posts were seen over 400,000 times and received close to 38,000 likes. The state with the most posts was Tennessee, followed closely by Minnesota, North Carolina, Arizona, and West Virginia. On behalf of the staff, seeing the amazing individuals that make up our community and their loved ones and friends that support all of us — we want to thank everyone for turning this country Hydrocephalus BLUE. What an amazing HAM 2015!

HA WEBINAR SERIES

Have you missed our latest webinars? Our interactive, free webinars are designed to educate our community on a variety of topics and are led by medical professionals or experts in their respective fields. All webinars are recorded and available on our website. Watch, listen and learn from the comfort of your home by visiting the publication page under Knowledge on our website.

Health Insurance Exchanges: The Patient Experience

Kelly Brantley, Director, Avalere Health
November 4, 2015

Adult Hydrocephalus Clinical Research Network Update

Mark Hamilton, MDCM, FRCSC
October 5, 2015

Congratulations to Our 2015 Scholarship Recipients!

The Hydrocephalus Association (HA) is pleased to announce the 2015 Hydrocephalus Association Scholarship Award recipients. HA's scholarship program was established in 1994 to provide financial assistance to capable and promising teens, young adults and adults who live with the ongoing challenges and complexities of hydrocephalus. Since the scholarship program was established, HA has awarded 135 scholarships to deserving future leaders of our community. We would like to thank everyone who applied for a scholarship and congratulate those of you who were selected this year. In addition to successfully managing their hydrocephalus, these students continue to excel in the classroom, volunteer and give back to help their local communities, and inspire their peers and all of us, demonstrating that hydrocephalus does not stand in the way of pursuing one's goals.



Margaret Wanja
Recipient of the
Anthony Abbene
Scholarship Funds

"I would encourage the parents to take their kids to school and support them in their future career development. I would like to raise the confidence of everyone with hydrocephalus because the future is bright... we have equal chances."

Margaret intends to graduate from high school within the next two years. Following, she aspires to join a college that offers vocational skill courses. Margaret's ultimate career goal is to become involved with a hydrocephalus organization in Kenya.



Ksenia Grozdova
Recipient of the Morris L.
and Rebecca Ziskind
Memorial Scholarship

"I must admit that living with such a severe condition made my spirit stronger and it is becoming stronger every day. This defined me as a person, made me goal oriented and morally strong, and I believe that is one of the things which helps me stay on track in science."

Ksenia recently completed her Masters in Theoretical Physics and is now at the King's College of London and Imperial College of London joint Centre for Doctoral Training to receive her PhD. After completing her PhD she would like to work to develop new ways of analysis and treatment of medical conditions, such as brain diseases and breast cancer.



Wilhelmina Gilles
Recipient of the Justin
Scot Alston Memorial
Scholarship Fund

"I try not to let having hydrocephalus dominate or define me, but focus more on getting the best out of life. It has been part of my life for as long as I can remember, and I hope to have embraced this for all that it is worth."

Wilhelmina is a student at Queen Mary's, University of London, where she is studying drama. As a testament to her hard work and great accomplishments, she has received a conditional offer to spend her second year of studies at University of California, Berkeley.



Sierra Marie Mondin
Recipient of the Mario
J. Tocco Hydrocephalus
Foundation
Scholarship Fund

"I think the most important thing about having a preexisting condition like hydrocephalus is knowledge of that subject. I was only a baby when I was diagnosed and was too little to comprehend what any of it meant. As I grew older, I still didn't take much of an interest in it and didn't really know how to tell people what it was and I just tried to ignore it. It wasn't until my VP shunt failed the first time that I thought, 'Wow, this is serious stuff and I want to know more.'"

Sierra is a student at UNC Charlotte where she will be receiving a degree in Civil and Environmental Engineering. She plans to further her education by receiving a master's degree in Geotechnical Engineering.

CONGRATULATIONS to all of our Awardees and Finalists!

These nine scholarships were funded by two Gerard Swartz Fudge Memorial Scholarship Funds, two Morris L. and Rebecca Ziskind Memorial Scholarship Funds, two Anthony Abbene Scholarship Funds, the Justin Scot Alston Memorial Scholarship Fund, the Mario J. Tocco Hydrocephalus Foundation Scholarship Fund, and the Hydrocephalus Association (special thanks to Lisa and Erik Chamberlin of Rockton, Illinois, for providing support of this scholarship). We are very grateful to all the funders and the Scholarship Committee for all their support and dedication.



John Agar

Recipient of the Gerard Swartz Fudge Memorial Scholarship Funds

"Do I like having hydrocephalus? No, but I would not want my life in any other way. While hydrocephalus has presented me with many challenges throughout my life, it has also made me a stronger person. I know that challenges are a part of life and because I have had to face many of them, I am more confident in my ability to overcome obstacles that stand in the way of my goals."

John is studying at Aquinas College. He intends to obtain a degree in Business and Sports management. His ultimate career goal is to become a general manager for the Detroit Tigers.



William Stokebrand

Recipient of the Gerard Swartz Fudge Memorial Scholarship Fund

"Having hydrocephalus encouraged my family and myself to be more involved in volunteering, as we spent many hours at the hospital, survived, and wanted to give to others in similar situations. Giving one's time to assist others is very rewarding and often makes me forget that I have hydrocephalus."

William is studying at Northwest Missouri State University in Maryville, Missouri, pursuing a four year degree in Mechanical Engineering. He aspires to become an engineer and hopes to start his own engineering company in the Midwest.



Meir Yishai Barth

Recipient of the Morris L. and Rebecca Ziskind Memorial Scholarship

"I have multiple challenges but I have also been told that I have many unusual abilities as well."

Meir is attending the University of Massachusetts Amherst to study Sociology, Political Science, Philosophy and Disability Studies. He hopes to craft a major that would allow him to study disability issues from an interdisciplinary perspective.



Nicholas Ryan Zubar

Recipient of the Hydrocephalus Association Fund

"Because of my hydrocephalus, I have experienced ambulance and care flight rides and am quite pleased that my chosen degree of Fire Science will assist me in helping others in ways that have been beneficial to me."

Nicholas attends the Fire Science Program at Western Dakota Tech. In addition to studying Fire Science, the program also requires a degree to become an Emergency Medical Technician, which he intends to pursue.



Jackson McCabe

Recipient of the Anthony Abbene Scholarship Funds

"I am extremely proud of the fact that I have never let my hydrocephalus and cerebral palsy hold me back in life, and I can't wait to continue with the U.S. Paralympic Soccer Team over the next four years."

Jackson attends Tulane University and is working toward a career in sports medicine and sports management where he can work with disabled athletes.

You inspire us all!

Navigating Social Interactions Growing Up with Hydrocephalus

By Dan Kricke



Social interactions as a kid with hydrocephalus were always a delicate balance. Not being a total dummy, I knew enough about my condition to be able to explain it in layman's terms from a young age. I remember always going to the first day of elementary school in

whatever grade I was in with a note from my mom explaining in further detail what hydrocephalus was and why, if I complain about a headache, it wasn't the act of a kid trying to just get out of doing a homework assignment. Looking back on it, I'm surprised I never took advantage of the condition to fake a headache for a free day off now and then. Seems like a missed opportunity.

But where were we? Right, social interactions! So, the teachers were mostly satisfied by the letter from home. I'm not sure if they ever followed up with my mom for more info or went to a library to read more or whatever, but they always treated me fairly, I thought.

Dealing with my peers was something I was less prepared for. Kids can be unpredictable. I was fortunate to have a good group of friends as a young kid, but I don't recall even my interactions with people I wouldn't consider "friends," ever being particularly harsh when it came to hydrocephalus.

I think fear of having to talk about being a "hydrokid" is one thing that feels overblown now that I'm older, though I look back and understand that, for a kid, it was overwhelming. As I said above, I knew enough about the condition to hit the nuts and bolts to anyone that wanted to know. But I never wanted to turn it into my whole story. As a kid, I loved Michael Jackson and WWF and Nintendo. I wanted to create video games, not have hydrocephalus. And I didn't want to go into a long discussion of hydrocephalus with anyone, let alone someone my own age. My story always boiled down to — you and I both have water in our brains but yours drains and mine needs help. But I remember being so sensitive to the whole topic, even though I can probably count on one hand the number of times it came up during my formative years.

Mostly it was the shunt that caught other kids' eyes. No one ever started a conversation saying, "So I heard you have hydrosnuffaluffagus?" It was always, "What's that vein in your neck!?" And again, "always" happened like five times over. Maybe a lot more kids wondered it, but it feels now like I spent more time worrying about it than it ever becoming a real issue. And, in retrospect, it wasn't like they were even making fun of it. It was just that sort of no-filter question that a child can get away with asking; that they'd probably just Google now. Mostly it was about a kid that wanted to know why I had something they didn't. A real asset, that tubing!

Up until I was about 12 years old, I had spent a lot of effort trying not to be different from other kids. I'm not sure whether everyone operates the same way, but I didn't want to stand out for fear of being teased. And, like I mentioned, I didn't want hydrocephalus to be my whole

story. Having a litany of medical problems can be hard to hide, but I did my very best, at least until I couldn't anymore because I was about to miss a few weeks of school for a medical procedure that most 12 year-olds have never heard of before. Having a "weird vein" in my neck that I had to explain to one or two kids a year was very different from explaining why I'd suddenly be out of class for a prolonged period of time to have brain surgery.

Who would like me when they knew I was so fragile? This, more than the IVs or the shunt revision or anything else, was a huge fear to me. It was a Baker-Wong pain scale 8 or 9 equivalent, as far as I was concerned.

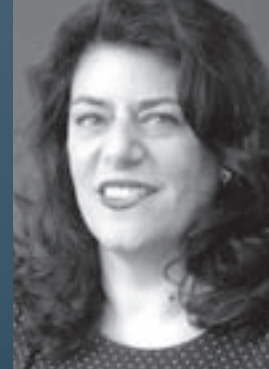
Girls were just starting to become an important factor in my life and now they were going to see me with a bandage and stitches on my head? This was not an ideal situation, or so I thought. What I learned is that you'd be surprised by who you can end up drawing support from.

My surgery when I was 12 was right around some sort of holiday sing-a-long that my school was putting on. Basically, we went to a local mall and sang. I don't remember it well because I wasn't going to be in it after I had just had a shunt revision. If I remember right, I hadn't been seen in school and by friends at that point for at least couple days, though I was out of the hospital for at least a few.

Up until I was about 12 years old, I had spent a lot of effort trying not to be different from other kids.

A FOND FAREWELL

The Hydrocephalus Association (HA) Board of Directors extends its appreciation to Dawn Mancuso for her substantial contributions to HA while serving as the Chief Executive Officer (CEO). She served as HA's CEO from December 2011 through August 2015.



Under her leadership, the association experienced much change and growth. One of Dawn's first tasks was to move HA from San Francisco, CA, to the Washington, DC, area, positioning the organization at the center of federal influencers impacting the lives of patients with hydrocephalus. With the office move came new staff and a new organizational capacity to raise awareness, increase education and support services, and raise funds to support both the organization and an aggressive research agenda. Dawn grew the organization's budget from \$1.6M to nearly \$3.5M, engaging major donors, industry partners, and the hydrocephalus community in awareness and fundraising efforts. This growth allowed the association to increase the amount of funding invested in hydrocephalus research, facilitating the creation of the Adult Hydrocephalus Clinical Research Network (AHCNRN), and planting the seed for the HA Network for Discovery Science (HANDS). She also built successful coalitions with key health organizations including the National Health Council, the American Brain Coalition, the Rare Disease Legislative Advocates and the National Organization for Rare Disorders.

Dawn's leadership, dedication, constancy and support has inspired staff and those actively involved in the Hydrocephalus Association. We wish her well on her next professional endeavor.

...education and support continued

I went because one of my brothers wanted to bring me to see my friends at the sing-a-long, probably thinking (correctly) that it would be good to see my friends for a bit and get out of the house where I was recovering. Because of everything mentioned above, I was so nervous about going. I may have been given a wheelchair for the expedition in case I got tired. I can't remember. But I do remember the kids coming up to me and being seemingly glad to see me, to see my cool stitches, the whole thing. I wasn't terribly popular or anything, but I remember everyone being exceedingly nice. It felt so good to feel like everyone cared.

Looking back, it seems so silly to think people were going to make fun of the kid with stitches in his head who just had a really scary sounding surgery. What kind of terrible kids would do that? My point in telling a story I only half-remember is to say that you shouldn't be scared of support. The support of people you're close to seems guaranteed, but

even people you're not that close to tend to go out of their way to be nice when you've been through a trauma. They can help you feel better and you shouldn't be afraid of them.

And although I was nervous at the time about being perceived as different from the other kids in school, it feels funny now to realize everyone is different and that's perfectly fine. We all have something we're going through, whether it's a medical condition or something else. I'm not saying you need to run up to everyone you meet and introduce yourself by talking about hydrocephalus, but you should never feel bad for having it and you shouldn't feel scared to tell people about it if they ask or if you just feel the need to talk about it. I spent way too much time with built-up anxiety about having hydrocephalus when I was a kid and whenever I did talk about it, the experience was never as big a deal to my classmates as it was to me.

Have you joined us on Social Media?



Our Community Networks

We hope you can join us at a local get-together this year! Visit our website for upcoming events and to join our online communities. If you'd like to start a network in your area, email support@hydroassoc.org or call (888) 598-3789.

AL	Online	All Ages
	Birmingham	All Ages

AR	Online	All Ages
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AZ	Online	All Ages
	Phoenix	NPH
	Phoenix	All Ages

CA	Online	All Ages
	Los Angeles	All Ages

CO	Online	All Ages
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CT	Online	All Ages
	Hartford	All Ages

DC	Washington	All Ages
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DE	Online	All Ages
	Middletown	All Ages

FL	Online	All Ages
	Central	All Ages
	South	All Ages

GA	Atlanta	All Ages
	Atlanta	All Ages

IL	Online	All Ages
	Chicago	Adults and NPH

IN	Central/Northwest	All Ages
	Clarksville/Louisville	All Ages

KS	Online	All Ages
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KY	Online	All Ages
	Louisville/ Clarksville	All Ages

MA	Online	All Ages
	Boston	All Ages

MD	Baltimore	All Ages
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MI	Online	All Ages
	Detroit	All Ages

MN	Online	All Ages
	Minneapolis	Peds/ Adolescents

MO	Online	All Ages
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NC	Online	All Ages
	Charlotte	All Ages

ND	Fargo(and Moorhead)	All Ages
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NY	Online	All Ages
	Buffalo	All Ages
	Long Island	All Ages
	New York City	All Ages

OH	Online	All Ages
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OK	Online	All Ages
	Owasso	All Ages

OR	Online	All Ages
	Portland/Vancouver	All Ages

PA	Online	All Ages
	Northeast	All Ages
	Pittsburgh	All Ages

RI	Online	All Ages
	Providence	All Ages

SC	Online	All Ages
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TN	Online	All Ages
	Chattanooga	All Ages
	Nashville	All Ages

TX	Online	All Ages
	Dallas	All Ages
	Houston	Peds/ Adolescents
	San Antonio	All Ages

UT	Online	All Ages
	Salt Lake City	All Ages

VA	Online	All Ages
	Richmond	All Ages

WA	Seattle	Peds
	Bremerton	Peds
	Eastern WA	All Ages

WI	Milwaukee	All Ages
	LaCrosse	All Ages

Nigeria	Lagos	Peds/ Adolescent
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Search Hydrocephalus Association Community Network on Facebook to find your local online

The Difficulties of Diagnosing Normal Pressure Hydrocephalus

According to a United Nations Development Programme study, the population of people over 60 is growing faster than any other age group. With more individuals entering this population, the Hydrocephalus Association is committed to educating the medical community and the public about the form of hydrocephalus called Normal Pressure Hydrocephalus (NPH), which typically presents itself in individuals 60 years of age and older. It is estimated that between 10 – 15% of the 5.2 million individuals diagnosed with Alzheimer's disease or other related dementia are, in fact, living with NPH. Unlike other dementias, NPH has a treatment option, and successful treatment can allow an individual to return to an active lifestyle. Education around proper and early diagnosis of NPH is critical, however, it remains misdiagnosed or undiagnosed in too many individuals. Why?

Normal Pressure Hydrocephalus, often difficult to diagnose, is characterized by the gradual onset of a triad (group of three) of symptoms, usually in the following order:

- **Gait disturbance (difficulty walking):** A hypokinetic gait consisting of small shuffling steps, a feeling of heavy feet ("magnetic" gait ~ feet act as though they are magnetically attracted to the floor), a tendency to fall, and difficulty using stairs. Making turns usually involves a series of choppy, short steps.
- **Urinary incontinence (impaired bladder control):** A frequent or urgent need to urinate, or the loss of control to hold back urine.
- **Mild dementia (cognitive impairments):** Forgetfulness, short-term memory loss, loss of interest in activities, or mood changes.

What makes the diagnosis of NPH difficult is the fact that symptoms of NPH occur in other conditions that are common in an aging population, such as Parkinson's disease (PD), osteoarthritis, and Alzheimer's disease (AD). NPH-like symptoms can occur in Alzheimer's (AD), vascular dementia and Parkinson disease (PD) or NPH may be a co-morbidity with AD or PD. In NPH, not all of the symptoms arise at the same time. The combination of dementia-like symptoms, walking problems, and urinary problems (the "classic" Hakim triad – named after Salomon Hakim, MD, PhD, the clinician who first defined NPH over 50 years ago) alert health care providers to the possibility of NPH. However, it may take years for all three symptoms to present (if at all). The triad is neither necessary nor sufficient to make the diagnosis. One may present with just gait

impairment and have NPH. On the other hand, even if the full triad is present, one cannot be assured of the diagnosis without further ancillary testing, detailed below.

Diagnosing NPH

A variety of diagnostic tests are typically used to diagnose NPH.

Brain imaging exams identify enlarged ventricles.

- CT scans involve the use of x-rays to produce cross-sectional images that allow clinicians to review different parts of the brain.
- Magnetic resonance imaging (MRI) produces images that detail the ventricular system (cerebrospinal fluid (CSF) filled cavities in the brain) and help to rule out other disorders (such as subdural hematoma, tumor, infection, or a structural abnormality). MRI can often help distinguish obstructive from communicating hydrocephalus which can influence the treatment of hydrocephalus.
- Cisternography, more involved than CT scan or MRI, is not widely used. Using the injection of tracers, it highlights absorption of the CSF.

Neuropsychological testing is the most accurate means of determining and documenting cognitive strengths and problems and can help provide a more accurate diagnosis of the range of neuropsychological problems. The testing involves answering questions and performing tasks.

- An individual's appearance, mood, anxiety level, and experience of delusions or hallucinations are evaluated.
- Cognitive abilities such as memory, orientation to time and place, attention, use of language, and abilities to carry out a range of tasks and follow instructions are assessed.
- Reasoning, abstract thinking, and problem solving are analyzed.

Gait assessment is often very useful in determining the degree of impairment of an individual. It is also useful for following patients after shunt surgery or endoscopic third ventriculostomy to evaluate the success of the surgical treatment.

Lumbar CSF removal predicts the response to shunting. When a large volume of CSF, typically 30-40 cc, is removed from the lower back region, one or more of the NPH symptoms may lessen

or reverse. Such symptomatic improvement with lumbar puncture is interpreted as meaning that a surgical shunt would be clinically beneficial. It is important to note that the reversal of symptoms from the lumbar puncture is temporary.

- Lumbar puncture (spinal tap) is an invasive procedure that removes fluid from the spinal CSF space. CSF pressure may be measured and fluid may be analyzed for abnormalities that might give a clue as to the cause of the problem.
- Extended lumbar drainage may be performed when there is no symptomatic relief from a simple lumbar tap, if the clinical suspicion of NPH is high.
- CSF outflow resistance is a more involved test that determines the capacity of the body to absorb CSF.

These diagnostic tests assist medical professionals in determining the existence and severity of NPH in a patient, as well as the potential

treatment options. They also assist in making the distinction between NPH and the previously listed conditions with similar symptomatic presentations, such as Alzheimer's and Parkinson's. This is very important because the treatment for Parkinson's or Alzheimer's disease and NPH is quite different. An estimated 80% of the 700,000 Americans with NPH still suffer through this devastating but treatable condition because they have been unable to get an accurate diagnosis and proper treatment. There are well-known cases where patients with NPH carry an erroneous diagnosis for a decade or more, remaining untreated for NPH and being locked in a state that is easily reversible when the correct diagnosis is made. It is critical for individuals and those within the medical community to know more about Normal Pressure Hydrocephalus. The Hydrocephalus Association is working with our Medical Advisory Board and members of the Adult Hydrocephalus Clinical Research Network to bring more awareness to NPH.

Texas Oilman Gets NPH Diagnosis After Nine Years Of Trying

Edited and reprinted with permission by JJ/Codman



Over a period of nine years, beginning in 1990, Bob Fowler, 73, former chairman of a Dallas oil company, hunter, golfer, devoted husband for 48 years, father of two children, and grandfather, almost lost it all as he went from doctor to doctor in search of a diagnosis for his steadily deteriorating mental and physical health.

During this time, he went from being a man who could run a multi-million dollar company to someone who couldn't think clearly or walk without falling. He lost his independence, he became incontinent, and ultimately his family considered moving him to a nursing home when the demands of his condition became overwhelming. He even wrote a farewell letter to his two-year-old granddaughter and his own obituary, thinking he would soon die from his condition.

It all started on a beautiful afternoon in Dallas back in 1990 when Bob had just finished a round of golf. While heading off the course, he fell for no apparent reason. As many might do, he chalked it up to poor physical condition, aging a bit, or just one of those things.

But over the course of the next two years, the falls became more frequent and he noticed a significant loss of balance and hand/eye coordination. He started to lose his appetite and had increasing difficulty thinking clearly. He retired from his job as chairman of his company because he felt his ability to function effectively was unacceptably reduced.

After his retirement, Bob and his son began a business relationship, which went well at first, but, as Bob's health continued to decline, he became less and less effective, which required his son, Bob Jr., to carry most of the work load.

By the late 1990's, his symptoms got so bad that he began to experience incontinence and had to sleep in a reclining chair in order to breathe. That was about the point at which his family began to discuss the option of putting him in a nursing home because his wife and son could not provide Bob with the kind of physical care he needed.

"There were things my wife had to do in order to fully care for me that no wife should have to do for her husband," recalled Bob. "I never realized at the time the hardship my family had to go through to care for me, especially during the last few months prior to my

diagnosis when I was physically an invalid. Having a serious illness is not only a true test for a marriage, but it's a challenge for the entire family."

During this time it had become difficult to leave the house – Bob couldn't enjoy activities most people take for granted, such as going out to dinner with his wife or even going to the movies, because he couldn't manage the stairs. He had already given up golf and hunting. He was depressed. His condition was deteriorating dramatically. He thought he was going to die soon.

Bob wrote a goodbye letter to his two-year-old granddaughter telling her how much he loved her, how much he would miss her and how sorry he would be if he was not around to watch her grow up. He even organized pallbearers for his funeral and wrote his own obituary, in which he emphasized his relationship with God.

Bob's family physician encouraged him to see a psychiatrist for depression. At first he was reluctant to do so because he felt seeking the help of a psychiatrist was a sign of weakness, but at the urging of his family, he finally agreed to meet with the church psychologist.

It turned out that this meeting would change his life. After falling backwards onto a coffee table during only his second visit, the psychologist urged him to immediately get an MRI – a test that his family physician had recommended just the day before.

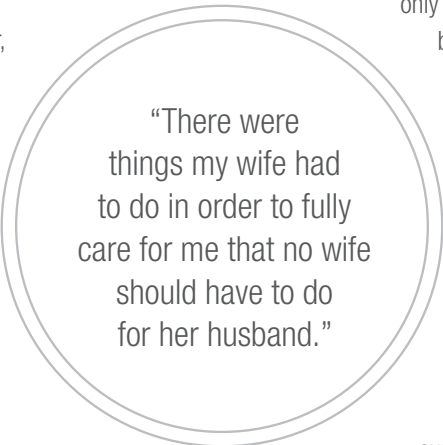
Feeling he had nothing more to lose, he went for one. The MRI showed Bob had enlarged ventricles in his brain, an indication that he had been suffering from NPH, a neurological disorder where cerebrospinal fluid (CSF) – a clear fluid that acts as a protective cushion for the brain and spinal cord – accumulates to an abnormal level within the brain. In addition, he had all the classic symptoms -- difficulty walking, mild dementia and incontinence.

The neurosurgeon who evaluated his MRI was astounded. "I can still remember his first words after seeing the film," Bob recalled. "He said he could not believe this had not been diagnosed before now. He also said that he needed to immediately relieve the intense pressure in my brain caused by the excess fluid or else I would be in significant danger." Bob's only response was, "I can't say I didn't try for all these years. Please do what you have to do!"

In August 1999, Bob had the first of three shunt surgeries. His neurosurgeon implanted a fixed pressure shunt into Bob's brain to drain the excess fluid away and relieve the pressure. He warned him that because it would be difficult to determine the exact drainage setting for the shunt, another surgery may be needed to replace it. Following his initial shunt placement, most of the symptoms Bob had been experiencing for so many years disappeared – he was able to think clearly and walk steadily again.

However, within a month, the shunt had to be replaced because the pressure was inappropriate. A second fixed shunt lasted only a week after implantation and had to be replaced as well, once again due to recurring symptoms from an inappropriate valve pressure.

After the second shunt needed to be replaced, Bob's surgeon proposed a new and innovative device at the time called a programmable shunt. Once implanted, the surgeon can adjust the pressure settings non-invasively using a magnetic device outside the body, rather than performing further surgery. This was the answer Bob and his family had been searching for all these years, and his road to full recovery began.



"There were things my wife had to do in order to fully care for me that no wife should have to do for her husband."

This programmable shunt remained in place throughout his life and was reprogrammed several times based on Bob's changing needs. Bob passed away a number of years ago, but lived the remainder of his life in good health and as active as ever in business, travel and recreation. Bob was forever grateful for his quality of life and the time he thought he would never get to spend with his wife, children and granddaughter. He became an outspoken advocate, working with J&J/Codman and the Hydrocephalus Association to raise awareness about NPH. He had the opportunity to tell his story nationwide and in Europe about his decade long struggle, and counseled those who were thought to have NPH or who were already diagnosed and facing surgery.

"I want to help as many people as I can," he said. "Everything I endured will be worthwhile if I can help make a difference and help others recover as I have and face treatment including shunt surgery with confidence."

Long-term Care - A Looming Crisis

By Marvin L. Sussman, PhD

Normal Pressure Hydrocephalus, or “NPH,” is most commonly seen in older adults. It is an accumulation of cerebrospinal fluid (CSF) that causes the fluid-filled cavities in the brain (the ventricles) to become enlarged, sometimes with little or no increase in intracranial pressure (ICP). It is estimated that more than 700,000 Americans have NPH, but fewer than 20% receive an appropriate diagnosis and effective treatment. Without appropriate diagnostic testing, NPH is often misdiagnosed as Alzheimer’s disease or Parkinson’s disease, representing possibly 10% of all those individuals diagnosed with a dementia as a primary condition or as a co-morbidity (when a disease occurs with another disease; in this case two diseases that cause dementia occurring together). NPH is one of the few causes of dementia that can be controlled or reversed with treatment by implanting a shunt to divert CSF from the brain to another part of the body, thereby reducing the volume of the ventricles. When NPH is a co-morbidity, the NPH component is treatable, although the dementia caused by the other disease may not be treatable. But for many NPH sufferers where NPH is the primary cause or is a comorbidity, shunt treatment is not available because patients have been misdiagnosed or remain undiagnosed.

Untreated NPH is progressive, causing unsteady gait, incontinence, and cognitive impairment, the three classic symptoms of the condition (the Hakim triad – named after Salomon Hakim, MD, PhD, the physician who discovered NPH). Not all three symptoms have to occur, and the gait or walking disturbance usually presents first. These symptoms progress and worsen over time to the point where an individual is completely dependent on care providers. As such, individuals with NPH may be unnecessarily institutionalized in a long-term care facility at a substantial cost to the government or families. Significant savings in the cost of custodial care may be achieved through correct diagnosis and treatment of NPH, allowing the patient to remain in their home environment. Keeping a family unit intact is more significant than any possible financial savings.

The Changing Demands on Long-term Care

Historically, long-term care was provided at home by family and friends. However, care at home is shifting to more formal care as both family dynamics continue to change and demand for long-term care rises. Within the family unit, three main factors are contributing to families seeking long-term care outside of the home. Over the last four decades, more women, historically the traditional caregivers,

have entered the workforce. In addition, retirement among both men and women is increasingly being delayed, making family members unavailable to serve as caregivers. Finally, families are becoming smaller and more geographically spread out.

In addition to changing family dynamics, other factors will contribute to an accelerated demand for long-term care over the next couple of decades, and this will also impact cost significantly for both families and government programs supporting our seniors.

- Baby boomers are entering their senior years;
- During older age, the incidence of dementia, incontinence, immobility, etc. increases; all three are causes of institutionalization.
- Life expectancy is increasing – with more years when assisted care will be required.

The Baby Boomer Population (“Boomers”), individuals born between 1946 and 1964, currently number approximately 76 million. They represent a disproportionately large population segment - about 28% of the U.S. population - with ranks swelling the elderly population segment who are at greatest risk to suffer dementia and other conditions requiring custodial care. By 2030, the number of the youngest Boomers will nearly double. By 2050, the youngest Boomers will reach 85 years-of-age and the size of this segment population will have tripled over current levels. Currently, approximately 37% of the over 85 year-old population will require paid long-term care. By 2050, approximately 14.7 million seniors are expected to require some form of long-term care. The costs for such care will significantly increase by then.

Longevity is increasing faster than improvements in the quality of health; typical seniors are expected to live longer, possibly requiring long-term care for a prolonged duration. Even with improvement in overall disability rates, the specific disabilities that have declined are not those that imply better health and lower long-term care costs. With longer life expectancy, the incidence of degenerative diseases requiring constant care in their advanced stages has increased. Dementia associated with Alzheimer’s disease (AD) and other neurodegenerative disorders such as NPH is of particular concern because 43% seniors over 85 suffer from these conditions. This increases both utilization rates and the length of time spent receiving

care, thus placing an even greater financial burden on seniors, families, and states and federal governments. Even today, as many as 15 million Americans provide unpaid care for someone with AD or other forms of dementia.

Many seniors never need formal long-term care, but 70% of those currently over 65 years will, and a sizable portion will need long-term care services for an extended duration. On average, an elderly individual uses long-term care for 3 years, with one in five requiring over 5 years of care. Among those entering a nursing home - the most costly and intensive form of care - 12% of men and 22% of women will reside there for more than 3 years. One in eight elderly women can expect to live in a nursing home for more than 5 years.

The Looming Financial Crisis

Long-term care costs are high and will continue escalating given the demands that are being placed on a growing long-term care industry. In 2014, the cost of one year in a nursing home was \$87,600 (private room) or \$77,380 (semi-private room); the average base rate for the services of an assisted-living facility is \$42,000. The costs for families piecing together care at home is also sizable. A non-certified home health aide costs on average \$20 per hour. One year of adult day care services is \$16,900. Since 2005, the price of both these services increased on average 4.5% – compared to the 2.5% overall inflation rate. Currently, Medicaid pays one-third of long-term care expenditures for the elderly, 34% is paid by Medicare, and 20% are covered out of pocket. Total annual expenditure on long-term care for the elderly is estimated to be \$231 billion, accounting for over 7.5 percent of total spending on health care for individuals of all ages and roughly 1.3 percent of the U.S. GDP. Total spending on long-term care is expected to increase 64% by 2030 and 153% by 2050.

These increases place a heavy burden on Medicaid and ultimately on taxpayers, who are typically working-age adults. Currently there are

approximately 3 employed adults per senior; by 2030 there will only be 2. This is a 33% decline occurring while both the need and the cost of long-term care are increasing.

An Economic Imperative

One in 10 seniors diagnosed with dementia is potentially living unknowingly with NPH, a condition that has come to be known as the “treatable dementia” by the press. While the number of individuals with NPH utilizing long-term care services is not quantified, the primary symptoms that lead to the need for support are those which progress when individuals remain untreated. Treatment could lead to significant savings for the healthcare system. More importantly for families and the individual living with the condition, treatment could allow people to return to a healthy and active lifestyle. Three cases have received national publicity in the media. These individuals, a well-known physician, an oil company executive and a dentist, all had NPH but were misdiagnosed for a decade or more as having Alzheimer’s or Parkinson’s disease with associated dementia. During this period before the correct diagnosis was made, all suffered from dementia, unsteady gait and incontinence until correctly diagnosed and treated with a shunt. They literally got their lives back after being successfully treated.

The economics of improving the diagnosis and treatment of NPH and delaying or eliminating the need for institutionalization in a long-term care facility are apparent. Please help the Hydrocephalus Association get the message out that dementia thought to be associated with Alzheimer’s or Parkinson’s disease could possibly be NPH and, with proper diagnosis and treatment, could reverse symptoms being experienced by their loved ones.

Reference: American Council of Life Insurers (ACLI) report: Who Will Pay for Our Long-term Care? November 2014

NPH Symposium in Philadelphia

As part of our current focus on spreading awareness about Normal Pressure Hydrocephalus (NPH), an information session was held recently in Philadelphia, PA. Organized by long-term volunteer, former board president and current board member, Sally Baldus, 40 local residents, mainly over the age of 55, gathered to hear Dr. Christopher Farrell, Assistant Professor of Neurosurgery at Thomas

Jefferson Hospital, outline the symptoms and treatments of this condition. Dr. Farrell got very high marks for his ability to make this topic understandable to laypeople. We hope this is the first of many such gatherings in other cities around the country that have the resources and population demographic pertinent to NPH.

Announcing 2015 TTC Scholarship Recipients!

The Hydrocephalus Association is pleased to honor the 2015 Hydrocephalus Association Teens Take Charge Scholarship Recipients. Through a generous grant from the Clare Rose Foundation, the Hydrocephalus Association is able to award five scholarships in the amount of \$1,000 each to these extraordinary young adults. We are grateful for the generous support of the the Clare Rose Foundation, and all of the individuals who have held events and contributed to TTC.



Madison Pardi

"Though hydrocephalus does not define me, it has taught me what it's like to work hard and what it means to be compassionate. It has helped me discover who I am today, and who I will be in the future."

Madison is a freshman at California Lutheran University, where she is studying Theatre Arts with a focus on performance. She is passionate about helping others with the condition; especially other teens. Madison is a member of the Teens Take Charge Advisory Council and has actively joined the Hydrocephalus Association in her local WALK and has participated in the National Conference on Hydrocephalus.



Logan Dieter

"I think it is important for kids with hydrocephalus to know that they are not alone; others have gone through similar things and are healthy now."

Logan recently started classes at Chamberlain College of Nursing where he is pursuing a Bachelor's of Science in Nursing degree. He plans to eventually work towards a Master's degree and becoming a pediatric neurosurgical nurse practitioner. Logan dreams of helping people with hydrocephalus and other neurological disorders, both physically and emotionally.



Daniel Erickson

"While I never would have chosen to have a chronic health condition, learning to deal with it has made me a stronger person."

Daniel is a freshman at Boston University, in the Kiachand Honors College, an elite program that admits roughly 150 students each year. He is majoring in International Relations and plans to have a career in public service, working internationally and helping to develop policies and practices that empower impoverished families to obtain resources and medical care to improve their lives.



James Moroz

"Hydrocephalus has no doubt been a part of my life that I wish I didn't have to live with. With that said, I am able to see what hydrocephalus has given me, as opposed to what it's taken away. Although some may see hydrocephalus as a burden to live with, I choose to investigate and embrace every unique pathway that continues to shape my identity."

James is currently enrolled in the Georgia Institute of Technology, where he is studying mechanical engineering. He plans to pursue a career in the energy industry.



Daniel Nelson

"I have never allowed [hydrocephalus] to stop me from accomplishing my goals. Actually, I would say my diagnosis of hydrocephalus isn't a curse; if anything, I would say it has been a blessing in disguise. I would say it has made me become a more academically disciplined person and helped steer me toward a profession I'll enjoy."

Daniel has just begun his studies at Saint Louis University, entering their Nuclear Medicine Technician Program, with a minor in Spanish. Daniel would like to continue his studies at Saint Louis University School of Medicine, studying pediatric anesthesiology. He aspires to work at the hospital where he was treated throughout his childhood.

Walks and Special Events

Year End WALK Wrap Up

2015 WALK/Special Event Results

2015 was another great year for HA WALKS and Special Events. HA held 37 WALKS across the U.S., all volunteer driven (initiated and coordinated), maximizing the amount of money which can be directed to our mission to promote a cure for hydrocephalus and improve the lives of those affected by the condition.

HA WALKS take place in cities and towns of all sizes – from Los Angeles, CA, (HA's biggest WALK) to Wichita, KS, and all sizes in between. This year's WALKS and special events are expected to raise more than \$1.4 million.

Several established HA WALKS had new volunteer leadership in 2015. These sites were Houston, Seattle, Central PA, San Francisco, Nashville and Phoenix. While 2014 WALK leaders in those sites had to step down for various reasons, HA was extremely fortunate to be able to recruit stellar volunteers to take the reins in those locales. Additionally, HA re-launched its Baltimore WALK.

Coordinating the WALKS is a labor of love for HA's volunteer leadership (most have a direct connection to HA's mission) and a tremendous amount of work, requiring sacrifice not only from the volunteer leaders but from their families, as well. We extend our most sincere gratitude to our WALK Chairs and Co-Chairs for providing this service to our community and our association.



New HA WALK Sites for 2016

HA is delighted to announce several new WALK sites for 2016, including:

Las Vegas, NV – Bjorn Berg - Chair

Northwest Arkansas – Kipp Coco - Chair

Dayton, OH – Alisha Fint, Angie Johnson - Co-Chairs

Pittsburgh, PA – Patty Cralley - Chair

Orlando, FL – Krista Ollendorff, Michelle Fairall, Vanessa Gaddy, Sukanty Oliva – Co-Chairs

Mansfield, PA – Danielle Gutshall - Chair

Several other prospective WALK sites are being considered. *(If you're interested in starting an HA WALK in your community please contact Randi Corey at randi@hydroassoc.org for more information)*

Long Island HA WALK - Celebrating 10 Years of Community and Caring

By Mia Padron



It was amazing to celebrate the Long Island WALK'S 10th Anniversary this past September. I have been involved with the Long Island HA WALK for 10 years, serving as co-chair with Jackie Davidson for the past 6 years. I remember that

first walk day so well, with maybe 50 to 100 people participating. It was a year after Tyler's diagnosis of hydrocephalus and I felt so alone. I felt there was no one to support or understand me and what our entire family was going through. It was at that WALK I found such a great connection and bonded with so many. Every year the event has increased in size. It personally affects me knowing how we have grown this WALK over the

years. This year we had over 1,200 people participating raising more than \$100,000 so far. It is truly wonderful to have so many families coming together for the same cause. I honestly feel like we are one big family, having developed such a strong connection over the years with so many of our participants. I love being here for them any time of day or night and I know they are there for me, too. My favorite memory this year was during Opening Ceremonies, looking out at the streams of people all there for the same reason, raising awareness and much needed funds for the cure. As I ended my opening speech my last comment was "I can't wait for the day we are all here celebrating the cure and not walking for the cause!" This is something I feel very strongly about, with all the research HA is doing I know my son Tyler and the other million plus Americans with hydrocephalus will see the cure during their lifetime.

Special Events

Special Events demonstrated significant growth in 2015. **Team Hydro**, chaired by Pam, Peter and Sam Finlayson, participated in the annual Sharkfest in San Francisco and Boston for its eighth consecutive year, raising more than \$48,000 for hydrocephalus research.

HA was once more the beneficiary of the annual **MX for Children**, a motocross event held nationwide, led by volunteer Brett Wise.

The **2015 Trick or Treat for HA** — a method for schools, scout troops and other groups of children to collect money for HA and its mission — had another successful year. If you're interested in your school or organization becoming involved with Trick or Treat, please contact volunteer leader, Heather Kluter, at hkkkluter@yahoo.com for more information.

A new special event, held on November 13th and 14th in Henderson, NV, was the **Hydrocephalus Invitational Basketball Tournament**, sponsored by the Desert Reign Foundation. Chaired by HA volunteer, Bjorn Berg, the tournament featured eight National Association of Intercollegiate Athletics (NAIA) teams representing Arizona Christian University, Benedictine University, Eastern Oregon University, Embry-Riddle Aeronautical University, Montana State-Northern, St. Francis, Vanguard University of Southern CA and Westmont College. The event raised over \$500 for HA and its mission.

HA was the beneficiary of two new third-party events.* The **Putt for Pete Golf Tournament** chaired by Jean Bigalek, was held in June in Prior Lakes, MN. The event raised more than \$15,000 for HA. Kudos to Jean and her committee for this outstanding result.

The **Bernard's Township Police Benevolent Association** (Bernard's Township, NJ) held a wine tasting event, with the \$4,000 proceeds directed to HA. Thank you to the PBA for their generosity and for choosing HA as the beneficiary.

Another third party event was held on Thanksgiving Day morning in Fitchburg, MA — the **18th Annual Thanks for Running 5K**. Chaired by volunteer Amy Maynard and attracting almost 200 participants, this long-term fundraising event raised \$8,705 for HA and its mission.

HA is profoundly grateful for all of its dedicated, hard-working volunteers, coordinating fundraising events and WALKS across the U.S. We couldn't do it without you!

** Third party events are events initiated and coordinated independently by volunteers. For more information about third party event fundraisers please contact Randi Corey at randi@hydroassoc.org*

HA's top 10 WALK sites for 2015:

WALK Site	Amount Raised (as of 11-4-15)
Los Angeles, CA	\$ 172,600
Chicago, IL	\$ 118,260
Seattle, WA	\$ 110,000
Long Island, NY	\$ 103,650
Denver, CO	\$ 77,125
South Florida	\$ 83,125
Twin Cities, MN (Minneapolis)	\$ 68,037
National Capital (Washington DC)	\$ 62,000
Greater New England	\$ 59,000
Charlotte, NC	\$ 54,260
Houston, TX	\$ 39,350

WALK Sites meeting or exceeding their budgeted goals and demonstrating significant year-over-year increases included:

WALK Site	% of Increase over previous year
Western NY	79.0%
National Capital	35.8%
Seattle, WA	25.3%
Chattanooga, TN	21.2%
Wichita, KS	19.2%
Atlanta, GA	13.9%
Los Angeles, CA	13.4%
Charlotte, NC	13.2%
Cleveland, OH	8.4%
Denver, CO	5.4%

Congratulations to all of
HA's outstanding WALK sites!

Legacy Society

By Kathleen Kramer

The Hydrocephalus Association first came to my attention in 1994 when, at age 43, I was suddenly confronted with a medical condition I did not know was a part of my history and had never heard of. Over a period of months, I had experienced increasingly severe headaches and problems with my memory and balance. I was struggling, but did not know why. After a weekend of explosive headaches, I discussed my symptoms with my mother who told me that as a child (long before MRIs), I had been diagnosed with hydrocephalus that was thought to be arrested. The doctors told my parents not to tell me of this diagnosis because knowing about it would just worry me. In fact, they did not learn of the hydrocephalus until I was three years old when they took me to doctors to find the cause of my headaches at that time.

This information soon led to my diagnosis being confirmed, and I met with Dr. Michael Edwards at the University of California, San Francisco. After our discussion, a third ventriculostomy was scheduled, and this is how I was introduced to the Hydrocephalus Association. As I was leaving his office, Dr. Edwards gave me a copy of HA's booklet, "About Hydrocephalus - A Book for Families." HA has been a source of information and support for me ever since my successful surgery.

I have attended four HA conferences. Through these conferences, the Hydrocephalus Association continues expanding its information and support for us all. A highlight was the Scottsdale conference where, for the first time, I met other adults who had experienced decompensated congenital hydrocephalus. My mother accompanied me to the 2004 San Francisco conference. She was impressed with the open exchange of information among persons with hydrocephalus, doctors, experts and parents. This is a far cry from the time when she was told by a doctor "you wouldn't understand it."

Given the success of the organization and the impact it has had on my life, I recently joined the Fudge Solomon Legacy Society to ensure the work of HA continues to advance. Making a slight change in my estate plans to ensure HA is listed as a beneficiary was all that was needed. I am certainly very grateful for HA and the hope the organization brings to so many.

THANK YOU SPONSORS! Together we are making a difference!

HA would like to thank all of our major corporate sponsors.





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Every Member Campaign



Your Membership Gift Makes a Difference

We would like to thank all of our loyal donors who join us each year to support HA's agenda to end hydrocephalus. Please continue to stand by our side and renew your membership today. We promise to put your membership dollars to work. We will continue:

- Providing a source of comfort and refuge for people affected by hydrocephalus, whether it's through our toll-free hotline and email, informative publications, online resources or physician directories.
- Sponsoring educational opportunities that bring together patients, doctors, scientists and advocates to share the latest in hydrocephalus treatment and care. View our Webinars on our website. Visit the Publications section under Knowledge on our website.
- Advocating for public funding of hydrocephalus research by deepening our relationship with the National Institutes of Health (NIH).
- Increasing our presence on Capitol Hill. Our advocacy efforts have successfully resulted in the inclusion of hydrocephalus on the list of approved conditions that can apply for grants from the Congressionally Directed Medical Research Program of the Department of Defense.
- Spreading the word, reaching out and building community. In 2015, we expanded our WALK program to 15,000 participants, advocated for more research funding at even more government agencies, and increased our social media presence, with over 23,000 followers on Facebook and Twitter. We will continue to use these vehicles to raise critical awareness.

As you can see, it's an exciting time to be part of the Hydrocephalus Association. Go online to send your member gift today or complete the member form on the enclosed envelope.