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Message from the CEO

Planning with the End Result in Mind

By Dawn Mancuso, CEO, Hydrocephalus Association



I love to garden, so nothing excites me quite like the change of weather that accompanies the advent of spring. After such a long, cold and wet winter this year, I think I was looking forward to the season even more than usual.

Now, most gardeners will tell you that one of the secrets to a successful garden – whether the harvest you are looking for is composed of vegetables or flowers – is some advance planning: preparing the soil, deciding what to plant, choosing whether to start with seeds or seedlings, determining which plants to put in the shade vs. full sun, planning how far apart to set the plants, and setting (and sticking to) a regimen of care (watering, weeding, feeding, etc.).

Running a non-profit like the Hydrocephalus Association takes the same kind of thoughtful planning. The environment is different – and the decisions to be made take a different focus – so I don't want to get carried away with the metaphor. No jokes here about how to make the best compost! But the concept of, first, thinking strategically about the desired outcome, and working back to the details about how to get that outcome, are the same.

HA's leadership – especially the Board of Directors and Staff – agree with this concept and have been working diligently on the development of a well-considered Strategic Plan that will drive a lot of the organization's work over the next five years and will assure that our donors' contributions are being put to the best possible use. The outcome identified is called the "Vision" in strategic planning parlance (meaning the vision of how the world will be different by the association meeting its mission). We are proud to share our new Vision:

Our vision is a future without hydrocephalus.

This new Vision will stretch the organization and all involved with the association to add the pursuit of a cure to our already monumental goal of finding better treatments for the condition.

Next, the HA leadership reinforced our commitment to the entire hydrocephalus community by defining the role we wanted the association to play in attaining this Vision:

The mission of the Hydrocephalus Association is to promote a cure for hydrocephalus and improve the lives of those affected by the condition.

We will accomplish this by collaborating with patients, caregivers, researchers and industry, raising awareness, and funding innovative, high-impact research to prevent, treat and ultimately cure hydrocephalus.

How will we accomplish this formidable Mission and Vision? Through a series of strategies and tactics being employed by HA's very active committees, each of which will work on one or two of the following Strategic Objectives:

- Increase the amount of high-quality, high impact research being conducted on hydrocephalus.
- Enhance patient outcomes through education and the improvement of treatments, and enhanced support services.
- Launch a national Advocacy Campaign.
- Develop and implement a national Awareness Campaign.
- Expand HA's focus on adult hydrocephalus.

Each of these Strategic Objectives has a series of what we call Measurable Results (or the bounty we hope to harvest once all the planning, planting/implementing, and tending are done).

How will we meet these Strategic Objectives and Measurable Results? That's where HA's committees and volunteers come in. Each committee is actively developing a series of multi-year plans to direct its initiatives.

At the end of the process, after all the thought, effort and seemingly endless discussions, what we have is a strong and clear direction — ***our Roadmap to a Cure*** — that will serve to guide and inspire everyone along the way. The future holds much promise if we work together, follow a plan, and unite for a cure.

A handwritten signature in cursive script that reads "Dawn".

Using the Newest Technology to Understand Hydrocephalus

By Ramin Eskandari, MD, MS, Medical University of South Carolina and former Mentored Young Investigator for the Hydrocephalus Association



Our understanding of infantile hydrocephalus pathophysiology (the study of abnormal biological processes which result in the signs and symptoms of a disease) contains many knowledge gaps, including insight into when and what regions deep within the brain are injured and how treatments affect this process. My recent studies, supported by the Hydrocephalus Association through the

Mentored Young Investigators Award, have utilized some of the newest technologies in the world of brain imaging - Diffusion Tensor Imaging (DTI) on MRI - to answer these complex questions. In an early study, we were able to relate the timing of ventricular reservoir placement and ventricular size with neurological function in a hydrocephalus animal model. In our current study, we examined white matter tracts deep within the developing brain to see how susceptible each was to the effects of hydrocephalus.

Our results suggest that white matter tracts within the developing brain have different vulnerabilities. The internal capsule, a white matter tract carrying information about the movement and sensation of the face and body, may be able to readily regenerate and repair itself. In contrast, the corpus callosum, a white matter tract connecting the two halves of the

brain, was highly sensitive to damage from the expanding ventricles and did not show signs of repair. In our study, the visual system was the most resilient to the damage caused by hydrocephalus as seen by DTI. Our DTI findings, in a clinically-relevant model of obstructive hydrocephalus, demonstrate the profound but regional effects of ventriculomegaly on white matter tracts. Future studies need to determine exactly how the white matter tracts were damaged and, in some cases, repaired on a cellular level.

I have recently started my own laboratory at the Medical University of South Carolina, where we are starting to study a very important question which, up to now, has remained a mystery. How do the progenitor cells of the developing brain (those that will go on to make the billions of brain cells needed for normal development) react to the pressures exerted on the brain in neonatal and infantile hydrocephalus? Our goal will be to determine what molecular signals are released when cells are being damaged by high pressure. If we can identify and isolate the active agents/molecules that signal brain injury in the most primitive of brain cells, we can potentially use these as a therapeutic target as well as a screening tool to determine when a child's brain is in danger or being damaged. The implications for the findings of this research are far reaching and will hopefully guide us ever closer to the goal of our lab, which is to FIND A CURE for hydrocephalus!

Mark your calendars for

JUNE 16-19, 2016

MINNEAPOLIS!

14th National Conference on Hydrocephalus

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

Predicting the Need for a Shunt after a Brain Bleed

Predictors for delayed ventriculoperitoneal shunt placement after external ventricular drain removal in patients with subarachnoid hemorrhage.

By Ariane Lewis, MD, Assistant Professor, Department of Neurology (Division of Neurocritical Care), NYU Langone Medical Center

Subarachnoid hemorrhage (SAH) is a type of bleed that can occur in the spaces surrounding the brain spontaneously or after an aneurysm ruptures. Patients with SAH often develop hydrocephalus and require placement of an external ventricular drain (EVD) to temporarily drain cerebrospinal fluid (CSF) and decrease intracranial pressure (ICP). The drain generally remains in place throughout the period of time after a SAH when the blood vessels in the brain are at risk for narrowing, which leads to reduced blood flow to the brain (the vasospasm period). Once this period has ended, the EVD is clamped to stop external drainage of CSF. Once CSF drainage has stopped, doctors determine if the hydrocephalus has improved and if the patient can tolerate removal of the drain. This is called a **clamp trial**. If the hydrocephalus is not improved or gets worse after the EVD has been clamped, the patient will require placement of a permanent ventriculoperitoneal (VP) shunt.

In some cases, a patient passes the clamp trial, the EVD is removed, and no VP shunt is placed. Later, however, the patient suffers from delayed cognitive and motor recovery, such as continued memory problems and trouble walking. If the doctors believe that hydrocephalus is causing the delay in recovery, they may decide that a VP shunt is required. This is termed **delayed VP shunt placement**. Little is known about the risk factors for delayed VP shunt placement in patients who pass a clamp trial and have their EVD removed. In

order to explore the risk factors associated with delayed VP shunt placement, we studied a retrospective cohort of SAH patients who required EVD placement during their hospitalization and then had their EVDs removed.

Subarachnoid hemorrhage (SAH) is a type of bleed that can occur in the spaces surrounding the brain spontaneously or after an aneurysm ruptures.

Of 91 patients who passed a clamp trial and had their EVD removed, 12 (13%) required delayed VP shunt placement at a median of 54 days (interquartile range 15-75 days) after EVD removal. Eight of these patients (67%) had documented clinical changes, such as headaches and trouble walking, and nine of these patients (75%) had enlarged ventricles on brain imaging that prompted delayed VP shunt placement. We examined many possible risk factors for delayed VP shunt placement including:

- age
- sex
- severity of the SAH (Hunt Hess and Fisher scores)
- neurologic exam on admission (Glasgow Coma Scale)
- presence of an aneurysm as well as its location/size/treatment method
- length of stay in the intensive care unit
- initial and final CSF red blood cell count
- initial and final CSF protein levels
- ventricular size prior to EVD removal
- presence of blood in the ventricles (intraventricular hemorrhage)
- development of infection of the ventricles (ventriculitis)

We found that two factors increased the risk for delayed VP shunt placement. These factors were: increased CSF protein within the first seven days of EVD placement and increased third ventricular size prior to EVD removal. Nine of the 12 patients (75%) who had delayed VP shunt placement were noted to have subjective clinical improvement at a follow-up appointment.

Delayed hydrocephalus after SAH is associated with delayed cognitive and motor recovery and delayed transition to independent activities of daily living. If we can diagnose delayed hydrocephalus early, we may be able to prevent additional neurological deterioration, but this diagnosis is difficult.





...research continued

HA Board Member Receives Distinguished Neuroscience Award

Professor John R. W. Kestle, MD, was presented with the Robert H. Pudenz Award for Excellence in Cerebrospinal Fluid (CSF) Physiology for the year 2013 at a special evening ceremony during the American Association of Neurological Surgeons' (AANS) annual meeting in Washington, DC, on Monday, May 4, 2015. The award is given to recognize an individual for significant research contributions to the field of hydrocephalus and CSF physiology. On hand to honor Dr. Kestle's research contributions were esteemed colleagues including Dr. Marion Walker, Dr. Sam Browd, Dr. Pat McAllister, Dr. Mark Hamilton, and Dr. Mandeep Tamber. Members of the HA Board of Directors, HA CEO Dawn Mancuso, and staff were also in attendance.

Dr. Kestle is a Professor and Vice Chair for Clinical Research in the Department of Neurosurgery at the University of Utah, a practicing pediatric neurosurgeon at Primary Children's Hospital, and the Chair of the Hydrocephalus Clinical Research Network (HCRN). He has lectured widely as a visiting professor and has made significant contributions as a principal investigator in the field of hydrocephalus and CSF management. Dr. Kestle's many contributions to pediatric neurosurgery have significantly influenced its practice to the great benefit of patients and their families. His dedication to the hydrocephalus community is further seen through his volunteerism, serving on the Hydrocephalus Association Board of Directors and Medical Advisory Board.

The award was initiated in 1988 by PS Medical, Inc., (Goleta, CA), now Medtronic plc, and is named after Robert H. Pudenz, MD, who was a recognized pioneer in the field of pediatric neurosurgery, research in cerebrospinal fluid physiology, and cerebrospinal fluid shunt technology for the treatment of hydrocephalus. The award is determined by a special selection committee established by the Neurosurgery business at Medtronic plc, and is comprised of previous awardees.

HA in Attendance

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

American Association of Neurological Surgeons (AANS)/Congress of Neurological Surgeons (CNS) Pediatrics Section Meeting
December 2-5, 2014 | Amelia Island, FL

National Health Council Voluntary Health Leadership Conference
February 12-13, 2015 | Ponte Vedra, FL

Adult Hydrocephalus Clinical Research Network (AHCRN) Investigator Meeting
March 13-14, 2015 | Alexandria, VA

Health Research Alliance
March 16-18, 2015 | Dallas, TX

Aging in America Conference
March 23-27, 2015 | Chicago, IL

American Association of Neuroscience Nurses (AANN) Meeting
March 29-April 1, 2015 | Nashville, TN

Hydrocephalus Clinical Research Network (HCRN) Investigator Meeting
April 16-17, 2015 | Toronto, Ontario, CAN

American Academy of Neurology (AAN) Meeting
April 18-25, 2015 | Washington, DC

American Academy of Neurological Surgeons (AANS) Meeting
May 2-6, 2015 | Washington, DC



UNITED FOR A CURE

Members making a difference, Dr. Michael Williams

It is not uncommon for patients to travel from afar to receive medical care from Dr. Michael Williams. Dr. Williams is an internationally recognized expert in the field of adult hydrocephalus. He co-chaired the first-ever NIH National Institute of Neurological Disorders and Stroke (NINDS) workshop on hydrocephalus. In 2008, he helped to create the International Society for Hydrocephalus and CSF Disorders (ISHCSF), hosted their first scientific conference in September 2009, and just completed his term as the president of the ISHCSF. He also is a member of the Scientific Advisory Panel to the Intracranial Hypertension Research Foundation. In 2013, he was invited by the Institute of Medicine to comment on NASA's Evidence Report on the Risk of Spaceflight-Induced Intracranial Hypertension/Vision Alterations. Dr. Williams is actively involved in patient advocacy with the Hydrocephalus Association, is a member of the board and Medical Advisory Board, and one of the founding members of the Adult Hydrocephalus Clinical Research Network. He and his staff host a support group in Baltimore, Maryland, open to all ages.

...research continued

Guidelines for the Treatment and Management of Pediatric Hydrocephalus



We are happy to announce the publication of "Pediatric hydrocephalus: systematic literature review and evidence-based guidelines," on November 1, 2014, in a supplemental issue of the *Journal of Neurosurgery: Pediatrics*. The report provides an in-depth analysis of current hydrocephalus treatment practices and the level of

evidence supporting each one. Nineteen treatment recommendations are given, addressing topics ranging from the treatment of children with intraventricular hemorrhage (IVH), infection protection and treatment, technical advances in catheter placement, assessment of one valve over

another, to defining how to judge the success of treatments. The goal is to guide clinical practice by identifying the best ways to treat and manage pediatric hydrocephalus, and the guidelines could have both commercial and clinical practice implications.

HA played an integral role in both the development and publication of the guidelines by serving as the patient voice in the development of the report and providing funding to publish the report. Dr. Ann Marie Flannery (pictured left), Debby Buffa, past HA Board Member, as well as three Hydrocephalus Clinical Research Network (HCRN) lead investigators, Drs. David Limbrick, Jay Riva-Cambrin, and Mandeep Tamber, are contributing authors on the publication.

Patient studies now enrolling

The Hydrocephalus Association knows that our community wants to be a part of the solution. That is why we launched a new area on our website called Patient Studies. This new area is designed to give patients and families the information they need to become engaged with the research community and enroll in hydrocephalus clinical trials or a hydrocephalus clinical research registry. Enrolling in a clinical trial or participating in a registry are two ways our community can become active participants in the quest to improve outcomes and find a cure for hydrocephalus.

The hydrocephalus clinical registries are part of our pediatric-focused Hydrocephalus Clinical Research Network (HCRN) and our Adult Hydrocephalus Clinical Research Network (AHCN). The data from these registries is used to understand the variability, progression, and current

treatment practices for hydrocephalus. The data is then used to inform the development of clinical trials. Clinical trials are used to test the effectiveness of treatments, whether that be testing a new drug to reduce the need for a shunt or determining the best way to reduce infection after surgery.

We will continue to update the Patient Studies area as new clinical trials are developed and when the results of a clinical trial are published. By developing this page, HA hopes to both inform our community about the clinical research being conducted and increase our community's involvement in the quest for a cure. Visit the page today at www.hydroassoc.org/patient-studies/

From 0 to 60: Driving with Hydrocephalus

By Krishna Jagannathan



I remember how excited my friends were in high school when they first got their license and I also looked forward to the day when I would be able to drive. For most teenagers, driving is an important rite of passage. They are no longer dependent on others to take them where they want to go. It takes a long time to become proficient at controlling the

car, observing the rules of the road and exercising judgment about the appropriate response to various scenarios in the driving environment, even for an individual without hydrocephalus. Having hydrocephalus adds a whole layer of complexity to the learning process. Granted, some people with this condition do not have any major medical problems and are able to lead a normal life. Others vary in the degree to which their ability is impaired. So what do you do to prepare your teenager for this milestone given their medical condition?

Most people with serious medical conditions can buy ID bracelets which list their condition and provide information about how to contact their doctor in case of an emergency. It had never occurred to either me or my parents to get one for me because I had my last shunt revision at 11 and fortunately never had to deal with medical complications resulting from a shunt malfunction since. But it is something I would strongly recommend for teenage drivers, even if they have had no past history of medical complications. Some of the symptoms of incipient shunt malfunction can actually mimic alcohol intoxication. If a problem occurs while the teenager is driving, which causes them to be pulled over, the police may delay getting prompt medical help because they misinterpret the cause of the behavior. It's critical for the teenager to exercise good judgment by restricting alcohol intake or completely abstaining before driving to avoid such misperceptions by law enforcement (and legally, teens should be abstaining anyway). This requires open and honest communication between teenagers and parents about the teenager's role in managing their condition.

Most of my challenges in driving have come from the side effects of the condition rather than medical issues. Hydrocephalus typically affects visual acuity, coordination, judgment and concentration, all of the skills which are necessary to drive. Just learning how to coordinate between controlling the steering wheel and applying the accelerator or brake can be a daunting

task when you have poor motor skills. I initially learned to drive on a stick shift, which was the car I would eventually be given to drive. Therefore, I had to coordinate shifting gears along with managing the other controls of the car. For someone like me, this was the most frustrating part of learning to drive because I did not have good coordination to begin with and seeing my friends master driving so easily affected my self-confidence. Since most cars today come standard with automatic transmission, this does not pose a problem for the teenager driver.

I still have problems judging distance or relative speed, which is a critical skill, especially in changing lanes. It always amazes me to see drivers effortlessly merging across two or three lanes of traffic on the freeway within seconds because it's a skill I have never mastered. I never

drive in the leftmost "fast lane" on the freeway even if I there is a

long distance to my destination, because I need a lot of clearance and time to change lanes and I am afraid

that I will never be able to change quickly enough

to get into my exit lane. If distance perception is a problem, the best solution is to maintain extra following distance between vehicles as well as teaching teenagers to constantly check their rearview mirror while driving to be aware of what is going on behind them.

I have trouble parking, even in clearly demarcated lanes, because I can't judge the distance between my car and the next lane once I am in the car, so I end up parking closer to one side or the other instead of exactly in the middle of the space. I generally avoid parallel parking, again because I can't accurately judge whether or not my vehicle can fit into a given space. It also takes me longer to reverse out of a space when there are cars parked anywhere behind me because I can't judge how far away they are from the back of my car. As of 2016, it is mandated that all new vehicles come with a rearview camera, which will certainly help with this issue. Of course, not everyone has the finances to buy a new vehicle, nor would they want to give a new car to someone who is a beginning driver or has difficulty driving.

When I first learned to drive, I had a lot of problems with navigating by myself. All I had was a Thomas Brothers physical map. So if I wanted to get from one point to another, I had to chart my route out on the map first, then write it down and commit it to memory. People with hydrocephalus can sometimes have difficulty telling the difference between left and right.

Over time with continued practice, I am fairly comfortable driving along routes I normally travel in the daytime.



On a map, of course, left and right are correlated with cardinal directions: north, south, west and east. If I am figuring out how to get somewhere, it isn't enough to tell me to go west 2 blocks and then turn right, for example because

I have no sense of what "west" means in terms of where I am currently located. Navigating while driving doesn't allow a lot of time to process and convert directions to an easily comprehensible form. Of course, now smartphones have GPS, so route guidance can tell you when and where to turn and even re-direct you in case you miss the turn. It's definitely a worthwhile investment to have some form of automated navigation system in the vehicle that the teenager will be driving.

Hydrocephalus can also affect memory. Even though I have lived in the same city all my life, except for familiar routes which I travel on a daily basis, I still have trouble navigating without GPS even if I have been to a place frequently before in the past. Before I go somewhere for an

appointment, I usually do a preview drive the day before. While GPS may get me to the actual address, I still need to familiarize myself with where to park, how to get from the parking area to the place where my appointment is and anything else that may interfere with finding my way, like construction activity. Anything that deviates from my expected route creates problems for me so I always have to plan ahead. I am currently self-employed, but it would have been a serious obstacle in my career if I had to drive for work and was expected to drive in new cities to get to a conference or a client meeting but didn't have the time to prepare in advance.

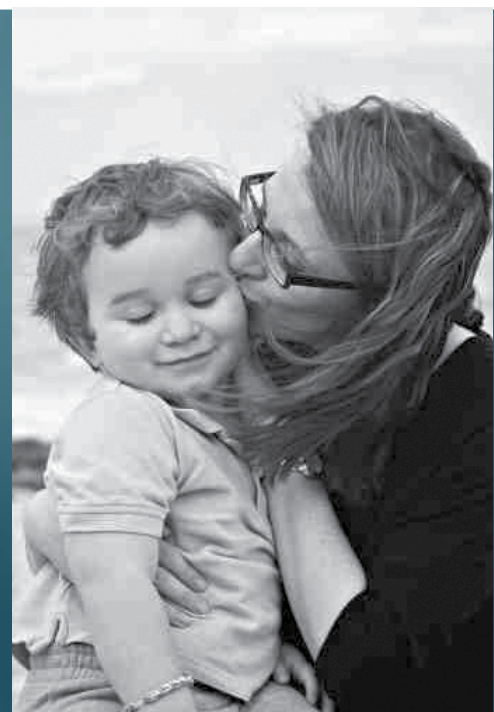
Driving at night is one of the skills a teenager should be comfortable with before getting a license. Just getting experience behind the wheel is insufficient because hydrocephalus can affect vision. For a long time, I used to avoid driving at night, because I could not see very well. Many high-end vehicles now have an array of technology available to assist drivers, including adaptive headlights, adaptive cruise control and braking, blind spot monitoring and lane departure systems. In time, these may be standard features in all cars, allowing teenagers with hydrocephalus to experience the same freedom and mobility as their peers without experiencing undue anxiety, as I did.

UNITED FOR A CURE

Members making a difference, Susan Fiorella

A fierce advocate. That's how many in the community describe Susan Fiorella, VP of Strategic Communications for Kaiser Permanente. When her son, Jacob, received a diagnosis of hydrocephalus after experiencing a stroke, she vowed to do everything in her power to get the word out and advocate for greater research funding and support for all patients affected by the condition. In the early Spring of 2014, Susan boldly shared her story at the annual Heartsong's Luncheon hosted by Children's National Medical Center and used this opportunity to educate hospital administrators about the impact of hydrocephalus on both patients and their families. She then wrote a letter to the CEO requesting that Children's host a hydrocephalus symposium at their hospital. She managed to navigate through the red tape and countless roadblocks to unite nearly 200 members for the first-ever Hydrocephalus Association Living with Hydrocephalus Education Day at the largest children's hospital in the area.

In the Fall of 2014, she joined other HA Hydrocephalus Action Network members for the 2014 Rally for Medical Research on Capitol Hill, meeting with Members of Congress and their staff to lobby for increased funding to support medical research. Susan again boldly shared her story to the Rally Day participants as part of the Advocacy Training prior to heading up to the Hill for the meetings. She continued her advocacy work with HA as part of a small, focused taskforce that successfully lobbied to have hydrocephalus included as one of a small handful of conditions eligible for medical research funding through the Department of Defense. Our ability to submit research proposals through the Congressionally Directed Medical Research Program (CDMRP) opens the door to \$247 million research dollars previously not accessible to our research community.



HA Webinar Series

HA is pleased to offer educational webinars to help you stay informed and current on the latest news surrounding hydrocephalus. These interactive, free webinars are designed to educate our community on a variety of topics and are led by medical professionals, researchers and others with a direct connection to hydrocephalus. The recordings from the webinars are available on our website.

The Next Generation of Hydrocephalus Researchers Part II June 16, 2015

Dr. Ramin Eskandari, Medical University of South Carolina and a former HA-sponsored Mentored Young Investigator, shares how his research is helping to optimize the timing of interventions in neonatal hydrocephalus and, in his new research, how brain cells react and recover under pressure.

Speak Up! Owning Your Own Condition April 30, 2015

This webinar for teens and young adults talks about educating others about hydrocephalus and provides tips and practical ways to share your story.

The Next Generation of Hydrocephalus Researchers Part I April 14, 2015

Dr. Yun Yung, Scripps Research Institute and a former HA-sponsored Mentored Young Investigator, discusses his exciting work focused on understanding and preventing post-hemorrhagic hydrocephalus.

Hydrocephalus Treatment Part I March 4, 2015

Dr. Jay Riva-Cambrin, Primary Children's Hospital in Salt Lake City, provides an overview of the history of endoscopic third ventriculostomy (ETV) and endoscopic third ventriculostomy with choroid plexus cauterization (ETV/CPC).

Finding Your Voice: Advocacy Training for Youth January 7, 2015

An introduction for teens on advocacy that covers writing, speaking, and influencing local, state, and national representatives, to help put hydrocephalus research funding, awareness, and teen and young adult concerns at the top of the agenda.

Hope in Progress: Research Update December 11, 2014

An overview of the current state of hydrocephalus research, the Adult Hydrocephalus Clinical Research Network, and HA-funded research projects.

Developing an Effective Individualized Education Plan (IEP) October 22, 2014

A webinar for parents and caretakers of school-aged children, teens, and educators who want to learn more about the IEP process as it relates to individuals with hydrocephalus.

What if it isn't Alzheimer's or Parkinson's Disease? September 10, 2013

Dr. Michael Williams, the Medical Director of the Sandra and Malcolm Berman Brain and Spine Institute at Sinai Hospital of Baltimore, discusses how the diagnosis of normal pressure hydrocephalus can be missed, and how it can be made.

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.

Learning to Date Me

By Bryant Williams



I met my future wife after I forgot what it was like to be sick. She knew me for a few years before we started dating and she knew that I had hydrocephalus, but she didn't know anything about it and, honestly, I didn't know much either.

What I did know is that I have trouble remembering things and that I get a little confused over simple things from time to time.

Also that my body is riddled with

scars and that, because of the mental issues I experience, I don't drive. I knew that I have been through more pain in a day than a lot of people are fortunate to not experience in a lifetime.

She learned all of these things early in our relationship and it wasn't easy for her to understand, but she stuck by my side through it all. However, what happened early in our relationship would be the true test. I had my first shunt malfunction in about eighteen years, and it did not go well. I remember a few of the now seventeen shunt revisions and I remember the pain, but what I do not remember is the look and emotions on the faces of my family members.

Well, this time I was able to witness and understand it as an adult and my fiancée handled it like the true angel that she is. Only nine months into our relationship I entered an operating room screaming at the top of my lungs, begging to be fixed. As I lay in the bed, I yelled at her telling her to leave my room because I didn't want her to see me like this. I don't remember much else from that moment, but I know she was there when I woke up from surgery.

What came after is the pain I still experience over two years later. The doctor was not able to remove the old shunt completely and a portion of it still rests inside my neck. It hurts daily and, from what I'm told, nothing can be done. Much like this old, stubborn shunt that isn't going anywhere, neither is she. When I'm having a bad day, she knows and makes my day as easy as possible. She hates to see me in pain.

She also loves to travel. Her brother is an airline pilot so flying is something that she doesn't fear and enjoys doing. Flying is something that she's done with her brother before she met me and something that I simply do not like to do. I flew for the first and last time to get to and from

vacation. But like many others who have hydrocephalus, I was miserable. I was blindsided by a terrible headache and there was nothing I could do about it. Through those flight she held my hand and looked into my eyes and reminded me that after this, I never have to fly again.

The biggest reason I'm telling you this story is because throughout my years of dating, before I met the love of my life, I didn't know if anyone out there would be able to handle the memory problems, the confusion, the inability to drive and the scars. I've forgot her birthday, not on the day but throughout the year I've had to ask for a reminder. She's held the weight of making sure I get to where I need to be. She stays grounded to get to and from vacation so I do not have to be in pain. The list goes on and on.

Many of you might be out there wondering if you'll ever find the one for you. The one who will accept you for what hydrocephalus has done and I'm here to tell you that you will. He or she will not just be your future husband or wife but they will be your rock, your memory, the one who straightens out your moments of confusion. But most importantly, they will be the one who reminds you that the pain will end soon and that you will be back to your old self once the surgery is over.

Hydrocephalus may be the reason for your scars and many other noticeable problems, but it will never be the reason that you're not loved, either by that one special person or by your family and friends. So when that headache comes along or you notice those scars in the mirror, never forget that you're loved and you will be loved through those headaches and regardless of those scars.

Have a Car, Truck, or RV that you're ready to get rid of?

Consider a tax deductible
donation benefiting the
Hydrocephalus Association.

IT'S EASY – 2 WAYS TO DONATE:

Online: <http://www.v-dac.com/org?id=94-3000301>

Call: 877-999-8322



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	<i>All Ages</i>
	Winfield	<i>All Ages</i>
AR	Online	<i>All Ages</i>
AZ	Online	<i>All Ages</i>
	Phoenix	<i>NPH</i>
	Phoenix	<i>All Ages</i>
CA	Online	<i>All Ages</i>
	Los Angeles	<i>All Ages</i>
CO	Online	<i>All Ages</i>
CT	Online	<i>All Ages</i>
	Hartford	<i>All Ages</i>
DC	Washington	<i>All Ages</i>
DE	Online	<i>All Ages</i>
	Middleton	<i>All Ages</i>
FL	Online	<i>All Ages</i>
	Central	<i>All Ages</i>
	South	<i>All Ages</i>
IL	Online	<i>All Ages</i>
	Chicago	<i>Adults and NPH</i>
IN	Central/Southwest	<i>All Ages</i>
	Clarksville/Louisville	<i>All Ages</i>

KS	Online	<i>All Ages</i>
KY	Online	<i>All Ages</i>
MA	Online	<i>All Ages</i>
	Boston	<i>All Ages</i>
MD	Baltimore	<i>All Ages</i>
MI	Online	<i>All Ages</i>
	Detroit	<i>All Ages</i>
MN	Online	<i>All Ages</i>
	Minneapolis	<i>Peds/ Adolescents</i>
	Moorehead/Fargo	<i>All Ages</i>
MO	Online	<i>All Ages</i>
NC	Online	<i>All Ages</i>
NY	Online	<i>All Ages</i>
	Buffalo	<i>All Ages</i>
	Long Island	<i>All Ages</i>
NY	New York City	<i>All Ages</i>
OH	Online	<i>All Ages</i>
OK	Online	<i>All Ages</i>
	Owasso	<i>All Ages</i>
OR	Online	<i>All Ages</i>
	Portland/Vancouver	<i>All Ages</i>

PA	Online	<i>All Ages</i>
	Northeast	<i>All Ages</i>
	Pittsburgh	<i>All Ages</i>
RI	Online	<i>All Ages</i>
	Providence	<i>All Ages</i>
SC	Online	<i>All Ages</i>
TN	Online	<i>All Ages</i>
	Chattanooga	<i>All Ages</i>
	Nashville	<i>All Ages</i>
TX	Online	<i>All Ages</i>
	Dallas	<i>All Ages</i>
	Houston	<i>Peds/ Adolescents</i>
	San Antonio	<i>All Ages</i>
UT	Online	<i>All Ages</i>
	Salt Lake City	<i>All Ages</i>
VA	Online	<i>All Ages</i>
	Richmond	<i>All Ages</i>
WA	Seattle	<i>Peds</i>
Nigeria	Lagos	<i>Peds/ Adolescents</i>

...education and support continued



A Sad Farewell to a Friend of our Community: Jerome Kersey

It is with deep sadness that we share the news of the passing of retired NBA player Jerome Kersey, February 18, 2015, from a blood clot in his leg that traveled to his lung. Kersey finished his professional basketball career as a small forward for the Portland Trail Blazers, helping them reach two NBA Finals. He was 52.

Many of us had the opportunity to hear him speak and to chat with him personally at our 2014 National Conference on Hydrocephalus held in Portland, Oregon, this past July. At 6-foot-7-inches, he was not hard to miss in our crowd. But it wasn't his height that attracted attention. It was his warm smile and genuine interest in our community and, particularly, our kids at our Kids' Camp.

One Key to College Success? Good Relationships!

By Madeleine Darowiche, Teens Take Charge Advisory Council



One of the most important things you can do for yourself in college is to establish good relationships with your professors. I cannot stress that enough. Especially if you attend or will be attending a larger university, during the first week of classes I would suggest going up to them and introducing yourself so that the professor can put a name with your face. If they know who you are early on, they will be more likely to help you, should you need it, later in the semester.

From my experience, most professors will be willing to help you, but you must be proactive and seek them out yourself. Here are some tips from my own personal experience to help you if you start struggling and/or falling behind.

- **Talk to them.** Most professors will not do anything for you unless you go talk to them first. I understand how nerve wracking that can be, but in most cases it will certainly be worth it. I have had a few professors who really haven't been as helpful as I'd like, and when that happens, the best advice I can give is to keep on doing the best you can and work to your full potential; give it your all. That is honestly all you can do.
- **Seek some advice.** If there is another staff member whom you are close with, such as an advisor, I would also suggest speaking with them and seeing what they have to offer for advice.
- **Use office hours.** Something else I would suggest is to drop by during office hours. If you are unavailable when the professor you want to speak with has them, talk to them before or after class, and most will be more than happy to arrange an alternate time that works for both of you.

If you know there
is an area you struggle in,
seek extra help as soon
as you can

- **Attend class regularly.** Each semester you will most likely have different experiences as professors' personalities vary. You will have some really awesome ones who go above and beyond to help students, and then you will have ones who just read directly off PowerPoint slides in class. Regardless of the professor takes attendance or not, I would recommend attending class because it shows the professor that you are about your grades and want to do well.
- **Don't wait until the end of the semester.** I am thankful that I already knew how to talk to authority pretty well prior to going to college because it has definitely served me well. If a situation arises where you feel you should speak with a professor, go do it! Don't hesitate or wait until the last few weeks of the semester. Remember, that is when everyone is trying to fix their grades, so it is much better to nip it in the bud right when you start noticing that you are struggling. Then there is enough time for you to hopefully bring your grade up before you no longer can.

Due to hydrocephalus, math has always been a challenge for me, like it is for many of us, but this semester I haven't had to worry about that at all. My professor for math this semester has been tremendous. I chose not to tell her about my hydrocephalus, but she is aware of the accommodations I have in place. She has done everything in her power to help me succeed, but that works both ways. As I touched on earlier, if you know there is an area you struggle in, seek extra help as soon as you can. I go to this professor's office hours nearly every day. Because I have remained diligent and dedicated, she is always willing to help me. Sometimes, I won't understand the way something gets taught in class, so she will try to help me understand

it in a different way, if possible. I am currently doing very well in math, but it has taken a lot of hard work. With a little dedication, effort, and will, I know that all of you who also struggle with math or another subject can succeed as well. And while academics and your grades should always come first, there is still time to be with friends and enjoy your college experience. You can do this! I hope my experience and tips help. Best of luck, especially to those of you entering college next fall!



UNITED FOR A CURE

Members making a difference, Megan Rivkin

Megan is a Junior at Adlai E. Stevenson High School in Illinois, and a member of our Teens Take Charge Advisory Council. Her younger brother, Brady, has hydrocephalus. A couple of years ago, she created "Brady's Dream" to raise funds for hydrocephalus. Since its inception, she has been an active fundraiser and advocate for hydrocephalus in her local community. Earlier this year, Megan nominated the Hydrocephalus Association (HA) for the Stevenson High School 2015 Spirit Fest. Megan was joined by our Education Manager, Jennifer Johnson, at a presentation to the National Honor Society Executive Board and the Spirit Fest Committee. Megan also stood in front of her fellow students and shared her family's journey with hydrocephalus and the meaningful volunteerism she has been able to do through the Hydrocephalus Association to support the mission of HA and help spread general awareness of hydrocephalus. Among the eight charities in the selection pool, the Hydrocephalus Association was selected as the 2015 Spirit Fest Charity. This selection means HA could receive over \$20,000 as the charity recipient.

...teens take charge continued

It's Good to be the King... Or Meet Him!



#NeverGiveUp #KeepGoing
Sound familiar? Many of you have followed the tweets of Tomas Rodriguez (@ThomasRoBeltran), a member of our Teens Take Charge program and record-holding swimmer. On December 4, 2014, in Madrid, Spain, his mom, Rosanne Beltran, had the honor of accompanying her son Tomas to the 2014 Spanish National Sports Awards Ceremony at the Pardo

Royal Palace hosted by the King of Spain. The National Sports Awards are issued by the Spanish Sports Council and recognize individuals and groups that have made a significant contribution to the field of sport. Tomas, selected from among Federated Intellectual Disability Athletes to attend the event, had the opportunity to meet His Royal Highness King Felipe VI of Spain, Queen Letizia, Queen Sofia (the King's mother) and Infanta Elena (the King's sister.) Tomas trains with Spain's Future Paralympian Swimming Team as an S14 swimmer as well as trains with his city swim team, Club Natación Pozuelo. Recipients at the ceremony ranged from well-known athletic stars to a seven year-old who displayed exemplary sportsmanship during a youth league soccer game. There was so much incredible athletic talent in one place at one time!

JOIN US!



Are you between the ages of 12 – 25 living with hydrocephalus, or a close friend, sibling, son, or daughter of someone living with hydrocephalus? Become a member of Teens Take Charge! Here's how you can get involved:

- Join us on FACEBOOK and TWITTER and help create a community of teens making changes happen.
- Meet the TTC Advisory Council: Fiona Wilcox, Danielle Padron, Megan Rivkin, Tess Jacobsen, Harrison Silver, and Madison Pardi. You can chat with them via Facebook posts or messages.
- Sign up to receive updates from TTC. Visit our website and click the STAY INFORMED button. Be sure to specify 'Teens Take Charge' as your alert type.
- Show your support for teens and young adults affected by hydrocephalus. Purchase a Teens Take Charge t-shirt in our online store. Our Store is located under the Get Involved menu option.
- Submit your story! We are inviting young adults to guest blog on the Hydrocephalus Association's website. If you are interested, please contact Jennifer@hydroassoc.org.
- Don't forget to download valuable resources that can provide important information for you and your loved ones. Visit our Publications page on our website or search through our Hydrocephalus Resource Library.

Walks and Special Events

Gabby Giffords and Mark Kelly to Serve as Honorary Chairs of Phoenix WALK



HA is honored to announce that former U.S. Congresswoman Gabrielle (Gabby) Giffords and her husband, astronaut Mark Kelly, have agreed to serve as the Honorary Chairs of HA's Phoenix WALK! Most will remember that Ms. Giffords was the target of an assassination attempt in January 2011 in Tucson. Developing hydrocephalus as a result of the traumatic brain injury she suffered, Ms. Giffords has made a remarkable recovery from her injuries after undergoing extensive rehabilitation.

Gabby's husband, Captain Mark Kelly (U.S. Navy, retired), is impressive in his own right. A former naval aviator and an astronaut, he spent more than 50 days in space, commanded both the space shuttle *Endeavour* and the space shuttle *Discovery*, and is one of only two individuals who has visited the International Space Station on four different occasions. He is an American hero who exemplifies leadership and courage under pressure. Captain Kelly inspired the HA community when he delivered the keynote address at HA's 2012 National Conference held in Bethesda, MD.

HA is honored to have Ms. Giffords and Captain Kelly's service as Honorary Chairs of the 2015 Phoenix WALK and their support of HA and its mission. The Phoenix HA WALK is scheduled for Saturday, **October 24th at Freestone Park**, 1045 E Juniper Avenue, Gilbert, AZ. For more information, visit the Phoenix WALK web page at <http://hawalk.kintera.org/phoenix> or email phoenixwalk@hydroassoc.org.

UNITED FOR A CURE

Members making a difference, Mia Padron and Jackie Davidson

Never underestimate New Yorkers on a mission... or get in their way! Our Long Island Hydrocephalus Association WALK celebrates its 10 year anniversary this year. The WALK is co-chaired by Mia Padron and Jackie Davidson. Mia met Jackie nine and a half years ago when Mia attended her first WALK. Mia's son, Tyler, was born with hydrocephalus, but not diagnosed until he was 23 months old. Jackie's son, Jordan, also has hydrocephalus, so the two moms found a shared commitment for awareness, support and advocacy. In 2009, the two took over as chairs for the Long Island WALK, one of the most successful events for HA, last year raising over \$100,000. They also currently co-lead the Long Island Community Network with Andrea Moore. But Mia and Jackie don't stop there. For the past six years, Mia and Jackie have worked with New York State Senator John Flanagan to pass an annual state resolution declaring September Hydrocephalus Awareness Month for the State of New York.



...walks and special events continued

HA WALK/Special Events Department Institutes “Account Manager” System

HA's WALKS and Special Events have experienced tremendous growth in the past five years -- growing from 18 WALKS raising \$547,000 in 2009 to 38 WALKS raising \$1,542,200 in 2014. As the number and size of the WALKS have grown, so have the needs of their volunteer leaders, requiring increasing the WALK and Special Events Department staff. We're delighted to announce that Liz Trabucco, who previously divided her time equally between the Development Department and WALKS/SE Department, will be transitioning to working full time for WALKS/Special Events by September! In an effort to provide better service and support for our hard working WALK Chairs the WALK/SE Department has implemented an “*account manager*” system. Each WALK site or Special Event has been assigned one of the three staff members, Randi Corey, Michael Ticzon or Liz Trabucco, to serve as its “account manager.” The account manager handles all aspects of that WALK or event. We're eager to see how this new structure improves service and support for HA's volunteer leadership so that they can continue to grow their WALKS, raise awareness about hydrocephalus, and connect our local families.



Pictured above:

Liz Trabucco, Special Events Coordinator

Randi Corey, Director of Special Events

Michael Ticzon, Special Events Coordinator



**HOLD THE
DATE!**

★
**Sept. 16 +
Sept. 17**

RALLY FOR
**MEDICAL
RESEARCH™**

ADVOCACY TRAINING & RALLY HILL DAY RECEPTION
Wednesday, September 16, 2015

Hydrocephalus Association's Advocacy Day
on Capitol Hill
Thursday, September 17, 2015

Plan now to come to Washington, DC, and be part of a strong, powerful patient rally. Share your story (like no one else can) and encourage your legislators to support critically-needed medical research funding.

More details will be shared in coming weeks and months.

MARK YOUR CALENDARS NOW!

2015 HA Walks

HA is pleased to share this year's WALK schedule. Whether you've participated in one of HA's WALKS before or you're new to the event, we invite you to join us for a great day of fun for the whole family. The money raised with HA WALKS is used to fund HA's program services (support, education and advocacy) as well as cutting edge research to find the answers to this complex and complicated condition. We hope to see you there!

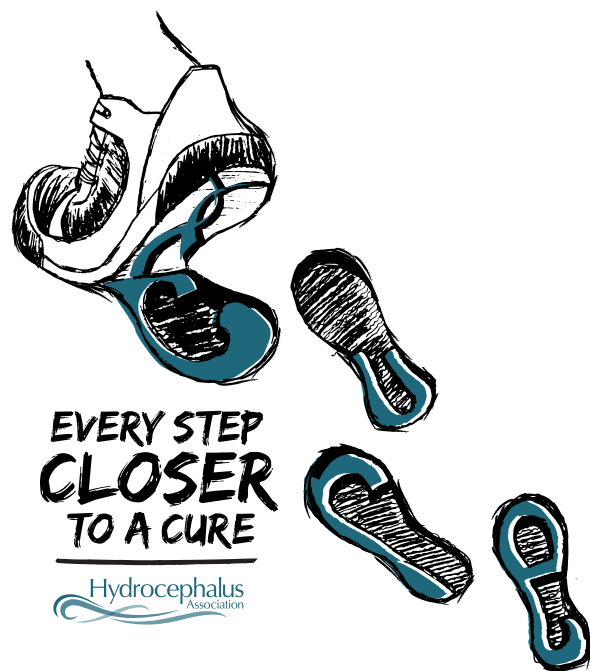
State	Market	2015 Event Date	Web site	Email
AL	Central AL	11/01/15	http://HAWalk.kintera.org/alabama	centralALWALK@hydroassoc.org
AZ	Phoenix	10/24/15	http://HAWalk.kintera.org/phoenix	phoenixWALK@hydroassoc.org
CA	Fresno	10/25/15	http://HAWalk.kintera.org/fresno	fresnoWALK@hydroassoc.org
CA	Los Angeles	09/13/15	http://HAWalk.kintera.org/losangeles	losangelesWALK@hydroassoc.org
CA	San Francisco	09/26/15	http://HAWalk.kintera.org/sanfrancisco	sanfranciscoWALK@hydroassoc.org
CO	Denver	08/09/15	http://HAWalk.kintera.org/Denver	denverWALK@hydroassoc.org
CT	Middlebury	09/20/15	http://HAWalk.kintera.org/middlebury	middleburyWALK@hydroassoc.org
DC	Washington	10/04/15	http://HAWalk.kintera.org/nationalcapital	nationalcapitalWALK@hydroassoc.org
DE	Smyrna	09/19/15	http://HAWalk.kintera.org/smyrna	smyrnaWALK@hydroassoc.org
FL	South Florida	11/07/15	http://HAWalk.kintera.org/southflorida	southFLWALK@hydroassoc.org
GA	Atlanta	09/12/15	http://HAWalk.kintera.org/atlanta	atlantaWALK@hydroassoc.org
IL	Chicago	08/29/15	http://HAWalk.kintera.org/chicago	chicagoWALK@hydroassoc.org
IN	Indianapolis	08/15/15	http://HAWalk.kintera.org/indianapolis	indianapolisWALK@hydroassoc.org
KS	Wichita	10/10/15	http://HAWalk.kintera.org/wichita	wichitaWALK@hydroassoc.org
KY	Louisville	09/26/15	http://HAWalk.kintera.org/louisville	louisvilleWALK@hydroassoc.org
MA	New England	09/27/15	http://HAWalk.kintera.org/newengland	newenglandWALK@hydroassoc.org
MD	Baltimore	10/10/15	http://HAWalk.kintera.org/baltimore	baltimoreWALK@hydroassoc.org
MI	Detroit	08/23/15	http://HAWalk.kintera.org/Detroit	detroitWALK@hydroassoc.org
MN	Twin Cities	09/20/15	http://HAWalk.kintera.org/twincities	twincitiesWALK@hydroassoc.org
MO	St. Louis	09/19/15	http://HAWalk.kintera.org/stlouis	stlouisWALK@hydroassoc.org
NC	Charlotte	09/26/15	http://HAWalk.kintera.org/charlotte	charlotteWALK@hydroassoc.org
NY	Long Island	09/27/15	http://HAWalk.kintera.org/longisland	longislandWALK@hydroassoc.org
NY	Western NY	09/19/15	http://HAWalk.kintera.org/westernny	westernNYWALK@hydroassoc.org
OH	Cleveland	08/30/15	http://HAWalk.kintera.org/cleveland	clevelandWALK@hydroassoc.org
OH	Columbus	TBD	http://HAWalk.kintera.org/columbus	columbusWALK@hydroassoc.org
OR	Portland	06/13/15	http://HAWalk.kintera.org/portland	portlandWALK@hydroassoc.org
PA	Central PA	09/19/15	http://HAWalk.kintera.org/centralpa	centralPAWALK@hydroassoc.org
SC	Columbia	09/19/15	http://HAWalk.kintera.org/columbia	columbiaWALK@hydroassoc.org
TN	Chattanooga	10/24/15	http://HAWalk.kintera.org/chattanooga	chattanoogaWALK@hydroassoc.org
TN	Memphis	09/19/15	http://HAWalk.kintera.org/memphis	memphisWALK@hydroassoc.org
TN	Nashville	10/03/15	http://HAWalk.kintera.org/nashville	nashvilleWALK@hydroassoc.org
TX	Dallas/Fort Worth	09/26/15	http://HAWalk.kintera.org/dfw	dfwWALK@hydroassoc.org
TX	Houston	10/17/15	http://HAWalk.kintera.org/houston	houstonWALK@hydroassoc.org
UT	Salt Lake City	09/19/15	http://HAWalk.kintera.org/slc	saltlakecityWALK@hydroassoc.org
WA	Seattle	08/01/15	http://HAWalk.kintera.org/seattle	seattleWALK@hydroassoc.org
	Virtual WALK		http://HAVirtualwalk.kintera.org/	walk@hydroassoc.org
TN	Silverdale Baptist Academy	completed	http://kids2cure.kintera.org/sba	sbaSchoolWALK@hydroassoc.org

It's the Most Wonderful Time of the Year...

No, not the winter holiday Season (*although that's a close second*). It's the start of HA's 2015 WALKS! 2014 was another record-breaking year. HA supporters, 15,000 strong, participated in 38 WALKS across the country, raising \$1.5 million — 45% of the organization's total annual income. Making this achievement even more impressive, HA WALKS continue to be **100% volunteer initiated and coordinated**.

HA will hold 35 WALKS across the U.S. this year, with most of the established sites returning. We are also launching two new sites... **Baltimore, MD**, and **Columbus, OH!** Baltimore is being co-chaired by **David Brucker, Tim Brucker, Jaci Gove** and **Anthony McCarthy**, with help from **Nicole Zollickoffer**. Thank you for stepping up in support of HA's mission. We'd also like to welcome our volunteer leadership from Columbus: **Jeremy and Rachael Birkhimer** and **James Noser**, who are co-chairing HA's 2nd WALK site in the Buckeye state!

HA is also pleased to announce new WALK leadership in **Houston** (thanks to Beth Hansen and **Donna Stomp**), **San Francisco** (**Leesa Kirkish** taking the Chair there, ably assisted by **Emily Fudge, Pip Marks** and **Karima Roumila**), **Seattle** (thank you, **Betsy Conyard**), and **Phoenix** (**Nancy Brown**)!



Plan NOW for Trick or Treat for HA!

Now in its fourth year, **Trick or Treat for HA** is a great way for your child's school, club or organization (scout troop, 4-H, Key Club, church group) to get involved in learning more about hydrocephalus and raising money for HA and its mission: *to cure hydrocephalus and improve the lives of those affected by the condition*. Parents serving as local volunteer leaders recruit groups of kids to participate. Like Kids to Cure Hydrocephalus, **Trick or Treat for HA** has an educational component with the local volunteer Chair conducting a presentation to the school or group about hydrocephalus. HA will provide the presentation to the volunteer leader and send each school or group collection pails. On Halloween night (*or another date of the school or group's choosing*) kids take their collection pail with them during their Trick or Treat rounds, asking for donations. In 2014 **Trick or Treat for HA raised more than \$25,000**. Special thanks to National Event Chair, Heather Kluter, of Orange County, CA, for leading this successful event.

If you'd like to get your school, club or organization involved for this fall, **now** is the time to present the proposal to the school principal or group leader — **before** the summer. If you prefer not to use Halloween or "Trick or Treat," HA conducts the same program at Thanksgiving time, called **"Thanks for Giving."** For more information on participating in Trick or Treat for HA or Thanks for Giving in your community please contact Heather Kluter at hkluter@yahoo.com or info@hydroassoc.org.

Silverdale Baptist Academy & Preschool Sets the Pace for WALK Season!

Congratulations to HA's first WALK of the year, a school WALK in Chattanooga, TN. The Silverdale Baptist Academy and Preschool held their second annual Kids to Cure Hydrocephalus WALK on April 22, 2015. Chaired by Chara McLaughen, who also chairs HA's Chattanooga WALK, the kids came out to support one of their own classmates, Ema McLaughen. This year's event was another outstanding success, with 350 students raising

This year's
event was another
outstanding success with
350 students raising
more than \$11,000!

more than \$11,000 – over more than twice their goal!

Great work by the students, teachers and staff at this fine school and HA's volunteer Kids to Cure Hydrocephalus Chair!

Interested in exploring the idea of starting a Kids to Cure Hydrocephalus event at your child's school? Please contact HA at walk@hydroassoc.org for more information.

Making the Hydrocephalus Association a Part of My Legacy



My name is Haylea Lynn Blank. I am currently 25 years old and have had 21 hydrocephalus-related surgeries. Even though I am a young adult, it is never too early to make your own medical decisions and consider what happens after you are gone. I am always thinking about the future, and looking at the past allows me to

be focused on my goals in life. I decided to join the Fudge Solomon Legacy Society to give back to a great organization, the Hydrocephalus Association, who is focused on eliminating the challenges of hydrocephalus. Their focus is on the hydrocephalus community, education and support, advocacy and research, which is very important to me. I want the Hydrocephalus Association to be a part of my legacy because there needs to be a better treatment for this condition and I HOPE one day there is a CURE!

It is unbelievable how many people don't know what hydrocephalus is and that it can occur at any age, and also that there are several different types. I pray each day there will be a cure within my lifetime as well as better treatment for individuals who have already been diagnosed. It is unfair that so many children have more brain surgeries than birthdays. I believe in supporting the Hydrocephalus Association mission so that future generations have a fighting chance at a brighter future. Educating the general population is very important for everyone to be aware and understand what hydrocephalus is, how it can be diagnosed, as well as treated and maintained. The research that is being done for hydrocephalus is so valuable it is hard to describe. By joining the Fudge Solomon Legacy Society, my legacy will provide continued education for hydrocephalus and other areas that need funding.

A little bit about myself:

I am a twin born prematurely, diagnosed with hydrocephalus at one month old. I had a VP shunt with several revisions from one month old until I was 13 years old. I was diagnosed with Dandy Walker when I was 13 years old, which was probably present at birth. On December 19, 2002, my current neurosurgeon, Dr. Martin M. Henegar, along with one of his associates, Dr. Michael Heafner, Sr., performed an endoscopic third ventriculostomy (ETV) and externalized my VP shunt. I had my VP shunt removed by Dr. Heafner, Sr., on December 27, 2002. I have been shunt free since then. I have had a few other revisions of the ETV, a 4th ventriculostomy and a 4th craniotomy with fenestration because of scar tissue that continues to build up and around the burr holes in my brain. My last surgery to date was an ETV revision that was done August 4, 2008.

Advocating for hydrocephalus and participating in Community Network events and WALKS is a very important part of my life ever since I found the Hydrocephalus Association back in 2002. I want my legacy to show there is more than just my accomplishments and work. I want my legacy to mean something and give hope to future generations that deal with hydrocephalus.

Thank you for allowing me to join The Fudge Solomon Legacy Society. I hope you will consider joining, as well. If you are interesting in joining The Fudge Solomon Legacy Society, please email giftplanning@hydroassoc.org. We also welcome an opportunity to speak with you in person by calling (888) 598-3789.

THANK YOU SPONSORS! Together we are making a difference!

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



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...walks and special events continued

Governor and First Lady of Tennessee Meet Ema McLaughen



Photo by State of Tennessee Photographic Services

On April 15, 2015, Chara McLaughen, our Chattanooga Hydrocephalus Association WALK Chair, received a message from the reigning Miss Tennessee Hayley Lewis with a personal invitation from the Governor of Tennessee to meet him and his wife. Governor Haslam became aware of Ema after watching a PSA that Hayley made about hydrocephalus after last year's WALK.

"We were really honored to meet with Governor Haslam today and share with him Ema's story. He was so shocked to hear that over 1 million people in the U.S. have hydrocephalus," shared Hayley.

Since meeting Ema at the 2014 competition where she was crowned Miss Tennessee, Hayley has helped raise awareness about hydrocephalus by volunteering her time at local Hydrocephalus Association events with Ema at her side. But beyond public appearances, Hayley has made a friend in little Ema, who she met after Ema underwent three brain surgeries for her hydrocephalus and who she supported in a recent hospital stay where it was suspected that Ema was in shunt failure. At the Miss Tennessee Outstanding Teen pageant this March, Hayley sang Lee Ann Womack's I Hope You Dance to Ema on stage and then crowned her an honorary Iris Princess with the current Miss Tennessee Outstanding Teen Lexie Perry.

"Ema was very excited to travel to the state capital to meet Governor Haslam and his wife. As her mom, it was so important for me to have the Governor take notice of the incurable brain condition my daughter will have to endure for the rest of her life. We were honored to educate the Governor about hydrocephalus and our community here in Tennessee," stated Chara.

Hayley will be supporting our Chattanooga community at two more upcoming events. The KidzExpo this Saturday at the Chattanooga Convention Center where she will be in a photo booth hosted by the Hydrocephalus Association and the Chattanooga Lookouts baseball game on May 3rd where our Chattanooga kids will throw out the first pitch.

The Hydrocephalus Association would like to thank Hayley for all of her support for our entire Chattanooga hydrocephalus family.



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



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! We hope many of you will join us in September at the Rally for Medical Research as we advocate for continued funding for medical research.
- spreading the word, reaching out and building community. In 2014, 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 20,000 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 interior of the included envelope.