Message from Our CEO

Delivering on a Promise

In the last year, we have talked a lot about the need for more research on hydrocephalus and the work of the association to raise money and provide funding for that research. There’s good reason for this…we’ve made good progress on our promise to increase the amount of research being done, with the ultimate goal of eliminating the challenges of hydrocephalus.

One strategy for delivering on this promise has been the vision of HA’s board to build a strong presence in our nation’s capital, seat of the U.S. Congress and offices of the National Institutes of Health (NIH), two of the primary decision-makers around public funding of health-related research. We have made significant progress on this vision: for instance, we moved into new offices in Bethesda, Maryland (a suburb of Washington, D.C.) in August; we held a very successful Advocacy Day in concert with the National Conference on Hydrocephalus in June; and we have the great honor of having the Chairman of our Board, Paul Gross, named to the National Advisory Neurological Disorders and Stroke Council, the advisory council for the NIH’s National Institute of Neurological Disorders and Stroke (NINDS).

We reached another milestone in our progress just last week that I am very excited to share with you. Paul led a discussion among a broad group of representatives from four different Institutes within the NIH – the NINDS, the National Institute of Child Health and Human Development (NICHD), the National Heart, Lung & Blood Institute, and the National Institute of Biomedical Imaging and Bioengineering (NIBIB). Called the “Trans-NIH Hydrocephalus Meeting,” and led by Jill Morris, PhD, NINDS Program Director for Neurogenetics (which includes hydrocephalus), the gathering provided an opportunity for Paul to educate key officers within NIH about what our association is doing to advance research in the private arena and for Dr. Morris to share what NINDS, as one institute, has been doing to support hydrocephalus research. The meeting also provided an opportunity for Paul to share the findings of a study HA has been working on that shows how much NIH has been spending on hydrocephalus...
Getting to the Heart of Hydrocephalus 2012 Conference Highlights

From June 27 - July 1, 2012, 386 individuals and families gathered in Bethesda, Maryland, to re-establish our sense of community and educate ourselves about hydrocephalus at our 12th National Conference, “Getting to the Heart of Hydrocephalus.” The agenda was full of educational programs, networking/support events, and opportunities to socialize with others who live with hydrocephalus. It’s the only event of its kind, and was a heartwarming and informative experience.

Conference highlights included:

● Captain Mark Kelly, Commander of the final mission of the Space Shuttle Endeavor, who gave a rousing talk that challenged participants to dream big and not let obstacles stop them from pursuing their goals.
● Dr. Pat McAllister’s well-received presentation on “Anatomy and Physiology of Hydrocephalus.”
● A trip to Capitol Hill for our Advocacy Day where members of our community visited 96 Congressional members to advocate for expanded funding for hydrocephalus research.
● A wide variety of interpersonal support sessions for fathers of children with hydrocephalus, mothers of children with hydrocephalus, adults with NPH, young adults with hydrocephalus, siblings of hydrocephalus patients, spouses/partners with those living with hydrocephalus, and grandparents of children with hydrocephalus.
● The Robert Puilena Lectureship presented by Dr. Story Landis, Director of the National Institute of Neurological Disorders and Strokes (NINDS) at the National Institutes of Health (NIH) which addressed the importance of hydrocephalus research and how this research fits into NINDS’ mission.
● A report on “Public Funding Trends in Hydrocephalus Research” by Hydrocephalus Program Director at NINDS Dr. Jill Morris and HA Chairman Paul Gross.
● Intergenerational Panel of hydrocephalus patients and family members facilitated by Dr. Mike Williams, where our panelists shared their biggest challenges, lessons learned and hopes for the future.
● A panel presentation about the history across the ages of the diagnosis and treatment of hydrocephalus in both children and adults, as well as an inspiring memoir of the establishment of the Hydrocephalus Association and its accomplishments by HA founder Emily Fudge.
● Presentation of two Distinguished Service Awards to Dr. Howard Conn (posthumously) and Dory Kranz.
● A groundbreaking presentation on the Treatment of Hydrocephalus in Sub-Saharan Africa by Dr. Benjamine Warr reviewing the history behind his development of a new surgical treatment for hydrocephalus that eliminates the need for a shunt.
● Approximately 40 different break-out sessions on numerous topics covering the latest research findings, newest treatment options, and resources for addressing typical work-life challenges for hydrocephalus patients and families.

As you can see, there was something for everyone. You can find some of our conference presentations online under the Education and Support menu tab, National Conference on Hydrocephalus option.

Featured Articles

We Have Moved!

After 29 years of being located in San Francisco, California, the Hydrocephalus Association has moved its national headquarters to Bethesda, Maryland. The move puts our office just 2 miles from the National Institutes of Health (NIH) and 9 1/2 miles from the U.S. Capitol, positioning us to expand our advocacy and research while continuing our core services of providing support and education. Take note of our new address and phone!

4340 East West Highway
Suite 905
Bethesda, MD 20817
(301) 202-3811 main (888) 598-3789 toll free
(301) 202-3813 fax

Three Million Dollar Campaign Launched to Fund Five Year Research Initiative Plan

The Hydrocephalus Association publicly launched a $3 million dollar campaign called “A Reason for Hope” to fund its five year Research Initiative plan. Funds raised for the campaign will be dispersed to implement the key priorities detailed in the plan. Initiated quietly with major donors, the campaign has already garnered $1,700,000 in support of HAS research efforts.

There are some NEW faces at HA!
The Hydrocephalus Association had a number of representatives also taking part in this meeting. In addition to Paul, the HA CEO Dawn Mancuso as well as Board members David Browdy, Aseem Chandra, Barrett O’Connor, and Marvin Susman also participated.

Each and every day, we strive to deliver on our promise on behalf of everyone living with the challenges of hydrocephalus. We’re honored to do this work, and we thank you for your continued support in helping us meet this promise!

The Hydrocephalus Association would like to welcome its new staff to the HA team. The following staff members joined our current HA team members, Dawn Mancuso, Jennifer Bechard, Randi Corey, Neena Narayanan and Karima Roumila. Meet Amanda Garzon (Communications and Marketing Manager), Aishla Heath (Director of Development), Michael Ticzon (Special Events Coordinator), Amy Weist (Business Manager), and Ashly Westrick (Research Programs Manager). To learn more about our staff and see photos, visit our Staff page under the About Us menu tab on our website. www.hydroassoc.org

Pathways, Fall 2012 3

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HA would like extend a hearty congratulations to Dr. Benjamin Warf, associate professor of surgery at Harvard Medical School and director of the Neonatal and Congenital Anomaly Neurosurgery Program at Children’s Hospital Boston, for being named a 2012 MacArthur Foundation Fellow by the John D. and Catherine T. MacArthur Foundation. The fellowship rewards individuals for their “extraordinary originality and dedication” to their field of work. In this case, Dr. Warf is recognized for his outstanding work developing new treatments for hydrocephalus while living in Uganda.

Many of you will remember Dr. Warf as the inspirational Keynote Speaker at our 12th National Conference. Dr. Warf shared the story of developing a treatment for hydrocephalus that would reduce the problems associated with shunting Ugandan children, given the challenging environment for medical care in that country. An economically depressed environment with medical clinics few and far between the villages settled within a vast rural landscape, children with hydrocephalus faced the impossible obstacle of receiving an initial shunt placement and, when necessary, revision surgery should the shunt fail. Families often live days away from a medical facility with neurological capabilities.

Knowing that these families needed a treatment option that required less intervention and dependency on a medical device, Dr. Warf developed a novel treatment for hydrocephalus that combined a less common treatment called endoscopic third ventriculostomy (ETV) with another procedure called choroid plexus cataractomy (CPC). Previous attempts at using the ETV procedure alone in infants was not proving effective. This combination greatly increased the success rate of the ETV procedure in treating a broad range of children. His innovation eliminates the need for a shunt thereby reducing complications for kids that cannot seek care in a timely fashion.

In addition to being named as a prestigious MacArthur Fellow, the MacArthur award provides Dr. Warf with a $500,000 grant over five years to advance his research. The grant has few restrictions on how he applies those funds. In separate but related news, Dr. Warf received an NIH grant last month to enable the hospital in Uganda to build the capability for a clinical trial involving his new technique and to test the efficacy and neurological outcomes using ETV/CPC.

HA is continuing to meet with key Congressional leaders for hydrocephalus to $157.25 average per person per year on the national level, Congressman Leonard Lance recognized September as National Hydrocephalus Awareness Month.

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Health (NIH) as well as asking each of you to take time to write your elected official. In addition to seeking increased public funding, HA has also launched a 3-year $3 million dollar private initiative to raise funds for research. The initiative is called A Reason for Hope, and you can find more information on our website or by calling our office. To date, we have raised and granted more than $1.7M to research initiatives in the form of individual grants and grants to strategic partnerships.

Grant Giving

In order to select research grants which will have the best success in their own outcomes and for garnering future funding, we have established a broad panel of scientific advisors and reviewers to help us set priorities and review grant applications.

Since 2009 we have awarded 7 grants in our Mentored Young Investigator program in order to increase the number of young researchers to commit to a career in hydrocephalus research.

We awarded two Investigator Grants in Basic Science to research pharmaceutical interventions to treat intracranial pressure – the most painful and damag- ing manifestation of hydrocephalus.

We recently announced a Request for Applications for a grant co-sponsored by the Rudi Schulte Foundation to support high quality, innovative and timely research projects by established investigators that will further advance the understanding and control of the normal and abnormal regulation of cerebrospinal fluid (CSF) production, flow, resorption, pressure and pulsatility. The first submission deadline is January 4, 2013. More information can be found on our website.

Strategic Partnerships

HA will continue to pursue strategic partnerships which will further advance the research ecosystem. One important partnership HA has established is with the pediatric hydrocephalus Clinical Research Network (HCRN), founded in 2006. The two organizations have signed a partnership to ensure the continuation of HCRN’s substantial research into treatments and outcomes in hydrocephalus that benefit HAS memberships.

HA has also established a planning task force to develop a specialized clinical research network focusing on adult hydrocephalus. This research network, which does not yet have a formal name, will be built on the model established by HCRN. We look forward to seeing this network grow.

Bringing the Leading Minds Together

In order to be a leader in the research community, it is imperative for HA to continue to drive the research community forward. One way to do this is to bring together the scientific and medical communities together. We do this through hosting meetings and our national Research Conference.

Our research conference, “Opportunities in Hydrocephalus Research: Pathways to Better Outcomes,” was held this April in Seattle, Washington. Sponsored by NIH, the conference brought some of the best and brightest thinkers on hydrocephalus to discuss current (and future) research. The conference uniquely built upon the impressive success of the NIH-sponsored workshops “Hydrocephalus Myths, New Facts and Clear Directions” held in 2005 and “Improving Outcomes in Hydrocephalus: Bridging the Gap between Basic Science and Clinical Management” in 2009.

Finally, this fall Paul Gross led a discussion among a broad group of representatives from four different Institutes within NIH called the “Trans-NIH Hydrocephalus Meeting.” The gathering provided an opportunity for Paul to educate key officers within NIH about what our association is doing to advance research in the private arena and for Dr. Morris to share what NINDS, as one institute, has been doing to support hydrocephalus research.

Being the Table

Being in the midst of the discussions guiding funding priorities for public monies is critical for keeping hydrocephalus present in the minds of the decision-makers. In the spring, Paul Gross joined the 18 member National Advisory Neurological Disorders and Stroke Council -the major advisory panel to the National Institute of Neurological Disorders and Stroke (NINDS). The 18-member Council, composed of physicians, scientists and representatives of the public meets three times a year to review applications from scientists seeking government grants to support biomedical research on disorders of the brain and nervous system. Members also advise the Institute on research program planning and priorities.

Outcomes

Research is essential in the discovering of new treatments, preventing and gaining a better understanding of hydrocephalus. HA’s Strategic Research Initiative addresses three priority investment areas:

1. Stimulate the research ecosystem for hydrocephalus.
2. Improve clinical treatments and quality of life for those living with hydrocephalus.
3. Advance the study of the root causes of hydrocephalus.

HA seeks to support innovative research in hydrocephalus by addressing these priorities. This is an exciting time. In my new role, I want to be able to support HA in stimulating the investment in areas but, also, I hope to be able to get the word out to all of you on the important research being conducted and to further encourage and excite people about hydrocephalus research.

Hydrocephalus Association and Hydrocephalus Clinical Research Network Formalize Partnership

The Hydrocephalus Association (HA) and the Hydrocephalus Clinical Research Network (HCRN) announced in June that the two organizations have signed a partnership to ensure the continuation of HCRN’s substantial research into treatments and outcomes in hydrocephalus that benefit HAS memberships. HCRN Chairman Dr. John Keste joined the board of directors of HA and the organizations will work together to promote HCRN’s research.

The partnership expands HA’s Research Initiative beyond its young investigator and basic science awards with a burgeoning body of research intended to advance treatments for those who suffer from hydrocephalus. HCRN conducts multiple simultaneous studies, so it is able to advance research more quickly than traditional clinical studies. HA will promote HCRN’s research and funding needs to its members. HA’s funding commitment is substantial – more than $1M over the next three years. These funds support the shared data coordinating center located at the University of Washington patient populations and allows them to be studied more rapidly, as well as the research site coordinators at each center.

HCRN receives support from a variety of organizations including private donors, participating hospitals, foundations and the National Institutes of Health. While HCRN will always seek public funding for its studies and scientists’ careers, the partnership will allow HCRN to continue its promising work with more assurance of continued support.
Papilledema, Vision Loss, and Hydrocephalus

Papilledema is an optic disc swelling that is secondary to elevated intracranial pressure around the brain. (1) Papilledema can be very dangerous and can cause blindness. Patients should be periodically examined for papilledema so that timely intracranial pressure (ICP)-lowering measures can be instituted to preserve vision. (2)

It is critical that the patients consult with an ophthalmologist or a neuro-ophthalmologist (they may need to get a referral from their neurosurgeon). These specialists are not always easy to find, however, you may use American Academy of Ophthalmology’s website (http://www.geteyesmart.org) to locate one in your area. A thorough shunt check may be needed. The patient may need to undergo a spinal tap or ICP monitoring to determine the level of ICP.

The biggest concern with increased intracranial pressure is there is always the potential for visual loss secondary to the papilledema. If the shunt is not working and the ventricles are non-responsive then there is a very serious concern that if the shunt is not fixed the patient is at risk for going blind.

Most symptoms in a patient with papilledema are secondary to the underlying elevation in intracranial pressure. (3)

- Headache: Increased intracranial pressure headaches are characterizedly worse on awakening, and they are exacerbated by coughing or other type of Val-salva maneuver.
- Nausea and vomiting: If the rise in intracranial pressure is severe, nausea and vomiting may occur.
- Pulsatile tinnitus
- Some of these visual symptoms can occur:
  - Some patients experience transient visual obscurations (graying-out of their vision, usually both eyes, especially when rising from a lying or sitting position, or transient flickering as if rapidly toggling a light switch).
  - Blurring of vision, constriction of the visual field, and decreased color perception may occur.

(continued on page 11)
CONGRATULATIONS TO OUR 2012 SCHOLARSHIP RECIPIENTS!

We are so pleased and honored to announce a new scholarship available through the Hydrocephalus Association’s Teens Take Charge Program (TTC). TTC trains teenagers and young adults (and their siblings), who are affected by hydrocephalus, to take charge of the condition and become self-advocates with both health professionals and with their legislators. Through a generous grant from the Medtronic Foundation, the Hydrocephalus Association (HA) is able to award five scholarships, in the amount of $1,000, to teens and young adults (ages 17 to 25) who are affected by hydrocephalus. We commend these young adults for their academic achievements, extra-curricular activities and perseverance. They are an inspiration to everyone at the Hydrocephalus Association and to our entire community!

Sharri Powell

“I have learned what my strengths and weaknesses are, techniques that work for me, how to advocate for myself, and perhaps most important of all, how to be persistent in pursuing success even when things seem overwhelmingly difficult.”

Shawn Berg

“I have used my hydrocephalus not as a crutch but as a way to rise above and meet my challenges.”

Jamie Hill

“I have learned what my dreams and goals… I will continue to be the best Prisca that I can be. I have a goal that I have to reach. I have a purpose to fulfill. I will achieve.”

Prisca Patrick

“I will not stop working towards my dreams and goals… I will continue to be the best Prisca that I can be. I have a goal that I have to reach. I have a purpose to fulfill. I will achieve.”

Lucas Russell

“How Does Hydrocephalus Injure the Eye?

Visual information is transmitted to the brain by the optic nerve, a cord that runs from the eye to the brain. The meninges that surround the brain and spinal cord also surround the optic nerve. Thus, increases in cerebrospinal fluid (CSF) pressure around the brain can also produce pressure on the optic nerve. This pressure closes off the supply of food and oxygen to the optic nerve, causing it to swell.

The nerve can be damaged through high CSF pressure or because of lower pressure elevation that lasts for a prolonged time period. Damage to the optic nerve from papilledema can result in reduced vision, reduced color vision, and visual field loss.(4) Since some children and adults with hydrocephalus can develop different eye problems and high CSF pressure can damage vision, it is important for patients to have periodic check ups for any vision issues.

To learn more about papilledema and other eye problems and hydrocephalus please use the following resources:

- Download and read our information sheets from our website:
  - Eye problems Associated with Hydrocephalus
  - Visit the Hydrocephalus Resource Library on our website for articles and other publications.
  - Search the National Eye Institute (NEI): http://www.nei.nih.gov

(3) http://emedicine.medscape.com
(4) Fact Sheet: Eye problems Associated with Hydrocephalus
(5) Hydrocephalus Resource Library

(continued from page 8)
Joyce Schwartz Spreads Her Message about Normal Pressure Hydrocephalus

Joyce Schwartz did not have any symptoms of Normal Pressure Hydrocephalus (NPH) that she was aware of until the age of 50 when occasional incontinence began. She thought that maybe it was just taking her too long to get to the bathroom. Even though she was only 50, she was aging, she reasoned to herself. But it worried her enough that she did schedule an appointment with her primary care physician. After an examination, the doctor could not find anything wrong. So Joyce returned to work and her routine.

Then at the age of 55 she fell down a couple times at work for no reason. This was concerning but she kept going, dismissing the falls as clumsiness, for the most part. Despite the rationalization, she decided to return to her doctor. The doctor could not find a reason for the falls, but this time her doctor sent her to see a neurologist. The neurologist did an MRI and called her in to share the results. Joyce was told that her brain had shrunk but she shouldn’t worry about it. The neurologist never mentioned hydrocephalus or NPH. Joyce never went to see that neurologist again.

Instead, Joyce started searching the internet for information. She found the University of California at San Francisco (UCSF) Neurology Department and made an appointment. After testing with their team, Joyce finally received the diagnosis of NPH. She was 57 at the time.

The relief of having a diagnosis was short lived when she learned that she was not a candidate for a shunt. The symptoms continued to worsen, and eventually to a wheelchair. She was also experiencing short-term memory loss, though there was no one to confirm this except her husband because she was so removed from her previous life. In a last ditch effort, she decided to get one more medical opinion. She was now 60 years old.

Joyce called the Hydrocephalus Association (HA) in San Francisco and asked if they had a referral list of neurosurgeons who specialized in NPH. HA gave her the name of Dr. Brian Andrews in San Francisco, California. He explained the risks associated with the surgery and recommended she be treated with a ventriculoperitoneal shunt (VP). When presented with the surgical placement of a shunt, Joyce felt like she was left with no other option. She knew the symptoms would continue to worsen and that the possible benefits of the shunt far outweighed the way she was currently living her life with the NPH. She opted to do the surgery. She was 73 when the shunt was placed and the surgery went well.

Joyce is now 75. Since her shunt placement surgery two years ago, Joyce has been very happy with the results. She feels like she is living again. She walks by herself again, though a knee replacement has slowed her down a little. The most important thing, Joyce feels like she is living again.

Joyce is now a volunteer for HA as a peer supporter. She offers to talk to individuals as they are newly diagnosed. She has one powerful message to share with others who have symptoms that just don’t seem right:

“Keep researching and keep searching for the answer for you and don’t give up.”

On Thursday, the 28th of July, the second day of our 12th National Conference on Hydrocephalus, we held our second Advocacy Day on Capitol Hill, “Climbing Capitol Hill for Care.” Hundreds of members of the hydrocephalus community braved the intense heat of a Washington, DC summer day to bring our message of increased funding for hydrocephalus research to Congressional representatives and/or their staff.

Advocacy Day participants were prepared for their meetings by three leading professionals affiliated with Congress. Judith Schneider with the Congressional Research Service (CRS), a department of the Library of Congress, gave a hilarious and informative talk, “Getting to the Heart of Congress,” which educated everyone on the inner workings of Congress and offered invaluable tips for making the most of our meetings. John Lawrence, Chief of Staff to House Minority Leader Nancy Pelosi, and Amy Rosenbaum, provided an overview of strategies for approaching Congressional Representatives with our specific message. After being fully briefed, over 200 of our board members for Capitol Hill where we collectively visited 96 Congressional offices, criss-crossing each other’s paths between the U.S. Senate and the U.S. House of Representatives. The day ended with a reception in the U.S. Capitol. Paul Gross presented our first-ever Public Service Awards to Representatives Robert Andrews (D-NJ), Leonard Lance (R-NJ), and Rosa DeLauro (D-CT) to recognize their important contributions to the hydrocephalus community.

Hydrocephalus Association Brings its Message to Capitol Hill!
Bullying. We hold on to the 1950s image of the big kid on the playground taunting, name calling, pushing, and intimidating other children. While that image still has validity, bullying is not the exclusive domain of boys nor is it necessarily one child bullying other children, as stories of peer group bullying in the 1950s image of the big kid on the playground taunting, name calling, pushing, and intimidating other children. The behavior is repeated, over time. Both kids who are bullied and who bully others may have serious, lasting problems. (stopbullying.gov)

For our community, it is an opportunity for us to listen to our teens and young adults share their unique stories of being bullied because of their hydrocephalus and to give them the proper tools they need to respond effectively. It is also a chance for us to learn, for parents of young children to prepare, and for all of us to support each other.

- More than 160,000 U.S. students stay home from school each day from fear of being bullied. (Pacer Center)
- The most common reason cited for being harassed is a student’s appearance or body size. 2 out of 5 teens feel that they are bullied because of the way that they look. (DoSomething.org)

People used to call me a “water head” from the time I was born until elementary school (even after I had my shunt placed at eleven days old). When I was a freshman in high school, the distant editor in my neck broke. When I came back from having my first shunt revision after Christmas, some of my classmates made jokes about me because they thought that I had cancer, when really I had to have my head shaved due to the shunt revision. After my freshman year, people realized that I was just like any other high school student, but I had lifelong limitations including cerebral palsy, hydrocephalus and visual deficits. Now, I am a freshman in college, and people ask me questions (as they should) instead of bully or stare and make me look like an idiot. Sara, age 19

- Bullying directly affects a student’s ability to learn. Students who are bullied find it difficult to concentrate, show a decline in grades, and lose self-esteem, self-confidence, and self-worth. (Pacer Center)
- Students who are bullied report more physical symptoms, such as headaches or stomachaches, and mental health issues, such as depression and anxiety, than other students. (Pacer Center)
- Students can be especially effective in bullying intervention. More than 55 percent of bullying situations will stop when a peer intervenes. (Pacer Center)

The situation started when I was talking to one of my friend’s about my condition. I told my friend that I have somewhat of a bump on my head due to the shunt the bully, when hearing this, called me a nobby-headed freak. This name calling continued for several weeks, making me very upset. Then upon talking to my Grandfather about the situation, he gave me the idea of talking to the bully and telling him how bad it is to live with hydrocephalus. After I explained everything, he stopped.

Wyatt, age 17

- 56% of students have personally felt some sort of bullying at school. Between 4th and 8th grade in particular, 10% of students are victims of bullying. (DoSomething.org)
- In some cases, bullying has led to devastating consequences, such as school shootings and suicide. (Pacer Center)

I was first diagnosed with hydrocephalus at the age of 10 and shunted at 11. Prior to being in for surgery, another student stated, “I hope you die.” At such a young age, it was shocking to hear another kid say those words. Jennifer, age 24

- Bullying is a community wide issue that must not longer be ignored or thought of as a rite of passage. Students, parents, and educators all have a role in addressing bullying situations and changing school culture. (Pacer Center)

It can happen at any age from my experience. And it was due to my having hydrocephalus. Personally I have never told my employers off-the-bat that I had hydrocephalus because in the past I had had several problems with management and co-workers afterwards. I had one manager at a job I worked for flat out mock me and make fun of me in front of co-workers and customers. Right after, I burst out into tears trying to explain to him I had a medical condition. Some people never grow up.

Jasmin, early 20s

One of the best ways to begin to make change is to provide the tools individuals and parents need to address bullying. If you’re a parent, take some time to visit these sites with your child. Some of the sites are really interactive and engage kids through videos, petitions, and informational graphics.
Haylea Blank:
What is something you do to take your mind off of hydrocephalus?
I am 22 years old and have undergone 21 surgeries related to hydrocephalus. I have had to endure fourteen surgeries including the ventriculoperitoneal (VP) shunt I had placed, one external ventricular drain (EVD) with an Endoscopic Third Ventricleostomy (ETV), one surgery to remove my VP shunt, three ETV revisions, a 4th ventriculostomy, and a 4th craniotomy with fenestration. The last procedure I had was on August 4, 2008. I also have Dandy-Walker Syndrome which affects my 4th ventricle and causes issues with the 3rd ventricle. When I have headaches I sometimes listen to music, either some of my favorite country music or soft piano music. I never knew that piano music could be so soothing. I also like to watch my favorite movie Dirty Dancing with Patrick Swayze and Jennifer Grey. If I have an extremely bad headache that feels like my brain is in a soup can (an analogy I say to my Neurosurgeon) then I like a cool, dark room and LOVE to sleep. It usually helps and the headache goes away after a few hours.

Hydrocephalus is a part of my life and it ALWAYS will be, but I do not let that stop me from achieving my dreams and working at a job I love to the fullest. I pray I don’t have any other issues in the future more serious than random headaches, but if I do I am very glad to know I am NEVER ALONE in this FIGHT.

“Remember that you were given this life because you’re STRONG enough to live it.” ~ Unknown

Wyatt Barris:
Stress about grades, sports, and many other things, is doubled when you live with the ongoing challenges of hydrocephalus. The constant migraines and being absent from school can take a major toll on your grades and school work, which brings added stress. The way I deal with stress is by listening to music or writing in my journal, but these activities can be, but I do not let that stop me from achieving my dreams and working at a job I love to the fullest. I pray I don’t have any other issues in the future more serious than random headaches, but if I do I am very glad to know I am NEVER ALONE in this FIGHT.

“Remember that you were given this life because you’re STRONG enough to live it.” ~ Unknown

Abby Shares Her Life Experiences With Hydrocephalus!
Hi! My name is Abby. I turned 12 years old at the end of August and this is a snapshot of feeling my life. I was born in Albuquerque, New Mexico. When I was born, I was very sluggish and tired. My parents found out that I had hydrocephalus a few weeks later and at 26 days old I had my first shunt placed. Since I was born 11 years ago I have endured 10 surgeries but only 3 were due to hydrocephalus. Hydrocephalus is only one of the medical challenges I have.

I sometimes feel like I’m different from everyone else because I have so many medical issues. I want people to understand how I feel burdened with all of the medical symptoms on my shoulders. One of my other medical problems is in my blood vessels. On my left arm I have a venous malformation (vein that grows out of control and can fill up with blood clots) that ruptured when I was three years old. I have two more vein malformations on my right hand.

Medical struggles have brought burdens and blessings to my life. Some of the burdens include surgeries, feeling sick, having trouble with my vision, and sometimes feeling stupid because people make cruel comments. It is not fun because sometimes I feel sick when I’m trying to have fun. On the other hand, my medical challenges have also brought me blessings. Some of the blessings are meeting new friends and going to exciting places like that I never would have gone to if I did not have these medical problems. Some of the places include Cleveland, OH, Denver, CO and San Francisco, CA. My family and I travel to different states for the Hydrocephalus Association’s National Conference on Hydrocephalus, like the one we went to this summer in Washington D.C. Another blessing is that I know other people feel with their conditions since I have a condition too. I have numerous hobbies but my most important interest is drama. I had the opportunity to perform in a play at my church. My character was named Abby, which is my nickname! My most meaningful play was Pinocchio in May of 2012. The characters I played were the pantomiming policeman and the evil clown. I feel so alive when I act and it makes me forget about all of my medical problems.

Even though I have hydrocephalus it does not affect my path to my future. In my future I want to become a veterinarian, actress, a canine police officer or a spy agent. I want to become a veterinarian because I would have the chance to work with animals. Becoming an actress would be nice too because that is the time when I feel the most alive. Also, I like when I get flowers and when people come to see me perform because I know they love me!

Even though when I came into the world I was very sluggish and tired because of my medical issues, I am proud of the great person I am today! I am just a normal person like you. I have been teased in the past and I probably will be teased in the future. One way I have stopped people from teasing me is to give them information about my conditions. Last October, I was given the opportunity to perform an assembly at my school about hydrocephalus, which was very successful. I showed them Booze from the Hydrocephalus Association that has a shunt in it. I also taught the kids that one of the things I have learned is that no matter what, “Sticks and stones may break my bones but words will never hurt me.” My presentation gave the message, “Don’t you let anyone boyart you down just because you’re different because you’re amazing just the way you are!”

I hope to continue increasing awareness about hydrocephalus and trying to find a cure for everyone with hydrocephalus.

2012 WALKS and Special Events – The Year in Review
by Randi Corey, National Director of Special Events and Volunteer Support
When I think of one of my favorite parts of Thanksgiving Day was watching the Macy’s Thanksgiving Day parade from New York City on television. One of the tidbits of information they imparted that impressed me, even at that young age, was that the day after the parade they would start working on next year’s parade. As I grew older I understood that better – that many things in life are not in a straight line but circular.

At it is with the Macy’s Thanksgiving Day Parade, so it is with HAs WALKs and Special Events. Since the majority of HAs WALKs occur between September and November, one could make a case that HA has a “WALK season” although, I and probably many of our volunteer WALK Chairs, might disagree. Just like Macy’s Thanksgiving Day Parade, there is not one but several! The first WALK is held in July in Seattle. Although we expected these events could complicate the workings of our volunteer force and our well-oiled machine, we truly didn’t appreciate the extent of the challenges that would accompany these reforms and new ventures.

Looking back to 2012, in many respects I will always think of this year as a test…especially testing the patience of our WALK and event Chairs…as well a tremendous demonstration of their tenacity and determination. In addition to all of the usual work to bring their event to fruition, they were challenged in ways they, or we, couldn’t have imagined. Some of the obstacles they encountered were the national WALK/SE department being understaffed for several months, the office relocation from the west coast (Sacramento, CA) to the east coast (Chicago, IL) accompanied with a complete turnover in national administrative staff and the
learning curve for new staff. Things that previously had run smoothly and almost seamlessly didn’t this year. Despite all of the frustrations, HA’s WALK and special events Chairs stayed the course. They did more themselves. They came through like the champions that they are. Their drive, their passion, their determination and determination. You made it happen!

And so I reflect, if this is what we can accomplish with all of these challenges, what can we do when we don’t have these distractions? Knowing our Chairs, they won’t be afraid to hold us to it. Special thanks and gratitude to all of this year’s WALK/SE Chairs and their dogged tenacity, I’m pleased to announce that current year-end projections is that HA WALKs and special events will achieve (and perhaps exceed) its $1,006,000 goal!

Now that the major dust has settled and new staff is in place, our WALK and Special Event Chairs have our promise that we will do everything in our power to bring WALK/SE support back up to its previous high standards. Knowing our Chairs, they won’t be afraid to hold us to it. And in I reflect, if this is what we can accomplish with all of these challenges, what can we do when we don’t have these distractions?

*Since all HA WALKs and special events are 100% volunteer initiated and volunteer coordinated when a WALK or special Event Chair resigns it can unfortunately often result in HA losing that site/event and its revenue until new volunteer leadership steps up to bring it back or keep it going.

2012 Special Events

<table>
<thead>
<tr>
<th>Birthday Celebration</th>
<th>City/Market</th>
<th>State</th>
<th>Chair/Co-Chairs</th>
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</thead>
<tbody>
<tr>
<td>Miami FL</td>
<td></td>
<td>Glenn Ebert</td>
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<thead>
<tr>
<th>Extreme Athletes (Marathon-type events)</th>
<th>Nationwide</th>
<th>US</th>
<th>n/a</th>
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<table>
<thead>
<tr>
<th>MX for Children</th>
<th>City/Market</th>
<th>State</th>
<th>Chair/Co-Chairs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Houston, Salt Lake City, Utah, St. Louis, Las Vegas, TX, UT, OR, MO, NV &amp; Colorado, Canada</td>
<td>Paul Gross</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Richardson’s Farmers Craft Show</th>
<th>City/Market</th>
<th>State</th>
<th>Chair/Co-Chairs</th>
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</thead>
<tbody>
<tr>
<td>Mt. Pleasant, MI</td>
<td>Angie Raulerson</td>
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<tr>
<th>Richardson’s Farmers Craft Show</th>
<th>City/Market</th>
<th>State</th>
<th>Chair/Co-Chairs</th>
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</thead>
<tbody>
<tr>
<td>TX, UT, OR, MO, NV &amp; Ontario, Canada</td>
<td>Les Richardson Ben Simpkins</td>
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<thead>
<tr>
<th>Spirit of America Ride - Tampa, FL to Denver, CO</th>
<th>City/Market</th>
<th>State</th>
<th>Chair/Co-Chairs</th>
</tr>
</thead>
<tbody>
<tr>
<td>TX, UT, OR, MO, NV &amp; Colorado, Canada</td>
<td>Mark Paulison Mary Sodano</td>
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<tr>
<th>Spirit of America Ride - Tampa, FL to Denver, CO</th>
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<th>State</th>
<th>Chair/Co-Chairs</th>
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<tr>
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<td>Mark Paulison Mary Sodano</td>
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<thead>
<tr>
<th>Team Hydro Swims for a Cure/Sharkfest</th>
<th>City/Market</th>
<th>State</th>
<th>Chair/Co-Chairs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcatraz/San Francisco</td>
<td>CA</td>
<td>MD</td>
<td>Pam Finlayson Sandy Finlayson Sam Finlayson</td>
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<tr>
<th>Team Hydro Swims for a Cure/Sharkfest</th>
<th>City/Market</th>
<th>State</th>
<th>Chair/Co-Chairs</th>
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<tbody>
<tr>
<td>Potomac River/Newburg</td>
<td>CA</td>
<td>MD</td>
<td>Pam Finlayson Sandy Finlayson Sam Finlayson</td>
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<thead>
<tr>
<th>Thanks for Running (15th Annual)</th>
<th>City/Market</th>
<th>State</th>
<th>Chair/Co-Chairs</th>
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</thead>
<tbody>
<tr>
<td>Fitchburg, MA</td>
<td>Amy Maynard</td>
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<thead>
<tr>
<th>Thomas A Simms Jr. Masons Lodge # 170 Poker Run</th>
<th>City/Market</th>
<th>State</th>
<th>Chair/Co-Chairs</th>
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</thead>
<tbody>
<tr>
<td>Oak Grove, KY</td>
<td>Robert S. (Steve) Taylor</td>
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<thead>
<tr>
<th>Zeleisky Event</th>
<th>City/Market</th>
<th>State</th>
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<tbody>
<tr>
<td>Pittsburgh, PA</td>
<td>Eric &amp; Sara Zalesky</td>
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<thead>
<tr>
<th>Zumba-thon</th>
<th>City/Market</th>
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<tbody>
<tr>
<td>Miami, FL</td>
<td>Roxana Ramos</td>
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2012 WALKs

<table>
<thead>
<tr>
<th>Event Category</th>
<th>City/Market</th>
<th>State</th>
<th>Chair/Co-Chairs</th>
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</thead>
<tbody>
<tr>
<td>WALK</td>
<td>Birmingham, AL</td>
<td>Lauren Morrow</td>
<td>Nalini Patel</td>
</tr>
<tr>
<td>WALK</td>
<td>Phoenix, AZ</td>
<td>Maggie Bobrowitz Jill Friedrich</td>
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<tr>
<td>School WALK</td>
<td>Capri Elementary School, CA</td>
<td>Debra Graham</td>
<td></td>
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<tr>
<td>WALK</td>
<td>Fresno, CA</td>
<td>Kelly Fielstrom</td>
<td>Cheryl Merrell</td>
</tr>
<tr>
<td>WALK</td>
<td>San Francisco, CA</td>
<td>Maureen Pardi Miaja Roscina</td>
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<tr>
<td>WALK</td>
<td>Denver, CO</td>
<td>Phyllis Rogers</td>
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<tr>
<td>WALK</td>
<td>Steamboat Springs, CO</td>
<td>Christian &amp; Laura Karch</td>
<td></td>
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<tr>
<td>WALK</td>
<td>Hartford/ New Haven</td>
<td>CT</td>
<td>Jennifer Jeans</td>
</tr>
<tr>
<td>Run/WALK</td>
<td>Washington, DC</td>
<td>Martha Fleury Barrett O’Connor</td>
<td></td>
</tr>
<tr>
<td>WALK</td>
<td>Smyrna, DE</td>
<td>Katie Wilber</td>
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<tr>
<td>WALK</td>
<td>Southern Florida</td>
<td>FL</td>
<td>Eileen Rodger</td>
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<tr>
<td>WALK</td>
<td>Atlanta, GA</td>
<td>Jen Taylor</td>
<td>Kymmi Wilson</td>
</tr>
<tr>
<td>WALK</td>
<td>Chicago, IL</td>
<td>Stacy Buckner</td>
<td>Katie Cook Zahirita Kadima Andrea O’Shea</td>
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<tr>
<td>WALK</td>
<td>Columbus, IN</td>
<td>Sarah Billman Elizabeth Shaler</td>
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<tr>
<td>WALK</td>
<td>Wichita, KS</td>
<td>Mary Havens Rachel Inskeep</td>
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<tr>
<td>WALK/Concert</td>
<td>Louisville, KY</td>
<td>Jennifer Bruce Brittney Neidig</td>
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<tr>
<td>WALK</td>
<td>Boston, MA</td>
<td>Jennifer Martinage Jennifer Miles</td>
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<tr>
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<th>City/Market</th>
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<th>Chair/Co-Chairs</th>
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<tbody>
<tr>
<td>WALK</td>
<td>Detroit, MI</td>
<td>Dan and Sara Naragon</td>
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<tr>
<td>WALK</td>
<td>Minneapolis, MN</td>
<td>Heath Sorenson</td>
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<tr>
<td>WALK</td>
<td>St. Louis, MO</td>
<td>Maurice Woodnutt</td>
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<tr>
<td>WALK</td>
<td>Graham, NC</td>
<td>April Brantley</td>
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<tr>
<td>WALK</td>
<td>Londonderry, NH</td>
<td>Lisa Barton Melissa Remillard</td>
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<tr>
<td>WALK</td>
<td>Albuquerque, NM</td>
<td>Kathy Carrillo Karen McCabe</td>
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<tr>
<td>School WALK</td>
<td>Eugene Auer Elementary (Long Island)</td>
<td>NY</td>
<td>School Mia Padron</td>
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<tr>
<td>WALK</td>
<td>Long Island, NY</td>
<td>Jackie Davidson Mia Padron</td>
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<tr>
<td>WALK</td>
<td>Cincinnati, OH</td>
<td>Julie &amp; Shawn Robinson</td>
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<tr>
<td>WALK</td>
<td>Portland, OR</td>
<td>Jerrid &amp; Tara Miller</td>
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<tr>
<td>WALK</td>
<td>Middletown, PA</td>
<td>Jackie Fullerton Danielle Gutshall</td>
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<tr>
<td>WALK</td>
<td>Chattanooga, TN</td>
<td>Chara McLaughlin</td>
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<tr>
<td>WALK</td>
<td>Nashville, TN</td>
<td>Melissa Arsenault Genia Hartings</td>
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<tr>
<td>WALK</td>
<td>Houston, TX</td>
<td>Margaret Powers</td>
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<tr>
<td>WALK</td>
<td>Salt Lake City, UT</td>
<td>Sarah Ann Whitley</td>
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<tr>
<td>WALK</td>
<td>Seattle, WA</td>
<td>Paul Gross Gina Azar</td>
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<tr>
<td>WALK</td>
<td>Milwaukee, WI</td>
<td>Patti Lampen CassieSieberlist</td>
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18 HYDROCEPHALUS ASSOCIATION 19 PATHWAYS, FALL 2012
New HA School WALK Program, a Win-Win
By Randi Corey, National Director of Special Events and Volunteer Support

A new fundraising/education program was introduced in the fall of 2011 – Kids to Cure Hydrocephalus. Raising $4,100 from 110 student participants, Kids to Cure Hydrocephalus – a combined public education and fundraising initiative – was led by veteran Long Island WALK Chair, Mia Padron. Mia’s 10-year old son, Tyler, lives with the challenges of hydrocephalus and Mia wanted to increase his peers’ knowledge about the condition. As part of the program Mia spoke to each class in Tyler’s school, the Eugene Auer Memorial Elementary School, teaching them about hydrocephalus in an age-appropriate manner. She read the children’s book about hydrocephalus “Detour Ahead” to each class. Mia emphasized hydrocephalus is not contagious, how shunts work and the importance of wearing a helmet for biking and skateboarding. A shunt manufacturer’s representative accompanied Mia for the education sessions, bringing visual aids to share with the class (brain anatomy models, a shunt, etc.) Then Mia’s son, Tyler, answered his classmates’ questions about his condition and treatment. Mia reported that the evening of the education sessions she received calls from the parents of several of Tyler’s classmates, telling her that their children had come home and related to them all they learned about hydrocephalus.

Several days later the event wrapped up, ending with a little hike (a “walk” or other activity – usually the parent of the child with hydrocephalus attending the school) – or gym, etc. – usually the parent of the child with hydrocephalus attending the school

Volunteer to coordinate the event including the education sessions and the WALK or another activity – again, usually the parent of a child with hydrocephalus attending the school

A child with hydrocephalus in the school – usually elementary school aged but not necessarily

The child must be willing to share his/her condition with his/her classmates - if your child doesn’t want anyone at school to know about his/her hydrocephalus this program is NOT a good fit

Parent of the child with hydrocephalus must be willing to speak to the students (either at a school-wide assembly or by class) to teach them about hydrocephalus in an age-appropriate manner

A Kids to Cure Hydrocephalus is obviously a much smaller event than the typical HA WALK. It can be planned and completed in approximately 6 weeks. HA hopes the program spreads throughout the U.S. Not only will it raise additional money for HA program services and research, but it will also help educate a generation about hydrocephalus, and that is definitely a “win-win”!

School WALK Kits are available for parents interested in starting a Kids to Cure Hydrocephalus event in their community. If you would like more information please contact HA’s Director of Special Events, Randi Corey at randi@hydroassoc.org. Please include your phone number and the best time to reach you.

Raising Awareness…From Coast to Coast!

Strength. Perseverance. Endurance. Spirit. Do these traits sound familiar? Of course, these are all words that describe individuals touched by hydrocephalus. These words also describe Mark Paulissen and Mary Sodano. Their spirit of adventure and love for bicycling spurred them onto a journey of a lifetime. Sponsored by Celsius drink company, Mark and Mary challenged themselves to ride 2,500 miles across the country to raise awareness about hydrocephalus and to help raise funds for the Hydrocephalus Association (HA). Their ‘Spirit of America Ride for Hydrocephalus’ is also their way of paying tribute to Mary’s niece, Madeleine Darawiche, and the courage she’s shown having undergone seven brain surgeries for her hydrocephalus.

Mark and Mary left Tampa, Florida, on September 5th en route to Denver, Colorado, where they arrived on October 4th. The couple tracked their adventures by using social media tools and a blog that gave the day-by-day account of their travels and travails. On their journey they raised $3,100 for the Hydrocephalus Association. You can still read their daily blog www.celsiusbrightconnections.com. Thank you, Mark and Mary, for allowing us to be a part of your incredible adventure!
Ode to a Pediatric Neurosurgeon

To our Medical Advisory Board and associated medical professionals:

I created this poem as a thank you to the pediatric neurosurgeons for their care of my two daughters with hydrocephalus through the years. However, during this season of thankfulness, I would like to extend my thanks to ALL of the medical professionals that work with our families. Please know that you, our medical professionals; neurologists, nurses, researchers, all who work day in and day out to make life a little easier for those with hydrocephalus are truly appreciated. Thank you from the bottom of my heart.

Ode to a Pediatric Neurosurgeon

Never sleeping,
Family...Who?
Cries of children
Parents, too-

Breaking hearts
Brilliant smiles
Holding hands,
Sitting just awhile.

Eyes that tear
Hearts that ache
Wish you could fix
All who come to you this day.

Bone tired, never enough sleep,
Hugs from parents
And their children, keep
You forging on
day by day

Praying you are helping
In some small way.

Holding hands,
Brilliant smiles
Parents, too-

Beating hearts
Strong and bold
To the parents
And their children, too.
YOU,
Pediatric Neurosurgeon
Are OUR hero
By all that you do.

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