

The staff of the Hydrocephalus Association wishes everyone a

HAPPY New Year!

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

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

There are some NEW faces at HA!

The Hydrocephalus Association would like to welcome 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), Aisha 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

research in the last 10 years, pointing out that funding has actually decreased in the last two years.

These presentations resulted in some very frank discussions about the outlook for future research funding in light of federal budgetary challenges, what resources exist within NIH to assist researchers, and what more the Hydrocephalus Association could be doing to better prepare researchers focusing on hydrocephalus to be good candidates for federal research grants. Feedback from this meeting will be very useful to our Board and our Research Committee in setting direction for the association's research initiatives.

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 Sussman 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! 

wife, former Congresswoman, Gabrielle Giffords, telling our members to "Fight Fight Fight."

- 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 Pudenz 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 ground-breaking presentation on the Treatment of Hydrocephalus in Sub-Saharan Africa by Dr. Benjamin Warf reviewing the history behind his develop-

ment 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. 

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 HA's research efforts.

Featured Articles

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 educational four days.

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. Captain Kelly brought a special message from his

“We anticipate reaching our \$3 million goal by the end of 2013,” said Dawn Mancuso, CEO of the Hydrocephalus Association. “With our recent partnership with the Hydrocephalus Clinical Research Network, we can demonstrate very real improvements in treatments for hydrocephalus that can come from investing in our research plan.”

HA developed its Research Initiative plan starting in 2009 with its Mentored Young Investigator award aimed at solving a critical shortage of new researchers in hydrocephalus research. The Research Initiative plan calls for continued career development grants, research conferences, and the funding of basic science and clinical research. The mission of HA’s research program is to improve treatments and outcomes for those who suffer from hydrocephalus and to eventually find preventions or a cure. Funds raised by the “Reason for Hope” campaign represent a significant change in the private research funding landscape for hydrocephalus that should lead to increased public funding for the condition. 

September was Hydrocephalus Awareness Month...and We Were BUSY!

The goal of Hydrocephalus Awareness Month is to bring attention to and understanding about the condition of hydrocephalus among a number of key target audiences, such as public policy makers who have an impact on the amount of public funding available for research; the medical and scientific communities who actually dedicate their lives to treating patients and conducting research; and advocates like you and me who can be motivated to share patient stories and experiences with the media, community leaders and others.

This year quite a few people took up the mantle of Hydrocephalus Awareness Month and showed all of us how to make a difference. We would like to commend these individuals on their extraordinary efforts:

- Mark Paulissen and Mary Sodano undertook a 2,500 mile bicycle ride across the country to raise awareness about hydrocephalus and to help raise funds for the Hydrocephalus Association.
- State Hydrocephalus Awareness Month proclamations were attained in several states.
 - NY State Senator John Flanagan proclaimed September Hydrocephalus Awareness Month, thanks to the dedication and hard work of HA WALK Chairs Mia Padron and Jackie Davidson. Read more about how they did this.
 - In Arkansas, Governor Mike Beebe declared September Hydrocephalus Awareness Month as well, thanks to the hard work of Cessilye Lawson who connected with Mike Beebe’s office.

- At the national level, Congressman Leonard Lance recognized September as National Hydrocephalus Awareness Month.

- David Walters, Abby Woods, Madeleine Daraowiche, Joyce Schwartz, Milton Newman all shared their unique stories with a special blog, *Voices from Our Community*.
- Members of the hydrocephalus community continued to encourage their Congressional representatives to join the Congressional Hydrocephalus Caucus. Congressmen Joe Wilson and Mick Mulvaney from South Carolina, Representatives James Langevin & David Cicilline from Rhode Island, and Congressman Tim Murphy from Pennsylvania all joined in September! Kudos to Amanda Pierce (SC), and Jenna Sciulli (PA) for their diligence in encouraging this participation!
- Many hydrocephalus community members were spotlighted in local media stories this month. Among them were Emma and Chara McLaughlin from Tennessee, Tracy Taback from Connecticut, Katie Cook from Illinois, and Mandy Houston from Virginia. See our featured “Hydrocephalus in the News” column on our web site for these and other stories.
- Linda Davis participated on a panel speaking on living with chronic pain for the U.S. Pain Foundation’s INvisible Project in Rhode Island. For more information on the Invisible Project, visit the www.invisibleproject.org or the U.S. Pain Foundation at www.uspainfoundation.org.
- Volunteers ran 14 different awareness-building (and fundraising) WALKS in September, in many different places around the country. Over 5000 volunteers and walkers used their attendance – and their feet! — to raise awareness locally.

We’re so proud of all of those who took the initiative and got involved. Hydrocephalus Awareness Month may now be behind us for this year, but it’s not too late to have an impact and to help build awareness all year long. Check out our new Advocacy Toolkit on our web site – it will give you lots of easy-to-implement ideas for making your voice heard now and in the future. Are you active on a social media platform? We hope you use one of our Facebook banners on your Facebook page. Visit our Cover Photos album on our Facebook page to choose a banner you like for your Facebook profile. Do you know a lot of people in your local community? If so, do you regularly share what you know about hydrocephalus with your friends and neighbors? Do you like to do volunteer work? If so, are you helping out with a local support group or hydrocephalus WALK?

Hydrocephalus may not be a rare condition, but in some circles, it is rarely discussed and understood. Help us move forward. Let’s change awareness around hydrocephalus – get involved today! 

HA Advisor Receives Prestigious MacArthur Award



HA would like to 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. In 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 needed, 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 cauterization (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. 

Research

Research Update

By Ashly Westrick, Research Programs Manager.

As the new Research Programs Manager; I am excited to dive into the world of hydrocephalus. Like many of you, I have been learning about current hydrocephalus research and HA’s role in advancing that research. In 2009 we began our Research Initiative. At that time, we identified several problems in the hydrocephalus research ecosystem that HA sees as critical to address.

1. There are simply not enough researchers – clinical or bench scientists – studying the condition.
2. The complexity of the condition makes it difficult to understand, treat and approach scientifically.
3. The basic causes of hydrocephalus are poorly understood or even unknown making it difficult to galvanize collaboration around specific hypotheses or advancements.
4. Shunts, the primary treatment, are fraught with problems.

Since 2009, there have been many developments with HA and research, including many exciting successes. There

is still a lot of work to be done but I am delighted to help HA further the role of research for hydrocephalus. In my new capacity as Research Manager, I would like to take this opportunity to provide an update on HA’s research initiative and the wonderful advancements that are being made with the support and guidance of HA as we deliberately and methodically strive to change the research ecosystem around hydrocephalus.

Current Funding Trends in Hydrocephalus Research

Overall, public spending on hydrocephalus research totaled \$6.4 million in 2011. Over the last 4 years, total NIH funding on hydrocephalus research was approximately \$30 million. This is low based on the prevalence / burden of the hydrocephalus patient group compared to other conditions. Compare approximately \$7.50 per person per year for hydrocephalus to \$157.25 average per person per year for Parkinson’s disease. As part of our Advocacy initiative, HA is continuing to meet with key Congressional leaders regarding increased funding for the National Institutes of

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 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 pharmacological interventions to treat intracranial pressure – the most painful and damaging 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 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 partnership 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 HA's 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 facilitate bringing 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 past July 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 the 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 at 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, preventions 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 addresses these priorities. This is an exciting time. In my new role, I want to be able to support HA in stimulating the investment 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.

Opportunities in Hydrocephalus Research: Pathways to Better Outcomes

Our research conference, "Opportunities in Hydrocephalus Research: Pathways to Better Outcomes," was sponsored by the National Institutes of Health (NIH) and brought some of the best and brightest thinkers on hydrocephalus to the city of Seattle to discuss current (and future) research. Doctors, scientists, engineers, and other field leaders came together to push the discussion of hydrocephalus research in that much needed direction: forward.

The 2012 conference was unique in several important ways. First, the primary goal was to make the conference focused on the patient. To that end, planners looked at hydrocephalus research from the patient perspective and collectively sought out areas of research that held early promise for improving patient care. Secondly, unlike most meetings, individual investigators did not comment solely on their own work. Instead recognized experts summarized the current state of their field of expertise and provided educated guidance on those areas of research that hold the most promise for early "winnable" achievements in improving patient care. Along these lines, participants recognize that many important advancements will take longer and experts identified the long-term goals that may lead to advanced treatment options or potential cures for hydrocephalus.

The majority of the presentations delivered at the conference can be found on our website under the Research menu tab, then under 2012 Hydrocephalus Research Conference.

HA Medical Advisory Board Member Receives Grant from NASA



Congratulations to Michael A. Williams, M.D., medical director of The Sandra and Malcolm Berman Brain & Spine Institute (BSI) at LifeBridge Health. Dr. Williams, who is a member of the Hydrocephalus Association's Medical Advisory Board, and served as the co-chair of our 12th National Conference on Hydrocephalus, recently received a grant of approximately one million dollars from the National Space Biomedical Research Institute (NSBRI) and NASA's

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 HA's membership. HCRN Chairman Dr. John Kestle 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 Utah which pools 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.

Human Research Program to help investigate questions about astronaut health and performance on future deep-space exploration missions. The grant from NSBRI will fund a three-year project, which will assess the accuracy of two noninvasive methods of measuring spinal fluid pressure, as compared to measurement through a spinal tap, which is not possible in space.

Dr. Curtis Rozzelle Joins the Hydrocephalus Clinical Research Network

Dr. Curtis Rozzelle will represent Birmingham Children's Hospital and oversee their participation in the Hydrocephalus Clinical Research Network (HCRN).

HCRN Ground-Breaking study Up and Running

By John Kestle, MD, MSc, FRCSC, FACS

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The Hydrocephalus Clinical Research network (HCRN) has successfully launched a new, potentially ground-breaking study across the Network. This study, titled Ventricular Involvement in Neuropsychological Outcomes in Pediatric Hydrocephalus, or VINOH for short, is funded by a Mentored Young Investigator award from the Hydrocephalus Association received by Dr. Jay Riva-Cambrin at Primary Children's Medical Center in Salt Lake City, Utah. This study is looking into the short term implications hydrocephalus may have for school-aged patients concerning school performance, cognitive functioning, and social well-being. In addition, this study will be addressing the very important question of if and to what extent ventricle size impacts both, neuropsychological and clinical outcomes. Another exciting aspect of the VINOH study is the collaboration it has initiated across all HCRN Centers between the neurosurgical and neuropsychological staff, who are instrumental in the VINOH Study's success. It is hoped

that the collaboration begun between the care providers from these two different departments may continue in the future and serve to further improve outcomes for hydrocephalus patients. Congratulations to the Primary Children's Team in getting this study going for the Network and hydrocephalus patients! 

Dr. Jay Wellons Recruited to Lead Vanderbilt's Division of Pediatric Neurosurgery

Dr. Jay Wellons of the Hydrocephalus Clinical Research Network (HCRN) has been recruited by Vanderbilt to lead their Division of Pediatric Neurosurgery. He recently was awarded his MSPH degree by the University of Alabama, Birmingham. Dr. Wellons will continue to serve as Principal Investigator for HCRN on the line of studies on hydrocephalus due to intraventricular hemorrhage in premature babies. 

Support and Education

Papilledema, Vision Loss, and Hydrocephalus

by Karima Roumila, Director of Support and Education

Did you know that papilledema and vision loss can occur due to increased intracranial pressure? 82% of our Facebook community answered yes, that they knew about this issue.

What is Papilledema?

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.get-eyesmart.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 characteristically worse on awakening, and they are exacerbated by coughing or other type of Valsalva 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.

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CONGRATULATIONS TO OUR 2012 HA SCHOLARSHIP RECIPIENTS!

We are pleased to announce the 2012 Hydrocephalus Association Scholarship Awards recipients. The scholarships program marks its 18th year and we are very proud to honor these amazing young adults. Despite the challenges and obstacles of having hydrocephalus, these future young leaders of our community are able to further their education, help their community and inspire their peers.

These scholarships were funded by two Gerard Swartz Fudge Memorial Scholarship Funds, two Morris L. and Rebecca Ziskind Memorial Scholarship Funds, two Anthony Abbene Scholarship Funds, the Justin Scot Alston Memorial Scholarship Fund, the Mario J. Tocco Hydrocephalus Foundation Scholarship Fund, and the Giavanna Marie Melomo Memorial Scholarship Fund.

We are very grateful to all the funders and the Scholarship Committee for all their support and dedication. 



Carly Bowles



Amanda Broom



Mary Conyard



David Creighton



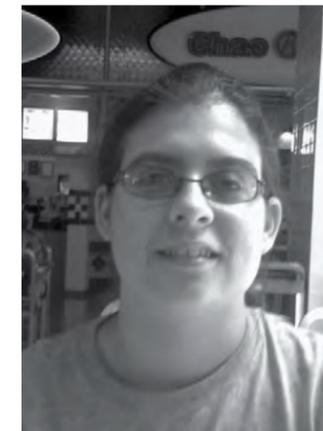
Molly Fuchs



Elizabeth Norris



Lindsey Pamlyne



Ashley Reber



Maria Wiggins

CONGRATULATIONS TO OUR 2012 SCHOLARSHIP RECIPIENTS!



Shawn Berg

"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."

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, extracurricular activities and perseverance. They are an inspiration to everyone at the Hydrocephalus Association and to our entire community! 



Jamile Hill

"Just because a person has hydrocephalus it does not mean that they are unable to learn. Informing others about hydrocephalus and the strength and perseverance of individuals with this disorder is important to me."



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."



Siobhan Powell

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



Lucas Russell

"Be active and involved in sports and other activities that interest you. You cannot control everything that happens in life, so try not to worry about what you cannot control and live your life to the fullest and embrace what you have been given."

(continued from page 8)

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 chokes 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 Life-Threatening Complications of Hydrocephalus
- Visit the Hydrocephalus Resource Library on our website for articles and other publications. Search using keywords like vision and eye problems in the search field to read published articles about the topic.
- Visit the National Eye Institute (NEI): <http://www.nei.nih.gov>

- (1) Whiting AS, Johnson LN: *Papilledema: clinical clues and differential diagnosis. Am Fam Physician. 1992 Mar;45(3):1125-34.*
- (2) Trobe JD. *Papilledema: the vexing issues., J Neuroophthalmol. 2011 Jun; 31(2):175-86.*
- (3) <http://emedicine.medscape.com>
- (4) *Fact Sheet: Eye problems Associated with Hydrocephalus*
- (5) *Hydrocephalus Resource Library* 

Hydrocephalus Association Launches Spanish-language Pages on Hydrocephalus

The Hydrocephalus Association proudly announces the launch of our Spanish-language information pages on hydrocephalus. Our October launch fell at the midpoint of Hispanic Heritage month (mid-September through mid-October) as well as served as a celebratory ending to September's Hydrocephalus Awareness month.

The Spanish-language pages provide critical information to Spanish-speaking families regarding hydrocephalus, including the symptoms, causes, and treatment options. The pages also contain links to our Spanish-language print materials available for download. This project, led by Karima Roumila, Director of Education and Support, is one more step forward in welcoming the Spanish-speaking community into our current information-sharing and support network. We are excited about the opportunity to serve the nation's growing Hispanic population.

The Spanish-language pages can be found on our website under the Education and Support menu option. 

Our Support Group Network

Looking for a local support group? Below are our current support group locations. If you have questions or would like to start a support group in your area, please email Jennifer Bechard at support.liaison@hydroassoc.org or visit our HA Support Group Network page on our website.

Alabama	Birmingham	Minnesota	Minneapolis Twin Cities
Arizona	Phoenix Tucson	Missouri	St. Louis
California	Chico Fresno Los Angeles	North Carolina	Charlotte
Colorado	Denver	New Jersey	Morristown
Connecticut	Hartford	New York	Long Island
Florida	Miami Orlando	Ohio	Southern
Georgia	Atlanta	Oklahoma	Owasso
Iowa	Cedar Rapids	Oregon	Portland
Illinois	Chicago	Pennsylvania	Philadelphia Pittsburgh
Kansas	Kansas City	Texas	Houston
Massachusetts	Boston	Utah	Salt Lake City
Maryland	Baltimore	Virginia	Richmond
Michigan	Detroit Mid-Michigan	Washington	Bremerton Seattle

“Learning to Live with It” was Not an Option

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 they informed her that they felt there was nothing they could do to help her. The doctors did not want to place a shunt because her ventricles were so enlarged that they felt the surgery was too risky and that she might not make it. As an alternative, one neurosurgeon suggested a shunt at the bottom of her spine. The procedure was performed but this did not help. Joyce was back to square one. She resigned herself to accepting that she would gradually deteriorate until she passed away.

Joyce returned home and just lived with it for a while. At the age of 59, she retired from work. Over time, the symptoms continued to worsen, especially with regard to her balance. She started using a cane, then moved to a walker, 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.

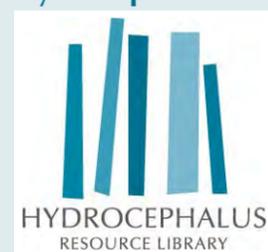
Joyce called the Hydrocephalus Association (HA) in San Francisco and asked if they had a referral list of neurosurgeons who specialized in NPH. HA gave her the name of Dr. Brian Andrews in San Francisco, California. He explained the risks associated with the surgery and recommended she be treated with 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, and feels that everything has gradually improved. She has seen gains in her memory and while her incontinence has not disappeared altogether, it has also gotten better. She started doing physical therapy after the surgery and began walking 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. And 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.”

Hydrocephalus Resource Library



The Hydrocephalus Resource Library is a database of articles, documents, and other print materials on a wide range of topics concerning hydrocephalus. Visit our Hydrocephalus Resource Library today! Look for the Hydrocephalus Resource Library under the Education and Support menu option or click on our button on our home page.

Hydrocephalus Association Brings its Message to Capitol Hill!



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 a

Cure.” 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 us boarded buses 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.



Congress Discusses Hydrocephalus and our Military

by Paul Gross, HA Chairman of the Board of Directors

On July 18th during the debate over the annual defense spending bill, Representative Robert Andrews (D-NJ), a senior member of the House Armed Services Commit-

tee who recently wrote to Defense Secretary Leon Panetta regarding the incidence of hydrocephalus in the military, asked his colleagues to support him in asking the Department of Defence to help gain a better understanding of the incidence and cost of hydrocephalus among injured service members and veterans so that the appropriate amount of DoD research dollars can be allocated on finding better treatment options. Experts believe that two-thirds of our current and former military service members suffering from moderate to severe traumatic brain injuries are at risk of developing hydrocephalus – more than 24,000 potential cases, based on the latest information available. Hundreds more could develop hydrocephalus as a result of their injuries, but without the proper screening, their hydrocephalus could go undetected. During the debate, Congressman Andrews, presented the difficulties these veterans will face to the highest ranking Democrat on the House Appropriations Committee, Norm Dicks (D-WA). This dialogue greatly aided by our combined efforts on advocacy day on June 28, 2012.

Our Advocacy Toolkit Helps Our Community Stay Engaged

September was Hydrocephalus Awareness Month, a special time to raise awareness nationwide as many eyes turn to our cause as it receives some higher attention nationally. However, we should see every month of the year as our opportunity to raise awareness about hydrocephalus and the one million people living with this condition in the United States today. The recent election ushers in a new class of local, state, and national elected officials, making this an excellent time to raise our voices to make sure that sitting and newly elected officials know we are here and that we have a powerful reason to be heard.

What Can YOU Do?

There are a number of opportunities for you to help raise awareness of hydrocephalus in Washington, D.C., and around the country. We have created an Advocacy Tool Kit for you to use with specific tips on calling, emailing or writing your legislators, as well as sample documents to use with both legislators and the media. Visit our website under the Advocacy menu tab to access our Toolkit. There you will find tips on communicating with your elected official, sample documents including a letter template to mail to elected officials and a sample call script for calling your elected official, and tips on communicating with the media.

Remember to keep in mind what we are asking for:

1. Ask your Congressional Representative to support a significant expansion of the National Institutes of Health's (NIH) current efforts to establish a broader collaborative research effort into the incidence, causes and treatments of hydrocephalus.
2. Request that your legislator ask the Department of Defense (DoD) to gain a better understanding of how many of our veterans are now living with hydrocephalus, report how many federal dollars are now being used to treat hydrocephalus, and ensure that research dollars focused on traumatic brain injuries

- (TBI) are available to help develop a cure for hydrocephalus.
3. Ask that your legislator also help raise awareness of hydrocephalus by:
 - Liking our Facebook page.
 - Linking to our website from their website.
 - Following us on Twitter.

Let's commit as a COMMUNITY to engage our elected officials and the media in our cause. 

tal 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 hard 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, 90% 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 heading 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 no 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 have 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.

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 distal catheter 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 men-

Teens Take Charge



Let's Put A Stop to Bullying

"Bullying is unwanted, aggressive behavior among school aged children that involves a real or perceived power imbalance. The behavior is repeated, or has the potential to be repeated, over time. Both kids who are bullied and who bully others may have serious, lasting problems." (stopbullying.gov)

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 national media have shown. Even the landscape of bullying has changed. According to DoSomething.org, bullying occurs mostly in schools, on the bus, and in neighborhoods. However, bullying has reached beyond the traditional school grounds and now includes harassing or intimidating someone by text message, e-mail or posts on social media sites like Facebook and Twitter. Nearly 43% of kids have been bullied online. (DoSomething.org) For a child being bullied, it can be an intense and pervasive experience starting from walking to school in the morning and lasting until an electronic device is shut down before bedtime.

October was National Bullying Prevention Month. Tween and teen stars, politicians, school officials, and community leaders bring attention to this national problem. They share resources for tweens and teens, stories of bullying experiences, and facts about bullying in this country.

General Information and Resources

The American Association of People with Disabilities (AAPD)

(800) 840-8844 | www.aapd.com/

American Academy of Children & Adolescents Psychiatry (AACAP)

(202) 966-7300 | www.aacap.org/

PACER's National Bullying Prevention Center

(888) 248-0822 | www.pacer.org/bullying/

StopBullying.gov of the U.S. Department of Health and Human Services

www.stopbullying.gov

KidsHealth.org

www.kidshealth.org

Support and Resources for Kids

PACER Center's Kids Against Bullying

(888) 248-0822 | www.pacerkidsagainstabullying.org

Support and Resources for Teens and Young Adults

PACER Center Teens Against Bullying

(888) 248-0822 | www.pacerteensagainstabullying.org

Teens Health

www.kidshealth.org/teen/your_mind/problems/bullies.html

Do Something.org

(212) 254-2390 | www.dosomething.org/cause/bullying-and-violence = 

TTC Members Speak Up About Stress

Introduction by Jennifer Bechard, HA Support Group Liaison

School, parents, homework, sports, relationships and friendships are only a few things that can cause extra stress in a teenager's life. Adolescent years can be a stressful time period for anyone, but when you add a chronic condition like hydrocephalus to the mix it can further complicate everyday life for teenagers and young adults. Too much stress in one's life can affect a person physically and emotionally, so it is extremely important to find out what your stressors are, to seek help and discover different coping mechanisms.

Recently, TTC's Advisory Council Member, Wyatt Barris, asked our Facebook fans the following question: "Being a teen or young adult with hydrocephalus can be stressful. What are some things that you do to help you cope with it?"

Below, Teens Take Charge (TTC) Member, Haylea Blank and TTC Advisory Council Member, Wyatt Barris, share their personal experiences, tips and advice.

Haylea Blank:

What is something you do to take your mind off of hydrocephalus?

I am currently 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 Ventriculostomy (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 are just a few things in a wide range of stress relieving activities. You can ride bikes, run, or just step back and breath.

Life is stressful but we have the power to make life happy and fun. We cannot let any stress, whether it is related to hydrocephalus or not, hold us down.

Helpful Resources:

- **Stress Management** - http://www.helpguide.org/mental/stress_management_relief_coping.htm
- **Teen Health (Stress)** - <http://kidshealth.org/>
- **American Academy of Child & Adolescent Psychiatry: Helping Teenagers With Stress** - (<http://www.aacap.org>) http://www.aacap.org/cs/root/facts_for_families/helping_teenagers_with_stress

■ **Palo Alto Medical Foundation: What Stresses Teens Out?** - <http://www.pamf.org/teen/life/stress/whatstress.html>

■ **Fact Sheet: College and Hydrocephalus** - http://www.hydroassoc.org/docs/FactSheet_College_&_Hydro.pdf

■ **Fact Sheet: Headaches and Hydrocephalus**

■ **Transition Guide** - http://www.hydroassoc.org/docs/Hydro_Transition_Guide-10_13_09.pdf

Voices from our Community

Abby Shares Her Life Experiences With Hydrocephalus!

By: Abby Wood



Hi! My name is Abby. I turned 12 years old at the end of August and this is a snapshot of 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.

Sometimes I 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 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 dif-

ferent 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 how others 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!

2012 WALKS and Special Events – The Year in Review

by Randi Corey, National Director of Special Events and Volunteer Support

When I was a child 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.

As it is with the Macy's Thanksgiving Day Parade, so it is with HA's WALKs and Special Events. Since the majority of HA's 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, as the last WALK is held, we start working on next year's events. HA WALKs and events are a year-round endeavor.

2012 started out as usual. Several established WALKs and special events wouldn't be returning for 2012. Some new volunteers stepped up, adding new WALKs/Special Events to the calendar. We hoped these would result in a "positive net" -- more new WALKs/events (and revenue) than the previous year.* However, some of the new events

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 to my school about hydrocephalus, which was very successful. I showed them Boozle the bear 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 anybody beat 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.

Walk & Special Events

did not come to be for various reasons, resulting in only a small increase in the number of events over the prior year.

By early February we were on a roll – WALK Chair training meetings had been scheduled and were underway, new volunteers for established sites were in the process of being recruited...and then HA announced we were relocating the national office and closing the San Francisco facility at the end of July, which would result in major staff changes. This was also the year for HA's biennial conference, scheduled for June 26-July 1 in Bethesda, MD and an exciting new HA Research Conference, scheduled for early July in Seattle. Although we expected these elements could complicate the workings of our heretofore fairly well-oiled machine, we truly didn't appreciate the extent of the challenges that would accompany these reforms and new ventures.

Looking back at 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 to east coast (*packing, moving, unpacking*) 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. Tasks that the volunteer Chairs were accustomed to HA handling for them automatically...weren't. Email responses took a bit longer, there were some delays in delivery of materials topped off by some major errors by a new vendor. It also required national staff trying to become expert in fundraising software on the fly and numerous other frustrations -- great and small.

Despite all of the frustrations, HA's WALK and special events Chairs stayed the course. They did more themselves. They followed up, they asked, they nagged when necessary but they never once threw up their hands and said "I'm done - I don't need this!" (Although I'm sure more than one considered it...) They came through like the champions they are. Their drive, their passion, their determination and their willingness to do the hard work in less than ideal circumstances, indeed, makes them one of HA's most valued resources.

Thanks to our 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 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?*

Special thanks and gratitude to all of this year's WALK/Special Event leaders for their patience, caring, dedication and determination. **You made it happen!**

**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

Birthday Celebration	Miami	FL	Glenn Ebert
Extreme Athletes (Marathon-type events)	Nationwide	US	n/a
MX for Children	Houston, Salt Lake City, Seattle, St. Louis, Las Vegas, Toronto	TX, UT, OR, MO, NV & Ontario, Canada	Paul Gross
Nashville Legends Concert	Mt. Pleasant	MI	Angie Raulerson
Richardson's Farms Craft Show	White Marsh	MD	Les Richardson Ben Simpkins
Spirit of America Ride - Tampa, FL to Denver, CO		FL	Mark Paulissen Mary Sodano
Team Hydro Swims for a Cure/Sharkfest	Alcatraz/San Francisco Potomac River/Newburg	CA MD	Pam Finlayson Peter Finlayson Sam Finlayson
Thanks for Running (15th Annual)	Fitchberg	MA	Amy Maynard
Thomas A Simms Jr. Masons Lodge # 170 Poker Run	Oak Grove	KY	Robert S. (Steve) Taylor
Zelesky Event	Pottstown	PA	Eric & Sara Zelesky
Zumba-thon	Miami	FL	Roxana Ramos

2012 WALKs

Event Category	City/Market	State	Chair/ Co-Chairs
WALK	Birmingham	AL	Lauren Morrow Nalini Patel
WALK	Phoenix	AZ	Maggie Bobrowitz Jill Diedrich
School WALK	Capri Elementary School Campbell	CA	Debra Graham
WALK	Fresno	CA	Kelly Fjelstrom Cheryl Merrell
WALK	San Francisco	CA	Maureen Pardi Miaja Rocciola
WALK	Denver	CO	Phyllis Rogers
WALK	Steamboat Springs	CO	Christian & Laura Karch
WALK	Hartford/ New Haven	CT	Jenifer Jeans
Run/WALK	Washington	DC	Martha Fleury Barrett O'Connor
WALK	Smyrna	DE	Katie Wilber
WALK	Southern Florida	FL	Eileen Rodger
WALK	Atlanta	GA	Jen Taylor Kymmi Wilson
WALK	Chicago	IL	Stacy Buckner Katie Cook Zahadita Kudrna Andrea O'Shea
WALK	Columbus	IN	Sarah Billman Elizabeth Shafer
WALK	Wichita	KS	Mary Havens Rachel Inskeep
WALK/ Concert	Louisville	KY	Jennifer Bruce Brittney Neidig
WALK	Boston	MA	Jennifer Martinage Jennifer Miles
WALK	Detroit	MI	Dan and Sara Naragon
WALK	Minneapolis	MN	Heather Sorenson
WALK	St. Louis	MO	Maurice Woodruff
WALK	Graham	NC	April Brantley
WALK	Londonderry	NH	Lisa Barton Melissa Remillard
WALK	Albuquerque	NM	Kathy Carrillo Karen McCabe
School WALK	Eugene Auer Elementary School (Long Island)	NY	Mia Padron
WALK	Long Island	NY	Jackie Davidson Mia Padron
WALK	Cincinnati	OH	Julie & Shawn Robinson
WALK	Portland	OR	Jerrold & Tara Miller
WALK	Middletown	PA	Jackie Fullerton Danielle Gutshall
WALK	Chattanooga	TN	Chara McLaughen
WALK	Nashville	TN	Melissa Arsenault Genia Hastings
WALK	Houston	TX	Margaret Powers
WALK	Salt Lake City	UT	Sarah Ann Whitbeck
WALK	Seattle	WA	Paul Gross Gena Azar
WALK	Milwaukee	WI	Patti Lampien Cassie Siebenlist

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 the students participating in a "field day," although Mia points out it could just as easily be a "walk" or other activity. All participants were required to raise a minimum of \$15. Small incentive prizes were distributed to participants raising money.

Thinking about starting a Kids to Cure Hydrocephalus? Basic criteria:

- Volunteer to initiate the event with the school/school system leadership (principal, physical education 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 other 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 Daraowiche, 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! 



Thank You To Our Sponsors

HA would like to thank all of our 2012 major corporate sponsors. Together we are making a difference!



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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.
When in truth, all be told
You are a hero
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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Development/Membership

So Many Reasons to be Thankful. So Many Ways to Give

As the season of giving is upon us, the Hydrocephalus Association encourages you to give the gift of Hope this holiday by supporting life-saving research and patient education programs for our community. Since the inception of the organization in 1983, we have relied on the generous support of private donors, like you, to fuel our work and to help raise awareness in cities and towns across America. Thanks to you, we have grown HA WALKs from a local gathering in San Francisco to a national movement of over 10,000 people. It is because of you that HA has become the leader in the fight against hydrocephalus and the largest non-profit funder of research in the nation. And, it is through your determination to see HA's mission fulfilled, that we have moved to Washington, D.C., minutes away from Capitol Hill and the National Institutes of Health (NIH). We truly have so many reasons to be thankful and hope you feel proud of all that we have accomplished together over the past 29 years.

While we have made great strides, we have much more to accomplish and hope that you will continue to support our work by remembering HA in your holiday gift plans. Please fill out the attached form to provide a donation to help us in fulfilling our mission to eliminate the challenges of hydrocephalus through our core services of education, support, research, and advocacy. You can also donate through our website: www.hydroassoc.org.

We thank you in advance and wish you a wonderful holiday season. 



Name: _____ Telephone: _____

Address: _____

_____ Email: _____

Name of person with hydrocephalus: _____

Birth date: _____ Age at diagnosis: _____

His/her relationship to you: Self Child Parent Spouse Friend Professional member

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\$30 \$50 \$100 Other \$ _____

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