The goal of the conference is to provide tools and connections to address the medical, educational and social challenges of living with hydrocephalus and to provide the opportunity for an enjoyable get together! Hydrocephalus is a chronic condition for which there is no cure. Our patient-centered conferences empower all of us to understand, seek out and put into place, care programs and services that will meet our needs now and well into the future.

Highlights of the conference include an Advocacy Day in Washington, DC: Climbing Capitol Hill for a Cure!, the Robert Pudenz Lectureship by a panel of key speakers addressing hydrocephalus research; a motivational keynote speaker; our ever popular personal interconnection sessions, where you can meet other people in similar situations; our cornerstone educational sessions, presented by our highly respected team of medical professionals and researchers addressing different topics related to living
Our Conference Medical Chairs:

Marion L. Walker, MD
Professor of Neurological Surgery
Department of Neurological Surgery
Division of Pediatric Neurosurgery
University of Utah Health Sciences Center
Primary Children’s Medical Center

Michael A. Williams, MD
Medical Director, Sandra and Malcolm Berman Brain and Spine Institute
Director, Adult Hydrocephalus Center, Sinai Hospital Co-Director, Center for Gait and Mobility, Sinai Hospital of Baltimore

with hydrocephalus; an opening reception; and a talent show with a dinner dance for all.

Conference Registration:
Registration is available now online! For registration assistance, please contact David Huffy, Registration Specialist by phone at 518-399-7181 Ex. 26 or by email at David@sitesolutionsworldwide.com. For a paper registration form, contact Karima Roumila at 888-598-3789. To register online, please visit our website at www.hydroassoc.org.

Accommodations:
This year’s conference will be held at Bethesda North Marriott Hotel & Conference Center, 5701 Marinelli Road, Bethesda, MD 20852
To make your hotel reservations call 1-800-266-9432 and mention the Hydrocephalus Association Conference. Conference attendees must mention the Hydrocephalus Association conference to get the group rate. The cut-off date for the group block is June 5, 2012.

Conference Registration Fees

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<tr>
<th>Registration</th>
<th>Registration Fees Include</th>
<th>Early Bird Registration 1/23-5/15/2012</th>
<th>Late Registration After 5/15/2012</th>
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</table>
| Conference Registration  | • Access to more than 45 Educational Sessions  
• Advocacy Day in DC: Climbing Capitol Hill for a Cure!  
• Welcome Reception on Thursday evening  
• Continental breakfasts on Friday, Saturday and Sunday  
• Lunch on Thursday, Friday and Saturday  
• All beverage breaks with exhibitors  
• Talent show and Dinner Dance on Saturday evening | $300                                   | $380                              |
| Additional Family Members| • Access to more than 45 Educational Sessions  
• Advocacy Day in DC: Climbing Capitol Hill for a Cure!  
• Welcome Reception on Thursday evening  
• Continental breakfasts on Friday, Saturday and Sunday  
• Lunch on Thursday, Friday and Saturday  
• All beverage breaks with exhibitors | $275                                   | $300                              |
| One Day Conference       | • Talent show and Dinner Dance on Saturday evening  
• Access to educational sessions, special events and meals available on the day of choice                                                                                                                                  | $150                                   | $180                              |
Transportation:
For more information on the closest airports, metro line, airport shuttles fees and schedules as well as a variety of discounts to help you get to the conference, visit the Travel page.

Other Event Option Fees:
(Tickets for family/friends not attending the full conference and/or children not attending Kids Camp)

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<thead>
<tr>
<th>Event</th>
<th>Description</th>
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<tr>
<td>Welcome Reception</td>
<td>Thursday (12 and older)</td>
<td>$30</td>
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<tr>
<td>Welcome Reception</td>
<td>Thursday (Child)</td>
<td>$15</td>
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<tr>
<td>Dinner Dance</td>
<td>Saturday (12 and older)</td>
<td>$75</td>
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<tr>
<td>Dinner Dance</td>
<td>Children (4-11 years old)</td>
<td>$25</td>
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<tr>
<td>Dinner Dance</td>
<td>Children 3 &amp; Under</td>
<td>FREE</td>
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Kids Camp:
Kids Camp will be available again this year on both Friday, June 29th and Saturday, June 30th from 8am-5pm and will be located in the conference hotel. We have planned 2 days of fun and interactive activities for children ages 3-11 years old. The children will have breakfast and lunch with the conference attendees, however all other activities will be in their own special area.

The fees include breakfast and lunch both days and the Dinner Dance on Saturday evening.

<table>
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<tr>
<th>Age Group</th>
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<tr>
<td>Children Ages 3-6</td>
<td>$100</td>
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<tr>
<td>Children Ages 7-11</td>
<td>$160</td>
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Conference Schedule:
Sessions begin at 3:00 pm on Wednesday, June 27th and conclude by 10:00 am on Sunday, July 1st 2012. Much of the richness of the conference lies in connections and conversations outside of scheduled sessions. We invite you to join us!

HA Announces Dawn Mancuso as Chief Executive Officer

By Paul Gross, Chairman of the Board

I am pleased to share the news that Hydrocephalus Association has successfully concluded its search for a new Chief Executive Officer with the appointment of Dawn Mancuso, FASAE, CAE. We are very excited to have Dawn join HA as our new CEO, and I am really looking forward to working closely with her and having the benefit of her extensive leadership and advocacy experience. We couldn’t have asked for a better and more suited individual to lead our entry into Washington D.C.

In her new role as Chief Executive Officer, Dawn will be responsible for all HA programs with continued focus on effective research, support, advocacy and awareness initiatives. She will also oversee the financial and operational aspects of the organization, including the creation of a headquarters office in Washington D.C. Dawn will officially start in her new role on December 1st, 2012.

“I’m absolutely thrilled to join the Hydrocephalus Association – it is accomplishing so much with unlimited potential to make a real difference for individuals and families coping with hydrocephalus,” said Mancuso. “I feel very passionately about HA’s mission and am excited to have the opportunity to work as an advocate for the individuals and families affected by hydrocephalus.”

Mancuso brings significant association leadership experience to her new role at HA. For nearly fifteen years, she has served as Executive Director/CEO of the Association of Air Medical Services (AAMS), a non-profit trade association of 500 air and critical care ground ambulance service providers. Prior to that, she was Senior Vice President and Deputy CEO of the National Association of RV Parks & Campgrounds, and Executive Director of the Educational Dealers & Suppliers Association International.

Dawn has served on the Board of Directors of four separate, nationally recognized organizations and is currently a member of the American Society of Association Executives and the Association of Fundraising Professionals. Mancuso holds a Masters in Association Management (MAM) from George Washington University. She also received a Bachelor’s degree in International Law, Organization and Politics from Georgetown University’s School of Foreign Service.

Welcome Dawn!
Paul Gross, Chairman of the Board
HA Funds Research, Announces New Research Grants

By Gavin Reed, HA Research Associate

HA is pleased to announce two recipients of the Hydrocephalus Association’s grant program focusing on CSF Production, Flow, and Regulation. The long term goal of these grants is to create therapeutic interventions such as a pill that could control intracranial pressure. The grantees are:

Pat McAllister, Ph.D., Professor of Neurosurgery and Director of Basic Hydrocephalus Research at the University of Utah, will investigate abnormal development along the ventricular walls in the brain which causes blockage of normal cerebrospinal fluid flow. His team hopes to use this information to develop novel approaches to protect or repair a hydrocephalic brain.

Miles Johnston, Ph.D., Professor of laboratory medicine and pathobiology at the University of Toronto and Senior Scientist at the Sunnybrook Research Institute, will be investigating cerebrospinal fluid (CSF) drainage mechanisms, specifically the role that the lymphatic vessels of the brain play in relation to CSF clearance. His group hopes to test how these lymphatic vessels respond to pharmaceutical intervention in relation to CSF drainage.

The research awards granted to Dr. McAllister and Dr. Johnston total $400,000 in new funding for hydrocephalus research and, along with prior awards, represent major progress around HA’s five year research plan which includes the following three priorities:

- Supporting the field of Hydrocephalus Research with Mentored Young Investigator Awards and the sponsorship of scientific conferences
- Supporting clinical research aimed at reducing shunt failure and improving outcomes
- Making basic science investments to understand the root causes of hydrocephalus

These new awards, aimed at increasing our understanding of the dynamics of cerebral spinal fluid, are HA’s first investments in the pathophysiology of CSF as part of the third priority of the five year plan. The Hydrocephalus Association has now funded grants totaling $1,367,000 since it initiated its commitment to support and fund research in 2009.

HA Sponsored Research Publishes Significant Discovery

Jerold Chun, MD, PhD, a professor at Scripps Research and its Dorris Neuroscience Center, has discovered a significant factor in the development of congenital hydrocephalus. Chun describes the discovery as a proof of concept that could lead to medical treatments for hydrocephalus. His finding involves the discovery of abnormally high levels of a lipid called LPA in the brains of mice that develop hydrocephalus. They have shown that prohibiting the buildup of excessive LPA has a preventative effect on the development of hydrocephalus. Dr. Chun’s findings were published today in the September 7, 2011, issue of the journal Science Translational Medicine.

We are honored to have Dr. Chun as the Review Chair for HA’s current round of research grants focused on cerebrospinal fluid dynamics. He is also the mentor to postdoctoral fellow Yun Yung, PhD, who was a grantee from our inaugural Mentored Young Investigators award in 2009 and contributed to these findings around LPA and congenital hydrocephalus. We are very excited about the potential for their findings and we congratulate Dr. Chun on the recent publication of his results.
Advocacy Update: HA Points to Increased Funding but Calls for More

By Rick Smith, Former HA Acting CEO

We thought we would provide you with a complete update of our advocacy efforts. First, we have just completed an in-depth analysis of investments in hydrocephalus research by the National Institutes of Health. The good news is that spending has tripled since we began our advocacy efforts in late 2004. The bad news is that with less than $10 million spent in 2010, the dollar investment per affected person is well below what it should be given the estimated 1 million Americans that suffer from the condition.

Given current budget pressures and the pressure to reduce the national deficit, hydrocephalus research spending is likely to go down in 2011 and 2012.

These facts emphasize the importance of our work to make various branches of the federal government understand the magnitude of the plight of those who suffer from hydrocephalus. The Day of Testimony, our visits with senior staffers on various committees, and our relationship building with the leadership in the National Institutes of Health are critical components to a long term strategy to increase government investment in hydrocephalus research. We have updated our advocacy pages to reflect the breadth of our current programs and to highlight our recent accomplishments. We are thrilled to announce the appointment of our Chairman Paul Gross to the Advisory Council of the National Institute of Neurological Disorders and Stroke.
2011 Hydrocephalus Association Scholarship Awardees
CONGRATULATIONS TO THE 2011 SCHOLARSHIP AWARDEES!

Anupali Bewtra

Matthew E. Bosler

Jennifer Kathryn Thomas

Lauren N. Merrell

Sarah Hochberger

William Lorenzen

Katharine Magradey

Nicholas R. Marino

Heather Miller
Update on Pre-Existing Condition Insurance Plans

The following information was kindly brought to our attention by the National Health Council (NHC) and Janet Miller, MPA on behalf of the Centers for Medicare & Medicaid Services.

As you know, the Affordable Care Act (ACA) created the Pre-Existing Condition Insurance Plan (PCIP), which will offer health insurance coverage for people with chronic conditions who cannot otherwise obtain it. The plan directly relates to the NHC’s health care principles of expanding access to care and abolishing exclusions to pre-existing conditions. The Department of Health and Human Services on May 31 announced changes to the plan that will establish new eligibility standards and lower premiums in many states.

If your patients or clients are uninsured because of a pre-existing condition, getting health coverage under the Pre-Existing Condition Insurance Plan (PCIP) is now a lot easier and more affordable.

New eligibility standards and lower premiums in some states, announced by the Department of Health and Human Services on May 31, will now make this program created by the Affordable Care Act available to many more Americans.

These changes include:

**Reduced Premiums**: Premium prices were reduced up to 40% in some states effective July 1, 2011. Please visit www.pcip.gov and go to “State Plans” and click on your state of residence to see the current rates.

**Simplifying Eligibility**: Starting July 1, 2011, people applying for coverage in the federally-administered PCIP can demonstrate eligibility for PCIP simply by providing a letter from a doctor, physician assistant, or nurse practitioner dated within the past 12 months stating s/he has or, at any time in the past, had a medical condition, disability, or illness. This option became available to children under age 19 in February, and we are extending this pathway to all applicants regardless of age. In addition, a person applying for coverage must be a U.S. citizen or reside in the U.S. legally and have been without health coverage for at least 6 months.

**Partnering with Agents and Brokers**: Beginning this fall HHS will begin reimbursing agents and brokers for referrals to the PCIP program. This step will help reach those who are eligible but un-enrolled.

The program provides comprehensive coverage at the same price that healthy people pay and is already changing—and saving—lives. Enrollees receive primary and specialty care, hospital care, prescription drugs, home health and hospice care, skilled nursing care, preventive health and maternity care.

To qualify for this program, a person applying for coverage must: be a U.S. citizen or residing here legally; have been without health coverage for at least 6 months before applying; and have a pre-existing condition or have been denied health coverage because of a health condition. Eligibility is not based on income and enrollees are not charged a higher premium because of a medical condition.

If you know someone who you think might qualify for this program—available until 2014—please tell them to call toll-free at: 1-866-717-5826 (TTY 1-866-561-1604). The Call Center is open from 8 AM to 11 PM Eastern Time.

Thank you for helping us to extend the reach and impact of this important health coverage option for the uninsured.

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Workplace Communication Tips for People Living with Disabilities

by Dave Carl, job coach

My primary focus as a social worker is working with individuals living with disabilities teaching a variety of independent living skills including employment. Through my career I have seen the progress of people living with disabilities in the workforce who at first had very low self-confidence and communication skills. Many knew what they wanted but did not know how to ask for it or did not have the courage to ask for it.

It is important for employers and co-workers to understand that someone with a disability can be just as capable in the workforce as anyone else, but this understanding must begin with the individual living with the disability. I have a very obvious disability because I use a wheelchair, but I also have a few hidden disabilities as well, including learning disabilities. In my experience as a social worker and job coach, people living with hidden conditions like learning disabilities and who are entering the workforce after some time away, may need to work on their self-confidence, without which they may hang back from sharing with others. On a personal level, I had a hard time talking about one of my challenges—severe epilepsy which at one time affected my ability to concentrate. Through time I have learned how to work with my hidden disabilities so I can ask for appropriate job accommodations, while at the same time helping my clients find the accommodations they needed in order to be effective workers.

**Employment is not something that is easy for everyone but you**.

It is very common for everyone—whether you are an individual with a disability or not—to feel uncertain about
themselves and not very confident in the workplace. This feeling of uncertainty may linger, making someone with a few extra challenges have a hard time trusting others or believing that they are wanted. One thing it is important to realize is that you went through an interview just like the others and obviously there are qualities that your employer saw in you just like they saw in your coworkers. People whose life experience has been very difficult often hear—and remember—negative feedback much more than positive feedback, which they may not notice at all. Learn to challenge these feelings of self-doubt by paying attention to positive communication or remembering you were hired for a reason.

Good work communication requires both talking and listening—most people have to work on at least one.

If you are getting a job for the first time, understand that good work communication is hard work for even the most experienced member of the workforce. It requires speaking clearly as well as listening and processing information. Some people who are good listeners may be unable to ask for help when needed or find that their talents are overlooked. Employees who are good at talking may make mistakes because they didn’t listen closely to a set of instructions.

Like many of the issues that affect workers living with disabilities, communication differences are often minimized when employees talk to someone—a supervisor, a human resources worker—about their specific needs. Being upfront about something and providing a solution shows that you are aware of an issue and willing to improve. It can also reduce some of the worry or shame you may feel about something that is not a big deal. Some examples are: “I get a little nervous speaking in front of people—can I try out my presentation in front of someone first?” or “I heard your instructions, but would you mind writing them down and e-mailing them to me—I’m a visual learner.”

You don’t come to work to make friends, but you can’t be an effective worker without allies.

One of the first things I reinforce to new and returning workers is good personal boundaries. People who tend to be shy or anxious may be worried about the uncertainty of a new job setting—meeting all those new people after spending most of their time within a small support network may feel like a big stretch. For others, I need to teach the difference between the kind of friendliness expected between coworkers and the relaxed friendliness they might share with family and friends. It takes some finesse to know which coworker expects nothing more than a friendly good morning and which people are open to a short chat about an appropriate topic. There’s nothing wrong with asking someone—a coworker you trust, a friend or family member—for feedback on an interaction you weren’t sure about. Remember that every workplace has different expectations, so you aren’t the only one that has to learn the ropes.

Learn from setbacks.
Frustration is another area that will affect you from time to time, just like any worker. For someone who has low self-esteem or feels unsure on the job, one mistake can seem symbolic of a larger fear. I tell people that letting, “I didn’t do this one thing right,” turn into “I can’t do anything right,” makes it that much harder for you to pick up and try again. Instead, work on correcting the situation and remind yourself that everyone makes mistakes—not just you. If you get frustrated with a coworker, it is important to talk to the person in a calm way without showing anger. Learn about the chain of command and find out who are the appropriate supervisors to contact when you have a particular type of problem you can’t handle yourself. Above all, taking a moment to de-escalate and get some perspective is always a better idea than reacting impulsively.

Know your rights.
I recommend to my clients that they tell employers about any job accommodations they might need once they are hired—not necessarily during the interview. This is another example of something you need to take the lead on—most employers are not likely to ask you.

What is Reasonable Accommodation According to the Americans with Disabilities Act?
For clarification please visit http://www.ada.gov/ or http://askjan.org/

Employers may be asked to make certain changes, including:

- providing or modifying equipment or devices;
- job restructuring;
- part-time or modified work schedules;
- reassignment to a vacant position;
- adjusting or modifying examinations, training materials or policies;
- providing readers and interpreters; and
- making the workplace readily accessible to and usable by people living with disabilities.

An employer is required to provide a reasonable accommodation to a qualified employee with a disability unless the employer can show that the accommodation would require significant difficulty or expense.

Here are some tips to help people—even those who have been working for a long time—who may have a difficulty communicating with supervisors about accommodations.

- It is reasonable for you to talk to you supervisor about your concerns. Ask for a meeting with him or her to talk about what you need in order to do your job to the best of your ability.
While you are within your rights to ask, remember that you are still dealing with your boss and that a pleasant request works better than a demand.

Your workplace is within its rights to ask for documentation such as doctors’ notes confirming that you need what you are asking for, and that this is not discrimination.

Be confident when asking for what you need. Remember that you know yourself better than anyone and thus know what you need.

If you have any questions about your rights as an employee with a disability contact the agency below:

Employment Opportunity Commission
P.O. Box 7033
Lawrence, KS. 66044
(800) 669-4000 (Voice), (800) 669-6820 (TDD)

Dave Carl is a social worker and writer who helps people living with disabilities learn job skills and enter the workforce for what is often the first time.

Meet Boozle Bear, A Wonderful Educational Tool
By Lisa Sun, HA Administrative and Program Assistant

Our Boozle bear, who has hydrocephalus, was created by Dory Kranz and Sarah Zadorozynj. Boozle is used by doctors, nurses and parents to teach children about hydrocephalus and how shunting works. Boozle comes with a detachable ventriculo-peritoneal (VP) shunt which is donated by Codman. Anyone can learn to perform “surgery” on this bear. Since their creation, Boozles have been featured at WALK sites, in school meetings, various conferences, and even as a children’s’ workshop at our biennial conference. Kids have taken these bears to school, and Boozle is a great way for them to educate their peers about hydrocephalus.

We want to thank the many volunteers who have donated their time in helping to make these beautiful bears, a special big shout out to Annie Mason, Sandi Jacobsen, Staci Buckner and Colleen Talbot.

Annie has graciously shared with us her experience with making Boozle. Here is her encounter with the Bear:

In early 2011, I started a support group in the state of Virginia. When I received the materials for my first meeting, a Boozle bear was included. I knew that I had a young mother coming who had a child about 5 years old. With HA’s permission, I gave her the Boozle bear for her son. That same day I got the most endearing email from her, in which she described how his eyes lit up when he realized that this little bear “has a shunt, too!!!!”

A short time later I volunteered to take a box of Boozle bears that were incomplete and finish them. The big box arrived with all the materials that I needed and I set to work. I had the pattern instructions and about 20 bears that had the front section finished with stitched eyes and the inner muslin through which the “shunt” will be placed. The steps were laid out on the instructions and I started my own little production line. I made it my plan that I would work on these a little at a time, and keep in mind that these would eventually land in the hands of a little one who would delight in the fact that this little bear also had a shunt like them.

My favorite part is stuffing these little guys….it’s when they take on their own personality and cuteness. I decided to add a little ribbon of the Hydrocephalus Association aqua color to tie around each neck. I imagine that each Boozle bear can be a teaching tool for medical staff….but also must be a helpful for parents who are frightened about explaining to a small toddler who may not quite understand the process. Making these turned out not to be “work” at all; it’s pure JOY.
Normal Pressure Hydrocephalus (NPH) Outreach Initiative – A Call for Action!
By Tom Smith, HA Adult Services & Outreach Coordinator

The Need
Best estimates indicate that there are 350,000 persons in the United States living with Normal Pressure Hydrocephalus (NPH). Roughly five percent of persons diagnosed with Alzheimer’s or Parkinson’s disease actually have misdiagnosed NPH. NPH mostly affects people over the age of 55 and quite often looks like the results of the natural aging process.

Of the tragedies surrounding NPH, lack of correct diagnosis is perhaps the most regrettable and preventable. As an HA staff member who deals most often with NPH questions, the single most consistent thread in all of those conversations is the regret and anger felt by people with NPH or their loved ones for time lost and the unnecessary agony of watching a life slip away.

As a child of a person with NPH I can attest to this. Even though my father was diagnosed and shunted, not a week passes when I’m not brought up short by the thought of “what if”. What if a passing neurosurgeon hadn’t walked by the examination room noted my father’s gait and told the GP to look into NPH?

This happened after being misdiagnosed for almost a year and a half. It’s an appallingly slender thread of circumstance upon which to hang a life. The obvious next step is to spread awareness of NPH so that its diagnosis is no longer a matter of luck, but of procedure.

The Call
This brings us to the NPH Outreach Initiative. The initiative is a focused effort to get information about NPH into the hands of elder care professionals across the country.

We have new brochures and information aimed at getting the word to elder-care professionals and we need your help getting it into their hands.

Do you know of an elder care facility in your city/town/neighborhood/block? Would you be willing to hand-deliver educational materials regarding NPH to such a facility; or, pass along to us contact information of the facility so that we could mail to them directly?

If the answers to any of these questions is ‘YES’, please contact Tom Smith, HA Adult Services & Outreach Support Coordinator by calling 888-598-3789.

New Addition to the Hydrocephalus Book Club
By Jordan Faigen, National Campaigns Manager
HA would like to welcome ‘Just Like Any Other Little Beagle’ as the newest addition to our hydrocephalus resources. This coloring book, distributed by the shunt company Integra Life Sciences, is a great tool to teach children about the condition through a family friendly tale and interactive illustrations. Come follow young Barney beagle as he learns about his diagnosis with hydrocephalus and discovers how he is “just like any other little beagle”.

Hydrocephalus Association Support Group Partners, Pt. 1
By Jennifer Bechard, Support Group Liaison
Support groups are a vital and cherished resource to our hydrocephalus community. The Hydrocephalus Association currently has 28 support groups that provide open forums and educational meetings to individuals touched by hydrocephalus throughout the country. Support Group Leaders each have their own experiences with hydrocephalus and understand the trials and struggles surrounding the condition. These fearless individuals take the time to provide a welcoming space for discussion and knowledge as they support those affected by hydrocephalus. We invite you to meet some of our leaders:

Lori Smith – Support Group Chair: Detroit, MI
I am Lori Smith; my daughter has hydrocephalus and spina bifida. She is now ten and her only revision was at 3 months old. You can knock on wood for us now. My family and I volunteer with the Detroit Support Group. I recently became the co-leader for the support group and I am still adjusting to this new role. I first stumbled across the Hydro WALK in the Detroit area and my first thought was finally someone who knew what I was talking about. After the first WALK I started looking for something more than meeting once a year. Then I became more involved with the Hydrocephalus Association. I truly enjoy working with everyone I have met through the organization for as much as it is growing it still feels like an extended family.
Danielle Netherton – Support Group Chair: Chico, CA

Danielle Netherton, wife to Pete Netherton and mother to a one year old with hydrocephalus, is an elementary school teacher who became a stay at home mom. Danielle and her husband love taking their son, Tom, to the park for walks and anywhere outdoors with their dog Georgia. Danielle is a dedicated, passionate volunteer who devotes her free time to leading the Hydrocephalus Association’s support group in Chico, CA. Every last Saturday of every other month the Netherton family opens up their home to children, adolescents, and adults living with hydrocephalus. This past September, Danielle helped a teenager, Wyatt Barris, assemble a hydrocephalus awareness day at his local high school. Together they educated and informed students and faculty. They are proud and loving parents. We are grateful to have them as volunteers for HA.

Elizabeth Norris – Support Group Chair: Charlotte, NC

I am a new Support Group Chair to the Hydrocephalus Association, and held North Carolina’s first support group meeting in May 2011. Raising awareness, learning about, and informing others of hydrocephalus is what I love to do. I was diagnosed with hydrocephalus when I was 4 weeks old, and since then I have had 5 shunt revisions. I am 20 years old and a student at Lenoir Rhyne University studying Elementary Education. I love my life and I know that I am unique in my own way. I am fortunate that I do not have complications due to hydrocephalus, but because it is very unpredictable I am always alert. I love to help others, especially when it is something so close to my heart. I have become connected with many that are affected by hydrocephalus, through HA WALKs, Facebook groups, and simply just telling my story. In 2008, I planned and organized, on my own, a hydrocephalus WALK in my hometown. I have come to appreciate how much the HA did for my parents in the early stages of my diagnosis. Support and knowledge from others affected by hydrocephalus is the key to handling this life-long condition. I am excited to have joined HA as a Support Group Chair and to be a part of continuing this support.

Lori Poliski – Support Group Chair: Seattle, WA

Lori Poliski studied journalism at the University of Delaware and has a Master’s degree in education. She worked as a marketer for software companies for many years before she became an elementary school teacher. After she had William in 2005, who has had five brain surgeries as a result of his hydrocephalus caused by prematurity; she and her husband Paul Gross, who is the current board chair of HA, wanted to meet other parents with children who had hydrocephalus. There was no pediatric support group in the Northwest so they founded one in 2006, Children’s Hydrocephalus Support Group, in conjunction with Seattle Children’s Hospital neurosurgery department. (www.hydrosupport.org)

Meetings are held approximately five times a year with a family picnic held in the summer. Typical meetings host about 20-25 members and childcare is provided so children with hydrocephalus can meet other children with hydrocephalus. Meetings alternate between those with a speaker and those just for members. The meetings are held at the hospital. Leslie Kempthorne currently manages the support group meetings and Lori provides childcare with help from hospital junior volunteers.

Lori and Paul also founded the Hydrocephalus Research Guild (www.hydroresearch.org) in 2006 which benefits research efforts at Seattle Children’s Hospital. The guild has raised over $500,000 since its inception and funds are used for both clinical and bench science at the Seattle Children’s Research Institute. www.seattlechildrens.org/research/

They have two children, Claire and William, and live on a small farm with horses, goats, a cat and a dog outside of Seattle, WA.

If you are interested in becoming involved with the support groups please contact Jennifer Bechard at 734-890-2665.
This Way In: Should You Join a Health Insurance Exchange?

By Gina Shaw

The following article is reprinted by permission from Neurology Now, October/November 2011 – Volume 7 – Issue 5 – p 18–20

When the Affordable Care Act was signed into law in March 2010, one of the centerpieces of the plan was the creation of “health insurance exchanges.” These state-by-state marketplaces allow small businesses and individuals without insurance to band together in order to shop amongst competing insurance companies for more affordable coverage than is currently available to these individuals.

The hope is that, by 2019, these exchanges will provide health care coverage for some 24 million Americans—about half of all those currently uninsured. Most of them are expected to receive some form of subsidy to help pay for their coverage. People whose income hovers right around the poverty line, which is around $11,000 for an individual and $22,050 for a family of four, should not have to pay more than 3 to 4 percent of their incomes for reasonably good health insurance. People making less than about four times the federal poverty level (or about $44,000 a year for an individual and about $88,000 for a family of four) would be eligible for some money from the government to help them pay for their insurance. The less one makes, the bigger the subsidy.

So how are these exchanges going to work? Should you try to get insurance through one? The answers to those questions are still murky, although the details of just how the exchanges will work are starting to take shape.

Like “Open Enrollment”

In August, the Department of Health and Human Services (HHS) awarded a total of more than $185 million in grants to help 13 states and the District of Columbia build the exchanges. States have a deadline of January 1, 2013, to submit detailed plans. More than half of states have already taken steps toward launching theirs.

Meanwhile, in letters sent to the governors of each state, HHS outlined more of the procedures involved and resources available to move the exchanges along. For example, single people and families will get tax credits for the premiums they pay into one of the exchanges, and small businesses that participate will receive tax credits to allow them to give their employees a choice of plans. But key details are still missing—such as exactly which benefits will have to be provided by participating plans.

Ultimately, says Marc Nuwer, M.D., Ph.D., Fellow of the American Academy of Neurology (AAN), chief of clinical neurophysiology at the Ronald Reagan UCLA Medical Center in Los Angeles, and a national expert on health care reform, shopping for health insurance via a statewide exchange will probably be a lot like the “open enrollment” period that happens every year at large companies.

“Here at UCLA, for example, every year they send us out a table with six or eight choices for insurance, what each one will cost you, and a very brief summary of what that plan is like,” Dr. Nuwer says. “Then you can go online to get more information about each. That’s probably the same kind of information you’re going to get from your state.”

Who will be sending you that information? That’s not clear either. “In some states, the exchanges may be so large that they will be their own agency,” says Dr. Nuwer. “In other states, they’ll be within another state office. In any case, the agency that oversees the exchange will be in charge of negotiating reasonable prices and reasonable benefits to be available for the people of the state.”

Help for Chronic Neurologic Conditions

For many people with chronic neurologic conditions, health insurance exchanges may offer access to coverage that they have otherwise been unable to get, Dr. Nuwer says. Some examples:

- Younger individuals whose conditions—like multiple sclerosis or debilitating migraines—have limited their employment and kept them out of company-sponsored health plans.
- People who are self-employed or independent contractors—a flexible option that can be a great career solution for those whose neurologic conditions keep them from a full-time work schedule, but a career path that rarely offers affordable insurance.
- Older individuals who have not yet reached the eligibility age for Medicare.

“This will allow a lot of people who have been kept out of the insurance pool by cost, preexisting conditions, or both, to buy reasonably priced insurance,” says Dr. Nuwer. Because while many of the rules governing the exchanges are still evolving, one is set in stone: they can’t ask you how sick you are.

“You cannot be excluded from buying into a plan via a health insurance exchange, regardless of your past, current, and expected future medical problems,” explains Dr. Nuwer. “Those are off the table. They cannot be discussed when talking about signing up for a plan. They can’t even send you for a medical exam, according to my understanding of the rules.”

Right now, insurers are afraid to offer affordable individual plans, Dr. Nuwer says. “They think the only people who will buy them are those who think they’re sick,” he explains. “But if you lump together 100,000 people who mostly think they’re in good health, it becomes reasonable for private insurers to play and give the group overall a good deal.”

Not for Everyone

But that doesn’t mean every state’s exchange will be a good solution for everyone. And court challenges to the indi-
individual mandate—that is, the law’s requirement that everyone sign up for some form of health insurance—are moving forward. In August, the U.S. Court of Appeals for the 11th Circuit struck down the individual mandate, and it’s expected that the issue will eventually end up before the Supreme Court.

“You need a lot of people signing up for the exchange to keep the rates low,” says Dr. Nuwer. “Without the individual mandate, the ability of states to make that happen will be substantially impaired. Watch to see if your state is making a big effort to get a large pool of people signing up.”

In the meantime, if you work for a smaller business that offers health insurance, lobby them to keep their own benefits until the confusion over exchanges has settled down. “You don’t want January 1, 2015, to come and the owner of XYZ agency to declare that they no longer offer medical benefits because you can get them through the exchange,” Dr. Nuwer says. “It could be crazy over the first couple of years, and it sure would be better if you kept any benefit you have at work until it all settles down. If you have something, don’t give that up until you have a better idea of what the alternative is going to be with the new plans.”

**What Can You Do Right Now?**
Some states are resisting the idea of implementing health insurance exchanges (along with other provisions of the Affordable Care Act). Initial efforts to establish exchanges have failed in a number of states, including Louisiana, Arizona, and Florida.

So, if you think a health insurance exchange could help provide you with affordable access to coverage that you and your family need, then be the squeaky wheel. Contact your state legislators and tell them your story. Let them know why affordable health care coverage through a health insurance exchange is so important and urge them to work quickly to enact a program that will provide access to quality care for the people of your state who need it.

**For More Information:**
- Healthcare.gov, the government’s Web site focused on health care reform and the Affordable Care Act, has a section on insurance exchanges: www.healthcare.gov/law/provisions/exchanges/index.html
- The Kaiser Family Foundation has pulled together a wealth of background material on health insurance exchanges here: healthreform.kff.org/tags/exchanges.asp

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There are a Million Hydrocephalus Stories; This is the Story of Tracy

**Head Above Water**
*By Tracy Taback*

Today, I am a healthy 31-year-old woman who just happened to be born with hydrocephalus (water on the brain). My condition lay dormant and went undetected for 23 years until one morning I woke up and drove to work but was unable to get out of my car when I arrived. I remember sitting in the parking lot, scared out of my mind, thinking that something was obviously wrong and had been for a while, but I had chosen to ignore it.

On February 1, 2008 I underwent an ETV (endoscopic third ventriculostomy) at Hartford Hospital in Connecticut with Dr. Paul Kanev. I consider myself lucky to have been introduced to Dr. Kanev and also to be a candidate for the ETV procedure. This surgery was riskier than a traditional shunt insertion because my brain was actually pierced to create a new passage for fluid. I had heard the failure rate or chance for complications is significantly lower with ETV than a shunt, so the decision to have the first option was a no brainer for me (no pun intended).

The four and a half years between my diagnosis and surgery were some of the longest, most difficult years for my family, loved ones and me. I really can’t even imagine how difficult it was for my family to have had to see me like I was. Let me paint a picture for you. After the surgery when I asked my mom what I was like while I was sick she cried saying, “my 20-year-old daughter looked like an 80-year-old.” She then corrected herself saying, “an 80-year-old stroke victim” at which point I started crying.

I didn’t really have any idea how bad I was because my problem was in my brain, which distorted my whole perception and outlook. My parents were relentless in trying to find answers. They took me to many doctors, and even though everyone knew I had hydrocephalus, they told us that was not the cause of my problems and there was no need to do surgery.

I don’t have a clear memory of the progression of issues I had, but throughout this time I was told I was depressed and highly medicated; I fell down a flight of stairs.
which left me with a concussion, contusion, hematoma and broken collar bone at which point I was told I was suffering from a traumatic brain injury (TBI); I began to have trouble walking, talking and remembering things, but there always seemed to be another reason we were given for my problems. Apparently, the first multiple symptoms of hydrocephalus, depression and TBI are all the same. It obviously made sense for my doctors to attempt to help me without having to do surgery. Unfortunately, none of those things were going to treat my condition.

My parents were highly annoyed and offended when one of my doctors asked them if I was ever able to hop after he asked me to do so and I stood there dumbfounded, staring at my feet, literally not knowing how to make that happen. I had multiple MRIs during the four and a half years and was tracked by a Neurologist and Neurosurgeon the whole time. My parents brought me to a Physiatrist and Neuropsychologist, which are two doctors I feel lucky to have worked with. After grueling multiple hours of cognitive testing, the Neuropsychologist told us the test results suggested I would have had difficulty graduating high school and might not have even attended college. In actuality, I soared through high school and graduated Summa Cum Laude from Bentley University.

My ETV took all of 30 minutes and I have an inch long incision and small divot on my head that you can’t even see because I have so much thick, curly hair. My mom stayed with me in the hospital and I remember waking up the morning after surgery and telling her that I felt like I could just think and see more clearly. It was absolutely amazing! Later that day, two nurses got me out of bed to walk down the hall and by the next day I was steadily walking all alone. I will always have a Tectal Glioma brain tumor, but it is benign. There is no reason for concern as the tumor has virtually no impact on my life anymore. I will continue to see my neurosurgeon annually, but he’s my favorite doctor to see because he’s the one who fixed me.

There are a Million Hydrocephalus Stories; This is the Story of Hannah
by HA Member Susan Andersen Moore

Our daughter Hannah has a programmable VP shunt for her hydrocephalus. Here is a little of her story.

Hannah was born sometime in May of 2002. She was abandoned at 4 months of age on the footsteps of the Social Welfare Institute in Luohe City China. She was terribly emaciated, underweight, and sick. She had been born with thoracic myelomeningocele (Spina Bifida), and had not had corrective surgery. She was the first baby left at the institution, since it had been expanded to take care of special needs children in addition to the elderly care center that had been running for years. She had no name, no background, she only had the mattress ticking that she had been swaddled in. The people at the SWI named her “Dang Miao Miao”. Miao Miao means the heart of the tree.

The Director at that time was a woman with a very big heart. We were told that she paid for Miao Miao’s surgery from her own pocket. It was then that they had realized that she also had Hydrocephalus. They put in a VP shunt, and Miao Miao started to come into her own, she put on weight, and blossomed under the care of the ‘Aunties’ and ‘Uncles’ at the institute. Somewhere around the age of 2, she started to have problems with infections in her shunt. She was taken back to the hospital where they removed most of the shunt, (there’s still a piece that is stuck in her brain), and did not replace it. Three years later, we received Miao Miao’s file to review. We knew from the second we saw her picture and read her story that she was our daughter.

No child should be without the love of a family when they needed medical care. We put in our acceptance to adopt her in June of 2007, and brought her home for Christmas December 21, 2007. We named her Hannah Eadan Miao Moore.

Hannah’s first appointment with her Neurosurgeon was in January of 2008. After tests were run, and results reviewed, it was determined that Hannah needed surgery to relieve the pressure from the hydrocephalus as soon as possible. First, her surgeon did a ventriculostomy on her, in hopes that we could do without a shunt. Unfortunately Hannah’s ventricles were too enlarged and the fluid too great to be absorbed and it closed back up a few months later. Next she had a VP shunt put in, and she improved so much in such a short amount of time. She had her pressure regulated and adjusted a couple of times after that when she would complain of headaches or nausea, but so far no revisions.

HA note:
Tracy recently signed up as an HA Partner! She will be leading a hydrocephalus support group in Hartford, CT. This group is open to all ages. To find out more, contact the Hydrocephalus Association at 888-598-3789.
We kept thinking how lucky we were with all of her conditions that she was doing so well. No major scares until January of this year, when she couldn’t hold her head up, and kept crying her head hurt so bad. Then the vomiting started, with no accompanying fever. I knew it had to be something with her brain, and called her Neurosurgeon who met us at the hospital on January 1st, Happy New Year! After CT scans were done, Dr. O. came in to tell us that Hannah had developed ‘slit ventricle syndrome’, and they would need to pump her up with fluids to rehydrate her. She couldn’t hold anything down, she kept crying her head hurt even worse. She seemed to deteriorate more on day two, they reset her shunt again, and even more by day three, reset her shunt again. So they finally gave her something for the pain, and she settled a bit, and finally went to sleep. They did a brain tap, found that the shunt was working properly, and readjusted her shunt setting once again. By day four, you would never have known anything had been wrong. She just wanted to go home.

Hannah is an amazing child (as I know all children are). Her resilience and positive determination to overcome difficulties that most children never have to endure humbles us. In addition to the hydrocephalus & thoracic Spina Bifida, Hannah has a Chiari II, tethered cord, CAPD, CPP (she has a Supprelin implant in her arm), convergence insufficiency in her eyes. Now here’s the most amazing part, Hannah is totally mobile, no catheter, no braces, no additional devices other than her reading glasses. She made the honor roll again this year at school. This is the same child that 3-1/2 years ago didn’t know a word of English. She has vision therapy once a week and aquatic therapy, to help retrain her eyes, and increase her range of motion and balance. She takes dance, Chinese Folk Dance and Ballet and jazz. She especially loves to cheer her brother Harrison on at the Special Olympics games (he has severe Autism). She doesn’t really see that she is any different than any of her peers. She has an amazing enthusiasm for life and learning and helping others. Her hydrocephalus may cause her some discomfort at times, and limit what she is allowed to do physically, but we think it has actually benefited her in that she is stronger and more determined to excel, despite it. She has hydrocephalus, but it is not who she is, it is just a part of her, like having black hair and brown eyes. She just deals with it.

HA Visit to Capitol Hill Yields Insights into Hydrocephalus Research Funding

By Paul Gross, HA Chairman Board of Directors

HA had a very productive day on Capitol Hill on September 23rd. Our day began with a meeting with the staff of the Armed Services committee to explore the funding opportunities for hydrocephalus in the Congressionally Directed Medical Research Program (CDMRP) and the Defense Appropriations for Traumatic Brain Injury.

I was joined by Sergeant James Spence of the 191st Infantry Brigade out of Fort Lewis, Washington who has hydrocephalus after two tours of duty in Iraq; Dr. Michael Williams, Director, Sandra and Malcolm Berman Brain & Spine Institute; and our incoming CEO, Dawn Mancuso. We were given good leads on how to pursue our funding objectives.

Next, we participated in the Day of Testimony. We had a great set of speakers, from patients and advocates to medical professionals including neurologists, neurosurgeons and a neuropsychologist. All in all, the program was a good initial effort to raise awareness on Capitol Hill. In the afternoon, we had meetings with Representative Rosa DeLauro’s staff, the Energy and Commerce committee staff and the minority speaker’s staff. Each visit gave us insights into how to move forward with our agenda in these challenging economic times. We got a tough reality check, learning that specific disease research funding was highly unlikely in the current ‘deficit reduction’ climate. But everyone gave us hope and new angles to pursue. We were reminded that we need to be in this for the long haul and we are! With the appointment of our new CEO, who will be based in Washington, we are prepared to engage on multiple political and legislative fronts to bring attention and funding to the cause of hydrocephalus.

HA Chairman, Paul Gross, Joins NINDS Advisory Council

By Rick Smith, Former HA Acting CEO

I am pleased to announce that Paul Gross, Chairman of Hydrocephalus Association’s (HA) Board of Directors, has been selected to join the 18 member National Advisory Neurological Disorders and Stroke Council -the major advisory panel to the National Institute of Neurological Disorders and Stroke (NINDS). Paul joins three other new members and brings to the Council his entrepreneurial perspective, successful business experience, and a deep, passionate commitment to finding answers for people living with hydrocephalus.

NINDS, a component of the National Institutes of Health (NIH), is the nation’s primary supporter of basic,
translational and clinical research on the brain and nervous system. Its 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.

“In just a few years, Mr. Gross has done a remarkable job of engaging engineers, scientists and clinicians in plans to develop research that will lead to better treatment for people with hydrocephalus,” said Story Landis, Ph.D., Director of the NIH National Institute of Neurological Disorders and Stroke (NINDS). “I am delighted that he will be a member of the NINDS Advisory Council and look forward to his participation.”

We are delighted as well and offer our sincere congratulations to Paul on this very exciting and important appointment.

**NIH NINDS Forum Provides Insight into Hydrocephalus Funding**

*By Paul Gross, Chairman of the Board*

I attended the National Institutes of Health (NIH) National Institute of Neurological Disorders and Stroke (NINDS) nonprofit forum on June 1st. Of the 27 institutes that make up NIH, NINDS is the largest potential grantor in hydrocephalus research. The event is put on by the NINDS staff to allow patient advocacy organizations and research funders to get more information about how to effectively work with NINDS and the other institutes.

The day included a mix of education sessions on NIH basics, breakouts and networking sessions with NINDS program directors that are responsible for different portfolios of research across NINDS. It opened with some sobering news from NINDS Director Story Landis explaining that NIH’s budget has been cut by 1%. The major ramification of that budget cut is that fewer applications will get funded in coming years. On the positive front, Dr. Landis referred to hydrocephalus during her opening talk thereby acknowledging that we are on NINDS radar. Much of the discussion in the breakouts was about how we (the nonprofits) could collaborate to bring more funding to NIH and work across our diseases/conditions to make scientific breakthroughs.

In one-on-one conversations with program directors, we also got very positive feedback on the accomplishments of our partner and grantee the Hydrocephalus Clinical Research Network (HCRN). While the funding environment has become tighter, our strategy of funding young investigators was validated as a tactic to increase the potential for future NIH funding of hydrocephalus research. The Hydrocephalus Association has begun to build important relationships with a number of NIH program directors that will help us advance our government’s support of hydrocephalus research.
Elijah Speaks Up About Hydrocephalus!

By Elijah Lawrence

I was diagnosed with hydrocephalus before I was born. When I was four days old, I had my first shunt put in. Since then, I have had four revisions, but I have had my current shunt for five years. I am treated at the Children’s National Medical Center in Washington D.C. I have been very lucky because I have encountered very few barriers despite having hydrocephalus. I love to sing, act, and dance. I also love to write and play with my friends and dogs. Most of these activities are not limited by my hydrocephalus. One of the most memorable moments of my childhood was singing “Wonderful World” at the Hydrocephalus Convention in Baltimore, MD in 2006. Since then, I have had the honor of singing the National Anthem to open the U.S. Tennis Open in New York, and at the 56th Presidential Inaugural Concert. I also just sang the National Anthem at the 1st Hydrocephalus Walk in Washington D.C.

To other people living with hydrocephalus, my advice would be to not let it limit your imagination of what you can do and be. My parents have also told me that everybody is dealing with something and we are just dealing with hydrocephalus. It is important to let people know the details about hydrocephalus in order to raise awareness, prevent further cases, and maybe find a cure. But, at the same time, it is important not to let it define all of who you are.

Ashley Snyder

Hydrocephalus can be a downer. I was diagnosed with the condition at age three, so I sympathize with all of y’all who are saying, “of course it’s a downer… how can it not be?” and think that I’m stating the obvious. But, I think it’s all about perspective. Despite this condition, I find myself happy pretty much all of the time. I confess to occasionally dancing around the kitchen and singing in the shower. It’s a classic example of mind over matter. It is okay to have headaches, to hurt, to feel tired, or maybe even to feel scared sometimes. But you can’t let all of that consume you. If you do, you’re robbing yourself of a ton of happiness which you truly deserve.

Take some time to reflect on the good things in your life. For me I tend to think about a family that’s always there for me no matter what and friends who would do anything for me. Hydrocephalus seems like only a bad thing sometimes. But I promise you, it eventually makes you stronger and turns out to be a huge benefit. Despite all of the challenges all of y’all have faced, you have come out strong. Be proud of that. Think of any struggles you have as challenges instead. I for one never back down from a challenge and I know none of y’all ever do either, so kick some hydrocephalus tail and realize how much you rock.

Try not to worry all the time about what’s going on with you. I know that’s tough, but it will definitely be a good thing for you. Worrying burns energy and doesn’t give you anything in return, and who wants to do that? When life rains, don’t stand there and just get wet. With positivity on your side, you now have the world’s largest umbrella, and it is absolutely time to dance in the rain.

And most of all, embrace being who you are. Y’all are such fighters and you fought hard to get where you are, and that’s something to shout about. On your toughest days, if you just can’t seem to get out of a funk, look at this blog and remember these words: I’m proud of y’all. And y’all should all be extremely proud to be yourselves.
Hydrocephalus Virtual WALK

The Hydrocephalus Association’s WALK-a-thon program was once just a small group of San Francisco Bay area families taking a stroll to support each other and the hydrocephalus community. Now we have over 30 WALK events throughout the country with more than 8,000 participants, raising over $750,000! While we are always adding new WALK sites to our event schedule, we realize not everyone can easily attend a WALK event. In order to include as many individuals as possible in our WALK program we have created the Virtual WALK option. This online fundraising initiative allows people to register and hold their own symbolic WALK while still raising money for the Hydrocephalus Association (HA). We invite individuals to register and use their personal donation page to encourage friends and family to donate and spread the word about hydrocephalus. We welcome participants to hold their own neighborhood walk, host a backyard BBQ, have a bowling night or hold any other activity to bring their community together in the name of hydrocephalus.

Brenda Short, from Canada, took advantage of this unique WALK opportunity and shared her story with us:

“For my Virtual Walk I pushed my boy, who has hydrocephalus, Logan in his wheelchair while my older kids ran in a 1 mile race to earn points for their school’s running club. I always enjoy getting out and having Logan do the things his big Sister (9 yrs.) and Big Brother (7 yrs.) do, and the faster Logan goes the more he enjoys it. So far this year we have been in 4 Races and he is usually the youngest wheelchair athlete participating.”

Meagan from South Dakota also participated in our Virtual WALK program:

“My daughter has hydrocephalus due to aqueductal stenosis. She had endoscopic third Ventriculostomy (ETV) surgery at 7 months old. She is almost 5 and doing amazing. We are very blessed. We did a family walk along the Big Sioux River.

We look forward to hearing other stories from Virtual WALKers as the Virtual WALK continues to raise money and awareness for hydrocephalus.

Visit our website or go to http://walk4hydro.kintera.org/virtual to participate.

WALKs and Special Events: Last But Certainly Not Least!
By Randi Corey, HA Director of Special Events

2011 has been a spectacular year for HA WALKs and Special Events. HA’s 2011 WALKs and Special Event season raised over $1,000,000! This is a 55% increase over last year’s total. And all of it is due to HA’s WALK Chairs and all of the volunteers who work tirelessly to raise money to further our mission of fighting this life threatening, life changing condition – and increasing awareness of hydrocephalus.

HA’s final WALK was also its largest, raising over $112,000 for HA – the National Capital 5K Run/WALK! Held on November 20th, the day dawned clear and with fair weather. Over 750 participants gathered at West Potomac Park – serious runners, casual runners, walkers, families with dogs and strollers – all with one purpose: to help eliminate the challenges of hydrocephalus. A young HA member, Elijah Lawrence, led out the athletes with a moving rendition of the national anthem.

Representative Chris Van Hollen, 8th District, MD, a partner in our efforts to pursue more focus for hydrocephalus research from NIH, was unable to attend, but sent a letter of support.

Special Volunteers Conducting Special Events!
By Randi Corey, National Director of Special Events

As the year winds down Hydrocephalus Association would like to recognize those volunteers who conduct fundraising events for HA throughout the year. These volunteers initiate the event, plan and organize it, market it and implement it – and all in support of HA’s mission! These special events and the volunteers running them are an integral
part of HA’s annual fundraising program and we very much appreciate all they do on our behalf.

This year, HA Special Events raised more than $153,000 for HA’s mission: to eliminate the challenges of hydrocephalus! They ranged from six-figure, multi-year events to smaller first year initiatives. Special thanks to this year’s special events volunteer coordinators for all of their efforts on HA’s behalf.

Thank you to all of HA’s dedicated volunteers who made the above events possible! Your commitment and support in raising funds to fight hydrocephalus as well as increasing awareness of this chronic condition affecting over one million Americans is very much appreciated.

A very special thank you to Peter and Sam Finlayson, who coordinate Team Hydro’s participation in the Alcatraz Sharkfest – an open water swim from Alcatraz to Fisherman’s Wharf in San Francisco bay. Team Hydro started in 2008 with just four swimmers raising $10,000. Now over 65 participants are raising more than $114,000 dedicated to hydrocephalus research in memory of their sister, Kate, who lost her battle with hydrocephalus in November of 2010. HA very much appreciates Sam and Peter’s support of its vital research portfolio.

Next year’s Special Events calendar is already starting to fill up with everything from beauty pageants to dinner/auctions. If you are interested in planning, organizing and conducting a special event to benefit HA in 2012 please contact Randi Corey, the National Director of Special Events at randi@hydroassoc.org. She would be delighted to speak with you re: all of the “how tos.” Here’s hoping that HA’s 2012 Special Events results are even bigger and better!

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<th>Event</th>
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<td>Team Hydro-Alcatraz Sharkfest</td>
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<td>Motor Cross for Children</td>
<td>Across U.S.</td>
<td>Paul Gross</td>
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<td>Extreme Athletes for HA*</td>
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<td>DUH (Auto Show) &amp; Go Kart Event</td>
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<td>Concert by Jake Hill and Deep Creek</td>
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<td>Clarksville Motorcycle Ride</td>
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* Extreme Athletes for HA are individual marathon participants who use their marathon participation as a fundraising vehicle for HA.

To find a WALK near you, please visit our website at https://www.hydroassoc.org/hydrocephalus-walk/schedule-of-hydrocephalus-walk-events/

To find a support group near you, please go to our website at https://www.hydroassoc.org/hydrocephalus-education-and-support/hydrocephalus-associatioha-partners-network/
Throughout the 2011 WALK season I have worked with over 60 WALK Chairs to coordinate 30 plus events all over the country. The Hydrocephalus Association’s (HA) WALK program started in 1983 with a few families walking across the Bay Bridge in San Francisco, CA to support each other and raise hydrocephalus awareness. Today, HA has expanded this tradition of building strength in numbers with the help of our fearless and devoted WALK Chairs who never cease to provide welcoming and empowering WALKs to the community.

In addition to bringing hydrocephalus into the limelight, these WALKs give families who thought they were all alone a chance to connect with people who are going through similar experiences. People, who suffer daily from lack of community, create bonds with other members of the hydrocephalus community as they walk together and enjoy the day.

It is a joy to work with each and every chair as they strive to build a unique and enchanting event, filled with family friendly activities, educational opportunities and space to foster new friendships. I am continually in awe of each WALK Chair’s passion for the cause and their strength to persevere through numerous logistical road blocks. I applaud our WALK Chairs for what they have done, and continue to do, for our greater hydrocephalus community.

With our WALK Chairs taking the lead we have raised over $875,000 this year with 651 teams and over 10,000 participants. Our WALKs included mascots, a helicopter, DJs, neurosurgeons, singers, a dunk tank, bands and the Jr. ROTC and we are excited to see what next year brings. We are already preparing for our 2012 WALK season, which will include additional WALK locations, more participants and increased awareness of hydrocephalus. Check our WALK schedule in the near future for the most up to date information about the 2012 WALKs.

If you are interested in starting a WALK for the 2012 season please contact Randi Corey at 919-518-8283.

Hydrocephalus Association WALK and Special Event Partner Profiles

The Hydrocephalus Association (HA) proudly introduces you to some of our outstanding volunteer leaders – the 2011 WALK and Special Event Chairs! These men and women spend countless hours coordinating HA WALKs and special events in their communities. They possess great leadership, passion and initiative which in turn allows HA to increase its investment in education, support and research. We plan to feature these exceptional volunteer partners giving you the opportunity to get to know them.
In 2002 I was diagnosed with hydrocephalus and had a shunt placed within the same day. Since that time I have undergone 2 shunt replacement surgeries due to shunt failure/malfunction. As soon as I was diagnosed, I wanted more information about what to expect regarding long-term plans, including having a family, subsequent surgeries, potential complications, and research for improvements. I found the Hydrocephalus Association and appreciated their commitment to help people in situations similar to mine who are looking for answers. After being approached to help with the Salt Lake City WALK, I decided that I had an obligation to utilize resources available to me through personal and work relationships to raise money for the Hydrocephalus Association. I hope my contribution to this important cause will help further the work of the Hydrocephalus Association and support their valuable mission.

Miaja Rocciola – Volunteer Co-Chair: 
HA San Francisco WALK

My family and I have been participating in the Hydrocephalus Association San Francisco WALK for 15 years. My oldest daughter (who was diagnosed with hydrocephalus in utero) was only 10 months old the first year we participated. We pulled her in a red wagon and she slept the whole way! She will be 16 years old this October and has had 8 surgeries during this time. We know first-hand the challenges that people face with hydrocephalus and we are dedicated to the mission of eliminating those challenges. Participating in the WALK every year helps my family and I make a difference and to actually hope for a cure. This year we are hoping to help raise more money for research by increasing the Family Team participation in the WALK. The WALK is not only for raising money and awareness, but for social connections. The friendships that our families have made over the years have been invaluable. I look forward to the WALK every year because it is such a positive, fun-filled day of hope and love!

Sarah Billman – Volunteer Chair: 
HA Columbus, IN WALK

When I was 18 weeks pregnant with our first baby my husband, Joshua, and I went in to determine if we were having a boy or a girl. It could not be determined that day what the sex of our baby was, but it was clear that something was not right. I was sent to see a specialist. Who would have known that our lives would be forever changed by that visit? It was determined that we were having a girl, Mya Elizabeth. However, it was also determined that our little angel had hydrocephalus. In a matter of an hour we had information overload. I remember sitting there with my husband in a trance listening to the genetic counselor as tears ran down my face. Surgery immediately following Mya’s birth, a shunt, learning disabilities? What went wrong? Mya is now four years old and is the most amazing little girl I know. She underwent her first shunt surgery...
when she was 2 months old. Mya had her first shunt infection not even three months later. To date Mya has had eight surgeries related to her shunt. But, after all she has been through, Mya is always smiling.

In the four years that we have had our Hydro Girl I am still amazed by how few people know about hydrocephalus and what it is. After the rough summer Mya had last year I decided as her momma that I was bound and determined to do what I could to help spread the word. I first contacted the HA about any WALK’s in Indiana, but unfortunately there weren’t any. After talking with my husband and my sister, Elizabeth (Co-Chair), I decided that I was going to be the volunteer chair for an HA WALK in Columbus, Indiana. My goal is to spread the word about hydrocephalus and to get as many people involved as I can. This is the first year for our WALK in Indiana, but I know it is going to be a great success. My family is working to help spread awareness not only for Mya, but for the millions affected by hydrocephalus.

Jenifer Jeans – Volunteer Chair: HA Connecticut WALK

In 1978 my mom Andrea, already a mother of two sons, and my father welcomed my identical twin sister Alexandrea and me into the world. Alexandrea was born with severe hydrocephalus and has struggled with this condition for 33 years. Since birth Alexandrea has undergone over 20 shunt revisions as a result of hydrocephalus. I have been at my sister’s side throughout our life, holding her hand the entire time. When we reached adolescence, and continuing into adulthood, I realized that there were not many individuals who knew what hydrocephalus was or how to help those who live with this condition. With this realization I decided that I needed to tell my sister’s story and bring awareness to the issue. Alexandrea is truly my inspiration. She has fought long and hard and is truly a miracle. Throughout her struggles she has always continued to smile; Alexandrea has never given up – not once; she continues to fight when many individuals would just give up. There have been many physicians who have insisted Alexandrea was not going to make it, yet she did. Alexandrea has shown me that life is truly precious and it is something that we should never take for granted.

It is my hope that starting a HA WALK in Connecticut will encourage others to tell their stories, while raising awareness and money to find a cure for hydrocephalus. With guidance and support provided by HA’s national office as well as family and friends, I hope our inaugural WALK in Connecticut will be a tremendous success. Although chairing a WALK is not an easy task, it is truly a labor of love for me. In my heart I know Alexandrea (who is unable to speak for herself) is truly overjoyed that I have taken on this endeavor, and I know she wants her story, as well as other individual’s stories, told. It is my hope that one day there will be a cure, and no one will need to know what hydrocephalus is.

Imagine No Hydrocephalus
by Rick Smith, Former HA Acting CEO

As we put the final touches on our five year Research Initiative Plan, we wanted to find an additional way to convey our hope for the impact of increased hydrocephalus research. We released a video on Youtube in honor of this and National Hydrocephalus Awareness month. As we set our sights on our mission to eliminate the challenges of hydrocephalus, we think this video offers a powerful expression of our vision – a future with no hydrocephalus.

Wonderful Resource for Parents of Kids Living with Hydrocephalus.

PACER Center is the most fabulous resource! It is a parent training and information center for families of children and youth with all disabilities from birth through 21 years old. Located in Minneapolis, it serves families across the nation. Parents can find publications, workshops, and other resources to help make decisions about education, vocational training, employment, and other services for their children with disabilities. They provide endless, state of the art resources that all parents of children with hydrocephalus can benefit from.
Hydrocephalus a Global Health Issue
by Tom Smith, HA Adult Services and Outreach Coordinator
A congressional hearing was held on August 2nd, 2011 in front of the House Subcommittee on Africa, Global Health, and Human Rights which discussed research and treatments for hydrocephalus that could benefit children around the world. Benjamin Warf, MD, a pediatric neurosurgeon at the Children's Hospital in Boston, MA was on the panel of experts testifying in front of the committee.

‘Hydrocephalus Treatment in Uganda: Leading the Way to Help Children’ discusses Dr. Warf’s innovative technique of combining Endoscopic Third Ventriculostomy (ETV) with Endoscopic Choroid Plexus Cauterization (CPC), which, as the name suggests, involves cauterizing parts of the Choroid Plexus, the tissue that produces Cerebral Spinal Fluid (CSF).

Every year Dr. Warf travels to Africa to donate his time providing treatment to children living with hydrocephalus. While doing so, he developed his technique in order to provide treatment that avoids shunt-dependence in the patient, as serial shunt revision is simply not an option for most people living in under-developed countries.

HCRN – Moving the Dials on Hydrocephalus Treatment
The Hydrocephalus Clinical Research Network (HCRN) is published a paper in the Journal of Neurosurgery. The paper was about their program to standardize treatment of hydrocephalus in all of their centers and showed a significant drop in post-surgery infection rates.

We would like to extend our congratulations and heartfelt thanks to the HCRN and the tremendous impact their work is already having on the world of hydrocephalus.
Name: ___________________________ Telephone: ___________________________

Address: _________________________________________________________________
______________________________________________________________

Email: _________________________________________________________________

Name of person with hydrocephalus: _____________________________

Birth date: ___________________________ Age at diagnosis: ___________________________

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

☐ Enclosed is my unrestricted donation of:
☐ $30 ☐ $50 ☐ $100 ☐ Other $ __________

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