

30 years



Message from Our CEO

The Power Among Us



In the last few weeks, I have been privileged to represent the hydrocephalus community at a number of interesting and important events having to do with chronic medical conditions. The first of these was the Voluntary Health Leadership Conference, an annual event hosted by the National Health Council (NHC). NHC is an organization that represents the over 133 million people with chronic conditions/dis-

eases and their families, through the 50 patient advocacy groups who are members of the NHC. This conference featured presentations by notable government officials such as: Dr. Story Landis, Director of the National Institute for Neurological Disorders and Stroke (NINDS) at the National Institutes of Health (NIH), the U.S. government agency responsible for funding much of our nation's medical research; and Dr. Margaret Hamburg, commissioner of the U.S. Food & Drug Administration (FDA), the agency responsible for approving medical drugs and

devices before they go to market. The conference offered a marvelous opportunity to get updated on the latest legislation being debated in Congress. I also benefited, as will all of HA, from the lessons learned and shared by leaders of other disease-focused organizations about what has worked (and not worked) in their operations.


The second meeting was the Rare Disease Day Conference held on the NIH campus. Presented by the Office for Rare Diseases Research at the National Center for Advancing Translational Sciences (known as NCATS) and the NIH Clinical Center, this two-day symposium celebrated rare disease research efforts across NIH, the Federal Government and the patient advocacy community. HA Research Programs Manager Ashly Westrick and I participated in discussions as far reaching as the work being done by the Department of Defense (DOD) to develop "human organs on chips" for use in drug screening and toxicity assessment; updates on the Global Rare Disease Patient Registry Data Repository; and patient-centered outcomes research at the Agency for Healthcare Research and Quality (AHRQ).

Attending both of these events has given our organization a higher profile among policy makers and key research agencies, and has helped HA play an important role rep-

resenting the entire hydrocephalus community in national conversations about the future of chronic disease research. Now, as I think back on the two conferences, I also see that they are symbolic of an impressive sea-change in the role patients now play in directing their own care and in demanding resources be applied to the development of new treatments. We see it when we note that the recent healthcare reform legislation created the Patient-Centered Outcomes Research Institute (PCORI). We see it whenever we go into a hospital today and find that the hospital has posted a “Patients’ Bill of Rights” on the wall. We see it at meetings of the FDA, the NIH, the DOD, and other agencies where seats are regularly being held open for and filled by patient advocates. (HA’s own Past Chairman Paul Gross currently sits on the NINDS Advisory Council.) We saw it again just a few days ago when President Obama issued a White House Directive to federal agencies conducting research to develop and implement policies for increasing public access to published research that was funded

with taxpayer dollars. Moreover, this directive supports the FASTR bill (The Fair Access to Science and Technology Research Act) currently under consideration by Congress.

This year, we are proudly celebrating the Hydrocephalus Association’s 30th anniversary. Back in 1983, HA’s founders and original members were on the cutting edge of a patient advocacy movement that clearly has come a long way in three decades. There is still much to be done, but reflecting on how much progress has been made should bolster our optimism about how much more we can do together. Few have said it better than the famous American scientist, Margaret Mead:

“Never doubt that a small group of thoughtful, committed, citizens can change the world. Indeed, it is the only thing that ever has.” 

Featured Articles

January Board Meeting Welcomes New Board Members


At the end of January, the Hydrocephalus Association’s board of directors had it’s first meeting for 2013. Our board consists of a group of dedicated individuals who are unequivocally engaged and committed to meeting our mission – to eliminate the challenges of hydrocephalus. All 17 board members participated in the meeting, coming from all parts of the United States. To have 100% attendance at a meeting is certainly a palpable marker of the individual and collective dedication found among our board members. (Of note: two board members even participated in the entire 6-1/2 hour meeting via speaker phone.)

Two outstanding individuals joined our board for the first time: Cliff Goldman from Roslyn, New York, and Shannon O’Connor, from Centennial, Colorado. We will be sharing more in-depth introductions to Cliff and Shannon in future articles, but we are thrilled to have both of these smart, enterprising and passionate people joining our leadership team!

Prior to the board meeting, we started off with a formal new board member orientation program, followed by an Open House for all board members and the local community at HA headquarters in Bethesda, Maryland. This was a marvelous way to provide an opportunity for our local members to get to know the directors and staff, and to

engage everyone in informal dialogue about the organization.

The agenda for this board meeting featured the start of a strategic dialogue among the board members identifying and prioritizing the key challenges facing the association in the next 3 – 5 years. Our current Strategic Plan, which was developed and approved in 2009, covers the 5 year time period from 2009 – 2013. Thus, the board has started the process of developing a revised plan for 2014 and beyond. We will be sharing more very soon about the process being used, the opportunities for member input into that plan, and the goals to be developed. For now, we came away with lots of great ideas for avenues to explore and issues to address, thanks to the engaging and focused work of the board members.

As part of this strategic discussion, we posted a message on Facebook during the meeting, asking members of our community what they would like the board to be thinking about. We received quite a few responses that were shared with the board in real-time. As a result, we were able to factor these ideas into the discussions on the spot. Thanks to all who participated by sending us your thoughts. If you missed this Facebook post, do not worry...there will be other opportunities in the coming months to provide your input as well. 

HA Board Member Retires After Distinguished Career on Capitol Hill



After a distinguished career on Capitol Hill, HA Board Member John Lawrence retired from his service to Congress and the American people on February 1, 2013. According to the *National Journal*, Mr. Lawrence was the longest serving staff person in the House of Representatives. In his last position, Mr. Lawrence served as chief of staff during both of Congresswoman Nancy Pelosi's terms as Speaker of the House. HA is honored to have Mr. Lawrence on our board of directors and wishes him the best in his new professional endeavors.

A Guitar Rock Legend Builds Awareness of NPH

ABC News Worldwide featured a story on January 15th on guitar rock legend, Dick Wagner, and his diagnosis of Normal Pressure Hydrocephalus (NPH). The article, *Rock Star Nearly Loses Career with "Curable" Dementia* is another step forward in increasing public awareness of both NPH and hydrocephalus.

The story about Mr. Wagner follows him from the time he began to see symptoms through the placement of his shunt at the Barrow Neurological Institute in Phoenix, Arizona. Alicia Harper of Orlando, Florida, is also highlighted, sharing a similar story of a slow creep of symptoms that many individuals with NPH initially write off as part of the aging process. Unfortunately, this is a common thread in the stories we hear of NPH. The length of time to get a diagnosis and the proper treatment can often take years. There is another common thread as well, however: that with the proper treatment, most individuals get their lives back after having struggled with the progressively debilitating symptoms NPH can bring. Case in point, Mr. Wagner is once again on the music-circuit, playing concerts throughout Europe.

Often referred to as the "curable" form of dementia, NPH is mistaken for Alzheimer's or Parkinson's disease. While the condition was identified over 50 years ago, there remains little research into the condition. The National Institutes of Health (NIH) are currently funding only \$500,000 of research looking into causes and treatments for NPH, while the number of people affected are estimated between 345,000 and 540,000. At the Hydrocephalus Association, we do not think this is enough and we are working to change the research ecosystem with regards to NPH. This past year, we announced our investment in an adult extension of the work of our pediatric-focused partner, the Hydrocephalus Clinical Research Network (HCRN). This new effort, led by Dr. Mark Hamilton of

Cynthia Solomon Receives Spirit of Excellence Award

Cynthia Solomon, a founding member of the Hydrocephalus Association for which she won HA's Distinguished Achievement Award, has been awarded the Spirit of Excellence Award by the California Office of Health Information Integrity (CalOHII) by Deputy Secretary for HIE Pamela Lane. She was honored for founding FollowMe, a web-based personal health record company.

We want to congratulate Cynthia for her award and for her work in the medical sphere with at risk communities.

Calgary, is a group of physicians collaborating to study and standardize the treatments for all forms of hydrocephalus in adults, including NPH, in order to improve outcomes. The group also includes Dr. Mark Luciano from the Cleveland Clinic (interviewed for the ABC piece), and Drs. Williams, Relkin, Klinge, and Katzen from Sinai Medical Center, Cornell, Brown and Miami University respectively. We look forward to being a part of bringing this network to fruition, but our role in supporting the research community does not end with this network. We continue to raise critical funds toward the research of hydrocephalus with our *A Reason for Hope* campaign. Furthermore, through hosting research conferences and workshops, we continue to bring the medical and research community together to keep an active dialogue going around the causes, treatments, and potential cures for hydrocephalus.

This latest ABC article is one in a series of articles that have appeared in the past year. We have seen an increase in attention the national media has paid to NPH. To complement these larger stories, the Hydrocephalus Association has featured the personal journeys from hydrocephalus patients within our membership through our website blogs and Facebook pages. The NPH voice is rising and we are being heard. Consequently, the number of people turning for information and support from our association is also increasing. It encourages us to know that we can provide individuals with the critical information they need, people they can speak to for assistance with their questions and concerns, and a community of other individuals sharing their journey. If you are looking for information, you can turn to our NPH page on our website or download our free publication *About Normal Pressure Hydrocephalus: A Book for Adults and Their Families*. You can also call our office to request this, and other resources, be mailed to you.

We look forward to continuing to play an active role in raising awareness of NPH in this, our 30th anniversary year, as well as continuing to serve the NPH community.


Over the course of the year we will have a dedicated section to commemorating our 30th anniversary. This walk down memory lane will include interviews with our founding members, members of our Medical Advisory Board and our Board of Directors. It will also include the dedicated group of individuals – YOU – who come to us seeking support and information and remain connected to us through Facebook, our website, our fundraising WALKS, our advocacy activities, our Support Groups, and our National Conference. By stepping back in time, we hope that the voices of these individuals will help you share in the challenges, the triumphs, and the special memories that comprise the heart behind the work of our association.

Hydrocephalus Association at 30

In 1983, a small group of parents whose children had hydrocephalus came together seeking community. The children were all patients of Dr. Michael Edwards at the University of California, San Francisco Medical Center. Dr. Edwards and Lori Howell, his neurosurgical nurse, graciously hosted a few small, informal gatherings after Emily and Russell Fudge expressed their feelings of isolation and frustration when their son, Gerard, had his second shunt revision. This was a time very different from today. In the early 1980s there was no widespread public acknowledgment that the majority of shunts would need to be revised multiple times during a lifetime. There were no programmable or adjustable shunts. There were no MRIs. There were no such people as a Board-certified pediatric neurosurgeon or a Patient's Bill of Rights. This was a time before the internet, leaving parents, patients, and loved ones to seek out the scant information available in libraries and from their doctors. And there was nowhere to turn for support and guidance.

In 1984, Emily and Russell decided to host a more formal meeting, asking Dr. Edwards to speak about hydrocephalus and inviting many of his patients. At that meeting, they proposed creating an organization that could provide personal support to families affected by hydrocephalus. Their idea was met with great enthusiasm. With a \$1000 grant from UCSF and Dr. Edwards, the Hydrocephalus Foundation of Northern California was born. In 1986, it was incorporated and received non-profit status. From this heartfelt and unassuming beginning in 1983, the seeds for the Hydrocephalus Association were sown.

This year we commemorate our 30 year anniversary. We honor the resolve of this dedicated group of parents – Emily and Russell Fudge, Jennifer Henerlau, Pip Marks, and Cynthia Solomon – to create a place where people could come to find information, support, and friendship. Together they recognized the need for an independent, patient-focused organization to support individuals

affected by hydrocephalus and to provide their families and friends, who were desperate for information, with life-changing educational materials and group interactions. Thirty years ago this determined group could never have imagined that the Hydrocephalus Association would become the nation's largest and most widely respected advocacy group dedicated to hydrocephalus. 

One Vision Built on Determination

We sit down with two of our founding members, Emily Fudge and Cynthia Solomon, to discuss the early days of forming the association, including their vision and their challenges.

HA: How did the two of you meet and what drove you in those early days to begin working together to form what would become the Hydrocephalus Association?

EMILY: When our sons were diagnosed with hydrocephalus (my son Gerard was 11 and Cynthia's son Alex was 7), there was nothing out there for patients or their families. There was one small organization in Brooklyn, New York – The Guardians of Hydrocephalus Research Foundation – but they offered little in the way of educational materials.

CYNTHIA: Our common denominator was Michael Edwards [pediatric neurosurgeon at the University of California San Francisco (UCSF)]. Michael put up money and space to bring families together to talk. I met Emily at one of the very first meetings at UCSF in a room Michael had set aside. That was the beginning of the Hydrocephalus Association. Both Emily and I had sick kids and we kept running into each other at UC. The commonality was frustration as mothers and not getting answers. The kids would

get hospitalized and we wouldn't leave them. The doctors and nurses were not good at answering questions.

EMILY: There was no place to go – no internet and no statistics. We tried to find statistics on outcomes for people with hydrocephalus but they weren't available because hydrocephalus did not have an ICD code and therefore it was not searchable. What was coded was the primary condition, such as spina bifida or cerebral palsy.

CYNTHIA: I was married to a doctor at the time and I had access to medical books, etc. but the information on hydrocephalus was very negative. As the organization came together, Emily and I shared the strategy of developing more information and knowledge. We came at it from a more personal viewpoint: mothers of sons with hydrocephalus. We realized how important outreach was and that talking with and networking with other families felt productive. One Saturday a month we would organize a meeting with a speaker and invite other parents to join us. But my reason for being involved in the organization was to find the best surgeons, best doctors, and best information so Alex, my son, would have a fighting chance. If we got to do something and create something and be a part of something, then it was so we could keep our kids okay.

HA: What were your priorities?

EMILY: We had a couple of priorities in those early days. First, we needed to meet other people and get support. Second, we needed information. We realized that as parents we were out here in the dark. We felt that someone needed to be interviewing doctors, doing research and writing down information. Since no one else was doing it, we decided that it had to be us.

*HA: In 1986, *About Hydrocephalus – A Book for Parents* was published.*

EMILY: *About Hydrocephalus* began as the Masters project of a UCSF student in medical illustration. A number of our families were interviewed and photographed during the research process. Once it was published, UCSF gave us the rights to sell and distribute the booklet. We didn't make a profit but the booklet paid for itself.

HA: At this point you had a small group formed, you were meeting, and you had published a book on hydrocephalus. You also had a vision for where you wanted the association to go. What were some of the challenge you faced in those early years?

EMILY: Cynthia and I understood that doctors were people too and that we had to get to the doctors and talk to them—let them know that kids with hydrocephalus were not to be thrown away, that they were real people. To many

doctors, treating hydrocephalus was just a plumbing problem. The outcomes for many patients at the time were not optimistic, though we knew children who were having good outcomes. We wanted to get the doctors to understand that our kids were living, they had quality of life. We were confident that even more children could have a better outcome if there was recognition within the medical community that with appropriate intervention and related services, this was possible. This was the real challenge for us.

CYNTHIA: Michael [Edwards] helped get a booth for us at the AANS [American Association of Neurological Surgeons] annual meeting in Seattle. We got the table last minute and there were no hotels left. The only hotel left was a sketchy hotel where we were scared to sleep in the beds. We went to the meeting for one day and sat at a table that said Hydrocephalus Association.

EMILY: The only thing we had at our table was *About Hydrocephalus – A Book for Parents*, the first real resource ever published specifically to educate parents. It may be hard for parents today to understand because now they can call HA and get a wealth of resources. But back in the 1980's, this was not the case.

CYNTHIA: The nurses and doctors would come by the table and stop and talk in front of us as if we weren't there, saying "Oh, this is such a terrible condition."

EMILY: Some doctors would come up to the table, realize we were parents, and walk away. We tried standing in front of the table and stopping the doctors. They would say, "Oh those poor, poor kids. It's such a tragic thing." We would say, "We both have sons with hydrocephalus and



they're doing okay." They would shake their heads and walk away.

We were very lucky, though, because the neurosurgeon who served our kids steered us to some really good people like Fred Epstein, the head of pediatric neurosurgery at New York University. He had written an article for a pediatric journal entitled *The Impossible Dream* that talked about kids with hydrocephalus and how you can't just put in a shunt and say goodbye and let them go. They would be under your care forever and ever.

CYNTHIA: Our presence at the meeting was new for us, but it was also new for the physicians, too. They didn't want to talk to patients. The attitude then was that patients were too stupid to know or understand; and that talking to patients would take up way too much time.

EMILY: When we found the organization of pediatric neurosurgeons, we felt like we were home. We felt that these doctors had to be special people because who wants to deal with kids with hydrocephalus? They were very concerned about the quality of life for kids with hydrocephalus. When we went to their conference in Phoenix in 1988, we were allowed to attend their professional sessions. We walked into a room and they were talking about shunt revisions and problems. Alexa Canady [the first African-American woman neurosurgeon] stood up and she said to her colleagues, "You know, folks, there's more to hydrocephalus than just all the revisions and shunts not working." Then she brought up the concerns of long-term quality of life. Cynthia and I almost fell off our chairs.

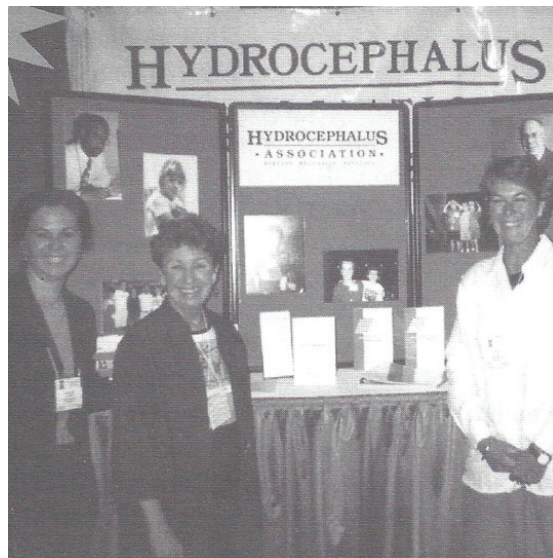
CYNTHIA: Hal Rekate, MD had his entourage of residents and doctors following him around at this meeting. Initially we were totally ignored. But then he came by our table and told us how important our work was. Just by stopping and talking to us, he gave everyone else encouragement to come by. When Hal came by our table, it was like being crowned, and after that we couldn't keep people away from our table.

EMILY: The docs loved us. They didn't have any educational materials to give their patients, so they were great about passing out our information. They were excited that they finally had something they could give to their patients.

When they realized they were just as concerned as we were about these kids and their futures, we were able to form a partnership. The challenge we met successfully was forming this collaborative relationship with doctors.

CYNTHIA: The meeting was a key defining moment. This type of partnership didn't really exist at the time with any medical condition. What they learned is that if you give patients the time and information and resources, you'll spend less time with them overall because the more we know, the less fearful we are. HA became a translator across the healthcare paradigm because in those days, doctors did not talk to patients.

HA: What would you say some of the other key moments or accomplishments are of HA?



*Jennifer Henerlau, Emily, and Pip Marks,
Annual Meeting of the Congress of
Neurological Surgeons, Philadelphia, PA, 2002*

CYNTHIA: In the early days, there were a lot of battles for parents not accepting the status quo and having to push. It bothered me that nurses didn't like me but it gets to the point where you don't care. Your kid's life is on the line. The doctors thought you were crazy. But parents know their child best. When parents learn not to panic and trust their instincts, then they are better able to advocate for their child and teach their children how to advocate for themselves. I do believe that we were one of the very first organizations to teach advocacy.

EMILY: People with hydrocephalus were totally alone and had no information. The key was we connected people, and educated ourselves and others with the help of the doctors.

CYNTHIA: We worked hard to bring the best doctors on board and eventually the cream of the crop became our medical advisory board. We chose the first members of the board, but very soon, doctors wanted to be a part of the medical advisory board. It was an honor for them. It was a medical culture shift, I believe. I think that HA can feel very proud of its role in early patient engagement. Our first patient/parent/professional conference was the first of its kind.

EMILY: We created a community where doctors talked to patients. The doctors came to our conferences. Seeing a patient talking to a neurosurgeon, one-on-one, at our conference was powerful. A neurosurgeon spent five minutes

just talking to a family. 25 to 30 years ago many people were seeing adult-focused neurosurgeons and not pediatric neurosurgeons, so to see doctors talk to patients and their families and answer their questions was very meaningful.

HA: In the early years, you also had the insight to reach out to the shunt manufacturers to involve them as well.

EMILY: We always talked about community and to us it meant parents, professionals, and industry. When we started going to annual meetings, we were able to connect with the shunt manufacturers, too. Shunts were a small part of their business. Doctors were saying [these companies] needed to pay attention to us. By being at the meetings and having doctors say they get all their shunts from X company, that connected us with the sales people and business side of hydrocephalus. This is how I met Ralph Kistler, who was with PS Medical at the time, which is now Medtronic. He still serves on our board of directors today.

HA: Cynthia, you were the one to make the initial contact with Marvin Sussman, who has become an active and engaged member of the Association from its inception, as well. How did you bring him onboard?

CYNTHIA: Marvin used to be a vice president with Cordis, a shunt manufacturer. Alex had had many surgeries because his shunt kept failing. I was mad at the world and trying to figure out what to do and where to go. I called Cordis and said I needed to talk to someone because I didn't understand how these shunts worked because it was not working on my kid. They transferred me to Marvin who spent a lot of time on the phone with me and sent me a packet of information on shunts, how they work and what they do. He went on to create wonderful ideas for us. It was his idea for me to fund the Resident's prize.

It seemed like we would reach out and we were able to get people on board. What fueled us was the fact that we didn't want to lose the kids.

HA: Where do you see HA five years from now?

EMILY: First, to continue to be on the forefront of researching and publishing first class, cutting edge information on hydrocephalus, shunts, and where the field is going. If someone wants an answer to a question or needs technical information, they go to HA.

Second, we need to continue to provide one-on-one support. You can't duplicate a personal phone conversation. Sitting down and talking over the phone to a family or meeting them in person is still crucial. HA needs to continue to provide the best personal support we can, using all types of tools.

Third, focus on the first generation of children shunted for hydrocephalus that are now adults. HA needs to con-

tinue to involve this generation, to empower them and educate them. TTC [Teens Take Charge] is crucial for the next generation's well-being and quality of life. HA needs to develop programs to sustain their involvement as they grow.

Fourth, I would love to see a lot more money for research – interdisciplinary research. I remember hearing a talk by a doctor who was a glaucoma specialist and hearing her discuss possible connections with hydrocephalus.

CYNTHIA: I'm so proud of what the organization has become and all the wonderful work that has been accomplished since I've been gone. I think it's on the right path. I think, given the way healthcare is going and the competition for research dollars, we're not going to be able to rely much longer on NIH. We're competing with so many conditions. I think the changes in how hydrocephalus is treated will come out of the research and the drive of HA. I don't think it will be one scientist here or one medical school there, but that the HA will create collaboration and coordination of all the research going on and the best practices and it will define, in the future, the way hydrocephalus should be treated and the management advances. Instead of being reactive, we've come full circle where we have an organization that's proactive. When we talk about consumer-centric healthcare, the HA is the epitome of that.



Join the Fudge Solomon Legacy Society

The Legacy Society provides an opportunity for supporters to ensure the organization's research, support, advocacy and education work continues by placing a future gift to HA in their wills, trusts or estate plans. When you join, you will demonstrate your commitment to HA's mission to eliminate the challenges of hydrocephalus and help to ensure the long-term reach of the organization's programs

If you would like to join or learn more about the Society, please e-mail giftplanning@hydroassoc.org or contact

Aisha Heath, CFRE
(888)-598-3789 ext. 17.

HA Partners with Rudi Schulte Research Institute for Research Grant

By Ashly Westrick, Research Programs Manager

In November 2012, we announced a new award in Cerebrospinal Fluid (CSF) Production, Flow, and Regulation Therapeutics and Diagnosis in partnership with the Rudi Schulte Research Institute (RSRI). RSRI has long been the sponsor of our research keynote speaker at our bi-annual education conference. This year, they expanded their partnership with us to co-sponsor our hydrocephalus research conference – “Opportunities in Hydrocephalus Research: Pathways to Better Outcomes” in Seattle in July 2012. That sponsorship was intended to help RSRI develop a picture of promising hydrocephalus research for the Institute to tackle. Having completed the consensus conference, we have now partnered with RSRI to fund the CSF grant. With this grant, we hope to encourage novel and innovative hydrocephalus research. At the conclusion of the review process, RSRI is expected to select one or two researchers and invest at least \$600,000 in advancing this research over three years. We received a total of 13 proposals and are enthusiastic about the science dedicated towards hydrocephalus research.


Final applications will be reviewed by our Scientific and Medical Review Committee (SMRC) comprised of a distinguished panel of hydrocephalus researchers. The Chairman of the Committee is Donna Ferriero, M.D., a Pediatric Neurologist from the University of California San Francisco (UCSF) Benioff Children’s Hospital. Dr. Ferriero is Professor in Neurology and Pediatrics at UCSF. She is also the Director of the Neonatal Brain Disorder Center at UCSF, and a member of the National Institutes of Health (NIH) National Institute of Neurological Disorders and Stroke (NINDS) Advisory Council since 2010.

The Committee reviewers include a number of highly talented and accomplished hydrocephalus researchers.

- William G. Bradley, Jr M.D., Ph.D., FACR, is Professor and Chairman of the Department of Radiology at University of California, San Diego. Dr. Bradley is past president of the ISMRM. He served on the Board of Trustees of the RSNA Research and Education Foundation (1995–2001) and as the Chairman of the Fund Development Committee of that organization from 1996 to 2008. He was honored with the Gold Medal of the RSNA in 2003 and that of the ACR in 2012. Dr. Bradley is currently on the Boards of the International Society for Strategic Studies in Radiology, the Association of University Radiologists, the Academy of Radiology Research and the Academy of Radiology Leadership and Management.
- David Frim, M.D., Ph.D. is Professor and Chief of Neurosurgery at the University of Chicago, and has clinical interests in hydrocephalus and congenital anomalies of the nervous system, epilepsy, functional and stereotactic neurosurgery. His research interests include hydrocephalus, chiari, cerebrospinal fluid dynamics, ICP, cognitive outcomes in neurosurgery, and neural substrates of injury and protection. Dr. Frim’s current investigations include studies of the neuroprotective effects of surfactant poloxamer molecules, investigations of the cognitive outcomes in hydrocephalus and Chiari patients, and development of treatment strategies for congenital complex anomalies of the nervous system.
- John Kestle, M.D. is Professor of Neurosurgery and Chief of the Division of Pediatric Neurosurgery at the University of Utah and Primary Children’s Medical Center. His clinical practice specializes exclusively in pediatric neurosurgery with a specific interest in pediatric epilepsy surgery. Dr. Kestle’s research is in clinical trials. He developed and chairs the Hydrocephalus Clinical Research Network (HCRN). He is also a director of the American Board of Pediatric Neurosurgery and was Chair of the Scientific Committee of the International Society for Pediatric Neurosurgery from 2009-2012. On March 25, 2013, he became Head at the Department of Surgery University of British Columbia in Vancouver.
- Miles Johnston, B.Sc., Ph.D. received his Bachelor of Science degree in physiology/pharmacology and his PhD in the Division of Experimental Pathology and Department of Pathology at the University of Toronto. He subsequently completed his Doctoral Training at the A.R.C Institute of Animal Physiology in Cambridge, England. Dr. Johnston has been the Senior Scientist of Clinical Integrative Biology at the Sunnybrook Research Institute and Professor of Laboratory Medicine and Pathobiology at the University of Toronto. His research investigated CSF transport and testing the hypothesis that discontinuity between CSF compartment and extra-cranial lymphatic vessels leads to hydrocephalus.
- Jill Morris, Ph.D. is currently Program Director at the National Institutes of Health (NIH) National Institute of Neurological Disorders and Stroke (NINDS). Her grant portfolio consists of multiple neurological disorders including hydrocephalus, cerebellar malformations, tuberous sclerosis, neurofibromatosis, and leukodystrophies. Prior to her arrival, Dr. Morris amassed an extensive history of genetic and neurobiology research. From 2003 to 2011, she was an Assistant Professor in the Department of Pediatrics in the Feinberg School of Medicine at Northwestern University and Children’s Memorial Research Center where her laboratory investigated the molecular basis of psychiatric disorders. Prior to her position


at Northwestern University, she was a Senior Research Biologist in the Department of Neuroscience at Merck Research Laboratories.

- Jan-Marino (Nino) Ramirez, Ph.D. is Professor of Neurological Surgery and Director of the Center for Integrative Brain Research at the Seattle Children's Research Institute. Dr. Ramirez has a general research interest in the neural control of rhythmic activity. His specialty is neural mechanisms involved in the generation of respiratory rhythms, neocortical activity, and epilepsy. He is also interested in the neuronal mechanisms underlying erratic breathing in Rett syndrome, familial dysautonomia, congenital hypoventilation syndrome, traumatic brain injury, and pediatric epilepsy, as well as burst firing in dopaminergic neurons, possibly linked to ADHD. Dr. Ramirez's current work is focused on hypoxic effects on mammalian respiratory neural networks. His work is supported by multiple National Institutes of Health (NIH) awards.

About RSRI: Rudi Schulte was one of the two founders of a shunt manufacturing company called PS Medical, later acquired by Medtronic. Through his ground-breaking work, the hydrocephalus shunt was developed, the leading treatment for hydrocephalus. Later, in order to further advance research in the treatment of hydrocephalus, Mr. Schulte generously created and endowed The Rudi Schulte Research Institute. Today, RSRI conducts studies to improve treatments for hydrocephalus and other neurological disorders. The Hydrocephalus Association is proud to be working with RSRI to help further this important work. 

Vanderbilt's Pediatric Neurosurgery Department Expands its Research Efforts



The Vanderbilt University Medical Center Reporter reports that Chevis Shannon, MBA, MPH, Dr.PH., will serve as the director of the Vanderbilt Pediatric Neurosurgery Clinical Research Initiative. Dr. Shannon will play an instrumental role in establishing Vanderbilt as a collaborator in the Hydrocephalus Clinical Research Network (HCRN). Before moving to Tennessee, Shannon served as the Assistant Professor and Associate Director of Clinical Research at the University of Alabama Birmingham Division of Neurosurgery. She was also our HA Birmingham, Alabama Support Group leader. 

An Eye on Research

APDC Helps Fund Self-Monitoring Shunt

The Atlanta Pediatric Device Consortium (APDC) is helping fund the development of a shunt that can be monitored wirelessly. The goal of the design is to simplify the detection of shunt malfunctions while reducing the patient's exposure to harmful side effects such as radiation from CAT scans to examine the shunt. The APDC is comprised of Children's Healthcare of Atlanta, Emory University, and Georgia Tech.

Monitor for Detecting Changes in Brain Pressure Heading to Medical Trials

The Wisconsin State Journal reports on Dr. Josh Medow, a neurosurgeon with the University of Wisconsin Hospital, who has created a monitor that can detect changes in brain pressure and send signals to a handheld scanner. The device is now heading into animal trials. We will continue to watch report on this development as it progresses.


New Protocol with Adjustable Shunt Reduces Cases of Subdural Effusion

Medwire news reports on a research study that shows that an adjustable Strata valve shunt set at the highest setting and slowly calibrated down in a patient being treated for idiopathic normal pressure hydrocephalus (INPH) reduces the cases of subdural effusion and shows improvement in gait and/or cognitive function.

Mary Smellie-Decker Award Recipient



The Hydrocephalus Association with the American Association of Neuroscience Nurses (AANN) created an annual award in 2010 to honor Mary Smellie-Decker, RN, MSN, PNP, for her work as a staff neuroscience nurse, nurse practitioner, and member of the HA Medical Advisory Board.

This year the Mary Smellie-Decker award goes to Nadine Nielsen, ARNP, Division of Pediatric Neurosurgery, Seattle Children's Hospital. Nadine embodies the qualities that Mary stood for – mentorship, teaching and leadership. As a pediatric nurse practitioner for neurosurgery she exemplifies care and passion for children with hydrocephalus. Nadine is also an active member of our community. She helped to translate *About Hydrocephalus: A Book for Families* from English to Spanish and is a lead author of chapter: Nielsen N, Pearce K, Limbacher L, Wallace D (2007) *Hydrocephalus*. In: Cartwright C, Wallace D, (eds) *Nursing Care of the Pediatric Neurosurgery Patient*. Springer, Berlin Heidelberg, pp 29-66. Chapter revised in 2012 for revision of new edition in June 2013. 

President Obama Announces Funding for BRAIN Initiative


President Obama announced in early April that he is proposing \$100 million in federal research dollars toward a brain mapping initiative that will ultimately open the door to better treatment options for many brain conditions, including traumatic brain injuries, Alzheimer's disease, and stroke.

A commitment from the White House to delve into the inner workings of the brain is a large step forward for the neurological research community. The Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative aims to unravel the mystery of the structure, function, and development of the brain. Researchers across disciplines are enthusiastic about the gains that will be shared by all through deepening our understanding of the fundamental working of the brain. For the hydrocephalus community, specifically, the benefits of interdisciplinary and cross-condition research bring us hope that we will subsequently also gain a better understanding into hydrocephalus and its diagnosis, treatment, and ultimately prevention.

The funding comes from the National Institutes of Health (NIH), the Defense Advanced Research Projects Agency (DARPA) and the National Science Foundation (NSF) with the intention of attracting partnerships among companies, research universities, foundations, and philanthropies. NIH will establish a working group to determine the goals of the Initiative and create a plan to achieve them. The working group will be chaired by Dr. Cornelia "Cori" Bargmann with The Rockefeller University and Dr. William Newsome from Stanford University. The White House states that funding details will be laid out in the President's 2014 proposed budget, which is expected to go to Congress around April 10, 2013.

We encourage you to visit the [White House Blog](http://www.whitehouse.gov) to view the official announcement and learn more about the BRAIN Initiative. www.whitehouse.gov.

Dr. Francis Collins, the Director of the National Institutes of Health, has produced a video that provides an overview of the BRAIN Initiative called *On The Clock: The BRAIN Initiative*. You can view the video online on the White House YouTube channel (www.youtube.com.)

NIH has also produced a detailed publication on the BRAIN initiative. It can be found on their website at www.nih.gov/science/brain/index.htm. 

Genetic Mutation Found as a Cause of Neonatal Hydrocephalus

A recent study has shown that a specific type of neonatal hydrocephalus can be caused by defects in cellular signaling pathways. The study, out of the University of Iowa, is being led by Val C. Sheffield, MD, Ph.D, and his research team using a mouse model of Bardet-Biedl syndrome (BBS). BBS is a rare disorder that can cause hydrocephalus, among other conditions.

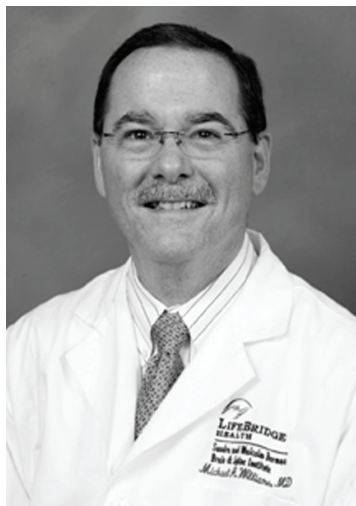
The researchers initially believed that a defect in the motile cilia, which moves the cerebrospinal fluid (CSF) through the ventricles, were to blame for the development of hydrocephalus. But they found that the motile cilia were not significantly abnormal. Calvin Carter, a graduate student in Dr. Sheffield's lab and Timothy Vogel, MD, began to investigate further into why BBS was causing hydrocephalus. They found that the BBS mice had defects in their gene function which caused increased apoptosis (cell death) and decreased cell proliferation which resulted in hydrocephalus. Furthermore, they found that the administration of lithium to pregnant mice whose pups were carrying the BBS mutation prevented hydrocephalus in the pups. This indicates that lithium could have the potential to treat this specific form of neonatal hydrocephalus.

The study's findings are significant because they identify a potential genetic mutation as a cause of neonatal hydrocephalus, as opposed to a physiological defect. Traditional approaches to understanding and treating hydrocephalus have revolved around the brain's structure and the consideration that hydrocephalus can be viewed as a "plumbing" problem. The discovery that lithium could ameliorate the effects of these mutations indicates a potential treatment for this specific type of genetic neonatal hydrocephalus.

Another aspect of this study that is important for hydrocephalus research is the involvement of a world-renowned research institute. One of the researchers working on the study, Dr. Val Sheffield, is a Howard Hughes Medical Institute Investigator (HHMI). There are approximately 330 HHMI investigators in the world. The HHMI urges researchers to take risk and to embrace the unknown. To have an HHMI investigator delve into the problem of hydrocephalus raises the profile of hydrocephalus and validates it as a valuable area of research in the scientific community. As an association, our hope is that more and more researchers will take note, further stimulating the number of research studies on hydrocephalus.

An interview with Dr. Sheffield can be found in *Neurology Today*, February 7, 2013 edition. 

Dr. Michael Williams Named President of the International Society for Hydrocephalus and Cerebrospinal Fluid Disorders




The Hydrocephalus Association would like to congratulate Dr. Michael A. Williams on being named president of the International Society for Hydrocephalus and Cerebrospinal Fluid Disorders (ISHCSF). The announcement was made at the association's conference in Kyoto, Japan which took place October 19 – 22, 2012.

Dr. Williams is a member of the Hydrocephalus

Association's Medical Advisory Board and served as the co-chair of our 12th National Conference on Hydrocephalus held in Bethesda, Maryland, this past June. He recently received a grant of approximately one million dollars from the National Space Biomedical Research Institute (NSBRI) and NASA's Human Research Program to help investi-

gate questions about astronaut health and performance on future deep-space exploration missions.

Dr. Williams is among the world's most recognized specialists in the field of hydrocephalus and CSF disorders. He is the director of the Brain and Spine Institute's Adult Hydrocephalus Center at Sinai Hospital of Baltimore, which provides internationally recognized expertise in the diagnosis, treatment and management of adults with hydrocephalus and related conditions.


In his new role as President, Dr. Williams will work to further the mission of the ISHCSF, which is to "advance the art and science of the field of clinical care and research in hydrocephalus and CSF disorders and thereby promote the best possible care for patients with these disorders." The Hydrocephalus Association heartily congratulates him on this latest acknowledgement of his leadership and expertise in the field of hydrocephalus. 

Hydrocephalus Clinical Research Network Update

A Major Milestone for HCRN and Hydrocephalus


By Dr. John Kestle

Each year the *US News & World Report* ranks children's hospitals. They send out a request for data from the hospitals and send surveys to doctors around the country to gauge the reputation of each hospital. Many of the questions are the same from year to year but occasionally new ones are added. For the first time, this year the survey asks if the hospital's Pediatric Neurosurgery Program participates in the Hydrocephalus Clinical Research Network.

We are very happy to see this. It means that the editors of *US News & World Report* consider HCRN participation to be important enough to include it as a criterion to evaluate children's hospitals. But it is also validation for the importance of hydrocephalus treatment in the specialties of pediatric hospitals. 

HCRN in Africa

By Dr. John Kestle

At the last HCRN meeting (November 2012), we discussed ETV/CPC (Endoscopic third ventriculostomy with choroid plexus coagulation). This procedure was pioneered by Dr. Ben Warf (Boston Children's Hospital) during his time in Uganda and he was a guest at the November HCRN meeting. He reviewed the technique and his data and we discussed the possibility of doing an HCRN study on this procedure. We felt that the first important step in that direction was for some HCRN members to gain additional experience with the technique. Dr. Warf kindly offered to train some HCRN investigators in Uganda. He makes periodic trips there to treat children with hydrocephalus at the Cure Children's Hospital of Uganda. In January, Dr. Riva-Cambrin from the Salt Lake City HCRN center, Dr. Whitehead from the Texas HCRN center and Dr. Rozzelle from the Birmingham, Alabama HCRN center worked with Dr. Warf in Uganda. Other investigators will be doing the same later this spring. We hope this experience will allow us to study this innovative procedure in the near future. 

Seizures and Hydrocephalus

By Karima Roumila, Director of Support and Education

Seizures are not an uncommon occurrence in people with hydrocephalus. However, no correlations have been found between the number of shunt revisions or the site of shunt placement and the risk of developing seizures.


Past studies have shown:

- Children who have been shunted for hydrocephalus and who have significant cognitive delay or motor disability are more likely to develop seizures than those without cognitive or motor delays.
- Seizures are not likely to occur at the time of shunt malfunction.
- The most likely explanation for the development of seizure disorder is the presence of associated malformations of the cerebral cortex.

Recent studies also show that patients who undergo hemispherectomy surgery for medically intractable epilepsy may develop hydrocephalus. A significant portion of these patients develop hydrocephalus on a delayed basis, indicating the need for long-term surveillance.

For more information on epilepsy/seizures and hydrocephalus read the following articles and/or visit our online Hydrocephalus Resource Library and search for articles using keywords like seizure, epilepsy.

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- Epilepsy Foundation: <http://www.epilepsyfoundation.org/> 

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.

Thinking About A Tablet As A Gift?

As technology gadgets have become the “gift to give,” there has been a concern about shunts and the use of tablets (iPads, Galaxy tablet...etc.) in the recent years. Can they change the shunt's setting?

Typically we hold an iPad or tablet device in our laps, and not balanced on our heads. And our houses contain magnetic devices that individuals with shunts are around on a daily basis. Why the concern with the tablets? As one mom pointed out, sometimes children are playing with their tablet, maybe in bed or on the floor, and they fall asleep. The tablet ends up near their head.

A group of investigators from the Department of Neurosurgery at the University of Michigan, Ann Arbor, Michigan, investigated the effect of a tablet computer on performance-level settings of a programmable shunt valve. They exposed programmable shunt valves to the tablet device with and without the cover at distances of less than 1 cm, 1–2.5 cm, 2.5–5 cm, 5–10 cm, and greater than 10 cm, 100 times for each distances, and they recorded any changes in valve settings.

After reviewing the results, the authors concluded: “... we acknowledge the likelihood that at least some of the changes in performance level that were observed would not have resulted in a clinically relevant change for a patient.” (Maher et al, *J Neurosurg Pediatrics* 10:118–120, 2012). The authors point out that the original iPad does not contain magnets, therefore these results do not apply to the device. What they found was that iPad 2 devices may alter programmable shunt valve settings, particularly when the tablet is in close proximity to the shunt valve, namely under 2.5 cm or within one inch away from the valve.

The “gift to give” can certainly bring a smile to someone’s face. But as with any device, have some knowledge at hand when you make your purchase. Know the type of shunt you or your loved one has. Is it a programmable shunt? Ask if the devices you want to purchase have magnets. Finally, once you have purchased your new gadget, use it knowingly and wisely.

For more details please read the original paper published in the Journal of Neurosurgery:

- Jennifer Strahle, M.D., Béla J. Selzer, N.P., Karin M. Muraszko, M.D., Hugh J. I. Garton, M.D., M.H.Sc., and Cormac O. Maher, M.D. *Programmable shunt valve affected by exposure to a tablet computer*. J Neurosurg Pediatrics 10:118–120, 2012 <http://thejns.org/doi/pdf/10.3171/2012.3.PEDS1211>

You may also read these recently published articles:

- *iPad Risky for Hydrocephalus Shunt Valves*, By Crystal Phend, Senior Staff Writer, MedPage Today: Getting too close to a newer iPad may cause magnetically set shunt valves to malfunction, researchers found. <http://www.medpagetoday.com/Surgery/Neurosurgery/33485>

- *iPad 2 and Other Tablet Computers May Interfere With Magnetically Programmable Shunt Valve Settings*, ScienceDaily, June 26, 2012, www.sciencedaily.com/releases/2012/06/120626092544.htm

Your Feedback is Important: National Conference On Hydrocephalus Survey

The Hydrocephalus Association strives to offer the highest quality educational and networking events during our National Conference on Hydrocephalus, traditionally held every other year in cities across the United States. We are constantly looking for ways to improve the event. We hope you will take some time to share your thoughts and comments with us by completing our online survey at www.surveymonkey.com/s/SLXJ2TP.

This survey should only take about 10 minutes of your time. Your answers will be completely anonymous and by filling out the survey you will be entered into a drawing for an Amazon gift card. All survey results will be compiled together and analyzed as a group. Please note that any questions marked with an asterisk (*) require an answer in order to progress through the survey.

Thank you in advance for sharing your opinions with us on this important matter!

Why I Joined the Fudge Solomon Legacy Society

By Sally Baldus

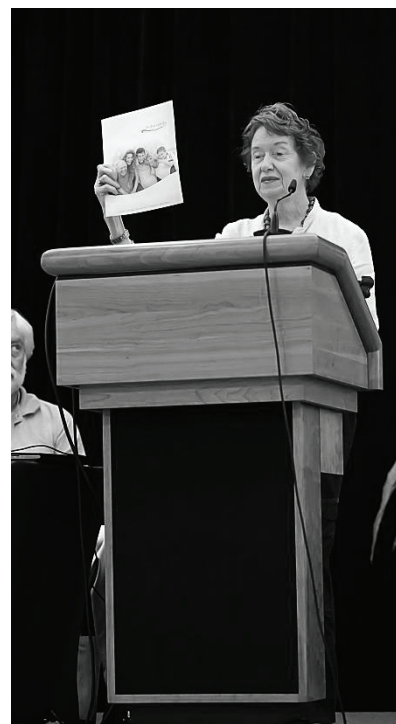
The Hydrocephalus Association has been a high priority of mine since its inception. When the Fudge Solomon Legacy Society was created, it was perfectly natural for me to step up and become a charter member.

I am the aunt of Gerard Fudge. My sister and brother-in-law, Emily and Russell Fudge (Gerard’s parents), along with Cynthia Solomon started the Association 30 years at the Fudge’s kitchen table. The Association quickly became my charity of choice and I have been a supporter from the beginning. Watching the HA grow into the internationally recognized “go to” group for hydrocephalus support, education and advocacy along with a focus on research, has been totally rewarding for me and my family.

I joined the Fudge Solomon Legacy Society by adding a gift to the HA in my will. It was so easy; no lawyers needed. I simply added wording leaving a specific amount and got the document notarized. I am committed to ensuring that the HA’s mission is fulfilled and feel that my contribution as a Legacy Society member will help make this possible.

If you or a loved one has been affected by this condition, I encourage you to join me and the other current Society members who are helping to insure the viability of the Hydrocephalus Association into the future. To receive a copy of the brochure or to schedule a personal consultation, please e-mail me at giftplanning@hydroassoc.org.

Thank you. *Sally Baldus*



Are You An Assertive Member of Your Health Care Team?

We asked on our Hydrocephalus Association Facebook Page:

"Many of us work with a team of health care providers. What are your top three tips on how you communicate with them to be an assertive and effective member of the team?"

We had received some really valuable input and feedback. Here is what some of you shared with us:

Karin Buchanan:

1. Do your homework! Learn everything you can about your/your child's condition from reputable sources.
2. Speak up! You are the expert on your own or your child's day-to-day life experience. Your knowledge will round out the big picture for the clinicians.
3. Get involved! Join a fund raiser or start your own that will help you feel empowered to DO SOMETHING to make a difference for your/your child's future.

Kathi Tackel Hodgkins:

"For a regular visit I put all questions in writing, present to nurse before visit. In an emergency, I have to be very direct about what my family member needs"

Lacey Beckelhymer:

1. Ask plenty of questions
2. Let them know as soon as there is an issue they can't help if they don't know what's going on
3. Awareness

Angela M. Carter:

"Know your medical history and complications"

The most important thing to remember as you work with your or your loved one's healthcare team is you are in a partnership. The key to this relationship is good communication.

It is important to be an active participant in the decision making process about the necessary care for you or your loved one. Going to a doctor's visit could make someone nervous, impatient and even scared, so preparing for the visit will help you get the information you need and facilitate the communication between you and healthcare team.


Remember:

- Be organized. Come to the doctor's office prepared with information about your symptoms.
- Prepare a list of your questions about your symptoms, medications you are taking.
- Consider taking a family member or a trusted friend, ask them to write things down for you and remind you about questions you shared and you wanted to ask the doctor
- Don't be rushed. Ask plenty of questions and feel confident that you understand the answers.
- Demonstrate your knowledge and flexibility by actively participating in the decision-making, planning and evaluation processes. Avoid aggression and conflict by assuming responsibility and taking every opportunity to be assertive.
- There is no need to feel intimidated. To achieve their objectives professionals need your help just as much as you need theirs. Be assertive- mutual respect is a great basis for a relationship!
- Make sure you understand the role of each member of the treatment team.
- If you think a second opinion would help, never hesitate to ask for one.

For more in depth tips on 1) how to partner with your healthcare provider and be assertive, and 2) how to select a doctor, visit our website or call us for the following fact sheets:

- *How to Be an Assertive Member of the Treatment Team.*
- *Second Opinions*
- *Questions To Ask Your Doctor*

Other helpful resources can be found at the following:

- *Talking With Your Doctor: A Guide for Older People.* National Institute on Aging. (<http://www.nia.nih.gov/health/publication/talking-your-doctor-guide-older-people>)
- *Talking with your doctor.* MedlinePlus. (<http://www.nlm.nih.gov/medlineplus/talkingwithyourdoctor.html>)
- *Quick Tips—When Talking with Your Doctor.* AHRQ Publication No. 01-0040a, May 2002. Agency for Healthcare Research and Quality, Rockville, MD.
- *How to Talk to Your Child's Doctor.* Nemours Foundation. (http://kidshealth.org/parent/general/sick/talk_doctor.html)
- *Talking to Your Doctor.* National Eye Institute. Also available in Spanish. (<http://www.nei.nih.gov/health/talktodoc.asp>) 

In the Footsteps of Our Founders: The HA Support Group Network

The Hydrocephalus Association (HA) started as a support group in 1983 when two of our founding members, Russell and Emily Fudge, found themselves feeling frustrated, confused, and alone after their son's second shunt revision. With the help of their son's neurosurgeon, they were united with other parents looking for answers and support.

For the last 30 years, HA has been the trusted source that patients, families and health professionals turn to for support and information. One of the ways HA is able to provide direct support to individuals who have been diagnosed with hydrocephalus, as well as to their family, friends and caregivers, is through our local support groups.

Following in the footsteps of our founding members, our support groups thrive throughout the country. This past year, the Hydrocephalus Association launched 8 new support groups and hosted 77 meetings in 25 states. While many of us venture to our first support group meeting looking for answers and for someone...anyone...who understands what we are going through, we often come back for the community and life-long friendships. Support groups host guest speakers, celebrate milestones and

achievements of its members, support individuals in need, and spark new friendships. All of this is made possible only through the dedication of our entirely volunteer team of support group leaders.

In addition, to our local support group meetings, HA initiated numerous closed groups on Facebook. These are overseen by local volunteers, support group leaders and WALK chairs. These closed groups are a setting where only members of the group can post to the wall or see what is posted. Similar to support group meetings, this new online forum provides a space for individuals to connect, share information give and receive support 24/7.

Support Groups are a valuable resource and we are profoundly grateful to our volunteers for their selfless dedication, time and effort. We hope you can join us at a meeting in 2013 and don't forget to connect with your local support group on Facebook! For upcoming meetings, please visit our Upcoming Events Calendar on our website or email Jennifer Bechard at support.liaison@hydroassoc.org.



Support Group Network

We hope you can join us at a local support group get-together this year!

AL	Birmingham	Peds/Adolescents
AZ	Phoenix	ANPH
	Tucson	All Ages
CA	Chico	All Ages
	Fresno (online)	All Ages
	Los Angeles	All Ages
CO	Denver	All Ages
CT	Hartford	All Ages
FL	South	All Ages
	Central	Peds/Adolescents/Adult
	Central	NPH
GA	Atlanta	Peds
IA	Cedar Rapids	All Ages
IL	Chicago	Peds/Adolescents
MA	Boston	All Ages
MD	Baltimore	All Ages

MI	Detroit	All Ages
	Mid	All Ages
MN	Minneapolis	Peds/Adolescents
MO	Online	All Ages
NC	Charlotte	All Ages
NJ	Morristown	All Ages
NY	Buffalo	All Ages
	Long Island	All Ages
OH	Online	All Ages
OK	Owasso	All Ages
PA	Philadelphia	All Ages
	Pittsburgh	Peds
TX	Dallas	All Ages
	Houston	Peds/Adolescents
UT	Salt Lake City	Peds
VA	Richmond	All Ages
WA	Bremerton	Peds/Spina Bifida
	Seattle	Peds

You're Not In This Alone

By Jennifer Bechard

As we look back, we ask where we would be without our volunteers. Our volunteer leaders across the country have helped weave the rich tapestry of our HA history. Jennifer Bechard, our Support Group Liaison, sits down with our Virginia Support Group Leader, Annie Mason.

HA: How did you find HA and why did you decide to volunteer?

ANNIE: In 2003 our daughter was diagnosed with hydrocephalus. Somewhere in the back of my mind I remember my own mother talking about a neighbor's infant who had "water on the brain" and that they were putting something into her brain to drain the fluid. My husband and I had so many questions and fears. After our neurosurgeon performed an Endoscopic Third Ventriculostomy (ETV) our daughter did quite well, but, as a parent, I wanted more information. After searching the internet for resources I found the Hydrocephalus Association (HA). HA has been a wonderful source for questions and answers. Searching the internet also provided me with connections to other individuals who are dealing with the condition, but many times they were infants or adults living with Normal Pressure Hydrocephalus (NPH). I wanted and needed to find parents and children who were closer to our 13 year-old daughter's age and eventually I did. Through email and phone conversations I asked where my husband and I could find a support group in Virginia. The answer was "there are none." Shortly after our daughter's second ETV surgery I partnered with the Hydrocephalus Association to start and lead the support group in Virginia.

HA: What resource has been most valuable for you and your family?

ANNIE: Our daughter's neurosurgeon handed me a booklet on the day we had our consultation before her surgery in 2005. I was so distraught that I could not look at it for weeks. As she continued to do well, and return to her daily routine I came across the booklet and browsed through it. It was an early edition of *About Hydrocephalus: A Book for Families*. It was after this that I went to the HA website and started to make contact with people at the association.

One of the first things that came to light was a WALK being held in Detroit. I felt compelled to watch the dollars grow, and read the stories about this young 20-yr-old girl who had so many surgeries that it was unimaginable. It gave me such pleasure to join the many who were stepping in to raise funds, raise awareness, and make this condition known to the world. Jennifer Bechard has become such an

inspiration to so many, and she was the one who encouraged me to start a support group in Virginia.

HA: What do you love most about being a support group leader?

ANNIE: Our support group is entering its third year as an established group. We have grown from one attendee at our first meeting to over 50 members who have come to meetings or have joined our closed group on Facebook. The families are awe-inspiring and what I love most is sharing stories of our challenges and discovering that we have so much in common, even as our group services all ages.

HA: What is your most cherished moment or memory?

ANNIE: I love my support group meetings as I have come to know so many families. My most cherished moment, however, will always be my first meeting. It was a dreary, foggy January evening and it turned out that only one lady joined my husband, daughter and me. We started with introducing ourselves around the table. When it came to this woman, whom we had just met, she told the story of her young 5 year-old and it was heart-wrenching. He had been through so much at his young age and this mom just needed someone to talk to who would understand. I let the rest of the evening be a conversation between her and our own daughter who has hydrocephalus. I could see that our daughter, who had recently had surgery and was now entering college, was giving this woman hope.

HA: What do you feel makes a "great" support group?

ANNIE: Some of our support group meetings have professional speakers, others offer practical topics. But foremost, "support" is what ALL of our meetings are about: hope for better treatment plans; hope for medical advancements; hope for a future with fewer hospital visits; hope for a cure. Sharing our stories and making new relationships through support groups is imperative to giving those affected by this condition a chance to know that they are not in this alone.

HA: If you could send a message to HA, what would it be?

ANNIE: I am so grateful to the Hydrocephalus Association. The fears and apprehension of those early days of diagnosis were alleviated for my husband and me, and especially for our daughter. We have been supported by her doctors, nurses and medical staff. We have also gained essential information from the association established by founding members, Emily Fudge and Cynthia Solomon, and all those who have worked so hard during the last 30 years. Together, we can look forward to a bright future for all the families who face the challenges of hydrocephalus.



Annie with members of the Richmond Support Group

Taking on High School with No Regrets

By Madeleine Darowiche



Starting high school can be tough, especially when you are dealing with a medical condition such as hydrocephalus. I started high school two years ago, and I am now a junior. Even though I luckily have not dealt with any shunt revisions in 6 years, I really felt the other effects of hydrocephalus during my freshman year. I was not real social, and when people would talk to me, I was terrified to even respond. I would always sit alone at lunch because I was so scared to interact with others. I would not say anything when a teacher would call on me. I also never told anyone that I had hydrocephalus.

Looking back, I think I should have because people might have been more understanding with me. There were people who tried to be my friend, but I think I would miss all the nonverbal cues which just made me seem even more aloof. I also was struggling in math as I always have, and even after my mom and I tried to explain the condition, my teacher kind of just shrugged it off. I was so miserable my freshman year because I was so scared of basically everyone.

Now in my junior year of high school, things are so much better. I have a great math teacher who is really patient and understanding. I have an A in math now and I used to get C's and D's. I have gotten more confidence in talking to people. I am still really shy, but I have come such a long way from where I was. Attending the National Conference on Hydrocephalus this summer really helped with my confidence.

My best advice for any of you high school freshmen is to not be afraid to talk to people. Most people will be nice. Do not be afraid to educate teachers and other students about hydrocephalus. Even if they do not listen, you will know you tried. I regret some of the things I did not do, but I am fixing them now. Do not make the first year of high school a year of regret. Everything will turn out okay in the end. Have that confidence that first year, and you will set up your four years to be awesome. Please listen so you do not make the same mistakes I did, if you already made them, do not be afraid to fix them, it is never too late, as I learned this year.

Here is a picture of me with my friend at the South Florida Hydrocephalus Association WALK. I had told her about the walk and my hydrocephalus back in August, when school started. She remembered it, and a few days before the walk she asked me when it was. I told her, and

she said she would come. I was skeptical about it, but she came, and I really got to know her better even though I have known her since freshman year. It made me realize, that for the first time since I began high school, I actually had a peer who really understood the condition and a real friend. This meant so much to me because I tried telling other students about hydrocephalus once I started junior year since I wasn't embarrassed about the condition after the conference. They never listened or showed interest.



RESOURCES:

- [Healthcare Transition Guide for Teens and Young Adults](#)
- [Teens Take Charge Facebook Page](#)

For more information, visit www.hydroassoc.org, email us at info@hydroassoc.org, or call us at (888) 598-3789. 

Preparing Yourself for College

Introduction by Jennifer Bechard

Article by Ashley Snyder



Are you getting ready to graduate from high school and take the much anticipated leap to head off to college? This is a very exciting time in one's life, but for individuals living with a complex medical condition like hydrocephalus it can also be a scary and intimidating step to take. We want you to know that you are not alone and that there are programs and resources available to support and guide you through the transition process. Teens Take Charge (TTC) Advisory Council Member Ashley Snyder shares her personal experiences and offers some great advice and tips for her peers as they begin to venture off to college and into the adult world.

After hours spent on standardized tests and multiple pencils chewed to shreds, you finally get into the school of your dreams. Thank goodness, right?! So you got where you wanted to go...but now what? College is one of the best opportunities of your life. Especially living with the challenges that hydrocephalus can present, if you know some basic tips and advice, college can be a walk in the park.

Currently, I am a sophomore studying speech pathology at Auburn University, and I have found the college transi-

tion to be pretty fun and easy, but there were some things that I definitely wish some kind soul would have told me on hindsight. One of the keys to college is communication with your professors. In a lecture hall of over two hundred students, it is easy to be lost, and just another face in the crowd. However, if you visit your professors at office hours or another meeting time that you set up together, you can get the individualized help you need, which is especially helpful if you have a hydrocephalus-related learning disability. If you require special accommodations, nearly all professors will meet them if you let them know about your special needs early in the semester. Extra test-taking time, a seat closer to the front board, and the opportunity to leave a few minutes early or arrive a few minutes late if you are wheel-chair bound are just a few of the accommodations that professors can and will make. Most college campuses also have an office of accessibility, where you can obtain handicap-parking passes, scholarships geared specifically to you, and a host of other valuable resources. The office of accessibility or its equivalent wherever you go, should definitely become your new best friend.

In addition to getting yourself set up in the classroom, it is also important to build yourself a new life away from home full of friends and fun. Try to get involved in one of the hundreds of organizations that there are on your new college campus. Whether it's joining a sorority, becoming a member of the band, or working with tons of other students as a part of the Student Government, getting involved will help you meet people similar to you. And since you already have a common interest and will be spending a lot of time together, making friends should be super easy. That being said, since college is an all-new experience for you with an all-new set of peers, you can also make the decision of whom you want to tell about your hydrocephalus. When I came to college, I chose to only tell a very select few people. Regardless of whom you decide to tell, make sure that your roommate or someone you see every day knows about your condition – that's best for your safety, just in case a problem should ever arise. Everyone else you can tell in your own time – it is your choice now, just like it is with so many other things now that you are a collegian.

It is so exciting to move away from home for the first time, and to finally be in charge of making your own decisions, almost completely on your own. Establish a routine for yourself, including waking up in time for class and breakfast, attending all of your classes, extra-curricular activities, maybe hitting the gym if that is something you usually do, and then establishing a schedule for bedtime. You will thank yourself for having a little bit of self-managed order later.

I am so proud of every single person reading this who has achieved the milestone of being accepted into a college while living with hydrocephalus. You are fantastic, and a testament of what you can achieve when you set your mind to something. You have already accomplished something

that many would have told you is impossible, and yet here you are living out your dreams. I know that with a little hard work and dedication all of you will go on to become the best doctors, nurses, school teachers or whatever you want to be. Always be you, and always be proud of it. Now that you have a little bit of advice for kicking tail at college as much as you have kicked hydro-tail, get on out there and chase your dreams – your future is waiting!

RESOURCES FOR TEENS AND YOUNG ADULTS

From the Hydrocephalus Association:

- College and Hydrocephalus Fact Sheet
- Healthcare Transition Guide for Teens and Young Adults
- 2013 Hydrocephalus Association Scholarship

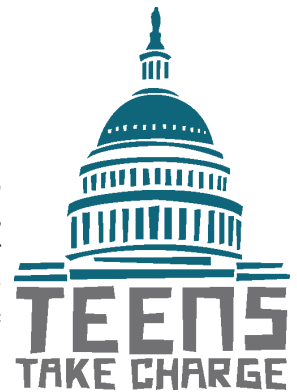
For more information, visit www.hydroassoc.org, email us at info@hydroassoc.org, or call us at (888) 598-3789.

Other valuable resources:

- Grants and Scholarships for Students with Disabilities through The College Grants Database (<http://www.collegegrant.net/disabilities/>)
- Spina Bifida Association (SBA) Scholarship - visit www.spinabifidaassociation.org and search Scholarships

Join Us!

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



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

Be Brave and Share Your Story! You Never Know Who Will Step In and Support You

By: Mindy Weinstein



At the age of fourteen, I didn't want to be viewed differently. I didn't want to be labeled as "the girl who had brain surgery and almost died." Years later, I have tried to change this way of thinking.

Unlike many people who suffer from hydrocephalus, I wasn't diagnosed until I was a teenager. The signs were there for years: excruciating headaches, nausea and blurred vision. For my parents, though, the diagnosis was still a shock.

Each and every person who has battled hydrocephalus has a unique story and account of his or her struggles. My hydrocephalus story really began in July 1994 when I was finally diagnosed. What should have been an average summer day was anything but. I woke up in the early hours that morning with a headache I had never experienced before. I had other symptoms, as well, that caused my parents to be alarmed. They decided to take me into the local urgent care.

I don't remember a lot from that day, so most of what I know is based on my family's explanation. When we reached the urgent care, my father had to carry me, as I had fallen into a deep sleep. Despite the signs I was exhibiting of hydrocephalus, the doctor diagnosed me with the flu and sent my parents and me home. That is when things took a worse turn. I became unresponsive and, call it a parental instinct, but my mother recognized something else was happening. My parents rushed me to the hospital where I was diagnosed with hydrocephalus. My brain had swollen to four times its normal size.

I was fortunate to survive, but I actually look at it as being blessed. At that time, I received my first shunt and the doctors determined I was born with an abnormality in my ventricles, which led to hydrocephalus.

Why Wouldn't I Shout it From the Rooftops?

You would think that I would have told everyone how it was a miracle I survived and had no side effects from hydrocephalus or the surgery. Instead, I kept it a secret from my schoolmates and went about life as normal.

Fast forward seven years when my shunt failed for the first time. I had been married a month and found myself at the hospital awaiting brain surgery—it was terrifying.

Again, I made it through. However, a few months later, the shunt became infected and was removed. We opted for the endoscopic third ventriculostomy (ETV) procedure, but really, we didn't have a lot of options.

It was an unnerving struggle during those years, because I had many close encounters with death. Even though there was uncertainty whether I would ever be able to have children, I am here almost twelve years later with two adorable sons. My severe headaches are also now a thing of the past.

I Stepped Out of My Comfort Zone


To this day, I don't talk about my condition often. I have had a hard time shaking the concern of being labeled and I don't want pity. It wasn't until last year that my husband pushed me to get the word out about our participation with the Phoenix Hydrocephalus Walk. He encouraged me to post something on Facebook for all of my friends, acquaintances and co-workers to see. He said we needed to raise awareness, and he was right. As a result of that one post, the company I work for, Foster Web Marketing, decided to get involved.

One of my co-workers led the way, as she rallied the office to sign up for the National Capital 5K Run/Walk for Hydrocephalus held in Washington, DC. It was all done without my knowledge, so that they could present it as a surprise to me. I was in tears when I heard the news.

There were fifteen people who ran as part of the Foster Web Marketing team, which included one spouse and three children. They endured the cold weather and laced up their sneakers to run in my honor. While some ran the course, the other amazing members of the Foster Web Marketing team gave their support and cheers from afar. Foster Web Marketing, along with the individual participants, was able to raise an impressive amount for the Hydrocephalus Association!

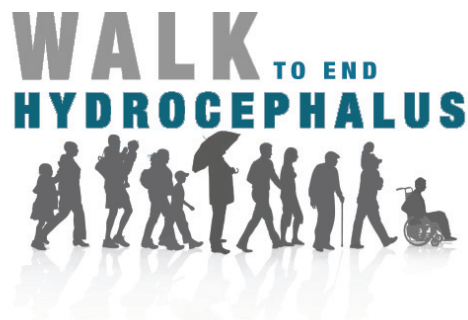
Why did Foster Web Marketing jump in and participate in for the National Capital 5K Run/Walk for Hydrocephalus? In their own words, "This is a cause near and dear to us because one of our team members has battled hydrocephalus." I would encourage other employers to follow the example of Foster Web Marketing and get out there and support your employees who battle hydrocephalus.

My Lesson for You

The moral of the story I am sharing is this: Be brave. Tell others what you have gone through. We all know awareness needs to be raised regarding hydrocephalus. You may be surprised who gets behind you to support this cause! Welcome to our new WALK Sites! 

WALK SCHEDULE 2013

Date	City/Market	State	Event
June			
15	Portland	OR	WALK
July			
20	Seattle	WA	WALK
August			
10	Anoka	MN	Hydro River WALK
10	Central PA	PA	WALK
25	Denver	CO	WALK
25	Detroit	MI	WALK
September			
7	Atlanta	GA	WALK
7	St. Louis	MO	WALK
13	Salt Lake City	UT	WALK
21	Middlebury	CT	WALK
21	Smyrna	DE	WALK
21	Columbia	SC	WALK
22	Long Island	NY	WALK
28	Charlotte	NC	WALK
29	Los Angeles	CA	WALK
October			
13	Fresno	CA	WALK
19	Albuquerque	NM	WALK
26	Chattanooga	TN	WALK
November			
9	Greater South FL	FL	WALK
17	Washington	DC	5K Run/WALK



Still in the Works!

Dates will be announced soon for these sites. Please check our website or call our office for the most up to date information.

Alabama – Birmingham

California – San Francisco

Illinois – Chicago

Kansas – Wichita

Kentucky – Louisville

Louisiana – Baton Rouge

Massachusetts – Greater New England

Minnesota – Minneapolis

New Jersey – Basking Ridge

New York – Buffalo

North Carolina – Graham


Tennessee – Chattanooga

Texas – Houston

No WALK near you?



Two WALK Chair Trainings, One Great Event!

New WALK Chairs and Veteran WALK Chairs have met in Charlotte, North Carolina to kick off the 2013 WALK season. Randi Corey, our National Director of Special Events & Volunteer Support, hosted our weekend training session with the help of Michael Ticzon, our Special Events Coordinator. Our new WALK Chairs met the weekend of February 9th for a comprehensive training on organizing a local WALK. Topics covered included WALK basics, event day logistics, securing corporate sponsorship, and WALK Committee structure. Our Veteran WALK Chairs came together the weekend of March 12th to review WALK logistics and to share lessons learned and new ideas. They were joined by CEO Dawn Mancuso and Director of Development Aisha Heath. 

Welcome to Our New WALK Sites!

We would like to give a warm welcome to five new sites joining the HA WALK list:

Baton Rouge/New Orleans, LA

Chaired by husband and wife Chans and Alida Arce-neaux we are very much looking forward to a new HA WALK in this part of the south. It was great having the opportunity to meet Chans and Alida at the New WALK Chair's training meeting recently. Chans and Alida are enthusiastic, energetic and eager to make it happen.

Buffalo/Rochester, NY

On the other end of the meteorological spectrum is HA's new WALK in Buffalo/Rochester, NY. The WALK is being led by Tri-Chairs Stacey Monaco, Jessica Walsh and Amanda Bernola. Stacey and Jessica both attended the recent New WALK Chair's training meeting and are geared up and ready to go! They're hoping to hold this first year WALK at Niagara Falls State Park (America's oldest State Park.)

Charlotte, NC

HA is thrilled to welcome new WALK site, Charlotte, NC to its list. Led by volunteer Chairs Christy Ruth and Susan and Rodney Slattery, we're looking forward to a great inaugural WALK in Charlotte. The date and site for this event is already set, so those of you in the NC/SC area should mark your calendars right now for September 28th at the Charlotte Knights Stadium (which is, by the way, located in South Carolina!) Special thanks to the Charlotte Knights for their generosity.

Columbia, SC

Speaking of South Carolina, HA welcomes its first WALK in Columbia, South Carolina! Jessica Caulder and Eris Speights are the two volunteer Co-Chairs for this event and we're confident that it will be great. We were happy to have the opportunity to meet Jessica at the New WALK Chair's training meeting a couple of weeks ago.

Los Angeles, CA


HA has been trying to launch a WALK in the "city of angels" for quite some time but this time it's for certain! Led by four (count'em – four!) Co-Chairs who each contribute complementary skills to the project there's no way this WALK won't be a success. Thanks to volunteer leaders: Tania Heise, Cortney Pellettieri, Amber Milliken (who also happens to serve as HA's LA Support Group leader) and Dan Solchanyk for bringing HA to LA! We met Tania and Amber at the New WALK Chair's training meeting and know that they and their Co-Chairs will do a dynamite job. The LA WALK is scheduled for September 29th at USC's Exposition Park.

Other WALK News:

Greater New England HA WALK – The Londonderry, NH WALK and Cambridge, MA WALK have combined to form the Greater New England HA WALK. This site (which is still planned for the Cambridge area) will encompass New Hampshire, Massachusetts and Rhode Island – as well as any other HA constituents in the New England area. The former Londonderry WALK site is only about 45 minutes from the former Cambridge site so it made sense to combine the two to form one larger site.

Denver, CO WALK hits 10! -- Congratulations to Phyllis Rogers, volunteer Chair, of the Denver, CO WALK and the event committee – 2013 will be Denver's 10th annual WALK! Phyllis has served as the volunteer Chair for this event since its inception – a true testament to her dedication and support of HA and its mission. Phyllis' first HA WALK had approximately 60 walkers. The event has now grown to more than 750 participants raising \$58,000! What a difference 10 years makes...!

HA WALKs and other special events are all volunteer-driven (volunteer initiated and volunteer coordinated.) If you, or anyone you know is interested in exploring the idea of starting a HA WALK in your community OR may be interested in volunteering to work on an existing WALK planning and organizing committee we would love to talk with you!


Please contact HA Director of Special Events, Randi Corey, at randi@hydroassoc.org. (Please include your phone number when you contact her.) We'd love to add your city or town to our list of HA WALKs! 

Every Member Campaign – Your Membership Gift Makes a Difference

The Hydrocephalus Association is pleased to announce the launch of the 2013 Every Member Campaign. Last year's campaign was a great success enabling HA to make significant strides with our advocacy and support work. We would like to thank all of our loyal donors who join us each year to move HA's agenda to end hydrocephalus forward. Please continue to stand by our side as we prepare to make 2013 a year of unprecedented growth in the fight against this condition. Knowing we can count on you for 2013, we promise to put your membership dollars hard at work. We will continue:

- Providing a source of comfort and refuge for people affected by hydrocephalus ... whether it's through our toll-free hotline and email, informative publications, online resources or physician directories.
- Sponsoring educational opportunities that bring together patients, doctors, scientists and advocates to share the latest in hydrocephalus treatment and care. This year we have several exciting webinars planned that will feature special guest speakers.
- Advocating for public funding of hydrocephalus research by deepening our relationship with the National Institutes of Health (NIH).
- Increasing our presence on Capitol Hill. We hope to conduct another advocacy day this year to educate new members and provide an opportunity for them to engage with our community. Last year, hundreds of members of the hydrocephalus community attended our Advocacy Day on Capitol Hill, Climbing Capitol Hill for a Cure.

Spreading the word, reaching out and building community. In 2012, we expanded our Walk program to 10,000 participants, advocated for more research funding at even more government agencies, and increased our social media presence, with thousands of followers on Facebook and Twitter. We will continue to use these vehicles to raise critical awareness.

As you can see, it's an exciting time to be part of the Hydrocephalus Association. In our 30th year, we are a bigger, better and stronger force in the fight against hydrocephalus! Go on-line to send your member gift today or complete the member form on the facing page. 

In Appreciation...

Van Nest Recreation Center

The Hydrocephalus Association would like to congratulate The Van Nest Recreation Center on their 100th Anniversary.

The organization was established in 1913 in the Bronx, NY and makes contributions to many worthy causes. To celebrate their anniversary, a gift was made to support HA's research efforts in honor of Dara Tannariello.

We appreciate your support!

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



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

GIVE TODAY

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

How would you like to receive your newsletter?

Continue to receive a quarterly print newsletter or opt to receive a monthly newsletter via email. In addition to being eco-friendly, this will allow the Association to put your donation directly to the support of our vital programs by cutting down on printing and postage costs.

☐ Please send my monthly newsletter via email to: _____

☐ I still prefer to receive a printed copy of the newsletter via the US mail.

Charge my: ☐ VISA ☐ MasterCard ☐ Discover ☐ AMEX Amount Charged \$ _____

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Signature: _____

☐ Please remove my name from your mailing list.

☐ I cannot afford a donation at this time but I would like to be counted as a member.

Please check all that apply:

☐ I am on SSI or Disability. ☐ My medical bills have exhausted my finances. ☐ My income is below \$30,000 per year.



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Bethesda, MD 20814-4447