



Craig and Vicki Brown, hosts of the
2013 inaugural Vision Dinner.

VISION

Looking Back...Moving Forward: Commemorating 30
years and setting our vision for the future.

Looking Back...Moving Forward

A 30th Anniversary Tribute



In 1983, a small group of parents whose children had hydrocephalus came together seeking community. Thirty years later, the Hydrocephalus Association has grown into the largest patient-advocacy organization dedicated to providing education and support to individuals with hydrocephalus and their families, and the leading non-profit funder of hydrocephalus research. Throughout 2013 we celebrated our 30th anniversary. As we wrap up this milestone year, I can't help but spend a few minutes reflecting on (and sometimes marveling at) all that has happened.

Thanks to our very generous supporters, HA has raised over \$3 million to fund our "A Reason for Hope" research campaign. This is a critical first step to establishing the foundation needed to see the medical breakthrough our community deserves. This year alone, HA has funded almost \$1 million in new research.

HA has also led the effort to establish a new collaborative research effort for the study of hydrocephalus in adults. Much progress was made this past year in that effort by contracting with a data coordinating center and developing data collection tools specifically for this adult-focused research.

Our awareness program has increased exponentially, with our inaugural Vision Dinner held in New York City this past October; a new video about living with hydrocephalus; a stronger, more vibrant presence in social media (Facebook, Twitter, LinkedIn, Pinterest and YouTube); an ever-expanding WALK to End Hydrocephalus program, including increased public relations focused on the WALKS in local markets; and our working with Congress and our participation in a number of coalitions in Washington, D.C., that help to raise the profile of the condition in public policy circles.

HA provides education and support in a growing number of ways – through publications, products, one-on-one support, local community networks & support groups, and educational programming/events. This year, HA added to its publication offerings new fact sheets and, for the first time, we also offered webinars for patients and caretakers. The first webinar entitled "What if It Isn't Alzheimer's or Parkinson's" was conducted by Dr. Michael Williams and received great reviews.

Despite all these positive changes, we also wanted to hold onto the culture of caring, the legacy so carefully planted and nurtured over the years by the founders of the association and all of the volunteers and staff who were involved with the organization along the way. To pay tribute to the association's 30 year milestone and to showcase our rich history and the extraordinary people who have been involved in HA, I hope you were able to read some of the blogs or newsletter articles from our "Looking Back...Moving Forward" series.

This newsletter will wrap up our 30th year commemoration as well as highlight exciting events planned for 2014. We have much to be proud of, and no shortage of work to propel us forward into the new year. I hope you have enjoyed our journey this past year, and we look forward to traveling the road with you in the year ahead. Wishing you a happy, healthy and safe 2014!

Milestones

1983
UCSF facilitates two informal gatherings of mothers of children with neurosurgical conditions, planting the seeds for our association.

1984
Dr. Michael Edwards, UCSF, speaks at the first meeting for parents of children with hydrocephalus and pledges \$1,000 to underwrite the formal formation of the group.

1983

1984

PORTLAND,

here we come!

COMMUNITY. CLARITY. CURE.

13th National Conference on Hydrocephalus

July 9-11, 2014

Doubletree by Hilton Portland
1000 NE Multnomah Street
Portland, OR 97232

- Educational tracks with interactive sessions tailored for each audience - parent, teen, adult, and NPH.
- Kids Camp for our youngest attendees.
- Our cornerstone educational seminars by our team of medical professionals and researchers with time for Q&A.
- The ever popular hands-on brain anatomy and physiology lab.
- Dinner and dance with talent show...and more!

The goal of our conferences is to provide tools and connections to address the medical, educational and social complexities of living with hydrocephalus.

Make your reservation today! Special group room rate: \$149/night plus 14.5% tax. For reservations call (503) 281-6111 and ask for in-house reservations. You can also call (800) 996-0510 or visit www.doubletreegreen.com to make reservations outside of normal business hours. Use code HY7 for booking online, or when calling make sure to mention the 13th National Hydrocephalus Conference. Please keep in mind that the cut-off date for the group block is **June 16, 2014.**

Registration is open! www.hydrocephalusconference.org



A Steering Committee is created and the group asks six professionals to serve as medical advisors, creating our Medical Advisory Board.

The Hydrocephalus Foundation of Northern California incorporates and receives nonprofit status. The first Board of Directors is inaugurated.

HA's 2013 Research Grant Recipient



The Hydrocephalus Association (HA) was pleased to offer funding for an additional research grant in our 2013 grant cycle. This grant will help advance the priorities established in HA's 2012 research conference, *Opportunities in Hydrocephalus Research: Pathways to Better Outcomes*. After an extensive review process by our distinguished Scientific and Medical Review Committee, HA has selected Timothy Vogel, M.D., for his proposal, "Role of neural progenitor cells in the development of neonatal hydrocephalus."

Dr. Vogel is a pediatric neurosurgeon and an Assistant Professor of pediatric neurosurgery and developmental biology at Cincinnati Children's Hospital Medical Center. He holds a B.A. in chemistry from Princeton University and a M.D. from Columbia University College of Physicians and Surgeons.

Dr. Vogel's study will focus on the cilia, hair-like structures on the surface of neuron progenitor cells (NPCs) in the brain. He will be exploring whether or not abnormal signaling through the cilia contributes to the development of neonatal hydrocephalus. Recent studies have shown that mutations of genes that disrupt cilia in the ventricles lead to the development of hydrocephalus. Dr. Vogel's research may put us one step closer to understanding the role cilia play in the functions of the brain, and the role NPCs play in hydrocephalus.

The research grant totals \$400,000 over 3 years. In awarding this research grant to Dr. Vogel, HA has now funded a total of \$2,400,000 in research grants since it initiated its commitment to support and fund research in 2009.

Congratulations to Dr. Vogel on this award!

WE DID IT!

TOGETHER we reached our goal to raise \$3 million dollars for the

A REASON FOR HOPE research campaign

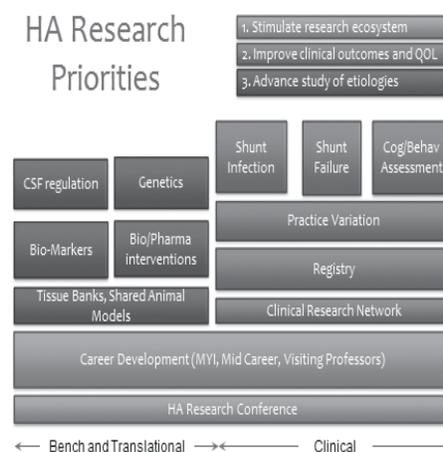
THANK YOU!

The Hydrocephalus Association is dedicated to the advancement of promising research that will promote the **understanding, diagnosis, treatment, and, ultimately, prevention** of and **cure** for hydrocephalus. As 2013 came to a close with the end of **phase I** of our **A Reason for Hope** fundraising campaign, we were able to raise a total of **\$3,065,046** for hydrocephalus research!

In 2011, the HA board of directors established three priorities for the use of research dollars:

- Expanding the field of hydrocephalus research with a variety of research awards, such as Mentored Young Investigator and Established Investigator awards, as well as the sponsorship of scientific conferences;
- Supporting clinical research aimed at reducing shunt failure and improving outcomes; and
- Making investments in basic science investigations designed to improve our understanding of the root causes of hydrocephalus.

HA Research Priorities



Milestones

Our first educational booklet, *About Hydrocephalus - A Book for Parents*, is published. HA currently offers seven booklets on various topics relating to hydrocephalus.

First National Conference on Hydrocephalus is held in San Francisco, CA. Held biennially, our conferences bring together medical professionals, representatives of health industry corporations, and individuals and families.

Rudi Schulte Research Institute (RSRI) Announces New Research Venture

We are excited to announce that the Rudi Schulte Research Institute (RSRI) and Mark Wagshul, Ph.D., will be conducting a joint research venture entitled, “MR Elastography: A noninvasive tool for management of shunted pediatric hydrocephalus.”

Dr. Wagshul is Associate Professor in the department of radiology at Albert Einstein College of Medicine, Bronx, New York. Dr. Wagshul received a B.A. in physics from Rutgers University and a Ph.D. in physics from Harvard University. He completed a postdoctoral fellowship at the National Institute for Standards and Technology (NIST), a federal technology agency that works with industry to develop and apply technology, measurements, and standards.

His proposed project utilizes the noninvasive MRI-based technique, magnetic resonance elastography (MRE), to determine the role brain compliance plays in pediatric hydrocephalus. There are three aims which Dr. Wagshul will be seeking: determining the relationship between the MRI measures of brain elastance and patient status; demonstrating the brain regions which are most affected by hydrocephalus; and finally, establishing the relationship between brain elastance and intracranial pressure. The ultimate objective is to use this new knowledge about brain elasticity to drive the development of alternative treatments for slit ventricle syndrome, which presents as severe headaches in shunted individuals with apparently working shunts.

The Rudi Schulte Research Institute partnered with the Hydrocephalus Association in July 2012 with the goal of finding significant advances in the treatment of hydrocephalus. To that end, a Request for Research Proposals in Cerebrospinal Fluid Production, Flow, and Regulation Therapeutics and Diagnostics was released and applications were reviewed by RSRI and HA’s 2013 Scientific and Medical Review Committee (SMRC), chaired by Donna Ferriero, M.D., a pediatric neurologist from the University of California San Francisco Benioff Children’s Hospital and a member of the NIH NINDS Advisory Council since 2010. The review resulted in Dr. Wagshul’s research being selected for this joint venture, awarding Dr. Wagshul \$600,000 over three years to conduct the joint research project. HA and RSRI are

excited about Dr. Wagshul’s future work and are eager to see the results from this important research.



Rudi Schulte was one of the two founders of PS Medical, which developed the Delta and Strata valves used in the treatment of hydrocephalus. The company was later sold to Medtronic, which has continued to advance those shunt technologies. Rudi Schulte founded the Rudi Schulte Research Institute in 1974 to continue research into hydrocephalus. The Hydrocephalus Association is pleased to have expanded our partnership to help RSRI target research that is meaningful to our members.

HA at the TABLE

NINDS-Nonprofit-Forum
September 10 and 11, 2013

The National Institutes of Health (NIH) National Institute of Neurological Disorders and Stroke (NINDS) hosted their annual Nonprofit Forum. The forum, “Progress through Partnership,” emphasized the role nonprofits play in linking scientists at NINDS with the patient community for better research outcomes. Paul Gross, HA board member and member of the NINDS Advisory Council, served on the planning committee that helped build the agenda for the event. Representatives from over 80 nonprofit organizations had the opportunity to listen to and interact with key NINDS officials, including Dr. Story Landis, director of NINDS, and Dr. Kathy Hudson, deputy director for science, outreach and policy at NIH.

“It’s been incredibly valuable to the hydrocephalus community that we have been invited to be on the inside track at NINDS, the largest funder of brain science in the country,” shared Paul. “It was also great being part of this extended team that connected senior leadership in NINDS to important issues in the not-for-profit advocacy organizations.”

The event featured a nonprofit-to-nonprofit education and collaboration session intended for leaders of patient advocacy organizations that are trying to improve their relationship with NINDS. Paul served as a guest presenter, delivering a presentation entitled, “Creative Advocacy Not Limited by Staff or Budget.”

HA exhibits at the annual meeting of the American Association of Neurological Surgeons (AANS) in Seattle, resulting in long-standing relationships with medical professionals.

Emily Fudge becomes the first Executive Director.

Use of Limited Sequence and Low Dose CT Scans in Pediatric Hydrocephalus

By Ashly Westrick, M.P.H.

Individuals with hydrocephalus frequently have multiple computerized tomography (CT) scans to evaluate shunt function. A CT scan, also called a CAT scan, is a diagnostic tool that combines a series of x-ray views and computer technology to create an image of the body. CT scans provide more detailed information than standard x-rays and can be a lifesaving tool in diagnosing hydrocephalus and, in some cases, identifying shunt failure quickly. However, these scans do come with some risk.

The dose of radiation delivered during a CT scan is 100 to 500 times higher than traditional radiography (x-ray). Studies have shown that the use of CT scans has increased in the last two decades, especially for pediatrics. While MRIs provide an alternative option that avoids exposure to radiation, many patients do not have a choice between an MRI and CT scan, either because an MRI machine is not available or the patient cannot have an MRI for a medical reason.

In a study published in *JAMA Pediatrics* in June 2013, researchers at the University of California, Davis, found a link between the use of CT scans in pediatrics and subsequent cancer risk. The study also found that the use of CT scans vary widely in clinical practice and suggests that there is an opportunity to reduce the dose of radiation through standardized protocols. It is not uncommon for children with hydrocephalus to undergo numerous CT scans throughout their life, raising the concern about the effects of the radiation exposure for the future. Studies such as the *JAMA Pediatrics* paper continue to bring awareness to the need for better understanding and standardized protocols for the utilization of CT scans in children.

Limited Sequence CT Scans

In a new study published in the *Journal of Neurosurgery*, Dr. Edward Ahn and his colleagues at Johns Hopkins wanted to determine if there could be a way to limit the amount of radiation children with hydrocephalus receive during CT scans. This study explored the use of limited-sequence head CT scans for children with hydrocephalus, which limits the radiation exposure by taking seven slices or snapshots of the brain instead of the standard 32 to 40

slices. Traditionally, standard CT scans are considered to provide a better picture of the brain while limited sequence scans, which take fewer slices, are considered to provide less clarity and accuracy in determining shunt function, therefore limiting the knowledge a clinician needs to make treatment decisions. The study entitled, “Analysis of limited-sequence head computed tomography for children with shunted hydrocephalus: potential to reduce diagnostic radiation exposure,” aimed to determine if limited-sequence CT scans can accurately evaluate children with hydrocephalus with the goal of reducing radiation exposure.

For this study, researchers reviewed standard CT scans and limited-sequence CT scans of 50 children aged zero to 17. The average number of total head CT scans for each patient was 13.4 for the four-year period. Approximately 42% of the study participants had at least 6 CT scans in one year. A total of 23% of the patients had received 18 head CT scans over the four-year study period. Two pediatric neuroradiologists and one neurosurgeon reviewed the scans. According to Dr. Ahn, they “determined that limited sequence CT was sufficiently accurate at detecting shunt malfunctions and estimated that the limited sequence will reduce radiation doses by an average of 91.8% compared to standard head CTs.” The researchers concluded that the limited-sequence scans were adequate and would not have compromised clinical outcomes. Based on these results, Dr. Ahn is looking to the next step of the research. “... [W]e are currently conducting a trial with the limited sequence head CT in the Johns Hopkins Pediatric Emergency Room. We hope to find similar results so that the limited sequence CT can be implemented in other emergency rooms that treat children with shunted hydrocephalus.” It is noted that the limited sequence protocol would not be applicable for initial screenings of suspected hydrocephalus, visualization of lesions or abnormalities outside the ventricular system, trauma or evaluation of an intracranial mass or lesion.



Milestones

Our first Resident's Prize is awarded to Dr. Eric Altschuler for the most promising research paper relating to hydrocephalus by a neurosurgical resident.

Our name changes to the Hydrocephalus Association to reflect our expansion and growth.

1989

1991

Low Dose CT Scans

Another study, “Low-dose head computed tomography in children: a single institutional experience in pediatric radiation risk reduction,” was just published in the *Journal of Neurosurgery: Pediatrics*. This study describes the experience of researchers at Seattle Children’s Hospital using low dose head CT scans in children. For this study, researchers reviewed all low-dose head CT scans for a one year time period. Two different doses were used - one-half and one-quarter of the dose of a standard head CT scan. The most common reason for receiving a head CT was for evaluation of the ventricles and catheter placement in hydrocephalic patients (70%). The researchers found that the use of the low-dose head CT substantially reduced the amount of radiation exposure while providing efficient image quality and diagnostic value.

The researchers noted that their institution has adopted the “as low as reasonably achievable” radiation dosing strategy to reduce the amount of radiation exposure. Full dose CT scans may be required in certain situations, such as diagnostic uncertainty or in patients with non-MRI compatible devices; however, the low-dose CT scans appear to be adequate for postoperative, follow-up and surveillance use.

Children with hydrocephalus represent a population that is susceptible to frequent imaging. The standard treatment method, a shunt, has high failure and malfunction rates, with approximately 40 to 50% of shunts failing in the first two years after placement. With the multiple imaging, this population has great concerns about the exposure to radiation and the potential future outcomes. The ability to find solutions that will lower a child’s exposure rate while still providing the clinically relevant information is highly sought. We look forward to sharing more about what researchers are learning about how to minimize the exposure to radiation many in our community experience.

References:

- <http://www.ncbi.nlm.nih.gov.ezp.slu.edu/pubmed/23754213>
- <http://www.nbcnews.com/health/multiple-ct-scans-kids-linked-later-cancer-risk-6C10272110>
- <http://www.ncbi.nlm.nih.gov/pubmed/24053675>



Seattle Children's
HOSPITAL • RESEARCH • FOUNDATION

Study Seeking Participants on the Clinical, Anatomic and Genetic features of Pediatric Hydrocephalus

Drs. William Dobyns and Hannah Tully at Seattle Children’s Hospital are studying the clinical, anatomic and genetic features of children with developmental hydrocephalus (otherwise known as primary, congenital, or non-acquired hydrocephalus). Their team is seeking to enroll additional patients in their research studies.

Families interested in participating are encouraged to contact the Seattle Children’s Research Institute. You will be given information about the study and they will obtain informed consent by phone or email. If you agree to participate, they will ask you to send clinical information about your child, as well as a copy of any brain MRIs your child has had. These will be reviewed and you can request a summary of their assessment. They will also provide kits for you to collect saliva samples from your child and other family members to send back to the Institute. DNA will be extracted from these samples and be tested for possible new genetic causes of hydrocephalus.

Not enough is known about what causes developmental hydrocephalus, how best to treat it, and how to counsel families about what to expect. Therefore, the Institute anticipates that their research will expand the current knowledge and help develop improved medical and counseling guidelines for affected patients and their families. Please note that the research may or may not benefit your child directly.

Research Contact Information:

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Clinical Research Associate
Seattle Children’s Research Institute
Center for Integrative Brain Research
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Seattle WA 98101
Email: brandi.bratrude@seattlechildrens.org
Phone (206) 884-1277 Fax (206) 884-1210

Our first Fact Sheet on adult-onset normal pressure hydrocephalus (NPH) is published. We now offer 14 Fact Sheets on various topics related to hydrocephalus.

The first recipient of the Gerard Swartz Fudge Memorial Scholarship is named, inaugurating our annual scholarship program. We now offer eight scholarships annually.

Insight into the Hydrocephalic Brain Using Diffusion Tensor Imaging

By Ashly Westrick, M.P.H., and Marvin Sussman, Ph.D.

HA is dedicated to providing our community with the latest updates on research in an easily understandable fashion. Sometimes the scientific and research journal articles can be daunting to those of us not in the medical and scientific fields. We received interest in understanding the paper published last February in the *American Journal of Neuroradiology* entitled, “Diffusion Tensor Imaging Properties and Neurobehavioral Outcomes in Children with Hydrocephalus.”

Increased intracranial pressure due to hydrocephalus can result in damage throughout the brain, including white matter structures such as the corpus callosum, internal capsule, and fornix. This damage has been reported to be a factor in poor neurological outcomes. In the study, researchers used diffusion tensor imaging (DTI) to quantify the diffusion properties in the white matter structures for children with hydrocephalus.

What is DTI? DTI is a form of MRI that allows the non-invasive mapping of the diffusion (spreading) process of molecules, mainly water, in the tissues of a living organism. Conventional MR imaging techniques allow for detection of major structural abnormalities, but are not sensitive enough to quantify white matter abnormalities. DTI allows researchers to understand the extent of tissue damage and how parts of the brain are connected. Water molecule spreading patterns reveal microscopic details about tissue structure in the normal or diseased tissues. One such detectable change is white matter structural alterations with trauma and disease. White matter is one of the two components of the central nervous system, and is mostly glial cells. Glial cells are non-neuronal cells involved in homeostasis, myelin formation, and protection for neurons. Changes in white matter may correspond with disease progression. In conditions causing structural abnormalities or tissue degeneration, DTI measurements can quantify these changes, and can be used as a non-invasive tool to monitor disease progression or therapeutic efficacy of an intervention.

Few studies have been done using DTI in pediatric hydrocephalus; the authors attribute this to the narrow time window between diagnosis of this condition and treatment. As many of us know from experience, once diagnosed, treatment in the form of a shunt placement or ETV quickly follows, thereby minimizing the window for studying white matter damage due to intracranial pressure. The current paper reports initial findings from

the imaging and neurobehavioral tests in children with hydrocephalus before surgical management.

The study evaluated a total of 44 children, comparing DTI images in 24 with hydrocephalus to 20 control subjects (all between birth and 51 months). Participants in this study were from an ongoing multicenter, prospective longitudinal imaging trial of pediatric hydrocephalus. The authors proposed that children with hydrocephalus would demonstrate abnormal diffusion or spreading properties as evidenced by tissue changes, that may be characteristically different in the white matter structures of the corpus callosum and internal capsule. In addition, researchers hypothesized that neuropsychological outcome measures, such as child’s independence skills, communication, daily living, social and motor skills, would be abnormal and would correspond with alterations in DTI measurements. Briefly, the main findings of the paper were:

- Diffusion properties in children with hydrocephalus demonstrated altered DTI in white matter regions compared to healthy controls.
- The patterns of abnormality in DTI measurements vary in different white matter regions.
- A strong correlation was found between the DTI indices and the motor skills reported by the parents, providing initial evidence for white matter alteration and functional deficits.

The authors conclude that DTI reveals alterations in the white matter structure in children with hydrocephalus, with preliminary findings suggesting a correlation with clinical motor deficits. As more data are collected, the researchers will continue to quantify the progression of white matter changes and how these changes impact clinical outcomes to both short- and long-term surgical outcomes.

The meaning? The goal of this research is to be able to learn and quantify the damage occurring in the hydrocephalic brain. This knowledge could help provide valuable information to medical professionals and parents on how to plan potentially earlier interventions to help their children overcome possible challenges. These are preliminary findings and more research is needed, but we are encouraged by the direction of this hydrocephalus research.

Milestones

TEAM Hydrocephalus walks the Bay Bridge and raises \$5,000, launching our Hydrocephalus WALK program.

1994

Our website is launched! People from around the world now have access to our resources.

1996

Preventing Hydrocephalus in Premature Infants

By Ashly Westrick, M.P.H.

Very premature infants are at high risk of developing post hemorrhagic hydrocephalus (PHH) as a complication to intraventricular hemorrhage (IVH). Most often these infants will need permanent ventricular shunting to regulate the cerebrospinal fluid (CSF) flow. However, shunting has a high rate of complication that frequently requires multiple revisions, resulting in a child having multiple brain surgeries. For this reason, a therapeutic method to prevent PHH is crucial and highly desired.

In a study published in *Brain*, researchers investigate the potential of the molecule decorin in preventing PHH. The results are exciting and show great promise for the development of a preventive therapy for hydrocephalus. Dr. James P. (Pat) McAllister, member of the Hydrocephalus Association (HA) Medical Advisory Board and an HA Experienced Investigator grant recipient, was one of the primary researchers in the study.

In the study, “Decorin prevents the development of juvenile communicating hydrocephalus,” published in *Brain*, researchers working in mouse models found that continuous infusion of decorin, a naturally occurring protein that influences cellular functions, prevented the development of hydrocephalus after IVH.

What is IVH? Intraventricular hemorrhage, most frequently affecting premature infants, occurs when the small blood vessels along the ventricle lining rupture. During IVH, factors released can induce an inflammatory response and fibrosis, the thickening and scarring of connective tissue. This inflammation and scarring can contribute to the development of post hemorrhagic hydrocephalus by impairing CSF flow and reducing drainage.

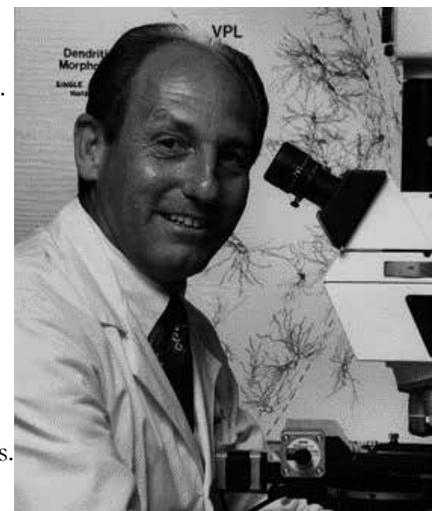
One such factor that can cause inflammation and scarring is the fibrogenic signaling molecule, known as transforming growth factor- β (TGF- β). TGF- β has been found to be in higher concentration in the CSF of hydrocephalus patients than in the CSF of normal controls, and thus has been implicated in the development of PHH. Decorin, a naturally occurring protein, has been reported to inhibit TGF- β activity, indirectly suppressing inflammatory scarring.

What does Decorin do to prevent post hemorrhagic hydrocephalus? In the current study, researchers found that decorin could prevent the development

of hydrocephalus in a mouse model of juvenile communicating hydrocephalus. For the study, rats were randomly assigned into one of four groups. The researchers found that the decorin treatment prevented ventricular enlargement so that the treatment group was indistinguishable to the intact or healthy group, indicating that the decorin prevented the development of hydrocephalus. The main findings of the study was that decorin reduced fibrosis in the subarachnoid space, suppressed the inflammatory response and protected against hydrocephalus-induced brain damage.

This study shows great promise in the development of potential therapies to prevent post hemorrhagic hydrocephalus. HA would like to acknowledge Dr. McAllister and his colleagues on this incredibly valuable study.

The abstract can be found <http://brain.oxfordjournals.org/content/136/9/2842.short>



The Fudge Solomon Legacy Society

A gift for the future.

Join today.

Call (888) 598-3789 or email giftplanning@hydroassoc.org.

About Normal Pressure Hydrocephalus (NPH) - A Book for Adults and Their Families is published, as is our *Directory of Neurosurgeons for Adult Hydrocephalus*.

HA presents at the Federal Drug Administration (FDA) sponsored conference, *Shunt Technology: Challenges and Emerging Directions*, the only nonprofit invited to present.

FIRST ANNUAL VISION DINNER

A TIME FOR AWARENESS. THE HOPE OF A CURE.

The Hydrocephalus Association's First Annual Vision Dinner, "A Time for Awareness; The Hope for a Cure," was held on October 11, 2013, in New York City at the Apella Alexandria Center. Generously hosted by Vicki and Craig Brown, major benefactors of the Hydrocephalus Association (HA), the evening united patients, neurosurgeons, scientists, advocates, and business leaders to raise the public profile of hydrocephalus and to share the need for greater research funding to cure the condition.

The evening debuted HA's *Reason for Hope* video that profiled the unique stories of members in our community. We would like to thank Stephen Brawerman, Jennifer Bechard Johnson and her husband Andrew Johnson, and Tanzanea Christian and her parents April and David and sister Zaire, for lending their voices, and Nikki and Brad Silver for providing funding to produce this powerful video. Attendees also had the opportunity to hear from two parents who are leading the way to further HA's research initiative and learn about the "hope" in progress, currently funded by the association.

Renowned pediatric neurosurgeon and 2012 MacArthur Foundation Fellow, Dr. Benjamin Warf, was the keynote speaker, sharing his revolutionary new surgical procedure to treat hydrocephalus in the infant population. The evening also honored three individuals for their tireless dedication to the elimination of the challenges of hydrocephalus through their affiliation with the Hydrocephalus Association. Paul Gross, Co-Founder, Hydrocephalus Clinical Research Network, received the Inspiration Award; Marion Walker, M.D., Professor, Neurosurgery, Primary Children's Medical Center, received the Service Award; and Emily and Russell Fudge, Co-Founders, Hydrocephalus Association, received the Leadership Award. United States Senator Charles E. Schumer and New York State Senator John J. Flanagan provided congratulatory letters praising the dedication of the awardees and the progress of the Hydrocephalus Association.

The Hydrocephalus Association would like to thank Craig and Vicki for their leadership and generosity in hosting this special evening to raise the profile of hydrocephalus and the important work of the Hydrocephalus Association for our entire community. For more information on how you can support HA's research initiative please e-mail hope@hydroassoc.org.



Honorees

2013 VISION AWARDS



PAUL GROSS
INSPIRATION

Paul Gross has played a critical role in the design and development of HA's research initiative, devoting time and securing significant resources to advance his work. He and his wife, Lori Poliski, who have two children - one with hydrocephalus - co-founded the Hydrocephalus Support Group and the Hydrocephalus Research Guild in their home state of Washington. Mr. Gross is one of 18 members of the NIH NINDS Advisory Council which helps set the strategy for the largest funder in brain science.

Milestones

Hydrocephalus Database Project begins with the intent of identifying and tracking key issues facing individuals and families living with hydrocephalus.

Emily Fudge retires as Executive Director.

2003

2004



MARION WALKER, M.D.
SERVICE

Since 1976, Dr. Marion Walker has devoted his career to meeting the needs of the pediatric hydrocephalus community. As one of the founding members of the American Board of Pediatric Neurological Surgery and past president of the American Society of Pediatric Neurosurgeons, Dr. Walker is highly regarded by peers and is an inspiration to the next generation of neurosurgeons.



RUSSELL & EMILY
FUDGE
LEADERSHIP

Russell and Emily Fudge were introduced to hydrocephalus in 1981 when their son, Gerard Swartz Fudge, was diagnosed at age 11. As an outgrowth of their determination to learn more about the condition, they joined forces with other parents to establish the Hydrocephalus Association in 1983. During the association's formative years, Emily, Russell and fellow co-founder Cynthia Solomon worked tirelessly, with the help of many committed volunteers, to increase the amount of information available about hydrocephalus. Their tenacity in identifying and building a collaborative community – of parents, patients, medical professionals and industry members – evolved into an international force providing support, education, advocacy and research.

First NIH-sponsored workshop on hydrocephalus, *Hydrocephalus, Myths, New Facts, Clear Directions*, is presented with significant input from HA.

First National Advocacy Day held in Washington, D.C. in conjunction with our 9th National Conference on Hydrocephalus, held in Baltimore, Maryland.



We would like to thank Medtronic, Aesculap and Sophysa for supporting this meaningful program for the hydrocephalus community.

Don't worry! You didn't miss it!

Listen to a full recording of our first Webinar,

“What if it isn't Alzheimer's or Parkinson's?”

Visit our NPH page on our website.

Our NEW Webinar Series

HA hosts our first webinar, “What if it isn't Alzheimer's or Parkinson's? Understanding Normal Pressure Hydrocephalus.”

By Karima Roumila and Jennifer Johnson, Support and Education Staff

The Hydrocephalus Association is pleased to announce our Education and Support webinar series. This series will consist of interactive, free webinars that are designed to educate our community on a variety of topics which include, but are not limited to, Normal Pressure Hydrocephalus (NPH), research and shunt technology. We will be featuring presentations from medical professionals, researchers and individuals with a direct connection to hydrocephalus.

During Hydrocephalus Awareness Month, we launched our webinar series with our first webinar entitled, “What if it isn't Alzheimer's or Parkinson's?” Have you ever wondered if that memory loss, bladder incontinence or gait problem could be something other than Alzheimer's or Parkinson's? Did you know that about 375,000 older Americans have Normal Pressure Hydrocephalus (NPH) and it is one of the few causes of dementia that can be controlled or reversed with treatment?

Dr. Michael A. Williams, Medical Director, Sandra and Malcolm Berman Brain & Spine Institute, LifeBridge Health at Sinai Hospital of Baltimore, Maryland, discussed how the diagnosis of Normal Pressure Hydrocephalus can be missed and how to do effective screening. The webinar included a question and answer session between Dr. Williams and audience members.

If you were not able to participate, you can listen to the full recording on our website. Visit our Normal Pressure Hydrocephalus page under Education and Support. A link to a recording of the Webinar is listed under NPH resources.

The Webinar Series is made possible through the generosity of our loyal partners. We would like to thank Medtronic, Aesculap and Sophysa for supporting this meaningful program for the hydrocephalus community.

Milestones

House of Representatives Congressional Resolution on Hydrocephalus is proposed which expresses the need for research into this chronic neurological condition.

Boozle Bear, a teddy bear with a shunt, is developed by former CEO Dory Krantz and Sarah Zadoroznyj to serve as a teaching tool for doctors, nurses, parents and children.

Looking Back...Moving Forward: Moments that Matter

Our “Looking Back...Moving Forward” 30th anniversary history series featured conversations with members of our community. Jennifer Bulthuis, our Minnesota Community Network leader, lives in Maple Grove with her husband, Curt, and their two children, Abby (7) and Jonathan (4). Jonathan was diagnosed with hydrocephalus just days after celebrating his first Christmas. He was six months old at the time. Jennifer became concerned when Jonathan wouldn’t sleep. At the time of his diagnosis he couldn’t sleep longer than eight minutes without waking up screaming and crying. After months of tests and various opinions from a variety of medical professionals, Jennifer and Curt finally had a diagnosis that left them in shock, not knowing what hydrocephalus was or what this meant for Jonathan or their family.

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

JENNIFER: The first year after we learned about Jonathan’s condition was really spent working on getting the best medical care we could find for him, making sure we were doing all that we could, and truly relearning our child. I kept hearing about how many people have hydrocephalus, but even with all the doctor’s visits, we still had not met a single person or family with a connection to hydrocephalus. I decided to look on the Hydrocephalus Association’s website to see if there were any groups in my area that I could join. As it turned out, they did not have a group....yet. I received a call from the support group liaison and was asked to start the group. In my professional life, I am actually a corporate meeting planner, so I decided to put my skills to good use and agreed to start and lead the first Hydrocephalus Association support group in my area!

HA: What do you think support groups do for the hydrocephalus community?

JENNIFER: In addition to the obvious - creating a network for families living with hydrocephalus - this support group really helps our members to realize they are not alone and it gives them a comfortable place where they can talk and share with people who understand.

HA: What has been one of your favorite moments of memories from a past meeting?

JENNIFER: There have been several, but I’ll share a favorite memory that involves a speaker. I contacted a neuropsychologist to speak to our group and the parents were thrilled! We all learned things about how the brain of someone with hydrocephalus may be affected by this condition and things to look out for in school and social situations. I think most of us were unaware of what is involved in executive learning and why this kind of thinking can be a challenge for a person with hydrocephalus. A few days after our meeting, I received an email from a group member, whose twelve year old daughter was born with hydrocephalus. She said her daughter was starting to struggle in school and that now she had some understanding of why, she had already been in touch with the neuropsychologist’s office to make an appointment, and said the meeting had been life changing for her and her daughter.

HA: What is the most rewarding thing about being a support group leader?

JENNIFER: I started this support group for two reasons. First, I started the support group so that we could educate our family about hydrocephalus and do everything possible to help our son. Second, I wanted Jonathan to meet other children with hydrocephalus and to be able to grow up knowing other kids have this condition, too. In 2012, we were at the HA Walk and I was talking to some parents of a young girl who has hydrocephalus. As we continued to talk, I watched their daughter walk over to our son, look right at him, and I heard her casually say to Jonathan, “Hey, I have a shunt too!” That was it, that was the moment that made all my hard work of bringing families together worth it. My son will never grow up feeling like he is the only one who has hydrocephalus or who has a shunt, thanks to this incredible group!



TEAM Hydro, started by the Finlayson family, swims in their first Alcatraz Sharkfest in the San Francisco Bay and the first School WALK, organized by Jodi Lawrence, is held in Oroville, CA.

ICD-9 Code for Normal Pressure Hydrocephalus issued by International Classification of Disease - Centers for Medicare and Medicaid Services through the efforts of HA and Dr. Michael Williams.

Our Community Network

We hope you can join us at a local get-together this year! Visit our website for upcoming events. If you'd like to start a network in your area, email support.liaison@hydroassoc.org or call (888) 598-3789.

AL	Online	All Ages
AZ	Phoenix	NPH
	Tucson	All Ages
CA	Chico	All Ages
	Los Angeles	All Ages
CO	Denver	All Ages
CT	Hartford	All Ages
DC	Washington	All Ages
FL	South	All Ages
	Central	Peds/Adolescents/Adult
	Central	NPH
IL	Chicago	Peds/Adolescents
	Chicago	Adults and NPH
IN	Central/Northwest	All Ages
KS	Online	All Ages
MA	Boston	All Ages
MD	Baltimore	All Ages
MI	Online	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
OR	Portland	All Ages
PA	Pittsburgh	Peds
RI	Providence	All Ages
TN	Nashville	All Ages
TX	Dallas	All Ages
	Houston	Peds/Adolescents
UT	Salt Lake City	All Ages
VA	Richmond	All Ages
WA	Bremerton	Peds/Spina Bifida
	Seattle	Peds
	Vancouver	All Ages
Nigeria	Lagos	Peds & Families



Search **Hydrocephalus Association Community Network** on Facebook to find your local online Community Network.

HA: What would you say to someone who wants to help and become involved with a support group, but might be hesitant to take that first step?

JENNIFER: To be honest, I never pictured myself as someone who would join a support group, but now I am running one! I would suggest to anyone who is interested in the support group to request information about upcoming meetings, to pick one that has a topic they are interested in, and to try it. There's no commitment, you don't have to join anything, and you can come to meetings when it works with your life.

HA: Where would you like to see HA 5 years from now?

JENNIFER: People still ask "what's hydrocephalus" when I tell them about Jonathan. In 5 years, I would like to see that HA has educated people on hydrocephalus and created a much greater awareness of this condition.

HA: What message do you have for other parents?

JENNIFER: That's a difficult question because I am definitely not an expert! I'm just a regular person, a wife, a mother of one child without hydrocephalus and one child with hydrocephalus. I would like to think that hydrocephalus does not define us as a family; it's simply a part of who we are and I am just trying to educate myself so that I can help my son and make the best decisions for our family. There are so many other parents and families out there who are doing the exact same thing.

HA: What message do you have for HA?

JENNIFER: Thank you! HA was the first place I reached out to when I was feeling alone and didn't know where to turn. I was immediately connected to fabulous resources and encouraged to start the support group. The support they give to our group is outstanding and very much appreciated!



Milestones

The Hydrocephalus Research Initiative is launched, adding funding and support of research to HA's mission. \$600,000 is raised towards the effort.

Mentored Young Investigator program is started, with five awards made to new researchers interested in hydrocephalus.

Dr. Nathan Selden Welcomes HA to Portland

Dr. Selden, a native of Portland, Oregon, joins Dr. Michael A. Williams and Dr. Marion "Jack" Walker as a Medical Chair for the 13th National Conference on Hydrocephalus.

For more than 30 years, the Hydrocephalus Association (HA) has been bringing families and professionals together at various events, including Community Network meetings, WALKs all over the country and at the biennial National Conference on Hydrocephalus.

Every one of our conferences is planned with the guidance and input of our Medical Chairs. As this year's conference will be in Portland, OR, we are honored to have Dr. Nathan Selden host the 13th National Conference on Hydrocephalus and join Drs. Marion L. Walker and Michael A. Williams as our medical chairs.



Meet Dr. Nathan Selden

Dr. Selden was raised in Portland, Oregon. He graduated 'with distinction' from Stanford University and then spent three years at Cambridge University as a Marshall Scholar, completing a Ph.D. in neuroscience. At Harvard Medical School, he was awarded the John E. Thayer Scholarship and graduated cum laude in neuroanatomy.

Dr. Selden trained at the University of Michigan and in pediatric neurosurgery at Northwestern University. His post-doctoral work on human basal ganglia anatomy won the 1998 Academy of Neurological Surgery Award.

Dr. Selden is the Campagna Chair of Pediatric Neurosurgery at Oregon Health & Science University, Neurosurgery Residency Program Director, and Vice-Chair of the Department of Neurological Surgery.

Dr. Selden's clinical focus is on neurosurgery for children, including epilepsy, hydrocephalus, brain tumors, and congenital malformations. At OHSU, he performed the first transplantation of neuronal stem cells in a human patient as part of a clinical trial treating Batten's disease. He has published extensive clinical evidence regarding spinal dysraphism and twice served as an author of the Pediatric Traumatic Brain Injury Guidelines. The NIH, the Oregon Child Health Research Center, and the Cameron Foundation have funded his research on brainstem functional anatomy.

Dr. Selden has a significant interest in lifelong neurosurgical education and educational science. He is Chair of the group that in 2012 developed new educational outcomes measures for all U.S. neurosurgery training programs, the ACGME Milestones. He also founded the Neurosurgery PGY1 Boot Camps which are attended by all incoming U.S. neurosurgery residents and are designed to improve safety and quality in training programs. In part for these efforts, Dr. Selden received the Parker J. Palmer Courage to Teach Award from the Accreditation Council for Graduate Medical Education in 2013.

Dr. Selden is the President-elect of the Congress of Neurological Surgeons (CNS), and will serve as its President from 2014 to 15. He also serves the Society of Neurological Surgeons, the residency program directors' society for neurological surgery, as chair of the Committee on Resident Education.

Have **YOU**
joined us?

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WATCH us!



PIN us!



HA launches the Hydrocephalus Resource Library, our Teens Take Charge program with sponsorship by the Medtronic Foundation, and the Fudge Solomon Legacy Society.

HA awards \$400,000 in Established Investigator grants on cerebrospinal fluid dynamics to Dr. Miles Johnston and Dr. Pat McAllister.

Facing the Future with Fierce Determination and Optimism

Many high school seniors in our community spent the winter break completing applications for college. The pains of filling out the paperwork and writing the essays can be felt throughout the entire family, as many parents will attest. For seniors writing their essays, it is also a time of self-reflection. They dig down deep to find the perfect words and sentiments that will truly reflect who they are, transforming lines on a page to a living, breathing human being. Elijah Lawrence is a member of our Teens Take Charge (TTC) Advisory Council, has been a summer intern in our HA office, and his family has had a close connection to HA for many years. Elijah gave us permission to share his college essay. As he reflects back on his life, he also reflects back on the values his parents have instilled in him, as well as the values, information and self-advocacy tools that TTC and HA strive to deliver to our community and, particularly, our young adults. Pull out the hankie...or at least be ready to clap loudly.

By Elijah Lawrence, TTC Advisory Council Member

Picture this: A four-year old bounds into the middle of a high school pick-up basketball game. A player pats him on the head and then recoils: "What is that?" Four-year old: "That's my shunt. S-H-U-N-T. Any other questions?"

Seventeen years ago, I was born with a serious neurological condition called hydrocephalus, literally "water on the brain." Four days after birth, neurosurgeons implanted a shunt deep in my brain to drain the chronic build-up of excess fluid due to a narrow third ventricle. Except for several days on morphine, a turban made of bandages, and a prominent bump under my scalp, I left the hospital a healthy baby.

Fast forward four years: I am a young boy undeterred by warnings about contact sports or cruel comments. And, a boy who knows more about brain anatomy than any preschooler should. Even then, I was eager to educate people about hydrocephalus and, of course, to fit in.

There are many challenges people with hydrocephalus face. I must pay attention to signs of potential shunt failure, which necessitate a quick trip to the nearest operating room for a "revision." As a young child, I participated in occupational and physical therapy classes to help with balance and coordination. I have worked very hard and successfully to control head movements, which required that I deploy my well-honed skill in countering teasing with confidence and humor.

My parents sent me to sleep every night with the message, "You can do anything and everything" and I believed them. I developed a wicked sense of humor; learned to dance, ride a bicycle and swim; and worked successfully with my teachers to ensure that I did as well as, or better than, the other kids.

I was also given the gift of a love of music, a strong voice, large "piano" hands, and a love of performing. One of my first experiences with a large audience was as the nine-year-old featured performer at the National Hydrocephalus Conference. I belted out Wonderful World and watched in amazement as rows of neurosurgeons and parents pulled handkerchiefs from their pockets and wiped their eyes.

Fast forward to 8th grade: I am in a summer camp production of Oliver. My shunt fails and I am rushed into surgery. Two days later, I am on stage performing, my bandages hidden under my oversized Oliver-style cap. The show must go on!

I firmly believe that my ability and passion for music are somehow linked to my hydrocephalus. Music has provided me with a platform for building confidence, having a special talent to share, and gaining a remarkably diverse group of friends and teachers. I am proud that hydrocephalus has never stood in the way of my education, my music or doing what I love to do.

Fast forward through high school: I live a healthy and rewarding life with my shunt still in place. The determined four-year old who stood up for himself on the basketball court is still a big part of who I am. Growing up with hydrocephalus has helped me learn how to overcome challenges and to face the future not with fear, but with fierce determination and optimism. In whatever career I pursue, I will seek ways to inspire these qualities in others with chronic medical conditions.

Picture this: A 30 year old vocal musician brings the roof down on a benefit concert for children with shunts. S-H-U-N-T. Any other questions?

Milestones

HA Chairman Paul Gross is appointed to the NIH National Institutes of Neurological Disorders (NINDS) Advisory Council.

Kids to Cure Hydrocephalus, a combined public education and fundraising initiative for schools, is established in our WALK and Special Events portfolio.

Congrats to our 2013 TTC Scholarship Recipients!

The Hydrocephalus Association is pleased to honor the 2013 Teens Take Charge Scholarship recipients. Through a generous grant from the Medtronic Foundation, the Hydrocephalus Association is able to award five scholarships in the amount of \$1,000 each to these remarkable young adults.

Amanda Korcal

Amanda is a student at Aquinas College, where she recently declared a double major in psychology and community leadership. After college, Amanda would like to work in a hospital setting where she can counsel children and their families who are struggling with chronic illnesses and conditions. Diagnosed with a chiari malformation at a young age, Amanda developed hydrocephalus after undergoing a chiari decompression. "Looking back at my childhood, I do not remember not having headaches," states Amanda. Despite the pain and obstacles, Amanda remains positive, and she is determined to use her personal experiences to help other children and families who are facing similar challenges.



Emily Reed

Emily is enrolling in college at Oregon State University, where she intends to obtain an undergraduate degree and master's degree in psychology. Born with hydrocephalus, Emily also has a mild form of cerebral palsy. She does not let life's challenges hold her back. This past year, after eight years of training, Emily received her black belt in martial arts; an extraordinary accomplishment. "Hydrocephalus has made me a more tolerant person of other people with challenges. I have a greater respect of how people with other challenges take control of their life and make something of themselves. I think it is inspiring."



Ruby Poole

Ruby Poole is currently attending Patty Hanks Shelton School of Nursing, which is an extension of Abilene Christian University. She is member of Alpha Kai Omega Social Club and participates in intramural basketball, baseball, soccer, and flag football. Diagnosed with hydrocephalus shortly after birth, Ruby has endured 19 surgeries and numerous hospital stays throughout her life. Through it all, she continues to exhibit strength, courage and perseverance. "Having hydrocephalus has made me a stronger person. I have had to overcome difficulties that my friends have not, but I would not change it," Ruby shares.



Danielle Denise Kulowitch

Danielle Denise Kulowitch has been accepted into the University of Montana where she will be majoring in Environmental Science. She aspires to work at the Environmental Protection Agency in Washington, D.C. Born with Apert Syndrome and hydrocephalus, Danielle has had to overcome more obstacles than most. As a child, she suffered from developmental delays. "I did not speak until I was three... I did not walk until I was two," she shares. Nevertheless, Danielle excels in school and, at seventeen years of age, has finished her high school requirements six months earlier than her peers.



Samantha Richardson

Samantha Richardson attends Carleton University, in Ottawa, Ontario, where she intends to finish her undergraduate degree in political science, and aspires to become a lawyer. Diagnosed with hydrocephalus at three months of age, Samantha has endured countless surgeries and hospitalizations. Through it all she has learned, gained strength and courage. She states, "Hydrocephalus is definitely my teacher, perhaps the greatest teacher I will ever have."



HA participates in the Congressional Hydrocephalus Caucus Briefing conducted in concert with the Pediatric Hydrocephalus Foundation and other organizations.

Dawn Mancuso starts as our new Chief Executive Officer.

Apolonia Speaks Up About Hydrocephalus

Interview with Jennifer Johnson, Education Manager



My name is Apolonia Feliciano and I am 19 years old. Throughout my life, I have had to face and overcome many challenges. I was diagnosed with communicating hydrocephalus at the age of two. Due to this, I had to undergo years of physical therapy and speech therapy. It was not until the age of nine that I began experiencing excruciating headaches. This resulted in numerous hospital stays. Unfortunately, doctors were not sure what caused

my hydrocephalus. Many individuals are born with it, but I was not. In the beginning, my physicians were very skeptical about placing a shunt in me because they thought it was not going to be an effective treatment. My doctors decided to start treating me with a medication called Diamox and doctors performed frequent spinal taps.

Unfortunately, as I grew older, my headaches became more frequent and more severe. It seemed like the medication was not helping me anymore and during one of my last spinal taps, a nerve was pinched which resulted in loss of sensation in my legs. After this, my doctors came to an agreement and decided to perform an endoscopic third ventriculostomy (ETV).

I did excellent for a month, but a follow up MRI showed that my ventricles were beginning to increase in size. In time, I began losing vision in my right eye. Consequently, my doctors recommended that it was time to insert a shunt to see if I would benefit. I was very optimistic about the shunt; however, I was not aware of the problems and complications that can arise with the mechanical device.

At first, my doctor decided to insert a VP shunt. I went a year without complications until January 2013 when I had my first shunt malfunction and underwent a revision. Following surgery came more surgeries, hospitalizations and complications. Eventually, my neurosurgeon decided to switch me to a VA shunt.

Since then, I have had to endure several more surgeries and I might have another in the coming weeks.

HA: What are your educational and career goals?

AF: My goal is to get a Bachelor's in nursing. I want to be a registered nurse. I would love to help other children who are sick because I know how it feels to be very sick. I know as a patient what a child needs from their nurse. I will also advocate for my patient, if needed, because I know how frustrating it can be to feel helpless.

HA: How has having hydrocephalus impacted your life?

AF: Because of my hydrocephalus I've had to miss a lot of days of school. Now I'm in college and I couldn't even finish my last semester. Hydrocephalus also resulted in me developing a sleeping and breathing disorder called sleep apnea. Growing up, I was scared and afraid that I would not wake up to see another day. Now, I have options and at night I am hooked up to a machine which ensures that I am receiving enough oxygen when I am sleeping.

The hardest obstacle I've had to face was undergoing nine surgeries in less than a year. I felt that when I finally thought that things were getting better and looking up, I would have to go back to the hospital. The past 10 years have been hard not only on me, but my mother as well. As a mother, she understands my pain and frustration. However, she hasn't lost hope. I remain optimistic. I know that I will have to undergo additional surgeries, but I know that I am not alone and I will not stop fighting.

HA: What message do you have for the general public or others living with hydrocephalus?

AF: My message to others with hydrocephalus is to never give up. When things get dark there's always a light at the end of the tunnel. God would never put you in a position that you couldn't handle. It's not easy to know that there is no cure, but I have hope that maybe one day there will be a cure.

Remember, it is very important to stay informed about what's happening. Do your research and advocate for yourself. You are your best advocate. Don't let hydrocephalus define who you are. It will make you a stronger individual.

Milestones

Second National Advocacy Day held in conjunction with our 12th National Conference on Hydrocephalus. Our inaugural Public Service Awards are presented to Representatives Andrews, DeLauro, and Lance.

HA formally partners with the Hydrocephalus Clinical Research Network, a collaboration of multiple research institutions working to dramatically improve the lives of children with hydrocephalus.

2013 WALKs and Special Events The Year in Review and Looking Toward 2014

By Randi Corey, Director of Special Events

As we end 2013, I am delighted to announce that HA's WALKs and special events **raised more than \$1.25 million** for HA's mission, a 17% increase over the previous year. Incredible results like these would not have been possible without the countless hours invested by our volunteer WALK Chairs and special event leaders. I wish I had the space to recognize all of our WALKs individually because they all deserve kudos and recognition, but in the interests of allowable space, I will have to limit myself to highlighting just a few.

Our new **Los Angeles WALK**, chaired by Tania Heise, Cortney Pelletieri, Jennifer Pope, Dan Solchanyk and Amber Milliken, who also serves as the leader of our Community Network, was an outstanding success. Raising \$130,000 with more than 800 participants, it was HA's largest first-year event ever. The new **Charlotte WALK** was very impressive, raising more than \$28,000, with Co-Chairs Christy Ruth and Susan Slattery at the helm. Other new sites included Columbia, SC, Western New York (held in beautiful Niagara Falls), a new school WALK in Minneapolis (led by 16 year-old Chair Dylan Johnson), and Basking Ridge, NJ, which raised over \$25,000 despite a late start and a solo Chair, Maura McEnroe.

HA's established WALKs posted some extraordinary results in 2013, too. Less than \$1,500 separates our 2nd and 3rd largest sites, with the **Chicago WALK**, under the leadership of volunteer Co-Chairs Stacy Buckner, Katie Cook, Zahadita Kudrna and Andrea O'Shea, raising \$90,889 (a 33% increase) and the **Seattle WALK**, with two new Co-Chairs, Dawn Adix and Jenifer Petersen, posting \$89,428. I also want to recognize the **Houston WALK**, under the leadership of new Chair Sarah Besuegli. Only in its second year, it had an 85% increase in revenue, totaling more than \$43,000. Other sites posting double-digit increases over their 2012 totals included St. Louis (82%), Atlanta (78%), Portland (58%), Louisville (48%), Connecticut (39%), Denver (37%), Washington, DC



WALK TO END HYDROCEPHALUS



Hydrocephalus is included as a category in the NIH RePORTER, making hydrocephalus funding dollars by the government transparent to the public.

Our Research Conference, *Opportunities in Hydrocephalus Research: Pathways to Better Outcomes*, co-sponsored by NIH and Seattle Children's Hospital, is held in Seattle, WA.

(28%), Wichita (26%), South Florida (14%), San Francisco (12%), and Long Island (10%.)

Two sites reached important milestones in 2013. **Denver** held its 10th annual HA WALK under the leadership of Chair Phyllis Rogers, who has led the WALK for all 10 years. **San Francisco**, HA's "first-WALK" and the one that started it all, celebrated its **20th anniversary**. Special thanks to SF WALK Chairs Maureen Pardi and Miaja Rocciola, ably assisted by Emily Fudge.

Special thanks to Kelly Kimsey, who stepped up as a new Co-Chair with Hailey Burnham just 10 weeks before the **Nashville WALK** when the original Co-Chair, Alicia Georgiou, had to step down.

Unfortunately, due to limited space, I cannot individually recognize our other 46 WALK Chairs, but they all did a fabulous job and we cannot thank them enough for their hard work, blood, sweat, tears, dedication and passion.

Special Events

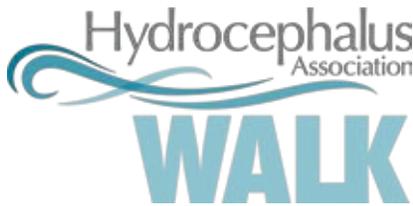
Special congratulations and kudos to Heather Kluter, from Orange County, CA, who took last year's **Trick or Treat for HA** pilot program and ran with it this past fall, recruiting other volunteer leaders across the country. HA's Trick or Treat participants raised more than \$25,000, thanks to Heather's leadership. Also, special recognition is extended to Amy Maynard, the volunteer Chair of the **16th Annual Thanks for Running 5K**, held on Thanksgiving Day. This year's run totaled over \$6,700. Other notable third party events include the annual **MX for Children**, under the leadership of Paul Gross, raising over \$46,300, the biennial **St. Lothar Golf Tournament**, hosted by Sara and Eric Zelesky, which raised almost \$3,000, and **Team Hydro**, led by Pam, Peter and Sam Finlayson, competing in the annual Sharkfest events, this year in San Francisco and Boston, raising almost \$46,000 for hydrocephalus research.



Milestones

HA's national headquarters moves to Bethesda, MD, to support our expanding advocacy and research initiatives while continuing our core services of providing support and education.

HA awards a research grant to Dr. Timothy Vogel and partners with the Rudi Schulte Research Institute to award a research grant to Dr. Mark Wagshul.



Looking toward 2014

If you have been playing with the idea of chairing a WALK in your area, we have two established WALK sites which are in danger of being canceled. The volunteers leading these two events need to step down, so we are actively seeking new, passionate Co-Chairs for the **Nashville** and **Albuquerque WALKs**. I'd like to thank Kathy Carrillo for leading the Albuquerque WALK for the past 8 years – we will miss you. If you are interested in exploring the idea of taking the reins for either of these two events, please contact me (randi@hydroassoc.org) and we'll discuss it in greater depth. Worried that you don't know how to do it or wouldn't know where to start? No problem – HA will train you. We currently have 34 sites across the country and most HA WALK Chairs work full time jobs outside the home, have families, often with a child with hydrocephalus, and still manage to Chair a successful WALK.

2014 is going to be an exciting and busy year for our WALK program, as it continues to grow at a phenomenal pace. In 2014 we'll have up to 44 WALKs across the U.S. Confirmed new sites include:

- Cleveland, OH
- Columbus, OH
- Dallas, TX
- Indianapolis, IN
- Las Vegas, NV
- Peekskill, NY
- New School WALK - Long Island, NY
- New School WALK - Chattanooga, TN

We also have two former sites that are being reintroduced under new leadership: Northern KY/ Cincinnati, OH, and Phoenix, AZ. We're delighted that new volunteers have stepped up, ready to bring these two sites back.

NOTE: If you're planning to commit to start a new WALK in your community but it isn't listed here, please contact Randi Corey at randi@hydroassoc.org immediately.

We're looking forward to another banner year for the HA WALK and special events program. It is a commitment, and requires a lot of hard work - there's no question of that. But there's no feeling in the world like holding a successful fundraiser for HA. It's one of the best ways to fight back against hydrocephalus. We hope you'll join us as we look toward another successful year.

Craig and Vicki Brown host the first annual Vision Dinner in New York City.

HA commemorates the 50th anniversary of the definition of Normal Pressure Hydrocephalus by Dr. Salomon Hakim. **Our next newsletter will be dedicated to adult onset hydrocephalus.**

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We would like to thank all of our loyal donors who join us each year to support HA's agenda to end hydrocephalus. Please continue to stand by our side and renew your membership today. We promise to put your membership dollars to work. We will continue:

- Providing a source of comfort and refuge for people affected by hydrocephalus, whether it's through our toll-free hotline and email, informative publications, online resources or physician directories.
- Sponsoring educational opportunities that bring together patients, doctors, scientists and advocates to share the latest in hydrocephalus treatment and care. View our NPH Webinar on our website. Visit the Resource section on our NPH page under Education and Support.
- 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.
- Spreading the word, reaching out and building community. In 2013, we expanded our Walk program to 12,000 participants, advocated for more research funding at even more government agencies, and increased our social media presence, with over 14,000 followers on Facebook and Twitter. We will continue to use these vehicles to raise critical awareness.

As you can see, it's an exciting time to be part of the Hydrocephalus Association. Go online to send your member gift today or complete the member form on the facing page.



Name: _____ Telephone: () _____

Address: _____

_____ Email: _____

Name of person with hydrocephalus: _____

Birth date: _____ Age at diagnosis: _____

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

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