

# Pathways

Summer Edition 2013

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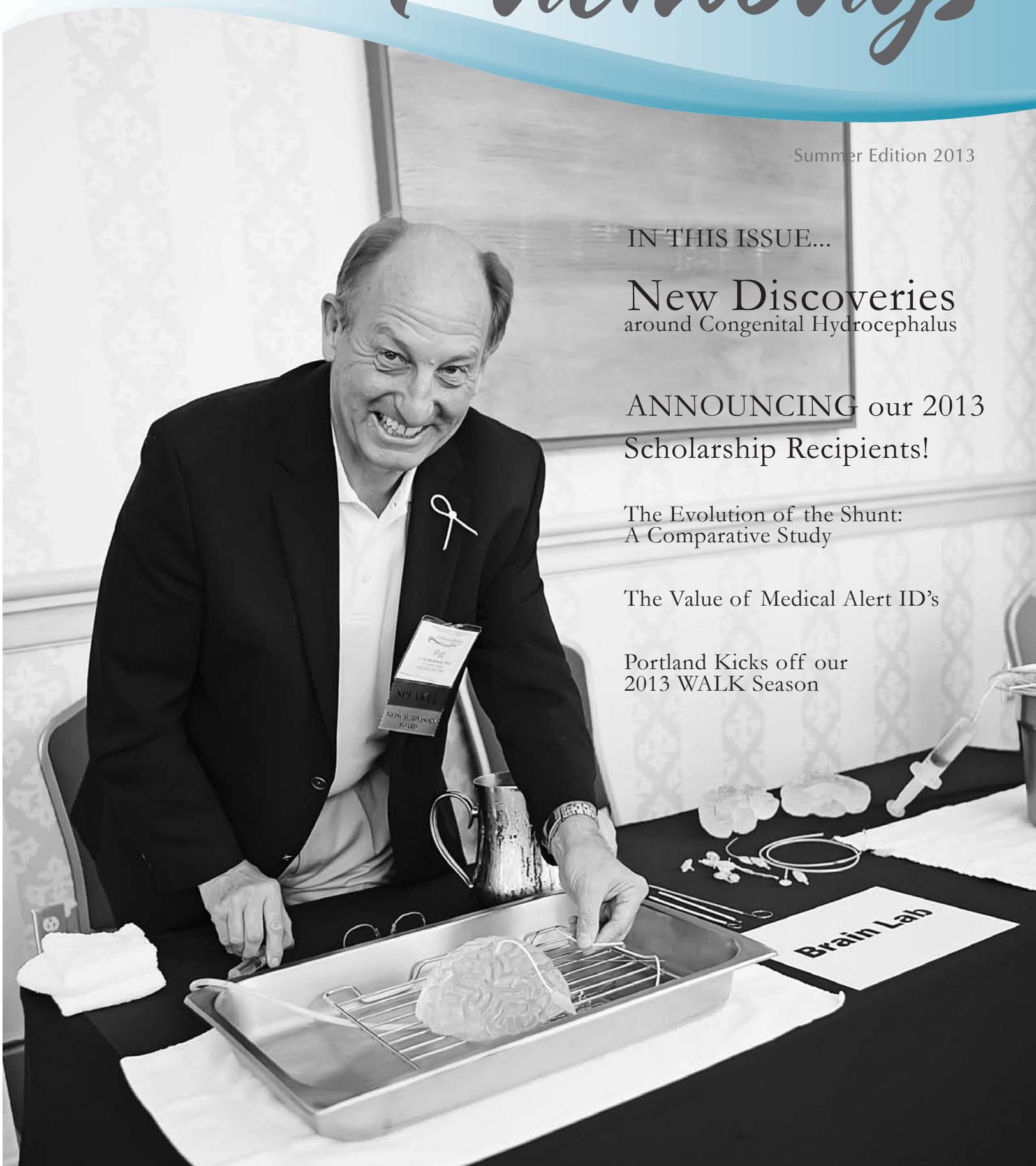
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# The Patient's Perspective



*A wise man should consider that health is the greatest of human blessings, and learn how by his own thought to derive benefit from his illnesses.*  
– Hippocrates

I've recently had some unexpected health issues that have given me some time to pause and see life from a different perspective. I don't share this to scare anyone – I am doing fine and mending very well. I share it because I've gained insights as a result of this experience that I do want to share with you.

Life as a "patient" is like living on a different planet. At least, that was my initial perception of it. I have always been someone who has been very healthy, rarely getting even a cold. When something untoward did come up, I have always bounced back more rapidly than expected, so that it became a temporary "blip" that was quickly forgotten. This was the first time I have had to face something more serious – including my first surgery. Out the window goes the "to do" list of everything that was once so important, and the schedule gets replaced with "must do's" defined by doctors, hospitals, nurses, testing facilities, etc. With that came all of the emotions I am sure everyone in the hydrocephalus community knows too well – the fear of the possible pain, the panic at the loss of control, the worry about the outcome. Moreover, you sometimes don't know what to feel because you are so conflicted – you are thankful for the caring, skillful doctors working with you, but get frustrated by their demands, their inflexible schedules, their less-than-perfect bedside manners. Or, you get annoyed by the mind-boggling paperwork associated with insurance coverage, logistical challenges of getting test results distributed to all the right places, and even the simplest tasks like finding a parking space at an overcrowded, inner-city medical facility. You don't want to be defined by your condition, but you wish others could understand what you are going through. You are thankful for the many family members and friends who jump to help you but feel guilty that you are uprooting and rearranging their lives to deal with your challenges. Still, you keep a positive attitude, knowing that it helps to speed recovery and make the experience more bearable.

Then, out of the blue, you make a connection with another patient – someone who has gone or is going through what you have. They listen. They share. They don't judge. They make recommendations based on their experiences. They give you hints about what you can do to lessen the possibility of side effects or negative outcomes. They rejoice with you when things go well. You really don't have to say much; they just know.

There is such strength in those connections. At its essence, this is the beauty and power of patient advocacy organizations – like HA. I thought I understood that before. After all, I have been a caregiver for family members who have faced illnesses, and I gained much from the information and education available through organizations similar to HA. However, it wasn't until the past couple of weeks that I can say I truly appreciate the service, the support that organizations like HA provide. On behalf of patients everywhere, I want to send a great big "Thank You" to all those patient volunteers – official and unofficial – who make it their business to help the newbies adjust to their new reality. This includes all those in leadership roles (such as Support Group chairs and WALK chairs) as well as those who share one-on-one or via social media (such as Facebook). Rest assured, your work impacts many.

Maybe the planet isn't so different after all. Maybe it is me who is different. And, thankful I am for that!

A handwritten signature in blue ink that reads "Dawn M. Manau". The signature is fluid and cursive, with a large initial 'D'.

## Why I Joined the Fudge Solomon Legacy Society

By Edith Gross

On January 10, 2005, my son Paul called urging me to come to Seattle right away as his son had just arrived ten weeks early. I flew from Philadelphia the following day, in time to learn that William had a pulmonary bleed and a brain bleed. Immediate steps were taken to save his life while his parents and I sat around totally dazed and frightened, praying for his survival. Today William is eight years old. He has hydrocephalus and cerebral palsy as a result of those bleeds. He didn't walk until he was four years old, but now has beautiful straight legs as a result of spectacular, innovative surgery performed by Dr. David Yngve in Houston. William has had five brain surgeries, but has been free of such treatment for the past six years. He is a bright, loving child with a very good sense of humor. He entertains his large family network with his jokes.

This child is so dear to everyone, but especially to me, which is why I became a member of the Fudge Solomon Legacy Society and have included the Hydrocephalus Association in my will. The focus of the Association is on research with the ultimate goal of finding a cure. The Hydrocephalus Clinical Research Network (HCRN), linked to the Association, connects a network of hospitals in North America with collaborative hydrocephalus research to improve the lives of those with hydrocephalus. I know that children and adults with hydrocephalus will benefit from the research that the Hydrocephalus Association supports.

If you have a grandchild or loved one affected by this condition, I encourage you to join me and other Society members who are helping to insure the viability of the Hydrocephalus Association to cure this condition. To receive a copy of the brochure or to schedule a personal consultation, please e-mail [giftplanning@hydroassoc.org](mailto:giftplanning@hydroassoc.org).

Thank You,

*Edith Gross*

Grandmother of William

Member, Fudge Solomon Legacy Society



**The Fudge Solomon Legacy Society**



A gift for  
the future.

**Join today.**

Call (888) 598-3789

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## Welcome Marisol Ortiz!



HA is pleased to announce a new addition to our team, Marisol Ortiz, who will serve as the Database and Donor Relations Manager. Marisol comes to us with experience working with databases at the Alzheimer's Association National Capital Area and a for-profit company called Ntrepid,

also in the DC area. She will play a critical role in helping HA deploy a new constituent management system and donor relations program. She may be reached at 301-202-3811 ext. 21.

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## Reminder: Please Note our New Address

The Hydrocephalus Association has been in our Bethesda, Maryland office for almost one year! Our national headquarters is now 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. Please note our new address and phone, if you have not already done so.

4340 East West Highway, Suite 905  
Bethesda, MD 20814  
(301) 202-3811 main (888) 598-3789 toll free  
(301) 202-3813 fax

## Medical Device Development and Evolution

By Marvin L. Sussman, PhD



The first commercially-available shunt was introduced almost 60 years ago. Over the past 60 years, significant developments and evolution of medical device technology has occurred in many fields of medicine. This article compares and contrasts the evolutionary

changes that have occurred in the field of hydrocephalus with the revolutionary changes that have occurred in two other fields: cardiac pacing and radiation oncology. What we find is that while the shunt has seen modifications that have had positive impacts for patients, more is needed if we are going to move the management and, one day, the cure of hydrocephalus into the 21st century.

A Brief History of Three Medical Devices: Cardiac Pacing, Radiology, and the Shunt

### Cardiac Pacing

The first cardiac pacemaker was an external stimulator designed and built in 1950 based upon design input by a cardiothoracic surgeon. A large external device, the size of a cart, was built using vacuum tube technology; it provided transcutaneous pacing using electrodes on the skin. It was crude and painful to use and, being powered from an AC wall socket, had a potential hazard of electrocution by inducing an abnormal heart rhythm. The engineers began to tackle the size of the unit as well as the power source.

The first commercially available silicon transistor was developed in 1956. This led to miniaturization and rapid development of practical cardiac pacemakers. In 1958, the first wearable external, transistorized pacemaker was used for a patient. It was housed in a small plastic box with controls for rate and output voltage adjustment. It was connected to wire leads which passed through the patient's skin to electrodes attached to the heart surface. The first fully implantable pacemaker into a patient occurred later that year, with electrodes attached to the heart's myocardium. The device lasted for three hours; a second device was implanted and lasted for two days. In



www.machine-history.com

1959, the successful use of a temporary transvenous pacer was first demonstrated. In 1960, primary cell mercury batteries were introduced that could power an implant for up to 18 months. These implantable devices all suffered from the poor reliability and short battery life associated with mercury batteries.

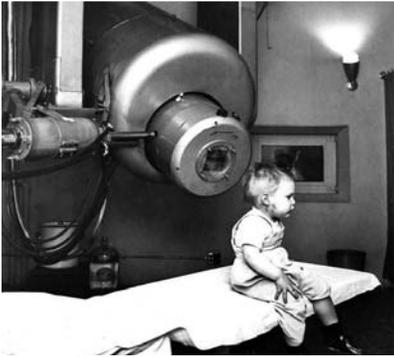
In the late 1960s, several companies developed isotope powered pacemakers, but they were surpassed, in 1971, by lithium-iodide cell battery which more than doubled pacer battery life and provided advance warning of impending failure. This was coupled with the introduction of heretically sealing technology to overcome the problem of the intrusion of body fluids into the unit, which was also affecting the reliability of the device.

More recent advances in the implanted pacemaker have focused on the transition to microprocessor-controlled pacemakers. This led to pacemakers that improved the heart's pumping efficiency, then eventually evolved into the ability to adjust the base pacing rate using rate response algorithms. Pacemakers now provide information via wireless transmission which the clinician uses to adjust the pacemaker function to the patient's specific requirements and provides data for inclusion in the patient's record.

### Radiation Oncology

Radiation oncology, as a field, was born not long after the discovery of x-rays in 1895. However, a new era of therapy occurred in 1956, when a linear accelerator, a device used by the radiation physicists for research purposes, was adapted for use as a tool for fighting cancer. A 2-year-old boy suffering from retinoblastoma, a cancerous tumor in his eye, was the first patient to be treated using X-rays produced by a research linear accelerator modified by physicists for medical use. This treatment saved the child's sight; for the rest of his life his vision remained intact. In 1958, the first commercial medical-use linear accelerator ("Linac") was introduced.

By the 1960s, high energy (megavoltage) Linac treatment machines heralded the next generation of treatment technology. They were capable of producing high energy, deeply penetrating radiation beams, which allowed the treatment of tumors deep inside the body without excessive damage to the overlying skin and other normal tissues. In subsequent years, radiation oncology experienced multiple technologic revolutions. By the late 1980s, computer tomography (CT) was linked with Linacs to create CT-based treatment planning. Software algorithms produced sophisticated treatment plans for radiation



Stanford University Department of Radiation Oncology

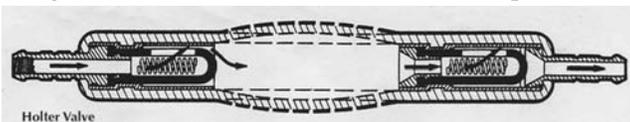
therapy allowing three-dimensional conformal radiotherapy (3D-CRT). This planning reduced radiation doses delivered to surrounding normal tissues, greatly improving the quality and delivery of radiotherapy. However, stray radiation scatter to surrounding healthy tissues remained a problem.

In 1992, Intensity Modulated Radiation Therapy or IMRT was introduced. Perhaps the most important “revolution” in radiation oncology to date, IMRT conforms the prescription radiation’s therapeutic dose to the volume shape of the defined target in 3 dimensions, thereby reducing the volume of normal tissues receiving high radiation doses. This reduces the potential side effects of radiation treatment. More importantly, IMRT also provides a method to safely escalate the radiation dose, allowing re-treatment of previously irradiated patients, potentially improving cure rates and giving repeat-treatment-patients the option of additional radiation treatments. IMRT has become standard practice for a wide range of tumors.

In 1998, ultrasound was combined with treatment planning so that radiation can be delivered to targets that move daily, such as the prostate. Currently, the field is undergoing another technologic revolution with the development of Image-Guided Radiation Therapy (IGRT) which provides the ability to perform cone-beam CT scans of the patient while the patient is on the treatment table allowing treatment to be adapted to tumor shape changes occurring over multiple radiation treatment sessions. This is expected to translate into higher cure rates and lower rates of toxicity.

### Hydrocephalus Shunts

The development of the biocompatible silicone elastomer - a type of plastic that could be implanted in the human body - allowed the introduction of hydrocephalus shunts. The first clinically-viable, valve-regulated hydrocephalus shunt, introduced in 1952, ushered in the modern era of hydrocephalus surgery and treatment. At that time, there was no effective medical intervention for hydrocephalus. In that year, two neurosurgeons working in conjunction with a hydraulics technician whose child had hydrocephalus, successfully implanted a silicone elastomer, ventriculojugular shunt regulated by a ball-in-spring valve design inserted at either end of a flexible piece of tubing.



Holter Valve

This device regulated and released controlled amounts of the cerebrospinal fluid (CSF) from the brain into the heart’s right atrium.

At about the same time, another neurosurgeon produced a one-way slit valve made of silicone elastomer. The development of the valve system combined with the application of new biocompatible materials allowed for the safe and reliable diversion of CSF without many of the complications of unregulated (systems without valves) CSF drainage. Other neurosurgeons soon introduced the concept of ventriculoperitoneal procedures, the distal end of the tubing ending in the abdominal cavity, in which these newer devices were used.

While the early shunts allowed for the management of hydrocephalus, patients still faced numerous repeat surgeries due to shunt malfunction and/or shunt infection. Focus turned to the creation of a more sophisticated valve mechanism that would control the rate of CSF flow through the shunt, taking into account the variables caused by regular daily activity.

The 1970s saw the introduction of valves that addressed overdrainage or siphoning of CSF caused by an individual’s postural (standing, sitting, or lying down) change and vasogenic (blood flow) influences. As an example, moving to a standing posture causes a siphon or sucking effect, essentially “pulling” fluid out of the brain or lumbar region. The anti-siphon device was introduced in the early 1970s, followed by the gravity compensating mechanism in 1976. Flow regulated shunts were introduced in 1987. These valves maintain the drainage flow rate close to the rate of CSF secretion, regardless of patient position and other conditions that normally promote overdrainage.



Adjustable Valve

The problem remained that when these devices were not draining fluid properly, the individual had to undergo brain surgery to adjust or replace the shunt. The mid-1980s heralded in the programmable shunt. These shunts can be adjusted noninvasively using a magnet. The first magnetically-adjustable valve was marketed in 1984.

Advances also addressed reducing infection rates both during and after surgery. In 1976, the first commercially-sterilized shunt came to market. Antibacterial catheter coatings became commercially available in 2001. These advances in shunt construction have been coupled with standardized procedures produced by the Hydrocephalus Clinical Research Network (HCRN) that have dramatically reduced infection rates in the pediatric population.

There are now literally hundreds of options for valves, proximal and distal catheters. Further, device modifications to minimize overdrainage, antibacterial coatings, and magnetically-adjustable valves for fine-tuning CSF flow

Decade	Cardiac Pacing	Radiation Oncology	Hydrocephalus
1950-1954	(1950) External cardiac pacer (size of cart) (1952) Successful pacing of arrested heart		(1952) first silicone elastomer shunt developed
1955-1959	(1956) Silicone transistor (1959) Implantable cardiac pacer	(1956) Commercial LINAC used for cancer treatment	
1960-1964	(1960) Mercury battery introduced (1960s) Isotope powered pacers	(1960s) Megavoltage medical LINACs introduced	
1965-1969	(1969) Hermetic sealing		
1970-1974	(1971) Lithium powered pacers (1970s) Titanium cases		(1970s) ASD introduced. (1970s) In Utero treatment of hydrocephalus attempted
1975-1979	Dual chambered pacers		(1976) Gravity compensating LP shunt.
1980-1984	CMOS circuitry developed More physiological pacing systems Miniaturization of pacers	(1980s) CTs used for treatment plans	(1980s) Endoscopes for ETV (1984) Magnetically adjustable shunts. (1987) Flow regulated shunts
1985-1989	Sensors introduced Rate responsive pacing introduced		
1990-1994	(1994) Cardiac resynchronization reported	(1992) IMRT introduced for brain cancer treatment. IMRT use expands to other regions of the body	
1995-1999	Implanted cardiac defibrillator use becomes widespread	(1998) Ultrasound + LINAC for moving organ treatments Gated radiation delivery introduced for treatment of moving organs	
2000-2004		(2000s) IGRT introduced	(2001) Antibacterial catheters
2004-2010			
2010-			

rates, are all evolutionary modifications of the original clinically-viable shunt design.

Progress in imaging technology has allowed clinicians to treat hydrocephalus with greater success and safety. In the 1980s endoscopes again found a role in neurosurgery. The benefits include more accurate placement of ventricular catheters and creation of third ventriculostomies, primarily for aqueductal stenosis, in carefully-screened patients. Stereotactic localization, a minimally invasive surgical technique, led to more functional and safer approaches for the CSF drainage.

### Comparing Technology Development Over the Sixty Year Period

Great advances and achievements have been made over the course of the past six decades in many medical fields. Regrettably, the progress and advancements in the field of hydrocephalus has been slow and has not kept pace with those that have been achieved in other fields.

*Cardiac pacemakers* evolved from a cart-sized, AC line-powered device that was only adjustable for output voltage and rate to a fully-implantable, coin-sized device with long-life batteries, sensing circuitry and non-invasive adjustability

for parameters such as rate, pulse width, output current, parameters sensed, telemetry, etc.

*Radiation oncology* has progressed from providing treatment with a re-tuned research linear accelerator to one with sophisticated radiation treatment planning software that allows the delivery of radiation with pinpoint accuracy, combining radiation delivery with virtually real-time image guidance allowing radiation to be focused on a tumor whose volume is changing based upon the treatment delivered.

*Hydrocephalus management* moved at a much slower pace. Shunts have changed relatively little compared to the advancements made in other fields. Shunt tubing is made from the same material, silicone elastomer, although it has been made radiopaque to facilitate visualization on X-ray. Valves work based upon the same differential pressure principles across the valve and valve adjustments are by-and-large in discrete adjustment steps for setting the valve resistance when adjustable valves are used. Valves are available in multiple pressure ranges (as was the case with the first shunts). Magnetically-adjustable valves have taken over the field but, once set, they function in the same way that the first shunt functioned. Some shunts incorporate antibacterial coatings which appear to minimize infection

during the immediate post-operative period. After this period, the risks of infection are similar to untreated shunts.

The shunt system remains relatively unchanged consisting of an inflow (proximal) catheter, a regulating device (valve) and an outflow (distal) catheter. No commercially available shunt contains a sensor nor is there closed-loop, feedback control mechanism to adjust shunt function to the changing patient's needs. Telemetry of information that is now routinely available in cardiac pacemakers or neural stimulators is unavailable in shunts. There are no active shunts, although implantable pumps have been available for several decades.

## Conclusion

Clinicians in the 21st century will be required to continue to face the challenges presented by hydrocephalus. Treatment, until now, has focused on the management and alleviation of symptoms rather than the arrest and cure of the underlying processes that cause the imbalance between CSF production and absorption that cause the hydrocephalus condition. Treatment is plagued with one of the highest complication rates of any medical implant. Routine complications of the treatment modality (the shunt) are infection, obstruction, and overdrainage to name a few. Although some (regrettably the minority) of the patients with shunts can go for years without complications, even those lucky few are potentially one shunt malfunction away from a major crisis. At any time, and without warning, a shunt complication can require emergency intervention which may turn into a course in which many shunt surgeries are necessary.

Medical device manufacturers are commercial enterprises responsible to their shareholders to produce a profit. Product-development decisions are based upon market size and return-on-investment calculations.

The integration of the discoveries in basic science and clinical innovation from other fields will, hopefully, lead to the revolutionary technological and therapeutic developments that have brought fields such as cardiac pacing and radiation oncology into the 21st century. Due to the hydrocephalus market's comparatively small size against those of the cardiology or radiation oncology markets, revolutionary advances coupled with significant investments may not be commercially justifiable in and of themselves. Advancements in research in other fields, such as gene therapy, molecular biology, and neural regeneration, may be applicable to hydrocephalus and, thus, assist in moving development forward. Technological developments from other fields, such as closed-loop feedback sensing technologies developed for cardiac pacing and implanted neural stimulation devices and implantable pumps for intrathecal and other drug delivery, may be applicable to the management of hydrocephalus to eventually produce a "smart shunt." The concept of a functional cure rather than palliation may become achievable.

The Hydrocephalus Association has undertaken the research initiative to raise funds to attract and support the best and the brightest to develop revolutionary solutions to the problems that have plagued those impacted by hydrocephalus.

## New Shunt Systems Website Page Launched!

*By Karima Roumila, Director of Support and Education*

We recently asked on the Hydrocephalus Association's Facebook Page: *How many components do you think a shunt system has?* We were so pleased to see 87% responded with the correct answer. Yes, shunts typically consist of three major components.

1. An inflow (proximal or closer to the inflow site) catheter, which drains cerebrospinal fluid (CSF) from the ventricles or the subarachnoid space;
2. A valve mechanism, which regulates differential pressure or controls flow through the shunt tubing;
3. An outflow catheter, which runs under the skin and directs CSF from the valve to the abdominal cavity, heart or other suitable drainage site.

To better understand shunt system components, valve mechanisms, most common shunt systems, overdrainage control devices, Siphon-resistive devices (SRD) and the different symptoms of malfunction and/or infection, we are pleased to launch a "Shunt Systems Page" on our website, and a corresponding factsheet available for download or by mail. Call our office or email [info@hydroassoc.org](mailto:info@hydroassoc.org) to request our Shunt Systems Factsheet. You can also visit us online at [www.hydroassoc.org](http://www.hydroassoc.org). We encourage everyone to learn more about shunts!

### Other Resources:

Aesculap Inc.:

Toll free: 1-800-282-9000, [www.aesculapusa.com](http://www.aesculapusa.com)

Codman, a Johnson and Johnson Company:

Toll free: 1-800-225-0460, [www.codman.com](http://www.codman.com)

Integra Life Sciences:

Toll free: 1-800-654-2873, [www.integralife.com](http://www.integralife.com)

Medtronic Neurologic Technologies:

Toll free: 1-800-468-9710, [www.medtronic.com](http://www.medtronic.com)

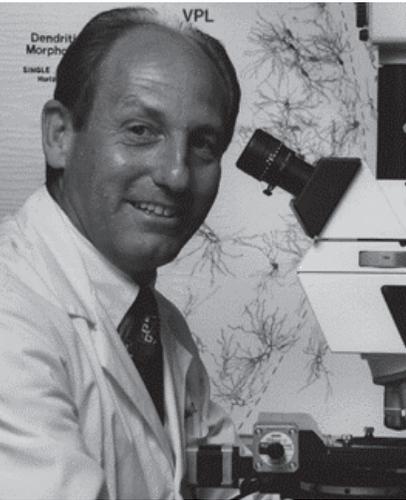
Sophysa:

Telephone: 219-663-7723, [www.sophysa.com](http://www.sophysa.com)

# New Discoveries

## HA Established Investigator Publishes Research Findings on Congenital Hydrocephalus

by Ashly Westrick, Research Programs Manager



James P. (Pat) McAllister, PhD, is the Director of Basic Hydrocephalus Research at the University of Utah. In 2011, he received a two-year Established Investigator grant from the Hydrocephalus Association. The journal article, “The role of the subcommissural organ in the pathogenesis of congenital hydrocephalus,” recently published in *Cell Tissue Research*, details his research findings.

The subcommissural organ (SCO) is located at the entrance of the aqueduct of sylvius (SA) in the brain and is highly specialized in the secretion of proteins. In 1954, Overholser et. al. hypothesized that these proteins prevented the closure of the aqueduct of sylvius, and that maldevelopment of the SCO could lead to stenosis (or narrowing) of the aqueduct, and consequently to the onset of hydrocephalus. Multiple studies have supported this hypothesis. However, it is unknown whether the hydrocephalus precedes or results from the maldevelopment of the SCO.

Dr. McAllister’s current study provides evidence that maldevelopment of the SCO precedes hydrocephalus, indicating that it is possible the maldevelopment is causing the hydrocephalus. The researchers compared HTx rats to normal rats. HTx rats are a mutant rat that presents with fetal-onset hydrocephalus with stenosis of the SA and dilation of the lateral ventricles starting at embryonic day 18. The researchers discovered abnormalities in the subcommissural organ as early as embryonic day 15 in the HTx rat, indicating that maldevelopment of the SCO occurs prior to hydrocephalus.

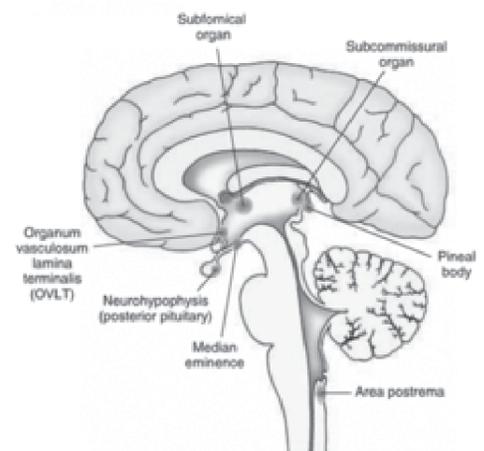
Furthermore, the subcommissural organ secretes glycoproteins, most of which aggregate and form Reissner’s fibers (RF). There is evidence that the Reissner’s fibers may be involved in the regulation of the composition of the cerebrospinal fluid (CSF). In non-affected rats, the central canal of the spinal cord displays RF running the whole length. Hydrocephalic rats were devoid of RF. The lack of these fibers could have two possible consequences.

First, it is hypothesized that the proteins secreted by the subcommissural organ provide a mass of negatively charged molecules that help to keep the aqueduct open. Without these proteins, there is a diminished amount of negative charges in the SA and this contributes to a narrowing of the aqueduct. Secondly, evidence suggests that the fibers are a key element for normal CSF flow through the aqueduct. The absence of RF could impact CSF hydrodynamics.

Another finding was that transthyretin (TTR) is present in higher concentrations in HTx rats than normal rats. TTR is a protein involved in the transport of thyroid hormones in the CSF. The main source of this protein in CSF is the choroid plexus. The choroid plexus of the hydrocephalic rat probably secretes more TTR than in the normal rat. This indicates that factors that modulate TTR levels in hydrocephalus CSF could be important to consider in hydrocephalus.

The ultimate hypothesis from the research is that the absence of the large mass of negatively charged molecules from the aqueduct of sylvius results in a narrowing of the aqueduct, impairs the flow of CSF through the aqueduct, and causes severe hydrocephalus.

More research is needed to understand the genetics of this mechanism but this paper provides valuable insight into the role of SCO in congenital hydrocephalus.



### REFERENCE:

OVERHOLSER, M. D., WHITLEY, J. R., O’DELL, B. L. & HOGAN, A. G. (1954). Ventricular system in hydrocephalic rat brains produced by deficiency of vitamin B12 or folic acid in maternal diet. *Anat. Rec.* 120, 917.

# New Understanding

## New Cause of Congenital Hydrocephalus Opens the Door to Collaborative Research Study

On April 29, 2013, the Institute of Biosciences and Technology at Texas A&M University formally announced that researchers discovered a connection between a form of congenital hydrocephalus and the gene, Rnd3. The study is led by Jiang Chang, MD, PhD., associate professor in the Center for Translational Cancer Research and a prominent researcher focusing on the abnormal development of heart tissue and how it leads to heart failure. After identifying the significant finding for hydrocephalus among his study subjects, Dr. Chang attended a local Hydrocephalus Association support group meeting to meet individuals affected by hydrocephalus and to share his findings with the Association.

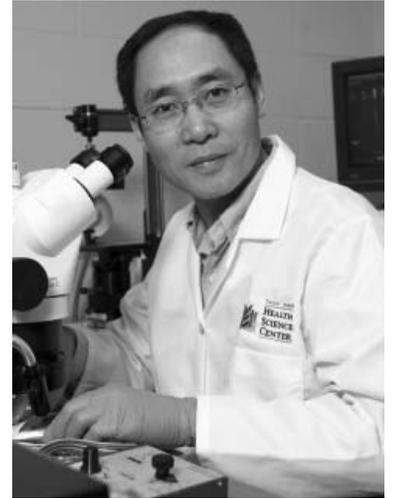
“This is just the beginning,” stated Dr. Chang. “I am more than happy and curious to further this study. I would like to explore collaborations by bringing clinicians and basic scientists into the study. The participation of hydrocephalus patients in the study is extremely important as well, given the fact that there are so many unknown questions about human hydrocephalus and a limited patient population. There are many things we can do in the disease prevention, treatment and prognosis, if we work together.”

While conducting heart research in mice, his lab discovered that the deletion of the gene Rnd3 resulted in the mice developing hydrocephalus. Explained in the most basic terms, they hypothesized that Rnd3 regulates a signaling pathway which promotes cell proliferation in the aqueduct. If the gene is present, the brain is regulated in the number of cells it produces that line the aqueduct. However, without the Rnd3 gene present, an abnormal growth of ependymal cells occurs thereby narrowing the aqueduct, constricting the amount of cerebrospinal fluid that can pass through, consequently leading to severe hydrocephalus. This study provides evidence that congenital hydrocephalus can be the result of a genetic mutation. A more detailed scientific summary of the findings are available in the journal *Proceedings of the National Academy of Sciences*.

Furthermore, the researchers discovered a possible pharmacological intervention that could treat and possibly prevent this form of congenital hydrocephalus. Researchers worked with pregnant mice whose pups had the Rnd3 gene deleted. By delivering compound E, a drug that is a signaling inhibitor, to the pregnant mice, they found that

the pups did not develop hydrocephalus. This is a particularly significant finding for those in the hydrocephalus community with a congenital form of the condition. It is estimated that 1 to 2 of every 1,000 babies are born with hydrocephalus.

This study provides evidence that congenital hydrocephalus can be the result of a genetic mutation. The discovery of the fundamental role of the NOTCH pathway could provide a potential target for pharmacological manipulation. HA has already introduced Dr. Chang to other established hydrocephalus investigators as well as to contacts at NIH to help accelerate his research. The next step for the researchers is to get FDA approval to perform drug trials in animals on potential therapies.



### HCRN Adds Centers in Vancouver and Tennessee

By Dr. John Kestle, MD, MSc, FRCSC, FACS

With the recent moves of HCRN investigators Dr. John Wellons to Vanderbilt University and Dr. John Kestle to University of British Columbia, HCRN has decided to expand its network from seven to nine centers to incorporate their respective hospitals in HCRN research. Each center will begin its trial period immediately which involves adding patients to the HCRN registry as well as participating in the HCRN Quality Improvement Study for post surgical infections. Dr. Kestle will continue in his role as Chairman of HCRN and Dr. Wellons will continue to be the lead PI on the Study of Post Hemorrhagic Hydrocephalus which is nearing the completion of its accrual of patients.

## Mentored Young Investigator Grant Updates

Our Mentored Young Investigator Award (MYI) program began in 2009 with the dual purpose of funding promising research relevant to hydrocephalus while fostering the development of young researchers. The award helps ensure that qualified young scientists enter the field of hydrocephalus research and receive research training and experience under the guidance of highly trained, well-respected researchers who have demonstrated success in their field of research. At the completion of the grant period, our goal is that these young scientists become high-caliber, productive, independent researchers with an enduring focus on research relevant to hydrocephalus. Ultimately, it is hoped that this support will help these young scientists to make successful applications for an NIH K or R award to continue their research in hydrocephalus, thereby enriching the hydrocephalus research landscape. Since the program began, we have funded seven MYI's. The work our MYI's have conducted is both substantive and insightful, and HA wants to take the opportunity to showcase their fantastic contributions to hydrocephalus research.

### Investigating Alternative Treatment Options for Hydrocephalus

By Ashly Westrick

Sonia Podvin, Ph.D, is a postdoctoral scholar at the University of California San Diego, who was one of two recipients of the Hydrocephalus Association 2011 Mentored Young Investigator Award. The hydrocephalus research world is one of collaboration, and the MYI grant has allowed her to connect with other hydrocephalus researchers.

“One of the most wonderful things about working in the hydro field is the drive to stick together and to share stories and ideas so that we can find the most effective research avenues to improve patients’ lives,” stated Dr. Podvin. She believes that facilitating the open lines of communication between patients, families, clinicians and basic science researchers is key to advancing hydrocephalus research efforts.

Dr. Podvin’s research as a molecular pharmacologist aims to develop safe, specific drugs to treat hydrocephalus. Her study, *Augurin is a novel choroid plexus-derived peptide hormone that regulates CSF*, investigates the function of the peptide hormone augurin. Augurin is an anti-inflammatory hormone that circulates in the cerebrospinal fluid (CSF) and may be able to control brain hydrodynamics. There are initial findings that suggest the loss of augurin contributes to CSF fluid dysfunction. Her research has two specific aims: (1) to develop an augurin animal genetic model in mice; and (2) to identify the unknown cell surface receptor of augurin. The ultimate aim, if the hypothesis is correct, is to pharmacologically manipulate augurin to treat hydrocephalus.

A challenge in Dr. Podvin’s specific research area is drug delivery to the brain. The blood-brain barrier (BBB) can prevent drugs from reaching the target cells. Developing a drug which can cross the BBB and not have undesirable side effects is important.

### Responding Directly to our Members

After posting Dr. Podvin’s research online, Angela, a member from our community, asked the following

question: *My son had hydrocephalus at birth due to aqueductal stenosis (AS). Would patients like this be a candidate?* Below is Dr. Podvin’s response.

Angela brings up a great question! Thanks for asking this. My advisers and I have wondered recently about the possible role of augurin in aqueductal stenosis resolution. I hope I can explain our hypothesis in a concise manner, which I always have trouble doing because I get excited about our project and get side-tracked talking about it.

We have found in our work so far that there is less augurin secreted into CSF in the injured brain (see reference 1 below) and this permits more cells to grow in the tissue lining the ventricles, subventricular zone (SVZ) (see reference 2 below). A hypothesis that we are putting together with these findings in mind is if a young baby has a stroke or a brain injury, augurin will cease to be secreted into CSF where it would normally reach target cells lining the brain ventricles. This will allow cells to proliferate thickening the the ventricle lining a bit, and in the very narrow passage of the aqueducts, obstructing CSF flow. We think that decreased augurin is normally a desirable injury response following brain injury because its target SVZ cells happen to be stem cells that proliferate and migrate to the injured site for repair. However, in very narrow ventricle regions there is a possibility that proliferation might cause an obstruction.

If we can develop augurin-based therapeutics, we hope they might be able to resolve AS. Since hydrocephalus is a chronic brain injury and thus secreted augurin levels might be chronically lower in hydrocephalus (this is a key question and we are hoping to address it very soon!), administration of augurin or molecules like it could potentially reduce this thickening. If we can show this is true in animal models this would be a huge finding that it might work in hydrocephalus patients!

I hope this makes sense. We’ll put on our thinking caps for more possibilities in AS. Thanks for the question!

Sincerely,

Dr. Sonia Podvin

Ref. 1: [Esophageal cancer related gene-4 is a choroid plexus-derived injury response gene: evidence for a biphasic response in early and](#)

late brain injury. Podvin S, Gonzalez AM, Miller MC, Dang X, Botfield H, Donahue JE, Kurabi A, Boissaud-Cooke M, Rossi R, Leadbeater WE, Johanson CE, Coimbra R, Stopa EG, Eliceiri BP, Baird A. PLoS One. 2011;6(9):e24609. doi: 10.1371/journal.pone.0024609. Epub 2011 Sep 14.

Ref. 2: Ecr4 expression its product augurin in the choroid plexus: impact on fetal brain development, cerebrospinal fluid homeostasis and neuroprogenitor cell response to CNS injury. Gonzalez AM, Podvin S, Lin SY, Miller MC, Botfield H, Leadbeater WE, Robertson A, Dang X, Knowling SE, Cardenas-Galindo E, Donahue JE, Stopa EG, Johanson CE, Coimbra R, Eliceiri BP, Baird A. Fluids Barriers CNS. 2011 Jan 18;8(1):6. doi: 10.1186/2045-8118-8-6.

Since receiving the MYI award, Dr. Podvin has been published twice: “Epidermal Growth Factor Targeting of Bacteriophage to the Choroid Plexus for Gene Delivery to the Central Nervous System via Cerebrospinal Fluid” in *Brain Research* and “Ecr4 expression and its product Augurin in the Choroid Plexus: Impact on Fetal Brain Development, Cerebrospinal Fluid Homeostasis and Neuroprogenitor Cell Response to CNS Injury” in *Fluids and Barriers of the CNS*.

## Study Seeks Participants to Evaluate Eye Movement Tracking For Detection of Hydrocephalus

Most people know that advances in eye movement tracking have impacted mobile technology and video games immensely in the last few years. In the Departments of Ophthalmology and Neurosurgery at New York University, similar eye-tracking technology is being developed to enable a correlation between eye movements and brain function. Since ancient Greek times, and contemporary with the earliest writings and pictures of hydrocephalus, there have been descriptions of abnormal eye movements in people afflicted by hydrocephalus. Before the era of modern imaging with CT and MRI scans, entire textbooks were dedicated to the diagnosis of hydrocephalus and other brain disorders by study of eye movements.

The study sponsored by the Thrasher Research Fund tests a new method of eye movement tracking technology to determine if it can assess the function of the nerves impacted by hydrocephalus that are responsible for vision and movement of the eye. The method consists of having the child watch a 3 to 4 minute video (e.g. cartoons) as it moves in a set trajectory while a camera records the child's eye movements. In a non-hydrocephalic subject, eye tracking shows a rectangular pattern with their eye movements, while a subject with unilateral hydrocephalus due to a small bleed in the brain, has an abnormal tracking pattern.

## MYI Publishes Article in Journal of Experimental Neurology

Joon Shim Ph.D., a recipient of HA's Mentored Young Investigator (MYI) award in 2009, has published an article about his findings: “VEGF, which is elevated in the CSF of patients with hydrocephalus causes ventriculomegaly and ependymal changes in rats” in the journal *Experimental Neurology*.

Dr. Shim's study investigated the role that vascular endothelial growth factor (VEGF) could play in the development of hydrocephalus. The data from the study supports the idea that VEGF was elevated in patients with hydrocephalus compared with controls. This indicates that VEGF may be a useful biomarker for hydrocephalus. The clinical relevance of this work is that anti-angiogenic drugs may be useful in patients with hydrocephalus. The findings of Dr. Shim's study can be found online at the Science Direct website (<http://www.sciencedirect.com>).

We congratulate Dr. Shim on his publication.

### Be a part of the study!

If you live in the Manhattan area and are interested in participating in the study, please read the guidelines below. The study enrolls 3 groups of subjects:

- People age 7 to 25 without hydrocephalus or a history of neurologic problems (to serve as study controls).
- Healthy and neurologically well people age 7-25 who have been shunted or undergone endoscopic third ventriculostomy (ETV) for a diagnosis of hydrocephalus (so that we can understand the baseline eye movements of these children)
- Patients age 7-25 with suspected shunt malfunctions (if stable) before and after shunt revision.

Participants in the study must have an ability and interest in watching television or a video and must be able to see well enough to view it. People who participate in this study will still need to have conventional methods of medical care as this method is purely experimental.

#### Study Site:

Room 5W55  
New Bellevue Hospital  
Department of  
Ophthalmology  
462 First Avenue  
New York, NY 10016

#### Investigators:

Uzma Samadani, MD PhD  
Shaun Rodgers, MD  
Jeffrey Wisoff, MD  
Howard Weiner, MD PhD  
David Harter, MD  
R. Theodore Smith, MD PhD

For information about enrolling in the study please contact Marleen Reyes at [brainresearch@nyumc.org](mailto:brainresearch@nyumc.org) or call: (646) 501-6846 or (347) 213-7791.

## Announcing our 2013 Scholarship Recipients!

The Hydrocephalus Association is pleased to announce the 2013 Hydrocephalus Association Scholarship Award recipients. We are very grateful to the funders for making these scholarships possible each year, and to the Scholarship Committee for all their time, support, and dedication. Since the scholarship program was established in 1994, HA has awarded 103 scholarships to future leaders of our community. We are proud to honor these remarkable young adults.



**Anna Elise Jones**

**Recipient of the Morris L. and Rebecca Ziskind Memorial Scholarship**

Anna Jones is a student at the University of Wisconsin-River where she is majoring in animal sciences. She has a strong passion for animals, loves being outdoors and is currently working for Cooperative Resource International (CRI) as a laboratory research technician. Born with hydrocephalus, it was not until Anna was almost 18 years old that she realized how hydrocephalus could impact her life. She endured multiple shunt revisions, which affected her short term memory and her study habits. Anna states, "...there are many times after a surgery where I feel the weight of what having hydrocephalus means and how uncertain the future really is." But Anna remains thankful and she feels fortunate to help others by sharing her story and the challenges of living with hydrocephalus. Anna plans on furthering her education by receiving a Master's degree in the field of reproductive physiology.



**Juliette Ohan**

**Recipient of the Morris L. and Rebecca Ziskind Memorial Scholarship Fund**

Juliette Ohan is graduating from California State University, Los Angeles with a Bachelor's of Science in Biology. Though often found in the classroom or lab, in her free time she practices yoga, Jiu-Jitsu, Judo, and martial arts. "These arts have given me a stronger body and a stronger mind, being careful of my condition but also never allowing it to keep me from doing anything I truly want to do." At the age of 18, after months of suffering from migraines, double vision and feeling nauseated, she was diagnosed with and was treated for hydrocephalus. Following graduation, she plans to become certified in Geographic Information Systems and pursue a Master's degree in Conservation Biology.



**Ana L. Ubierna**

**Recipient of the Gerard Swartz Fudge Memorial Scholarship Fund**

Ana Ubierna, a proud mother of two and teacher from Long Beach, California, is applying to the University of Southern California for the Masters program in Teaching English to Speakers of Other Languages (TESOL). Outside of teaching and being a mom, Ana finds joy in writing and practicing yoga. Diagnosed with hydrocephalus at the age of 22, Ana and her family had to deal with the financial stress and the emotional toll hydrocephalus can have on the family unit. After recovering from her last couple shunt revisions, she now feels she is on the right track to finish her education and to teach.



**Melissa Bruebach**

**Recipient of the Justin Scot Alston Memorial Scholarship Fund**

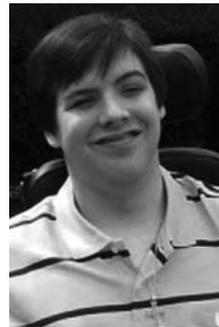
Melissa Bruebach is a student at Saint Norbert College in De Pere, Wisconsin, where she is majoring in accounting and minoring in Spanish. A few of Melissa's hobbies and interests include cooking, swimming, sewing, painting, and getting lost in a good book. Diagnosed with hydrocephalus at 10 months of age, Melissa has never let hydrocephalus or her other medical conditions impact her life. Despite having five shunt surgeries in one year, Melissa has a fighter's attitude and much compassion, not only for the other individuals living with hydrocephalus, but towards her nurses and doctors as well. "You should always try to be kind to others because everyone is dealing with their own battles, visible or not," counsels Melissa. After graduation, she will apply for her CPA.

**Jordan Rogers****Recipient of the Anthony Abbene Scholarship Funds**

Jordan Rogers is finishing her third year at the University of Denver where she will graduate with a Bachelor's of Science in Biology and minors in chemistry and Spanish. She is fond of reading, running, and spending time with her friends. She was diagnosed with hydrocephalus at 3 months of age and has since undergone 19 shunt revisions. The condition has taught her to always be thankful, to fight, and to never give up. Jordan says, "Although there are challenges in life, they can always be overcome with support from family and friends and most importantly, an optimistic attitude." She aspires to work as a physician's assistant so that she can make a difference in patients' lives in the same way that medical professionals have helped her.

**Timothy Beighley****Recipient of the Gerard Swartz Fudge Memorial Scholarship Fund**

Timothy Beighley is in his second semester at Reinhardt University in Waleska, GA, where he is majoring in religion and will obtain his degree to become a hospital chaplain. His main interests in life are helping others and being active in his community. Timothy is extremely devoted to his volunteer work within his community, from coordinating meals for families in the hospital to being a camp counselor at a special needs camp called Team Kids. Born 3 months prematurely with grade 3 and grade 4 brain hemorrhages, Timothy developed hydrocephalus, cerebral palsy, and scoliosis. Doctors gave Timothy a poor prognosis, but he continues to beat the odds every day. Even though Timothy has experienced many adversities, he uses his unique gifts to help inspire and motivate others.

**Emma Jane Maurer****Recipient of the Mario J. Tocco Hydrocephalus Foundation Scholarship Fund**

Emma Maurer has been accepted into the communications program at Liberty University where she plans to concentrate in journalism. She enjoys surfing, reading, cooking and going out to eat with friends. A National Honor Society student, she has been involved in numerous school activities. It took Emma a while to get comfortable with her condition, especially with her classmates. However in her junior year of high school, Emma felt the need to advocate for hydrocephalus awareness and raise funds for research. Through dealing with the challenges of hydrocephalus, she learned that embracing who you are is very powerful, as is telling friends and the people around you about your condition. Upon college graduation, she hopes to become a theater critic, an entertainment writer for a large newspaper, or a talk show host for the Sirius XM Live on Broadway.

**Abigail Fazelat****Recipient of the Giavanna Marie Melomo Memorial Scholarship Fund**

Abigail Fazelat was recently accepted into Montclair State University in New Jersey. She plans to major in English and transfer to New York University in her junior year to pursue studies in the film and literary industries. Abigail is a writer and poet. She also loves to dance, run and volunteer. Diagnosed at 3 months old, she was left with vision problems after one of her multiple shunt revisions resulted in a brain bleed that caused her to lose three-quarters of her peripheral vision in both eyes. Despite her vision problems and other challenges, Abigail still worked hard and was able to make the honor roll six quarters in a row. She hopes that by writing poems and short stories about hydrocephalus and her experiences, more awareness will be built around the condition and more people will be properly diagnosed and treated.

**Lindsay Kerr****Recipient of the Anthony Abbene Scholarship Fund**

Lindsay Kerr will attend Long Beach City College in California, where she will obtain an Associate's degree in order to become a teacher's aide in special education classes. She then plans to transfer to California State University, Long Beach, to pursue a Bachelor's degree in Special Education. Lindsay's ultimate goal is to become a Special Education Teacher of Visually Impaired Students. Two of her favorite hobbies are reading and working with nonprofit organizations, such as Best Buddies, Leo Club, and Starbright World. Lindsay has hydrocephalus, cerebral palsy, and a visual disability that necessitated the use of assistive technology to help her with school work. Her experience dealing with her school to get assistive technology has made her determined to pursue her career goals in special education.



*Congratulations to all of our Awardees and Finalists. You inspire us all!*

Hydrocephalus Association Scholarship Finalists:

**Jenny Andress**  
**Donna Anselmo**  
**Jacob Aplin Fletcher**  
**Mathew William Baer**  
**Alexa Bashford**  
**Robert William Beers**  
**Chantele Berry**  
**Aaron David Billian**  
**Diane Bojarcik**  
**Ashley Dawn Borchers**  
**Elliot Browning**  
**Rachel Bryant**  
**Darlene Buibas**  
**Michael Campisi**  
**Ella Carlin**  
**Danielle Covarrubias**  
**Alex Scott Crabtree**  
**Halley June Cronce**  
**Hannah Cross-Ahart**  
**Cristiane Cruz**  
**Brenda C. Tillit**  
**Brenlee Zirker**  
**Chad Czapor**  
**Katherine Anne D'Apice**  
**Kelli Dailey**  
**Kara Margaret Day**  
**Amanda DeDonatis**

**D. Hannah Dill**  
**Erin Doucet**  
**Lindsey Duddles**  
**Keving Figueroa**  
**Kira Marie Finan**  
**Cameron Fox**  
**Garrett Michael French**  
**Thomas J.R. Gagnon**  
**Adrienne L.**  
**Matteson Groner**  
**Clair Herrle**  
**Joshua Chase James**  
**Katie Jaspers**  
**Antonio Ochoa Luna Jr Jose**  
**Sam Kaitz**  
**Joseph Kern**  
**Michelle Ann Koehler**  
**Amanda Korcal**  
**Nathan Kucera**  
**Danielle Denise Kulowitch**  
**Jane Lockhart**  
**Olivia Maccoux**  
**Emily Mann**  
**Amanda McAllister**  
**Brandon McClendon**  
**Emily Meeker**  
**Erika Meints**

**Shannon L. Moore**  
**Corina Morton**  
**Lauren M Muffley**  
**Daniel Murawski**  
**Jeremy Nafus**  
**Ian Noll**  
**Mallory Oates**  
**Emily Orlo**  
**Jessica Anne Pauley**  
**Jennifer Perry**  
**Ruby Poole**  
**Alyssa Quintero**  
**Emily Reed**  
**Samantha Richardson**  
**Nate Riley**  
**Bryan Round**  
**Derik Sarver**  
**Tom Schultz**  
**William Sharpe**  
**Angel Silva**  
**Jordan Smith**  
**Samantha Snider**  
**Sara Stowe**  
**Justin Wayne Tefft**

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## **Why are Medical Alert ID's Valuable for People with Hydrocephalus?**

*By Jennifer Bechard, Support Group Liaison*

We asked our Facebook page: "Do you use a medical alert card/bracelet for your shunt or Endoscopic Third Ventriculostomy (ETV)? If YES, tell us, what kind do you use and what information do you put on it?" We received some excellent feedback from parents, caregivers and individuals living with hydrocephalus. Many utilize several forms of medical IDs', however, there were many individuals who were not aware that something like this is available or the importance of it.

Under emergency circumstances, time is critical and being able to quickly identify your medical condition is of extreme importance. If you or your loved one were to go into shunt or ETV failure and are unable to communicate, medical IDs can provide rapid identification for emergency responders and medical personnel. Without proper identification, common symptoms, such as headaches, dizziness, sleepiness and vomiting can be misdiagnosed and appropriate care could be jeopardized or delayed.

### **What types of Medical Alert IDs are available for people with hydrocephalus and where can they be purchased?**

Medical alerts come in various forms and shapes:

- Wallet Cards (patient ID cards)
- Bracelets
- Necklaces
- Dog tags
- Sport ID Bands
- USB Drives (as bracelets, key chains, necklaces, or just an old-fashioned flash drive)

The options seem endless! The different forms of medical alerts allow individuals to choose based on their personal preferences, as some may prefer a piece of jewelry and others may want a card instead.

One of the most commonly used medical alerts within the hydrocephalus community is a wallet card, also known as a shunt card or ETV card. You may be able to obtain a shunt card from your neurosurgeon or by contacting your shunt manufacturer. If you do not have a shunt, but were treated with an ETV, you may acquire an ETV ONLY card by contacting us directly at [info@hydroassoc.org](mailto:info@hydroassoc.org). Please know that we have a limited supply of the cards.

There are several organizations and companies that provide these different medical alert cards, jewelry and other devices and they can be purchased through multiple websites. Each of these organizations offers many different styles for men, women, and children. Here are a few resources:

#### Medic Alert Foundation

232 Colorado Avenue, Turlock, CA 95382  
(888) 633-4298, [www.medicalert.org](http://www.medicalert.org)

#### American Medical ID

949 Wakefield, Suite 100, Houston, Texas 77018  
(800) 363-5985, [www.americanmedical-id.com](http://www.americanmedical-id.com)

#### Lauren's Hope

4823 NW Gateway Avenue, Riverside, MO 64150  
(800) 360-8680, [www.laurenshope.com](http://www.laurenshope.com)

#### Rescue Me ID

230 N. Maple Avenue B1-327, Marlton, NJ 08053  
(866) 713-3808, Website: [www.rescuemeids.com](http://www.rescuemeids.com)

#### Sticky Jewelry

1698 34th St. N, St. Petersburg, FL 33713  
(727) 823-9500, Website: [www.stickyj.com](http://www.stickyj.com)

#### Macx USB Medical ID Bracelet

(Medical alert bracelet with flashdrive can be found at Target and other stores.)

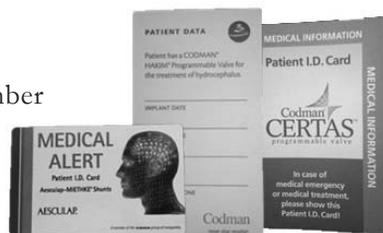
Many of the products can also be found at different retail stores such as Target, Amazon, and Walmart.

### What information should people with hydrocephalus include on their Medical Alert ID's?

1. For shunt cards you may use the following:

#### Patient Data

- Diagnosis: Hydrocephalus
- Implant Date
- Patient Name
- Neurosurgeon
- MD Phone Number



#### Product Information

- Type of shunt: Ventriculo-peritoneal (VP shunt, Ventriculo-atrial (VA), Ventriculo-pleural (VPL), Lumbo-peritoneal (LP)
- Valve manufacturer: Aesculap, Codman, Integra, Medtronic, Sophysa
- Product Code
- Serial Number
- If programmable, current valve setting

2. For patients with an Endoscopic Third Ventriculostomy (ETV):

- Patient Name
- Emergency Contact
- Telephone Number
- Neurosurgeon
- MD Phone Number

3. For patients who prefer jewelry or other devices:

The message on your medical alert device (bracelet, necklace, keychain, etc.) should be simple and to the point. "Hydrocephalus" should be engraved boldly on one side. The other side of the bracelet can have other information such as:

- "VP Shunt", "VA Shunt", "VPL Shunt", "LP Shunt", or "ETV."
- Emergency Contact and Telephone Number.
- Name of your Neurosurgeon and Telephone Number.
- A referral to another place for more information, for example "see wallet card for a full medical history."

Other information to consider adding to the medical IDs:

- Other medical conditions (i.e. spina bifida, cerebral palsy, epilepsy, chiari malformation, etc.)
- Allergies (Latex, Penicillin, etc.)
- Any other critical information such as Slit Ventricle Syndrome (SVS), number of shunts if you have multiple shunts, etc.
- "XYZ are the symptoms when my shunt malfunction..."

There are many ways you can take precautionary measures to ensure that emergency responders are aware and can act quickly. The Hydrocephalus Association urges patients to take action in managing their hydrocephalus. If you are unsure of what type of treatment you received last, you can contact your neurosurgeon or the facility where your shunt was placed and ask for your medical records.

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## From the NICU to Medical School

By Jennifer Bechard

*“Never underestimate the strength of the human spirit. Behind every illness we are studying, there are real people living it every day. It is important to never lose sight of those people. They are the reason we do what we do. Let them inspire you to always keep working harder, and never forget the profound difference even the smallest act of kindness and compassion can make.”*



A quote from Jamie Wright, our Support Group Leader in Houston, Texas. Jennifer Bechard sits down with Jamie to talk about living with hydrocephalus, her role as a support group leader, and her thoughts on HA.

Jamie was born six weeks prematurely and was diagnosed with post-hemorrhagic hydrocephalus. As a result, she was shunted when she was 20 months old. Since then, she has undergone 3 surgeries to revise her shunt. Jamie is now 25 years old and is currently in her second year of medical school at the University of Texas Medical School at Houston, where she is in a combined MD/PhD program. She plans on doing research on perinatal brain injury (brain injury in newborn babies) in the hopes of finding ways to prevent or potentially reverse the injuries that sometimes lead to hydrocephalus and cerebral palsy. With this in mind, she is currently interested in becoming a pediatric neurosurgeon or neurologist.

*HA: How did you find the Hydrocephalus Association and why did you decide to volunteer?*

JAMIE: I found the Hydrocephalus Association’s website while doing research on hydrocephalus for a class project in college. It was not until a few years later after meeting other individuals with hydrocephalus and getting

to know some parents of children with hydrocephalus that I decided to start a support group.

*HA: Why do you feel support groups are so valuable and crucial to our hydrocephalus community?*

JAMIE: I did not meet someone else with hydrocephalus until I was in college, but when I did it was great to be able to sit down and talk to someone who had been through it, too. After meeting some parents of children with hydrocephalus, I realized that they needed people who could relate just as much as their kids. I am realizing more and more all the time through my own experiences and the experiences of others just how much uncertainty and variability there is when it comes to hydrocephalus. It can be scary if you have no idea what to expect and frustrating when it feels like there is no one who understands your concerns.

*HA: What are three things you want your members to walk away with and/or gain from your support group meetings?*

JAMIE: I hope this group will help those affected by hydrocephalus to know they are not alone, allow them an outlet to voice their concerns and frustrations to understanding ears, and give them a means to become more informed about hydrocephalus.

*HA: Where would you like to see your support group and the Hydrocephalus Association in 5 years?*

JAMIE: Our support group is in the largest medical center in the world, so I hope to see it bring together a diverse group of patients and families each month, and be a place where they can not only find connections, but friends.

As for the Hydrocephalus Association, I hope they continue to grow and are able to reach out to more people with support groups and WALKs in even more cities across the country. As a future clinician and researcher, I would also like to see their continued involvement in the Hydrocephalus Clinical Research Network (HCRN) along with the newly forming network for adult patients. In addition, I also hope to see continued growth of their laboratory research grant programs.

*HA: What message do you have for the medical community, students in medical school and/or researchers?*

JAMIE: Never underestimate the strength of the human spirit. Behind every illness we are studying there are real people living it every day. It is important to never lose sight of those people. They are the reason we do what we do. Let them inspire you to always keep working harder, and

never forget the profound difference even the smallest act of kindness and compassion can make.

*HA: What message do you have for other young adults living with hydrocephalus?*

JAMIE: Don't let a diagnosis define what you are capable of doing. If you want something, reach for it. It may not be easy but few things worthwhile ever are. Do everything you can with the gifts you have, even if it means getting a little bit creative, and don't be afraid to ask for help with the rest. Whatever you do, never stop moving forward. Every challenge is an opportunity to learn and grow in strength and wisdom. Finally, get involved. The best therapy for a difficult situation is action.

*HA: If you met another young adult who was recently diagnosed with hydrocephalus, what would you say?*

JAMIE: I can't tell you what the future will hold or promise you that it won't be hard, frustrating or at times, painful. I can tell you it will be okay, no matter what happens, because you have a whole community here to support you. Never be afraid to reach out and ask for help. We are here for you!

*HA: What message do you have for HA staff, the board, or founding members?*

JAMIE: Thank you so much for being here! I had not realized just how profound an impact the information you provide has until talking to someone diagnosed just a few years before me...before HA, and hearing what her parents went through trying to find information compared to my parents who still have the "About Hydrocephalus" booklet they received when I was first diagnosed. It is great to see how HA has grown and I am very excited about where your research, support, and advocacy efforts will take us! Thank you!

### Hydrocephalus Resource Library



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.

## Support Group Network

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

AL	Birmingham	Peds/Adolescents
AZ	Phoenix	NPH
CA	Chico	All Ages
	Fresno (online)	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
GA	Atlanta	Peds
IA	Cedar Rapids	All Ages
IL	Chicago	Peds/Adolescents
MA	Boston	All Ages
MD	Baltimore	All Ages
MI	Detroit	All Ages
MN	Minneapolis	Peds/Adolescents
MO	Online	All Ages
NC	Charlotte	All Ages
NJ	Morristown	All Ages
	Buffalo	All Ages
	Long Island	All Ages
OH	Online NY State	All Ages
	Online	All Ages
OK	Owasso	All Ages
OR	Portland	All Ages
PA	Philadelphia	All Ages
	Pittsburgh	Peds
TN	Nashville	All Ages
TX	Dallas	All Ages
	Houston	Peds/Adolescents
UT	Salt Lake City	Peds
VA	Richmond	All Ages
WA	Bremerton	Peds/Spina Bifida
	Seattle	Peds
	Vancouver	All Ages
Nigeria	Lagos	Peds & Families

### Don't see a Support Group in your area?

If you're interested in helping to start a local support group, please contact Jennifer Bechard at [support.liaison@hydroassoc.org](mailto:support.liaison@hydroassoc.org) or (301) 202-3811. We have traditional support groups as well as online support groups looking for leaders!

# Congratulations to our SENIORS!

Many of our members have recently celebrated their high school graduation. They excitedly leave behind the hallways, locker rooms, and cafeterias of their high schools and transition to the next phase of their lives, be it a college campus, a job, travel, or a well-deserved sabbatical. HA takes our hat off to all of you. We also take a moment to highlight two seniors who have made an impact in their own communities and in our larger hydrocephalus community.

## Normal on the Outside: A Teen's Journey with Hydrocephalus



*"I know that there are thousands of kids just like me dealing with the same things that I am, and it is my hope that my documentary will be able to help them know that they are not alone."*

— Liz Holthouse

Elizabeth Holthouse attended Willard High School in Willard, Ohio. For her senior project, she made a video documentary about her life called "Normal on the Outside," which includes the story of her complicated medical history, and candid interviews with her sisters about Liz's struggles and triumphs growing up. Since posting the documentary on YouTube in January, Liz has had over 8,140 views, including many from teens who relate to her story. HA sat down with Liz to interview her about her experience making the video and the message she wants to send to the world.

*HA: How did you come up with the idea for a video for your senior project?*

LIZ: I had to choose a topic with an end product, and I wanted a product that could help people. I had never really had a chance to tell my story, but always wanted to.

*HA: What was the most challenging part and the most fun part of making the video?*

LIZ: Probably deciding what things to film and what video and pictures to use. The most fun part was being able to video my siblings and being together with all of them.

*HA: Was the video shown at your school? If so, how did your classmates react?*

LIZ: The video was shown at my senior project presentation. It was also shown by other teachers to their classrooms. A lot of people came up to me and told me that they thought it was really good. One of my friends told me

that she thought of me differently after she saw the video and understood me better. It made a lot of people cry.

*HA: Were you nervous for your friends to see the video? For strangers to see the video?*

LIZ: I wasn't nervous for my friends to see the video because I think it was good for them to see so that they can understand what I have gone through in my life and why I am the way that I am. I wasn't nervous for strangers to see the video because maybe I can help someone just like me, or help people understand teens like me.

*HA: What kind of feedback have you gotten from the video?*

LIZ: People have told me that they thought the video was really good and that it helped them understand me better. They tell me that they will keep sharing it. They also tell me that they had no idea I had gone through so much. I had all of my surgeries at the Cleveland Clinic and some of the staff there have shown my video to help people understand what a lot of kids with disabilities are feeling.

*HA: What was your favorite comment(s) you received?*

LIZ: My favorite comment was from an adult in our community named Marty Sowers. He has faced many challenges with his disability. He thanked me for sharing my story and told me to continue telling it.

*HA: From your own life experiences and what you share about some of the challenges of living with hydrocephalus, what tips or suggestions do you have for teens just starting or in high school?*

LIZ: I look for other kids who might be feeling left out or lonely and talk to them. There are a lot of kids who feel like that, especially just coming into high school. I know how it feels, so I don't want other kids to feel that way. The most important thing is to be yourself. Not everyone is going to like you or accept you, and that's okay.

You can find Liz's video on the Hydrocephalus Association YouTube channel at [www.youtube.com](http://www.youtube.com).

## A Crusader, In Every Sense of the Word

On February 19th and 20th, during the last regulation home game for the men and women, the Whitinsville Christian basketball squad celebrated “Senior Night” to honor the athletic careers of the graduating seniors.

For senior Crusader, Nicole Wiegers, this night had even greater significance. Nicole’s team used the monumental night to raise awareness about hydrocephalus.

Wiegers was diagnosed with hydrocephalus at two months, after being born 14 weeks early, and has a ventriculoperitoneal (VP) shunt. The past year and a half have been tough for her, as her shunt has malfunctioned repeatedly, resulting in 11 surgeries to revise her shunt. As a result of the hospitalizations and procedures, Wiegers had to miss half of last basketball season and all of this season. Despite all of these complications, she still remained an integral part of the Whitinsville varsity basketball team. She maintained a positive attitude, and served as a source of inspiration for her teammates.

“The Whitinsville Christian girls basketball team has been missing a key player from their lineup for the past two seasons,” stated her coach, Kris VandenAkker. “Nicole has been so devoted to the team even though she has been in and out of the hospital dealing with her hydrocephalus condition. Nicole has had such a great spirit throughout the past two years even though she has had so many set backs. Earlier this season, a few of her teammates thought it would be special to have an awareness night where we would honor Nicole and try to bring awareness of hydrocephalus to Nicole’s school community.”

Nicole’s team decided to use her school’s “Senior Night” to share her story, educate the community to some of the challenges of living with hydrocephalus, and to raise money to fund hydrocephalus research. Wiegers and her family contacted the Hydrocephalus Association (HA) to help set



the event into motion. HA provided educational posters, pamphlets, and fact sheets about hydrocephalus to support the team in raising awareness.

During both the boy’s and girl’s contest, HA’s fact sheets were put inside each program so that everyone walking into the gymnasium could get a better understanding of hydrocephalus. Wiegers’ teammates made t-shirts with “hydrocephalus” on the front and Nicole’s name on the sleeve. The educational posters were spread across the gymnasium as an additional means of raising awareness. Everyone attending that evening, from the referees to the visiting team, left with a better understanding of the multitude of obstacles Wiegers has gallantly overcome.

The event successfully raised over \$1,000 in donations. The money has been presented to the Hydrocephalus Association to further advance the association’s research initiative to find better treatment options and, ultimately, a cure.

“It brought me so much joy when my basketball team decided to raise money to support the Hydrocephalus Association for Senior Night,” shared Wiegers. “On this night, even though I couldn’t play in the game, my feet flew across the court during warm-ups, and my teammates flew for me during the game! It felt like all my yearnings to play were fueled into them. They played great and won the game. I am extremely thankful for this opportunity to help raise awareness and money for more research, and the ability to join my team in helping people understand hydrocephalus.”



## Join Us!

Are you between the ages of 12 – 25 living with hydrocephalus, or a close friend, sibling, 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](mailto: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](#).

### Portland Kicks Off Our WALK Season!

It was a beautiful day in Portland, Oregon, on Saturday, June 15th, when our 2013 WALK season officially launched with the 4th Annual Portland WALK. More than 500 walkers came out for the event. Annie Bany, a local singer-songwriter best known for her alternative pop-country style, performed songs from her newly released album, *Barefoot and Young*.

“As Annie sang her song, *Barefoot and Young*, the lyrics ‘little ray of sunshine...’ struck a chord with me in terms of the hope and comfort this event provides to all those kids, adults, and families impacted by hydrocephalus,” stated Michael Schwab, a member of the Hydrocephalus Association Board of Directors and father of 11-year old Joseph, who has hydrocephalus.

The WALK was started four years ago by Jerrod and Tara Miller whose son, Grant, was born with hydrocephalus. They were pleased to have Annie join the festivities this year and perform as the walkers were coming in from the 2 mile walk. Moved by the event and her personal interactions with participants, Annie donated 100% of the proceeds of the sale of her CD to assist the cause. She also accompanied young 11-year old Chase Swearingen, who has hydrocephalus, as he spontaneously sang to the crowd at the end of her performance. To date, this year’s event has raised over \$33,000.



### Team Hydro Swims with the Sharks

On Saturday, May 19, 2013, Team Hydro swam in the 21st annual Alcatraz Sharkfest Swim, a swim from Alcatraz Island to Aquatic Park on the shores of the city of San Francisco, California. Team Hydro brought together 75 swimmers ranging in ages from 12 - 62 to brave the grueling, cold, open water of the San Francisco Bay for this 1.5 mile swim. As of swim day, the team had raised over \$23,000, with the expectation of raising at least \$50,000. To date, Team Hydro’s efforts have increased awareness and contributed over \$323,000 to hydrocephalus research.

Team Hydro was founded in 2007 by brothers Peter and Sam Finlayson, inspired by the courage, strength and sweetness of their sister Kate, who passed away from complications related to her hydrocephalus on November 27, 2010. Prior to the swim, the local affiliate of NBC aired an interview with Peter and 2012 Gold Medal Olympic water polo team member Jessica Steffens about the event.

# SCHEDULE 2013

June			
15	Portland	OR	WALK
July			
20	Seattle	WA	WALK
August			
10	Anoka	MN	Hydro River WALK
10	Central PA	PA	WALK
18	Chicago	IL	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
14	Western NY	NY	WALK
14	Nashville	TN	WALK
15	Minneapolis	MN	WALK
21	Middlebury	CT	WALK
21	Smyrna	DE	WALK
21	Columbia	SC	WALK
21	Houston	TX	WALK
22	New England	MA	WALK
22	Long Island	NY	WALK
28	Louisville	KY	WALK
28	Charlotte	NC	WALK
29	Los Angeles	CA	WALK
29	Washington	DC	Run/WALK

October			
6	New Jersey	NY	WALK
13	Fresno	CA	WALK
19	San Francisco	CA	WALK
19	Wichita	KS	WALK
19	Albuquerque	NM	WALK
26	Chattanooga	TN	WALK
November			
9	Greater South FL	FL	WALK
10	Central Alabama	AL	WALK

No WALK near you?



Ask about our  
**VIRTUAL  
WALK**

It's as easy as a  
WALK around the block!

# WALK



## Having trouble registering for a WALK?

You can register for a local WALK online by visiting our 2013 WALK Schedule on our website and clicking on the city where you would like to participate. If you are having any difficulty or do not have access to a computer, please call our Special Events and WALK Coordinator Michael Ticzon. He's happy to help you register for your local WALK!

**Michael Ticzon**  
(301) 202-3811 ext. 12  
michael@hydroassoc.org

# Thank You To Our Sponsors!



## Medtronic FOUNDATION

HA was awarded a major grant from the Medtronic Foundation to continue funding Teens Take Charge (TTC) and our Advocacy Day. These programs are critical to building awareness of hydrocephalus and voicing the needs of our community to elected officials. Medtronic NT will also join HA as a Platinum sponsor of the 2013 WALK and is supporting several other educational programs.

## AESCULAP

We are pleased to announce that Aesculap will serve as a Silver level sponsor of the 2013 WALK and has provided seed support to conduct HA's new webinar series that will be launched this summer. The webinar programming provides an opportunity for HA to bring experts in the field to share the latest in hydrocephalus research and treatment with constituents. Stay tuned for more information on these sessions.

## Rudi Schulte Research Institute

HA is pleased to partner with RSRI to fund up to two researchers that will help further our understanding of the dynamics of Cerebrospinal Fluid (CSF). RSRI will invest a minimum of \$600,000 to advance this research over three years. In addition, HA will seek to further augment this investment to increase the total funding level to \$1M during this period.

## Every Member Campaign

### Your Membership Gift Makes a Difference!

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 during this 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 over 10,000 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. 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.



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

**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.

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