

HYDROCEPHALUS RESEARCH UPDATE

Announcing New Mentored Young Investigator Grants



Jay Riva-Cambrin, MD



Sonia Podvin, PhD

Jay Riva-Cambrin, MD, a pediatric neurosurgeon of the University of Utah and Primary Children's Medical Center is leading a multi-center study across the Hydrocephalus Clinical Research Network (HCRN). This research links MRI's to established and novel measures of neuropsychological outcomes in children with hydrocephalus. Sonia Podvin, Ph.D. of the University of California, San Diego is exploring the role of a newly discovered hormone called augurin in the development of hydrocephalus. Dr.

Podvin's award is sponsored by the Kate Finlayson Memorial Research Grant.

The Hydrocephalus Association (HA) is funding seven Mentored Young Investigators (MYI) in 2011. The two new awardees join five other mentored young investigators who received awards in 2009. MYI awards provide investigators with two years of support at \$55,000 per year. These awards further the HA mission of eliminating the challenges of hydrocephalus by stimulating innovative research and by increasing the pool of physicians and scientists working in hydrocephalus.

The HA has now funded grants totaling \$830,000 since it initiated its commitment to fund research in 2009. The Association's new research grants program represents a significant increase in funding for hydrocephalus research. In addition, HA recently received a grant for \$400,000 that will be used to initiate ground-breaking new awards for mid-career investigators in translational research later this year.

We are in the final stages of creating a longer term strategic plan for the Research Initiative that we will use as the basis for an ongoing fundraising campaign and to drive the research agenda for hydrocephalus. These mentored young investigator grants represent a pillar of our plan to catalyze the hydrocephalus research ecosystem. 

2010 Hydrocephalus Association Resident's Prize



Every year the Hydrocephalus Association awards a resident's prize in neurology/neurosurgery to the most promising research paper relating to hydrocephalus. The paper is presented at the Pediatric Section meeting of the American Association of Neurological Surgeons/Congress of Neurological Surgeons (AANS/CNS).

The prize for 2010 went to Ramin Eskandari, MD, MS, for his paper: 'Effects of Early and Late Reservoir Treatment in Experimental Neonatal Hydrocephalus'. The prize is awarded by a panel of experts from the AANS/CNS Pediatric Section and reflects the opinions of some of the best minds in pediatric neurosurgery and related disciplines.

Congratulations to Dr. Eskandari and all of the candidates for 2010. They reflect the best and most forward thinking elements of the neurological community as well as our hopes for better treatment options and eventually, perhaps, a cure for hydrocephalus. 

Hydrocephalus Support Groups Thrive

by Jennifer Bechard, Support Group Liaison

Hydrocephalus Association Support Groups are off to a great start this year. Each week we are receiving calls or e-mails from enthusiastic, driven individuals determined to help others who are dealing with the challenges of hydrocephalus.

Every child, adolescent, adult and family member has a different story but there are two common threads: awareness and support are critical. In order to eliminate the challenges of hydrocephalus we must strive to make hydrocephalus a household word. By connecting with each other in groups we can share and support one another allowing us to deal with shared concerns.

The hydrocephalus community and the HA staff would like to welcome the latest members to our Support Partners community: Danielle Netherton in Chico, CA, Jennifer Bulhuis in Minneapolis, MN, Annie Mason in Richmond, VA, Chevis Shannon in Birmingham, AL, Sandra Frazier in Washington, D.C., Sarah Bezugly in Orlando, FL, Roxana Ramos in Miami, FL, Nicole Torres in Fresno, CA and Elizabeth Norris in Charlotte, NC.

Once again we would like to extend our profound gratitude to our partners for all their selfless dedication, time and effort. 

2012 Conference on Hydrocephalus, 'Save The Date!'

by Pip Marks and Karima Roumila

We are most excited to announce our 12th National Conference on Hydrocephalus, Getting to the Heart of Hydrocephalus, which will take place in Bethesda, MD on June 27th – July 1st 2012!

The goal of our biennial conferences is to give individuals, families and professionals the tools and connections they need to address the medical, educational and social challenges of hydrocephalus. One of the highlights of the 2012 conference will be a "day on the hill" in Washington DC.

There will also be plenty of interactive sessions, the cornerstone educational seminars by our top-notch team of medical professionals and researchers with time for Q&A, the ever popular hands-on brain anatomy and physiology lab,

and the dinner and dance with talent show.

Our patient-centered conferences empower all of us to understand, seek out and put into place, the care programs and services that will meet our needs now and well into the future. As the date draws closer we will keep you updated on the meeting details. 



Here Is What Some of You Said About The Last Conference!

“What a great conference! We’re so motivated to make a difference for Sofia and the Hydrocephalus community. Thanks for everything”

“I think that everything I can assess went perfectly at the Cleveland meeting. Personally had a great time and was so impressed by the questions that were asked and the enthusiasm of all participants”

“It was nice to meet many of you at the Hydrocephalus association at the Cleveland conference last week. It was a very well put together and well run conference. I met a lot of good people and learnt of several opportunities to become engaged and support the cause.”

Veteran Hydrocephalus WALK Chairs Training – A Meeting of Minds

by Jenna Ellis, Co-Chair of HA’s Detroit, MI WALK

In the past, (HA) WALK Chairs have gotten to know each other through emails and brief encounters at conferences. There was always a feeling that more time was needed to talk about WALK. This year veteran WALK Chairs from all over the United States gathered in one room to share ideas, get to know one another, and receive the greatest gift of all, “The Manual...”

Excitement was high as we stepped into the hotel that Friday night. Some people had already arrived, as others were expected to come later in the evening. A dinner was planned in order for everyone to get to know each other before we spent the whole next day getting educated on how to implement new ideas into our old ways. Everyone gathered at a local restaurant to share laughs and stories; this night was vital because we were able to see how much we had in common and that made everyone feel comfortable for the exciting day that followed.

Saturday morning everyone woke up well rested and full of questions. After breakfast, Randi passed out Powerpoint slides for us to follow along with. Soon after that we got the 2011 WALK Chair Manual. The first thought I had was that I shouldn’t open it because I wouldn’t be able to put it down. Not only did we have all of the materials we could possibly think of in our hands, but we also learned how to download a program called Dropbox so we had the resources on our computers as well. Although the plan may have been to have a discussion at the end of the presentation; having a room full of veteran WALK Chairs made that impossible. Ideas were flying, questions were a must and WALK fever had begun.

“The conference was outstanding. So much planning and thought goes into the conference that participants leave with so much valuable information and form new friendships,”

“I am the mother of a Hydrocephalus patient. I recently attended the 11th national conference in Cleveland and I wanted to send an email thanking you for doing such a great job. It has been a scary and confusing 7 months since my daughter was diagnosed. The limited information and awareness of hydrocephalus is disappointing and quite scary. The experience my family had in Cleveland completely exceeded our expectations. It was the perfect mix of information and comfort. The HA staff, physicians, families and patients were amazing to listen to and because of that we plan on attending as many conferences as we possibly can. I truly appreciate the time and effort that everyone put in to make the conference possible.” 

Randi had addressed our concerns about Corporate Sponsors, Family Teams, Family Kickoff Party, The Day of the Event, and how important it is to DELEGATE. I began realizing how valuable our WALKS are to the HA and how important it is that we not do everything on our own. A successful WALK is only possible with the support of our community and the wonderful volunteers that we trust to work side-by-side with us. After a very informative presentation by Randi, we were then on to Social Media and the nuts and bolts of our fundraising site; this is Jennifer Bechard and Jordan Faigen’s forte. They were great at explaining Facebook and really made us understand why Social Media has become so important; it also is a wonderful way for WALK Chairs to continue to share insight with one another. We finished our night with another wonderful dinner and everyone was pretty tired from the day’s events.

In the morning, we had a brief wrap-up and then most of us had to get to the airport in the early afternoon. It was sad to say goodbye to North Carolina, but you could tell that many of us were itching to start putting some of the ideas we had discussed into action. I can admit that at first I was feeling overwhelmed, but then Randi stressed that this is a process and not every idea will be implemented this year. With that being said and the organization that Randi has executed, I was instantly consumed with excitement. I think I can speak for everyone that we went home ready to work and to have a wonderful WALK season. It has become clear how essential it is to find people with the same passion and to converse about the many reasons why we WALK. 

Defining Research Terms—What do the terms “Basic”, “Clinical” and “Translational” mean when used to describe biomedical research studies?

By Donna Schaffer, HA Research Associate

In the field of biomedical research, the terms “basic research” and “clinical research” are often used to distinguish between two different approaches to studying the causes and treatment of disease. Simply stated, in basic research a question is pursued for the purpose of increasing knowledge and understanding of underlying biological processes without regard to its application. Basic research usually occurs in a laboratory setting, often with animal subjects. By contrast, in clinical research a question is pursued for the purpose of prevention, treatment, or cure for disease. Clinical research (AKA applied research) takes place in the clinical setting with humans as the study subjects.

Within the domain of clinical research, perhaps the best known study type is the “clinical trial”. The clinical trial involves the administration of a test regimen to humans to evaluate its efficacy and safety. It is frequently referred to as the “gold standard” in biomedical research and is the

study design required by the Food and Drug Administration (FDA) prior to the approval of pharmaceutical agents.

There are other forms of clinical research which, while conducted in the clinical setting with patients as the study subjects, may not, like the clinical trial, be interventional in nature. These clinical studies may involve prospectively observing the outcomes of a group of patients over time (cohort study) or retrospectively comparing a group of persons with a disease against a group of persons without a disease (case-control study).

When research findings originate in the laboratory or other limited settings or study populations, they may require “translation” from “bench to bedside”. So a somewhat newer term, “translational research”, has been coined to describe research that aims to bring knowledge gained from basic research or early clinical research into mainstream clinical practice. A variety of study types and research methods may be used in translational research.

Because all three of these terms — basic, clinical, and translational — are dependent upon the context in which they are used, it’s always a good idea to ask about a study’s aims, methods and outcomes to better understand the research. 

Support & Education

BRAIN AWARENESS WEEK

by Karima Roumila, HA Community Programs Director

The Dana Alliance for Brain Initiative launched Brain Awareness Week (BAW) back in 1996. The Hydrocephalus Association proudly partners with the Dana Foundation for this global campaign to increase public awareness about the progress and benefits of brain research. This global coalition of BAW partners includes more than 2000 universities, K-12 schools, hospitals, patient groups, museums, government agencies, services organizations, and professional associations.

BAW was held on March 14-20, 2011. To celebrate BAW we ran a series of blogs to increase our understanding of the brain, hydrocephalus and to explore the many ways we can all make a difference in increasing hydrocephalus research.

For more educational resources on the brain go to the Dana Foundation BAW website.

PART I : Anatomy And Physiology of The Brain

(From: About Hydrocephalus A book for Families)

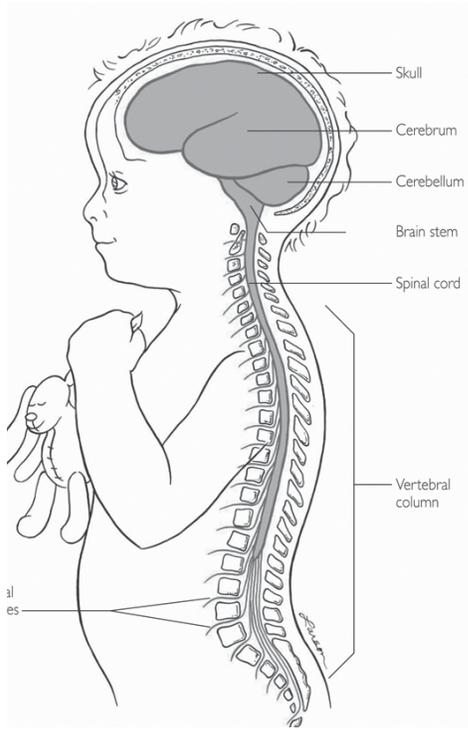
Brain, Spinal Cord and Their Protective Coverings:

The brain and spinal cord form the central nervous system. These vital structures are surrounded and protected by the

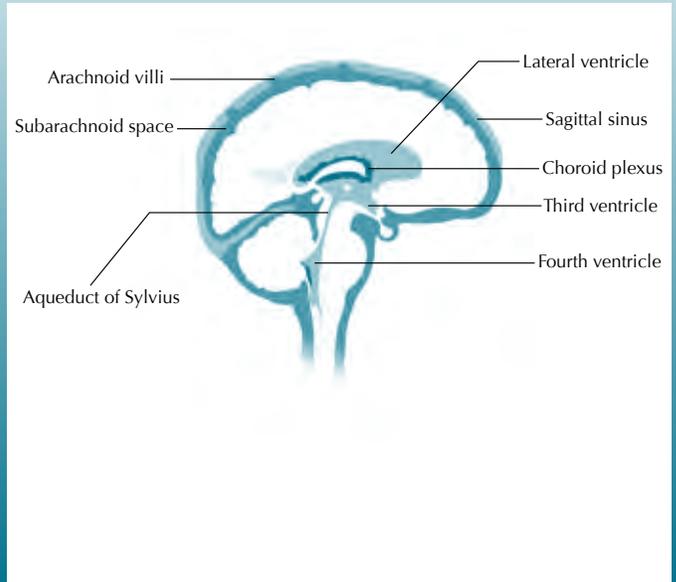
bones of the skull and the vertebral column. The bones of the skull are often referred to as the cranium. In infants, the skull is actually composed of separate bones, and an infant’s soft spot (anterior fontanel) is an area where four skull bones nearly come together. The places where the bones meet and grow are called sutures. The vertebral column, which encases the entire spinal cord, is composed of bones called vertebrae. The spinal column begins at the base of the skull and extends all the way down to the tailbone.

The brain’s major components are the cerebrum, the cerebellum and the brain stem. The cerebrum is the central processing area for the body’s incoming and outgoing messages. It is also the area responsible for speech, thought and memory. The cerebellum primarily helps coordinate our body movements. The brain stem controls basic functions like heart rate, breathing and blood pressure. The spinal cord extends from the brain stem, through a very large opening (the foramen magnum) in the base of the skull, and down the spine. At the level of each vertebra in the spine, nerve fibers arise from the spinal cord and emerge through openings between the vertebrae. These are the spinal nerves, which carry messages to and from various regions of our bodies.

Lying between the brain and skull are three other protective coverings. These are the membranes (meninges),



Cerebrospinal fluid (CSF) circulatory pathway: The drawing shows a view of the brain. The black arrows show the major pathway of CSF flow. The gray arrows show additional pathways.



which completely surround the brain and spinal cord. An important fluid—the cerebrospinal fluid (CSF)—flows in a space between these membranes that is called the subarachnoid space. CSF is essentially salt water, and it is in constant circulation and serves several important functions. The brain floats in CSF.

PART 2 : Exploring Areas of The Brain Affected by Hydrocephalus

Cerebral Spinal Fluid (CSF) is produced within the cavities of the brain that are called ventricles. As you look at the drawing, imagine the ventricles as chambers filled with fluid. There are four in all: the two lateral ventricles, the third ventricle and the fourth ventricle. As you can see, the ventricles are interconnected by narrow passageways. Your neurosurgeon can learn valuable information about the patient's condition by closely monitoring the size and shape of these ventricles.

CSF is formed within the ventricles by small, delicate tufts of specialized tissue called the choroid plexus. The solid arrows in the drawing: cerebrospinal fluid (CSF) circulatory Pathway, show the major pathway of CSF flow. Beginning in the lateral ventricles, CSF flows through two passageways into the third ventricle. From the third ventricle it flows down a long, narrow passageway (the aqueduct of Sylvius) into the fourth ventricle. From the fourth ventricle it passes through three small openings (foramina) into the subarachnoid space surrounding the brain and spinal cord. CSF is absorbed through blood vessels over the surface of the brain back into the bloodstream. Some absorption also occurs through the lymphatic system. Once in the bloodstream, it is carried away and filtered by our kidneys

and liver in the same way as are our other body fluids.

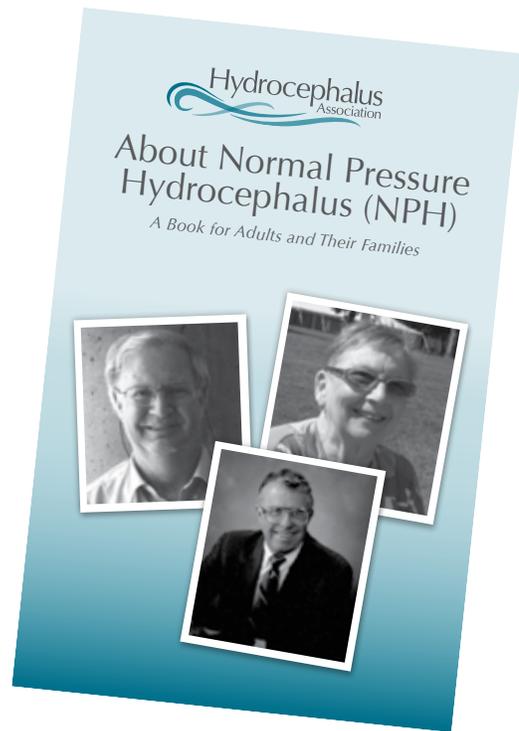
The ventricular system is the major pathway for the flow of CSF. CSF also flows directly from the ventricles into the brain tissue surrounding them. This is shown by the broken arrows. Here the CSF passes through the spaces between the cells to where it eventually enters the subarachnoid space. It is believed that the brain tissue does not absorb any CSF, but simply provides another pathway for the fluid moving to the subarachnoid space. Some small amounts of CSF are also absorbed into lymphatic channels along the membranes covering the nerves (nerve sheaths) as they leave the brain stem and spinal cord .

Our bodies produce approximately a pint (500 ml) of CSF daily, continuously replacing CSF as it is absorbed. Under normal conditions there is a delicate balance between the amount of CSF that is produced and the rate at which it is absorbed. Hydrocephalus occurs when this balance is disrupted. Although there are many factors that can disrupt this balance, the most common is a blockage, or obstruction, somewhere along the circulatory pathway of CSF. The obstruction may develop from a variety of causes, such as brain tumors, cysts, scarring and infection. 



NEW NPH BOOKLET RELEASED

The Hydrocephalus Association's Support and Education department is committed to keeping our hydrocephalus related educational materials updated. When you consider the scope of the material, booklets, fact sheets, directories, webpages and other e-resources, etc., you can appreciate that this is a process that never truly ends. Whenever we begin to run out of a printing of a booklet, we do our best to update it for the next version. We are happy to announce the release of the latest edition of 'About Normal Pressure Hydrocephalus (NPH) – A Book for Adults and Their Families'. Admittedly, not much has changed in the world of NPH, but what small changes that have occurred are now reflected in the new booklet. We have also added some personal stories and photos of some of the members of our NPH community. We would like to express our gratitude to Codman, A Johnson and Johnson Corporation, The Medtronic Foundation and Medtronic Neurological Technologies whose generous grants made this possible. 



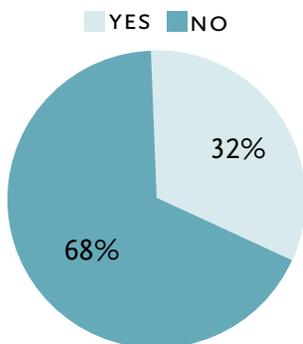
Traveling with hydrocephalus!

By Debby Buffa, Hydrocephalus Association Board Member

We asked on our Facebook member page:

"If you are planning to travel this summer have you inquired about neurosurgeons in the area you are visiting, in case of an emergency?"

Here is what you said:



After looking at the results, we had asked Debby Buffa, Hydrocephalus Association Board Member, mother of two young adults with hydrocephalus and a support group leader, to share her experiences, wealth of knowledge and tips to take into consideration in preparing for a trip. We include a list of resources at the end of this article.

I know many of you have questions about travel and flying with hydrocephalus and shunts. I am a mom of two daughters, now ages 29 and 30, who have had hydrocephalus and shunts since early childhood. I have managed a neurosurgery office for the past 18 years and have run a hydrocephalus support group since 1987. First, the best resource you have is your neurosurgeon. Always check with your physician first as you may have certain health problems that may affect your travel plans.

My daughters have been to Jamaica, Costa Rica, England,

France and throughout the States, including Hawaii. My oldest has had many revisions; therefore, we were pretty nervous about her flying to far-away places, particularly Europe and Hawaii. My younger daughter traveled to Costa Rica for her honeymoon and we were worried about what would happen if her shunt malfunctioned while she was there.

The first thing we did was make sure they had copies of their last operative note; this usually shows what type of shunt was placed and where. We ordered a copy of the last CT/MRI scan. Usually it is best to have a baseline CT which shows what the ventricles look like when the person is healthy and then have another scan from a time when the person needed a revision. This way any neurosurgeon can see what happens when the shunt is not working properly. In cases of slit ventricle syndrome, you may also want to take a copy of the history and physical (H&P) report that is dictated on admission to the hospital. This would usually mention that the patient has slit ventricle syndrome and the ventricles don't dilate when there is a malfunction. You can ask your doctor to copy your operative note and H&P for you. For the CT/MRI you call the radiology facility where they were taken and ask them to make you a CD.

Then we needed to make a plan on where they would go if they became ill. The HA website is a wealth of information. You can find a directory of neurosurgeons who treat hydrocephalus and there are suggestions and articles regarding travel, flying and hydrocephalus. It is a good idea to also check with your own neurosurgeon who may have their own suggestions as to whom you should see

in an emergency. In the States, we searched for a major university medical center which would have neurosurgeons covering the emergency room. Neither daughter has problems with flying; one has a venticuloperitoneal (VP) shunt, the other a ventriculoatrial (VA) shunt. If you are traveling overseas contact HA to get further information regarding available surgeons/facilities. If you are traveling to a place you would not feel safe being treated, then find out the closest major medical center in an American city that can be flown to easily. Remember, this is about being proactive, as it is always better to be safe than sorry.

Each daughter carries a small card with type of shunt, neurosurgeon office & exchange number, primary physician, insurance, and emergency contacts. This information has been added to their cell phone as well. On my older daughter's group tour to Europe she explained her condition to the organizer and assured them she was fine to travel and had made plans for an emergency. There are also programs that will fly you in an emergency to an American hospital, but I am not personally familiar with these. Make sure your insurance covers your travel

in a foreign country because not all do. You may want to purchase travel insurance just as a safety net.

As parents, we will always worry about our children regardless of whether they have hydrocephalus or not. Being prepared is one way to ease our minds and be assured that we are doing the best we can. The key is to let them live the life they were meant to.

Give them wings and let them fly.

To read the full article, please visit our website at www.hydroassoc.org.

Useful links and resources:

For a list of Neurosurgeons go to www.hydroassoc.org or call our office. To find doctors outside the US visit the American Association of Neurological Surgeons, www.aans.org

Visit [Hydrocephalus Resource Library](#) for more articles on flying and hydrocephalus (type keywords flying, barometric pressure, magnetic fields).

For medical alerts visit: [MediAlert Foundation](http://www.medicalert.org) at www.medicalert.org or call them at 1.800.432.5378

Hydrocephalus and Your Medical Records

by Pip Marks, HA Director of Support and Education

Empowered patients are those who become active members of their healthcare team. Obtaining and keeping copies of your medical records, including images (CT scans and MRIs), is good advice for any person receiving medical attention. For those who have hydrocephalus or other chronic conditions it is even more crucial that these medical records are preserved. By keeping a copy of your records, you can reduce unnecessary duplication of tests and can assist new physicians or specialists in seeing the full picture of your health.

One option for storing and transporting your records to and from appointments is to purchase an art portfolio holder. These carrying cases are usually sold in art supply stores and can easily accommodate large images and documents while providing privacy and protecting the items from the elements. Another idea is to keep electronic copies of this information (password-protected) on a jump drive/USB flash drive that you can easily take with you to appointments. It is easiest if you ask for a copy of documents, images, and test results after each visit. It will save you from a headache later if you do not have to remember where and when a particular test was performed.

Thank you Genetic Alliance for this great tip! 

Hydrocephalus and Your Vision

by Pip Marks, HA Director of Support and Education

Changes in eye vision of any kind are critical to report as they may well be related to shunt failure/malfunction. Consult with your doctor, neurosurgeon or ophthalmologist, immediately if you ever experience any kind of change in your vision: blurriness, gray outs, double vision, etc.

Increased intracranial pressure can cause swelling of the optic nerve – a condition known as Papilledema. Papilledema can cause vision loss from mild deterioration to total blindness. Ask your doctor for a referral to an ophthalmologist. 

Hydrocephalus Resource Library: Shunt Taps for Shunt Malfunction in Hydrocephalus



Each week we will feature an article from our Hydrocephalus Resource Library. Since shunts are the mainstay treatment for hydrocephalus, we will begin with an interesting paper regarding malfunction and taps. Shunt malfunction can often be difficult to diagnose. MRI and CT scans are commonly used, but ventricle size does not always change in people with malfunctioning shunts. It is critical that further shunt studies be performed to assess shunt function.

We thank Drs. Rocque, Lapsiwala and Iskandar from the University of Wisconsin, Madison, dept. of Neurosurgery for this excellent paper. Please go to www.hydroassoc.org to view the article or call our office to have one sent to you. 

New Hydrocephalus WALK Chair's Training Meeting – A Study in Dedication And Commitment

By Randi Corey, HA Director of Special Events

On Saturday, Feb. 26th at 8:30 am, I stood looking across the room and saw 13 volunteers of all ages, ethnicities, and backgrounds looking back at me expectantly. They had come from cities all across the nation to be here. Many of them overcoming airline delays and other difficulties caused by the volatile winter weather we have experienced this year.

The occasion was the Hydrocephalus Association's inaugural New WALK Chair's Training meeting in Charlotte, NC. These volunteers gladly sacrificed a weekend to sit in a fairly typical hotel meeting room (albeit a nice one) to listen and learn how to be a great Chair for an HA WALK. They also came together to meet each other, exchange notes about their connection to hydrocephalus and share their experiences and hopes for their events.

Although the day was long (with a PowerPoint presentation 163 slides long) and the subject matter was less than wildly exciting, these men and women were engaged, courteous and attentive – in short, a fabulous group. They learned more than they probably ever wanted to know about all of the aspects involved with coordinating an HA WALK: how to choose a site, find the right date, chart the ideal route, recruit a committee, generate corporate sponsorship and many other topics. They also received the first, hot-off-the-presses, edition of our new, expanded WALK Chair's Manual – all 337 pages!

And through it all, they never faltered. If any were experiencing anxiety about what they had signed on for it never showed, they were calm, cool, collected and confident. The questions were probing, the discussion animated at times and through it all they exhibited the most prized attributes of WALK Chairs: commitment, organizational skills, a willingness to approach strangers for help and fundraising, a quiet determination to make this happen and the most important thing: a passion for the mission!

Conversation and camaraderie continued during dinner. Our new WALK chairs shared many things. They shared ideas, shared "war stories" about their family member with hydrocephalus, shared phone numbers and email addresses (promising to keep in touch) and shared their hope for a better future for those they love.

The Hydrocephalus Association is extremely fortunate to have dedicated, committed, passionate volunteers like these to take this fight to their own towns and cities. For all that they have done and all that they will do over the coming months HA would like to thank the new "Class of 2011" for giving us their time, their talent and their treasure! 

Kudos to our new WALK Chairs:

Jill Diedrich (Phoenix, AZ)

Jenifer Jeans and Cate Kolbash (Connecticut)

Martha Fleury and Barrett O'Connor (Washington, DC)

Kymmi Wilson (Atlanta, GA)

Danielle Gutshall (Hershey/Harrisburg, PA)

Judy Bulliner and Chara McLaughen (Chattanooga, TN)

JoAnna Marie Van Brusselen (San Francisco, CA)

Miaja Rocciola (San Francisco, CA)

2011 WALK Schedule

August	6th	Pennsylvania – Hershey/Harrisburg
September	3rd	Utah – Salt Lake City
	4th	Colorado – Denver
	10th	Georgia – Atlanta
	10th	Indiana – Columbus
	17th	Missouri – St. Louis
	18th	California – San Francisco
	24th	Connecticut – Middlebury
	25th	Massachusetts – Cambridge
October	25th	Illinois – Chicago
	25th	Minnesota – Minneapolis
	25th	New York – Long Island
	8th	Pennsylvania – Philadelphia
	9th	California – Fresno
November	15th	Kansas – Wichita
	22nd	New Mexico – Albuquerque
	22nd	North Carolina – Graham
	29th	Tennessee – Chattanooga
November	5th	Florida – South Florida (Boca Raton)
	5th	New Jersey – Princeton
	13th	Arizona – Phoenix
	13th	Alabama – Birmingham
	20th	District of Columbia – Washington

If you live in or near any of these areas and would like to get more involved by serving on the WALK committee, please contact the HA national office at info@hydroassoc.org. Any and all of these WALK Chairs would welcome your help!



HYDROCEPHALUS WALK 2011

Here is a small sample of pictures from our 2011 WALK season. Once again, people from all across the country come together to create awareness of hydrocephalus and raise funds for research while having a great time. Hence the smiles. 





Tax Act Brings Changes to SSI / Medicaid Treatment of Refunds, Tax Credits :

(Article reprinted with the permission of the Academy of Special Needs Planners)

Several little-noticed provisions of the recently-enacted law that extended the Bush-era tax cuts fundamentally alter how the Supplemental Security Income (SSI) and Medicaid programs treat tax refunds and other tax credits, making it easier for people with special needs to maintain their benefits.

The Supplemental Security Income (SSI) program provides a small cash benefit to people with special needs who meet very stringent income and asset requirements – most SSI beneficiaries also receive Medicaid coverage. An SSI recipient's monthly cash benefit is reduced by \$1 for each dollar of unearned income a beneficiary receives and by \$0.50 for each dollar of earned income that a beneficiary receives for working. Unearned income includes gifts, food and shelter, and other one time payments like inheritances and lottery winnings, and, until these changes took effect, unearned income also included tax refunds and some tax credits. This meant that a SSI beneficiary could lose his benefits if he received a large tax refund.

Under the new law, tax refunds are no longer considered countable income for SSI or Medicaid purposes. Furthermore, any money received through a tax refund will not be a countable resource for 12 months following receipt of the funds, and SSI and Medicaid recipients will be under no obligation to segregate the funds from their other resources (SSI recipients can only keep \$2,000 of resources and still qualify for benefits). Because of the change in the law, an SSI beneficiary can now retain his tax refund, even if it puts him over the \$2,000 resource limit, for up to one year from the date of receipt, which is welcome news for beneficiaries who usually have to count every penny in order to avoid a disruptive loss of benefits.

The new law also changes the treatment of several other important tax credits. Under previous rules, Making Work Pay, Earned Income, Advanced Earned Income, and Child Tax Credits were all excluded as countable income for SSI and Medicaid purposes, but if the income was retained, it had to be spent within nine months of receipt. Now, the 12-month rule applies to all of these tax credits and, furthermore, First-Time Homebuyer Tax Credits that were previously countable as income and as a resource are now exempt and subject to the same countability rules as the other tax credits.

In one more piece of good news, the law applies to any refunds or credits received after December 31, 2009, which means that, in limited cases, applicants who were initially denied SSI or Medicaid benefits due to receipt of a tax refund or credit may actually be retroactively eligible for benefits. The Centers of Medicare and Medicaid Services have also indicated that seniors and other people seeking

Medicaid coverage for long-term care will not be subject to transfer-of-asset penalties if they give away their tax refunds or credits during the 12-month grace period.

The relevant provisions can be found in Section 728 of the law, officially known as the Tax Relief, Unemployment Insurance Reauthorization and Job Creation Act of 2010. 

Hydrocephalus Teens Take Charge: Haylea Speaks Up!

by Haylea Lynn Blank

I was born premature at twenty-six weeks of gestation. I was one of twins. We were both born at twenty-six weeks because my mom went into premature labor, which could



not be controlled with medicine in the hospital. Due to being born early I had a fourth-degree bleed in my head that resulted in obstructive hydrocephalus. I was born on May 13, 1989 along with my twin sister. My sister passed after five days due to immature lung development. I had immature lungs that could be treated with a drug called Surfactant and ventilation. I was

maintained on a ventilator in the hospital until my lungs matured and I was able to breathe on my own. Following several CT scans my Obstructive Acquired Non-Communicating Hydrocephalus became apparent to the doctor's at North Carolina Wake Forest Baptist Medical Center. I had my first ventricular-peritoneal (VP) shunt around one month old. I had numerous revisions from June 1989 to December 2002 when everything changed in my life.

I found out I also have Agenesis of the Corpus Callosum and possible Dandy-Walker Syndrome (associated with the fourth ventricle of the brain). I developed abdominal pseudo cysts in my abdomen which continued to feel up my distal shunt catheter which caused several problems for my shunt in 2001 and 2002. As of December 27, 2002- I have been SHUNT FREE! I had the alternative surgery for Hydrocephalus called the Endoscopic Third Ventriculostomy thanks to my current Neurosurgeon Dr. Martin M. Henegar.

I thank God everyday that I am SHUNT FREE, but I also worry that the burr holes will close up one day because of scar tissue. The end of my journey did not STOP on Dec 27, 2002, because I was back in the hospital in January 2006, June 2006, Aug 4th 2006, Aug 30th 2006, and Aug

4th 2008 with scar tissue blocking over the ETV burr holes and dealing with issues from the Dandy-Walker and/or arachnoid cyst (which was part of my brain (4th ventricle)) and Hydrocephalus. Even without the tubes and shunt problems, Hydrocephalus is NOT cured... their needs to be more research done so everyone with Hydrocephalus or has family members and friends with Hydrocephalus can lead a "normal" life without brain surgery at least every 2 years based on statistics.

I will say it is amazing how we heal fast after BRAIN surgery, who knew after the first day or so. It is a miracle we bounce back pretty quickly and get back to our "normal" lives. We are special and everyone deals with Hydrocephalus differently, I was fortunate to graduate high school on time in June 2007 and go start right into college. I am currently pursuing an Associate's degree in Health Information Technology dealing with Medical Records. I

am working part time at a local hospital in the Medical Records department pursuing my dreams and living life to the fullest.

Finding a Cure for Hydrocephalus is PRICELESS! I hope one day we will not have to worry when we start to have headaches is our shunt failing and/or is the ETV closing up. There needs to be a CURE so future generations don't have to have brain surgery all the time! There needs to be MORE Research done to find other alternatives to ETV and shunts. It is crazy to believe that a lot of people have seen the Hospital and/or the Operating Room more than they have seen birthday. We need to find a CURE for HYDROCEPHALUS because everyone no matter what age should not have to live with the unknown and the future possibilities of more surgery. 

Community

Hydrocephalus Snowshoe WALK a Hit

by Christian Karch

The Inaugural Hydrocephalus Association Snowshoe WALK on March 12 in Steamboat Springs, Colorado was a great success! The WALK brought together the hydrocephalus community and generated quite a bit of media exposure, raising awareness through excellent media coverage including live TV, a live radio interview, and a front page article in the local paper.

Grammy nominated front man and crowd pleaser, Pat Waters of Missed the Boat, entertained with classic rock on his guitar. Atlas Snowshoes supplied 65 free snowshoe rentals for all ages. Favorite local restaurants, Ore House, Freshies, Riggio's and Chef Mike, supplied delicious hearty soups and the homemade breads and cookies that kept walkers energized. Even the mascots, "Puppy Dog" and "RED" Robin, were full of energy, making sure the little ones didn't get bored. Event chairs, Sofia, Laura and Christian Karch, received many phone calls from event goers expressing their enjoyment. There were 126 snowshoe walkers traveling between 2k and 3k on freshly groomed trails. The silent auction back at the Lodge had something for everybody, ranging from a two night stay in the 5 star Hotel Charter in Beaver Creek, Colorado to a remote controlled car. The weather was pleasant and most participants "hung out" on the deck long after the WALK to eat and listen to the music from Pat. The Steamboat Springs Touring Center is already booked for the 2nd annual HA Snowshoe event on March 10th, 2012 with many new ideas to grow and make the event even more fun.

How about a real Olympian showing up!?!?

Over \$40,000 was raised. A big thank you to our families, friends, sponsors, donors, walkers and all the great volunteers who made this event a fun day in the High Rockies. 



Dr. Salomon Hakim – a Giant in the Field of Hydrocephalus

by Marvin Sussman, Ph.D., HA Board Member and Pip Marks, Director of Support and Education

Respected Colombian neurosurgeon Salomon Hakim, MD, PhD, who worked extensively in the field of hydrocephalus, has died at the age of 88. Dr. Hakim passed away in a Bogota hospital in the early hours of Thursday morning, May 5, due to a cerebral hemorrhage. Dr. Hakim, whose family name means “doctor” or “wise man” in Arabic, earned his medical degree from the Universidad Nacional in Bogotá and continued his medical education in neurosurgery at Harvard, also earning a Ph. D. in neuropathology. During his neuropathology fellowship research, Dr. Hakim performed necropsies on patients who died from CNS neurodegenerative conditions such as Alzheimer’s disease. He noted, in many of the cases, the brain ventricles were enlarged without destruction of the brain cortex. At that time, nobody was able to explain the reason for this observation. This led Dr. Hakim to hypothesize that these patients suffered from what he described as “Normal-Pressure Hydrocephalus” or NPH after finding a 16-year-old living patient with this condition.

Dr. Hakim’s influence in hydrocephalus has been both long and broad, springing from the active mind of a medical scientist and clinician working at the bedside and in the operating room, laboratory and workshop. Through the recognition and description of an entirely new disorder and the development of complex devices advancing hydrocephalus treatment he has touched the lives of millions of the young and old stricken with hydrocephalus. Dr. Hakim first described “Normal Pressure Hydrocephalus” in 1964 and initiated the surgery dramatically improving the quality of life in these elderly patients. Today, in many areas of the world, NPH, a chronic neurological disorder characterized by enlarged ventricles and a triad of clinical symptoms affecting gait, cognition, and urinary continence, is referred to as “Hakim Syndrome” to honor his accomplishments.

His technical genius is evident in the over thirty patents he held. His designs were not only innovative, but also robust, often becoming among the most widely used shunt devices still in use to the present day. Not satisfied with available hydrocephalus valves, Dr. Hakim invented and developed a number of hydrocephalus valves based upon the spring-loaded, ball-in-cone valve design. Dr. Hakim improved on existing valve technology which was based upon silicone elastomer slit valves and developed a unidirectional valve with the capacity to regulate the CSF pressure by adding a spring pressure control in a stainless steel cone and synthetic sapphire ball. This valve was introduced to the medical community in Colombia in 1966. It was more reliable and resisted occlusion by protein better than available valves of the time. Most modern hydrocephalus valves are now built based on this ball-in-

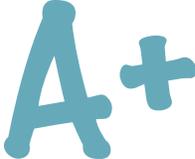
cone design. He devised the first shunt system which adjusts drainage with body position and one the first systems which could be non-invasively adjusted after implantation, as well as one of the initial non-invasively adjustable valves. These his valve designs and neurosurgical concepts remain cornerstones of modern CSF shunting. His passion for and devotion to helping those with hydrocephalus has spanned over five decades.

The Hydrocephalus Association was honored that Dr. Hakim spoke at its first patient conference on hydrocephalus. Over the years, Dr. Hakim has received numerous honors and awards. In 2010, at the national Hydrocephalus Association conference in Cleveland, Dr. Hakim was awarded the Hydrocephalus Association Lifetime Achievement Award for his lifelong contribution to the understanding and treatment of diseases of the CSF circulation.

Even today, over a half century after Dr. Hakim’s discovery, NPH sometimes goes unrecognized or is misdiagnosed as Alzheimer’s Disease or other neurodegenerative disorders. An estimated 9 to 14% of elderly living in assisted living facilities suffers from NPH. Thanks to Dr. Hakim’s curiosity and perseverance, a field of knowledge was started which led to the clinical management for one of the few dementias that is treatable. Together with his three sons, a biomedical engineer/scientist and two neurosurgeons, he continued to work on experimental studies of the hydraulics of the cranial cavity and the diseases which afflict it. His sons will continue his work in the field of NPH. 

Hydrocephalus Association Makes the Grade again

By Rick Smith, Acting CEO, Hydrocephalus Association

 I’m pleased and proud to forward some great news for the Hydrocephalus Association, and its many volunteers and donors: the National Health Council (NHC), the nation’s largest association of national health related organizations, has renewed HA’s Certification for Charitable Accountability.

The NHC requires all of its member organizations to meet a comprehensive set of standards in the areas of governance, human resources, programs, fundraising, finance, accounting and reporting, and evaluation. These standards are completely aligned with the Standards for Charitable Accountability adopted by the Better Business Bureau, and the Association meets ALL 20 of these standards as well.

Below are the links to both the National Health Council and the Better Business Bureau if anyone would like to learn more about these standards.

<http://www.bbb.org/us/standards-charity/>

<http://www.nationalhealthcouncil.org> 

From TeamHYDRO

The following is a blog entry written by Sam Finlayson very shortly before the last Sharkfest swim in which Team-HYDRO participated. The event was an enormous success and raised over \$100,000 to fund research to cure hydrocephalus. A few days before the Sharkfest event Sam visited Dr. Sonia Podvin's Lab. Dr. Podvin is a recipient of one of the Mentored Young Investigator Awards, a research program the Hydrocephalus Association initiated in 2009 and TeamHydro Funded in 2010.

A Visit to the Lab: Hydrocephalus Research Ongoing and Exciting! Hello Team Hydro! June 19, 2011

With less than a week before the swim, Team Hydro has again set a new record, raising more than \$82,000 (and counting!) to foster hydrocephalus research this year. How exciting! I hope that we can constantly remember what this represents. Each dollar brings a little more hope for the patients whose lives may change as a result of this work. Each lap we swim, conversation we have, and even Team Hydro t-shirt we wear represents the resolve that we have to keep going until a cure is found.

Last weekend, my parents and I had the privilege of traveling to San Diego to visit the labs at the University of California Hospital, where Dr. Sonia Podvin and her team are diligently working to unlock some of the mysteries surrounding the development of hydrocephalus. Their research, sponsored by last year's Team Hydro/Kate Finlayson research grant, investigates a newly discovered role that a protein called augerin may play in the production and regulation of cerebrospinal fluid (CSF) in the brain. Their work has shown that augerin is present most strongly in the choroid plexus in the ventricles of the brain (where hydrocephalus occurs), leading them to suspect that it plays a regulatory or even determinant role in the development of hydrocephalus in a given patient.



Dr. Podvin (left) and Sam Finlayson (right)

To investigate augerin's role in hydrocephalus, Dr. Podvin first investigated the effect that its regulation has on zebra fish. She and her associates demonstrated that altering the fish's augerin causes hydrocephalus to develop! The team is now working to see what happens when augerin levels are altered in mammals. Though the work is not yet completed, the research has already led to the discovery of new realms of research that will impact our understanding both of hydrocephalus as well as the



way that the brain as a whole responds to inflammation and to trauma. One thing is for certain...the research is exciting, but much more is needed if we ever want to solve the problem of this devastating condition!

Visiting the lab was a powerful reminder for me of the reality of the impact we may have through Team Hydro. As I said before, we have by no means closed the proverbial book on hydrocephalus, but through just one grant we've already started some important new chapters!!! And with each day of research, the next critical breakthrough in hydrocephalus treatment draws closer. Until a cure is found, and with our support, the researchers' diligent work will continue. But more importantly, the daily struggles of so many good people like our sweet Kate continue as well. Let's do everything we can to help this great cause move forward! If you haven't raised funds yet, it is never too late to start!! And you just might save a life with the dollars you earn!

A special thanks to Dr. Podvin and her amazing team of researchers for their incredible work, and of course to our Team Hydro fund-raisers and supporters for making such important research possible! You really have made a difference already!!!

I look forward to seeing you all NEXT Saturday!!

Go Team Hydro!!!!

Sam Finlayson 

Hydrocephalus Association Launches Dedicated Normal Pressure Hydrocephalus Page on the Website

The Hydrocephalus Association (HA) is proud to announce the release of a new informational page specifically dedicated to the needs of persons diagnosed with Normal Pressure Hydrocephalus (NPH). The new NPH page gives a broad overview of NPH, highlights the latest edition of our NPH booklet, illustrates and describes the three classic symptoms that define it, and provides access to resources that will prove helpful to people with NPH. The need for clear and useful information is one that we've striven to meet since our inception. The old website was designed to reach all populations living with hydrocephalus but was limited in its resources, making it difficult to give the different types of hydrocephalus the appropriate attention they deserved.

The information needs of our SHYMA/LOVA population are different from those of the NPH or congenital population and this is the first step in our effort to address these differences. Plans are being implemented to create additional specific landing pages for other types of hydrocephalus in the coming months.



Hydrocephalus Association Board Member Named Chief Operating Officer of The Feinberg School of Medicine At Northwestern University

Congratulations to David Browdy of Oak Park, Illinois—yesterday he was promoted to Chief Operating Officer (COO) of Northwestern University's Feinberg School of Medicine. Northwestern's Feinberg School of Medicine is a leading, research-intensive medical school located in Chicago, Illinois.

Among other things, Mr. Browdy is a reviewer for the National Institutes of Health National Center for Research Resources, a member of Board of Directors of the Hydrocephalus Association and the Chairman of the Association's Research Committee.

Commenting on Mr. Browdy's new post, Rick Smith, Acting CEO of the Hydrocephalus Association, noted, "David is an extremely effective leader, and the Feinberg School is fortunate to have him in this new position. Everyone at HA is very happy for David and we wish him all the best in his new role."

HCRN Developing New Study, Could Lead to New Test for Hydrocephalus

Dr. Dave Limbrick, MD, PhD, a neurosurgeon from St. Louis Children's Hospital, St. Louis, MO — a new member of the Hydrocephalus Clinical Research Network (HCRN) — is conducting a study that seeks to identify biomarkers for hydrocephalus. The study is in its early stages, and you can read more about it, along with other HCRN news at hcrn.org.

To read the full article, please visit our website at: www.hydroassoc.org.

Hydrocephalus Association Again Part of Combined Federal Campaign

Once again, the Hydrocephalus Association has qualified for inclusion in the Combined Federal Campaign (CFC), the federal government's workplace giving program. If you are a federal employee you can designate your contribution, or part of it, to the Hydrocephalus Association by designating your contribution to HA with code #10066.





Name: _____ Telephone: _____

Address: _____

Email: _____

Name of person with hydrocephalus: _____

Birth date: _____ Age at diagnosis: _____

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

Enclosed is my unrestricted donation of:

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

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