



Dedicated in loving
memory to

Cynthia E. Solomon

July 12, 1947- May 29, 2014

HA Founding Member
Mother
Advocate
Friend

“Her philosophy,...was you have to
leave the world a better place. If you
weren't working toward that goal, you
weren't doing enough.”

- Nathan, her eldest son



COMMUNITY. CLARITY. CURE.

13th National Conference on Hydrocephalus

Portland, Oregon

July 9-11, 2014

Message from our CEO **The Beauty in Biology**



As a gardener, I always look forward with great anticipation to the energizing beauty that accompanies the arrival of spring: crocuses followed by daffodils, signaling the time is right to start digging in the dirt and putting the plan for the vegetable garden into action.

This year, however, at least in many parts of the United States, winter lasted a lot longer than usual. Here in Washington, the cherry blossoms were late in blooming, and even now with Memorial Day recently passed, it may be still a little too cool to venture into the outdoor pool. My vegetable garden is really just getting underway.

While I can't say I waited patiently for spring to come, I found that same energizing beauty in a most unusual place – in the ideas of researchers and conversations that took place at a recent event held by HA. Titled “Biomarkers in Hydrocephalus Workshop,” this meeting brought together over 30 of the world's leading experts in biomarkers which was, for this layperson, like watching the first conclave of scientists, NIH/government officials and industry that was responsible for the “discovery” of the internet. You might be wondering what a biomarker is – I was, too. Simply put, a biomarker is a biologic feature that can be used to measure the presence or progress of disease or the effects of treatment. For instance, can we find a protein or a lipid in CSF fluid that could give us some indication of why hydrocephalus exists? Are there neuroimaging biomarkers that could be identified that will tell us definitively when a shunt is failing?

The scientists in attendance freely shared their latest research findings in all populations of hydrocephalus patients – pediatric, transitional and NPH -- and their latest thinking on where the next inquiry is most likely to reap new knowledge. They heard from Dr. Jill Morris, Program Director with the National Institute of Neurological Disorders and Stroke (NINDS), who described NIH's funding mechanisms for hydrocephalus research and some of the latest thinking about evaluation criteria for grant submissions. Participants listened to the “lessons learned” – both good and bad - shared by Dr. Anne Fagan, a world-renowned expert in CSF biomarkers in Alzheimer's, and Dr. Dan Ory who is well known for his work on biomarkers for Neimann Pick disease. They discussed what kinds of support (organizational and financial) could help them overcome obstacles faced in this line of research. In the words of HA's Chairwoman Barrett O'Connor, the keys to understanding hydrocephalus in a new way – not just as a “plumbing problem” – lie in this basic science work. And, everyone in the room felt the electricity, the promise, the truly awe-inspiring challenge of discovery that stands before us.

The seeds of exploration were sown in St. Louis at this HA-sponsored workshop. At the risk of carrying the metaphor too far, with careful cultivation and perseverance, one day – hopefully not too far off – this effort will yield a beautiful solution that helps meet the many challenges posed by hydrocephalus.

Special note: I would be horribly remiss if I didn't publicly thank Dr. David Limbrick, Deanna Mercer and everyone at Washington University in St. Louis for hosting and supporting this important workshop on so many levels – it wouldn't have been nearly as successful without their commitment to the effort.

In Memoriam Cynthia E. Solomon

We are saddened to share this unfortunate news about one of our own. Cynthia Solomon, a co-founder and lifelong supporter of the Hydrocephalus Association, passed away after a courageous fight with cancer on Thursday, May 29, 2014. Cynthia is an icon in the hydrocephalus community — dedicating so much of herself to making others' lives easier. Her presence is irreplaceable. She will be forever missed. – Dawn Mancuso, CEO

Cynthia E. Solomon July 12, 1947- May 29, 2014

Cynthia was born in Los Angeles and spent the past 41 years living in Sonoma, California. In her first 20 years in Sonoma, she was instrumental in running the practice of her then husband, Dr. Solomon, as well as launching the Victorian Court Bookstore and founding a synagogue in the Community Center.

After her divorce, she had many activities that fueled her passions, including co-founding the Sonoma Valley Community Health Center and the Hydrocephalus Association. In 2000, her company launched a software product that addressed the needs of vulnerable populations and, in 2012, she received the California eHealth Spirit of Excellence Award for her work with underserved populations.

Cynthia's oldest son, Nathan, says that what set his mother apart was her tenacity, describing her as a 'fierce' woman who would "never take no for answer." She was a firm believer in devoting her life to a cause—or multiple causes. "Her philosophy," he said, "was you have to leave the world a better place. If you weren't working toward that goal, you weren't doing enough."

In her final months, Cynthia received great pleasure from her wonderful friends and special comfort from her Prayer Group, her sister Daphne, her children and grandchildren.

She is survived by her adoring children, Nathan (Brandy), Alex and Sarah and two grandchildren, Ben and Miabella, as well as stepdaughter Michelle Bryant (Steve). She is also survived by her sisters Daphne Matthews (Timothy) and Diane Henderson.

In lieu of flowers, the family requests that donations be made in her name to the Sonoma Valley Community Health Center or the Hydrocephalus Association.



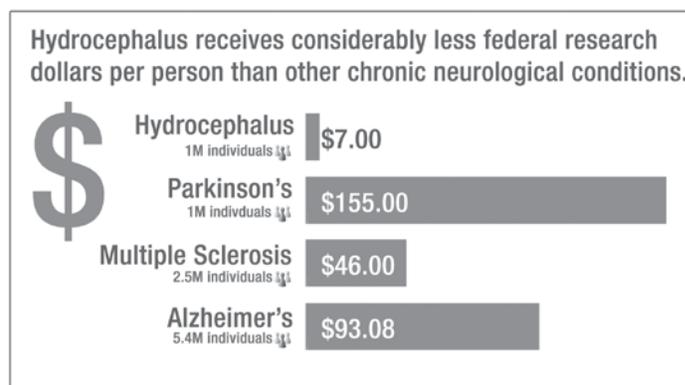
Innovative Analysis of Publicly-Funded Hydrocephalus Research

By Paul Gross, Past Chair of the Board of Directors,
Co-Chair of the HA Research Committee

A review of the history of public funding of hydrocephalus research funded by the National Institutes of Health (NIH) was recently published in the *Journal of Neurosurgery: Pediatrics*. The review is the result of the collaboration between Hydrocephalus Clinical Research Network (HCRN) Co-Founders Paul Gross and Dr. John Kestle with the Hydrocephalus Association (HA). It was found that over the 10-year period from 2002 to 2011, NIH funded \$54M of which nearly half (\$25M) was spent on the Management of Myelomeningocele Study (MOMS) randomized control trial. The next largest investment was nearly \$10M spent on device development. On basic science research, \$9 million was spent.

Grants were analyzed over time and many interesting trends were found. In the first five years, National Institute of Child Health and Development (NICHD) was the largest funder of hydrocephalus research (largely driven by the MOMS trial) but more recently the National Institute of Neurological Disorders and Stroke (NINDS) has taken the lead in funding hydrocephalus research. The majority of that funding has been focused on device development which was stimulated by the sole Program Announcement (PA-12-189), [a PA is an indicator of NIH interest without set aside funding], on hydrocephalus for improving shunts in 2009. This PA is for Small Business Innovation Research (SBIR) grants that have a federal mandate to be 2.8% of the NIH budget (moving to 3.2% over the coming years).

NIH has funded an average of five new hydrocephalus grants per year during the last five years of the analysis.



With the grant mix weighted toward SBIRs, it is estimated that there are only 20 grant applications per year! So the biggest conclusions from the analysis are:

1. Hydrocephalus needs more researchers conducting high impact, innovative research.
2. Alternative funding is very important given the challenging public funding environment. Private funding opportunities – such as HA's Research Initiative – are very important to advancing research and developing preliminary data to support applications for public funding.

The complete study article can be found in the *Journal of Neurosurgery: Pediatrics*, February 2014.

Dr. John Kestle Returns to Primary Children's Hospital, Salt Lake City, Utah

Dr. John Kestle returned to Primary Children's Hospital as a pediatric neurosurgeon and Vice Chair of Clinical Research, for the University of Utah Department of Neurosurgery. After an evaluation of the role of Chief of Surgery at University of British Columbia, Dr. Kestle decided to return to his core passions of pediatric neurosurgery, conducting clinical research into hydrocephalus and other neurosurgical conditions, and mentoring others in these areas. Dr. Kestle will also continue his work with the Adult Hydrocephalus Clinical Research Network (AHCRN) initiated by the Hydrocephalus Association.

BC Children's Hospital's Dr. Doug Cochrane will continue in his role as the PI in HCRN for that institution maintaining Hydrocephalus Clinical Research Network's nine center presence across North America.

Gerber Foundation Grant Supports HCRN Study

The Gerber Foundation recently awarded a research grant to HCRN investigator Dr. Chevis Shannon, Research Assistant Professor & Director of the Pediatric Neurosurgery Clinical Research Initiative at Vanderbilt University. Her study, entitled “Understanding the Impact of Post Hemorrhagic Hydrocephalus on Neurodevelopmental Outcomes in Premature Infants,” will compare neurodevelopmental outcomes at 18-22 months and 36-42 months (corrected age) between very low birth weight infants (VLBW) who undergo initial reservoir placement versus those VLBW infants who undergo initial subgaleal placement for temporary cerebrospinal fluid (CSF) diversion. The study will further examine VLBW infants who undergo initial temporization versus permanent VP shunt placement for CSF diversion. Additionally, these outcomes will be evaluated to determine the relationship of PHH-associated elevations in CSF levels of neurodevelopmental protein mediators.

This project is an ancillary project to two currently enrolling HCRN projects. HCRN Principal Investigator (PI) Dr. John Wellons is investigating the impact of temporization and permanent CSF diversion procedures in the treatment of hydrocephalus in this patient population in a study entitled “Shunting Outcomes in Post Hemorrhagic Hydrocephalus (SOPHH).” HCRN PI Dr. David Limbrick is studying CSF protein biomarkers to identify higher risk premature infants in an effort to facilitate earlier diagnosis of post hemorrhagic hydrocephalus in his study entitled “Cerebrospinal Fluid Markers of Post-Hemorrhagic Hydrocephalus (SOPHH Biomarkers).”

PI Eligibility for Dr. Shannon’s study includes all premature neonates with:

- Birth weights less than 1500 grams, and
- Grade III or IV IVH, and
- FOR scores greater than or equal to 0.50, and
- Greater than 72 hour life expectancy from other medical problems, primarily presenting or are referred prior to surgical intervention for PHH to HCRN Clinical Centers.
- The age range of enrollment is between 0 and 180 days.

This project aligns with the Gerber Foundation’s focus on pediatric health, specifically the need to identify ways to improve the health of premature infants that will impact their cognitive function both in the short and long run.



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A Clue to Better Understand and Treat Hydrocephalus

Shared from our friends at Seattle Children’s Hospital

Dr. Tamara Simon, MD, MSPH, and her research team from Seattle Children’s Hospital have discovered a clue that could help doctors better understand and treat hydrocephalus. Dr. Simon and her team used genetic sequencing to conduct the first-ever inventory of the complex assortment of bacteria and fungi found in the cerebrospinal fluid of eight children with shunt infections. They identified a surprisingly diverse variety of pathogens, many never before associated with shunt infections. This suggests that many different pathogens may conspire to drive the infections, indicating there might be something we can do to better treat and also prevent these difficult infections altogether.

Dr. Tamara Simon, MD, MSPH, is an Assistant Professor of Pediatrics and a Pediatric Hospitalist at Children’s Hospital of Seattle. She is also the principal investigator for the shunt infection section of the Hydrocephalus Clinical Research Network’s (HCRN) Registry.





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MOTIVATIONAL KEYNOTE SPEAKER Adam Page, Gold Medal Sled Hockey Paralympian

Adam Page knows the meaning of determination. At the age of 15, he was the youngest member of the 2007-08 U.S. National Sled Hockey team. Now 22 years old, Adam is a two time gold medal winner for the Sochi 2014 and Vancouver 2010 Paralympic Winter Games, respectively. Coming off of his winter game win, Adam will inspire us all, kids and adults alike, as he addresses the conference participants on going for the GOLD.

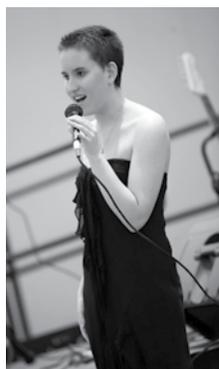


SCIENTIFIC KEYNOTE SPEAKER Dr. Stephen A. Back, MD, PhD

Dr. Back will address his important work on the development of strategies to promote regeneration and repair of injury to the developing brain. Dr. Back is a Professor of Pediatrics and Neurology, Oregon Health & Science University, Clyde and Elda Munson Professor of Pediatric Research, Director, Neuroscience Section, Pape' Family Pediatric Research Institute.

Educational tracks for Parents | Teens and Young Adults | Adults and Caregivers | NPH and Caregivers

- HCRN and AHCRN updates
- Neuro-Imaging: Scans, radiation and quick brain MRIs
- ETV/CPC
- Anxiety, Depression and Hydrocephalus
- Caregiving 101
- Coping with Hospital Stays
- If it's not NPH, What is it? Parkinson's, Alzheimer's and What Else?
- The ABCs of IEPs
- Life after High School, Transitioning into College
- Employment
- Sports, Activities, Gadgets and Hydrocephalus
- Shunt Infections



kids camp

for our youngest attendees.

...and don't forget our *talent show & dinner dance!*



The Results of a Strong Partnership

The HA Board of Directors has been very busy working on a new strategic plan for the future of the organization. To prepare for this effort, we were excited to solicit input from a broad spectrum of stakeholders in the community, including our Medical Advisory Board, the volunteer chairs for our WALKS and Community Networks, committee members, researchers, Teens Take Charge members, past scholarship winners, past conference attendees, and others.

Using an online Stakeholder Survey that we launched last fall, we asked respondents to provide answers to 21 questions evaluating current HA programs and services, and sharing insights on new activities the association should consider.

The response was simply AMAZING! We received approximately 600 completed surveys, providing the board with very valuable insights into the association's strengths, weaknesses and opportunities for the future. You might be interested to learn about some of the highlights that came out of the survey:

Over 80% of the survey responders believe that HA's current Mission Statement - "to eliminate the challenges of hydrocephalus" – is compelling as written. Many suggested, however, that the mission include some mention of finding a cure.

The second part of the Mission Statement describes how the goal of eliminating the challenges of hydrocephalus will be accomplished. The current language says that HA will do this "by stimulating innovative research and providing support and education for individuals, families and professionals dealing with the condition." Significant feedback was received

recommending the addition of awareness-building and advocacy initiatives.

In describing the most important outcomes of the association's efforts in the next 5 years, the responders identified "finding a cure," "better treatments," and "providing funding for research."

Responders saw HA's biggest challenges to meeting these goals were "securing adequate funding" and "lack of awareness about the condition."

The #1 action the association should take to prepare to meet these challenges was identified as "awareness-building activities/public education." Second was "increased fundraising," and third was "advocacy."

Priorities for future association activities were identified as "funding research," "increasing private and public funding," and "building awareness."

Overall, HA's current programs received good to excellent rating, and lots of ideas for new initiatives were shared.

- ✓ We asked you to get involved and help us raise the money we need to fund research. You answered.
- ✓ We asked you to get involved and build awareness and community in your local area. You answered.
- ✓ We asked you to provide guidance and direction for the future of the association. Again, you answered.

None of us alone can eliminate the challenges of hydrocephalus. With your help, we made big strides in 2013, and will work diligently to continue to do so in the years to come. Thank you for playing your part in that!

NEW Video Blog Series with Debby Buffa

HA is pleased to announce our new video blog series! Join Debby Buffa, HA Board Member, each month as she answers a new question from our community. You can view past episodes on our YouTube channel. To find us on YouTube, search "Hydrocephalus Association." We have aired:

The Journey with Hydrocephalus
Sports and Hydrocephalus
Transitioning from Pediatric-centered to Adult-centered Care

The Hydrocephalus Association would like to thank everyone who submitted questions to Debby for this blog series. If you have a question, please email it to jennifer@hydroassoc.org.



Mary Decker Mentorship Award Recipient Announced

By Karima Roumila, MPH, Director of Support and Education

The Hydrocephalus Association (HA) with the American Association of Neuroscience Nurses (AANN) created an annual award in 2010 to honor Mary Smellie-Decker, RN, MSN, PNP. Mary exemplified excellence in mentorship through her work as a staff nurse, nurse practitioner and member of the Hydrocephalus Association Medical Advisory Board. As one of the first neuroscience PNPs in the country, her passion and commitment for mentoring was demonstrated as she guided both novices and experienced nurses. The scholarship not only honors Mary, but aims to inspire neuroscience nurses to continue her legacy of excellence in patient care and professional mentorship.

This year's recipient of the Mary Decker Mentorship Award is Cathy Cartwright, RN, MSN, PCNS, Pediatric Clinical Nurse Specialist at Children's Mercy in Kansas City, Missouri.

Cathy exemplifies the qualities that Mary stood for: excellence in neurosurgery, specifically hydrocephalus; dedication to patients; teaching and educating about hydrocephalus; inspiring others; leadership; and tremendous passion and nurturing for children with hydrocephalus. We are so honored to have Cathy Cartwright as this year's recipient.

Cathy Cartwright, RN, MSN, PCNS

Cathy Cartwright is a Pediatric Clinical Nurse Specialist in neurosurgery at Children's Mercy Hospital in Kansas City, Missouri. Previously, she has been the nurse manager of several pediatric inpatient units, an instructor in pediatric nursing and a staff nurse in the pediatric intensive care unit. She received her BSN from the University of Missouri-Columbia and her Masters in Nursing from the University of Missouri-Kansas City.

Cathy received the 2011 March of Dimes Future of Nursing Award and most recently the Christina Stewart-Amidei Excellence in Writing Award from the Journal of Neuroscience Nursing and the Mary Decker Mentorship Award. She has written several articles on pediatric neuroscience and is the co-editor of the second edition of the book "Nursing Care of the Pediatric Neurosurgery Patient." She has spoken nationally and internationally on various pediatric neuroscience topics and served on the Board of Directors of the American Association of Neuroscience Nurses as Director, Secretary-Treasurer and President.

When not busy with nursing, Cathy likes to travel with her husband, root for Mizzou football, cook, eat and run.



Cathy Cartwright, RN, MSN, PCNS

Our Community Network

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

AL	Online	All Ages
AR	Online	All Ages
AZ	Phoenix	NPH
	Tucson	All Ages
CA	Online	All Ages
CO	Online	All Ages
CT	Hartford	All Ages
DC	Washington	All Ages
FL	South	All Ages
	Central	Peds/Adolescents/Adult
	Central	NPH
IL	Chicago	Peds/Adolescents
	Chicago	Adults and NPH
IN	Central/Northwest	All Ages
	Clarksville	All Ages
KS	Online	All Ages
KY	Louisville	All Ages
MA	Boston	All Ages
MD	Baltimore	All Ages
MI	Online	All Ages
MN	Minneapolis	Peds/Adolescents
MO	Online	All Ages
NC	Charlotte	All Ages
NJ	Morristown	All Ages
NY	Buffalo	All Ages
	Long Island	All Ages
OH	Online	All Ages
OK	Owasso	All Ages
OR	Portland	All Ages
PA	Pittsburgh	Peds
RI	Providence	All Ages
SC	Online	All Ages
TN	Nashville	All Ages
TX	Dallas	All Ages
	Houston	Peds/Adolescents
UT	Salt Lake City	All Ages
VA	Richmond	All Ages
WA	Bremerton	Peds/Spina Bifida
	Seattle	Peds
	Vancouver	All Ages



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

Congrats to our Reaching for Racquets Scholarship Recipients!

We are so pleased to announce the 2013-2014 Brian Christopher Newcomer Reaching for Racquets Tennis Scholarship Recipients! The scholarship was established in 2013 to support and encourage children with hydrocephalus to play tennis. It is intended to foster and promote confidence, friendship, comfort with social situations, and athletics.

Brian's parents, Jack & Margarita Newcomer, his girlfriend, Jessica Janik, as well as his brother and sister, Jason and Katherine Newcomer, created this scholarship to honor his memory. The scholarship was funded through generous donations from many people who knew Brian, and his loved ones. Brian died over a year and a half ago in a car accident at the age of 27. Although he had hydrocephalus, it did not stop him from playing tennis and coaching kids as he got older. We are so grateful to his loved ones for making this opportunity available to our children.



Brian Christopher Newcomer Reaching for Racquets Scholarship Recipients



Hunter is the oldest of three children. He is a natural comedian, sweet and loving. Hunter plays baseball, tennis, swims, and is a big fan of video games. He excels at math and enjoys drawing. Hunter's brother, Logan, was diagnosed with hydrocephalus at the age of five. Although Hunter does not have hydrocephalus, the condition has greatly impacted his life as it does for many siblings. Hunter is proud of his little brother's courage and braveness and has been by his side through it all.



Logan is a resilient six year old boy who has a spirited zest for life. Diagnosed with hydrocephalus at the age of five, his bravery to fight through the pain and surgeries inspires his family daily. Logan is limited to the sports he can play; yet, he has a passion to play everything. He, along with his brother, Hunter played tennis for the first time in the fall of 2013. They both loved the sport. Logan spends much of his time with his older brother. When it is nice outside, he is interested in riding his bike, playing catch with family, visiting the beach and parks, and taking hikes.



Jacob is a friendly, active, social four year old boy. He enjoys spending time with his family, especially his twin sister. He loves playing at the park, riding his bike and has dreams of playing any and all sports. In 2013, Jacob was diagnosed with hydrocephalus and recently his family discovered that he also has a brain tumor. Due to this, he will be receiving weekly chemotherapy treatments for the next year. Jacob's favorite sports are swimming, running and tennis.



Everett is a happy, kind, hardworking boy who is social and does well in school. He participates in a Brazilian Jiu-Jitsu program three afternoons a week and is an excellent drawer. In Everett's free time, he enjoys spending time with family and friends. He also likes playing Minecraft on the computer, building things with Legos, and riding roller coasters. Everett developed hydrocephalus at the age of nine due to a tectal plate glioma (benign brain tumor).



Alexander is an honor roll student, Boy Scout, and treasurer of the Yearbook. He sings in the chorus, is fond of attending Sunday school and putting together plays. In his free time, he plays the drums, video games, and likes to hang out with his friends. When Alexander was two years old he was diagnosed with hydrocephalus, and since then he has had to endure five brain surgeries.

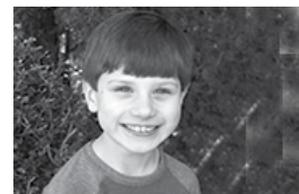


Garvin is a fun, loving, social boy who enjoys interacting with people. He takes Tae Kwan Do classes, participates in church activities, sings in the children's choir, and is learning to play the drums. Garvin's favorite sports are basketball and tennis. He likes listening to music and enjoys acting, often spending time at home putting on "performances." Born with hydrocephalus, Garvin has undergone three surgeries and struggles with math, science and language comprehension. However, he continues to remain happy and upbeat.

Patrick is a Boy Scout, has a dog named, Penny, and a brother and sister. Patrick is currently taking Karate and computer graphics at Duquesne University, which he loves. His favorite subjects in school are reading, science, and math. Diagnosed with hydrocephalus at the age of one, Patrick has undergone some complications requiring further surgeries and he battles migraines. Patrick dreams of becoming a scientist when he grows up and would like to study robotics or geology.



Owen is intensely curious, and loves discovering how things work. One of his favorite things to do is draw up new inventions, including a “machine to help kids feel better.” He has limitless energy and a deep joy for life and love for others. Owen was born prematurely, which caused a brain bleed and the subsequent hydrocephalus. After his shunt surgery at 3 weeks old, he has been very fortunate to not have needed any more surgeries. He takes the extra doctor visits in stride, and doesn’t let anything slow him down. Owen’s favorite subjects in school are math, science, and reading.



Max is in the sixth grade and he is a straight A student. He is self-disciplined, determined and is a master when it comes to debating. Max participates in Boy Scouts, plays baseball, racket ball, and collects baseball cards. He loves animals, especially dogs, and often helps his grandmother at her doggy daycare business. Max was diagnosed with aqueductal stenosis at ten months of age and was shunted at that time. Since then, he has had two shunt revisions. He also has a history of slit like ventricle syndrome (SVS). “We are so appreciative of Max receiving the 2013-2014 Brian Christopher Newcomer Reaching for Racquets Tennis Scholarship. Max is very excited about the opportunity to learn to play tennis!”



Jack is eight years old. He is homeschooled with his brothers and his favorite subject is history. Jack loves to play baseball, build puzzles, and he takes pleasure in playing outside with his friends. Jack was diagnosed with hydrocephalus when he was three months old. He had a shunt inserted shortly after, which failed when he was 7 months old. His doctors performed an Endoscopic Third Ventriculostomy (ETV) and he has not had any complications since then. When Jack grows up he wants to be a Major League Baseball (MLB) player.



Ryan is ten years old. He is home schooled with his siblings and his favorite subject is history. He’s involved in Classical Conversations, which is a homeschool group that meets once a week and he has achieved memory master. Ryan loves to read and play baseball. Diagnosed with hydrocephalus at birth, Ryan’s first shunt failed within a year of placement. Following his shunt malfunction, Ryan’s doctors thought that he would be an excellent candidate for an ETV. Unfortunately, Ryan’s ETV failed one month later. Ryan’s neurosurgeon was able to perform an ETV again and he has been doing well ever since.



Evan is six years old. He is homeschooled with his older brothers, Ryan and Jack. Ryan and Jack both have hydrocephalus. Although Evan does not, he has had to overcome several obstacles in life. Born prematurely at 31 weeks, the doctors did not think Evan was going to make it. When he was born the doctors discovered that Evan was not growing and that he was born with Intrauterine Growth Restricted/Small for Gestational Age (IUGR/SGA). Evan is still small for his age. He aspires to become a Lego Designer.



Alida is an adventurous and loving child. She likes the outdoors, nature and animals. On any given day, she may say she is going to be a dolphin trainer, a veterinarian or something working with animals. Alida is all about her family. She loves spending time with her grandparents, cousins, and the extended family of friends in the neighborhood. She loves to read and she excels at math and science. Diagnosed with hydrocephalus at five years of age, Alida says, “Most of the time I forget I have it because I can’t see it, but when I get a headache I know it’s there...”



And So It Begins...2014 WALK Season is HERE!

By Randi Corey, Director of Special Events

Our new year of HA WALKs and special events is underway. We are pleased to announce that we have 39 WALK sites this year plus the Virtual WALK, for people who don't have an HA WALK in their area. We are proud to announce that the first WALK on the schedule - Portland, OR - was held on June 14th, and two new outstandingly successful "Kids to Cure Hydrocephalus" (school WALKs) have already been held! Under the leadership of Chair Andrea Moore (with a special thank you to Mia Padron), the Jennie E. Hewitt Elementary School in Rockville Centre, Long Island, NY, raised \$10,000 for HA and its mission! The Silverdale Baptist Academy and Preschool in Chattanooga, TN, chaired by HA's Chattanooga WALK Chair, Chara McLaughen, raised over \$13,000! Our total for the Portland WALK has not been remitted yet, but all three events were an impressive way to kick off this year's WALKs and Special Events.

Almost all of the 2014 WALK websites have been launched and are **waiting for you to register!** HA's online fundraising tools make it easy for anyone to raise money by simply sending emails. It's never too early to start. Statistics prove that participants who register and start early have the best results.

A complete list of WALK locations is on HA's WALK webpage. Go to www.hydroassoc.org, select WALKs, select Schedule of WALKs, then choose the hyperlink to your local site. If you have a family member with hydrocephalus, we hope you're forming a **Family Team** to participate in your closest WALK site.

We are very excited to announce **7 new HA WALK locations** this year:

- Phoenix, AZ (HA is delighted to announce that its Phoenix WALK is back for 2014, chaired by Courtney Hemphill and Steph Royden.)
- Indianapolis, IN (Chaired by Sarah & Jacob McClellan and Kelly & Kyle McColley)
- Las Vegas, NV (Chaired by Dakesha Washington, Brittany Brown, Tiffany Thomas and Laquesha Valentine)
- Cleveland, OH (Chaired by Michelle Persensky & Jennifer Cole)
- Columbus, OH (Chaired by Rachael Birkhimer & James Noser)
- Memphis, TN (Chaired by Danielle Olison & Karen Green)

- Dallas, TX (Chaired by Drew & Sarah Null, Megan Redfearn & Christina Ridgle)

If you live in one of these areas and are interested in participating, visit our website for more information. If you would like to explore the idea of helping with the event planning and organizing, please contact the volunteer WALK Chair listed under "Event Info" on the WALK website. You can also contact HA's national office at walk@hydroassoc.org and we'll be happy to connect you with the local WALK Chair/Co-Chairs.

There is another change to the WALK roster: HA's former Minneapolis, MN WALK has a new name and a very exciting new venue! The **HA's Twin Cities WALK**, a name that better reflects the area, is scheduled for September 7th at the...Mall of America! The 2013 Anoka River School WALK (sponsored by the Legacy Christian Academy last year) has merged with HA's Twin Cities WALK and we're looking forward to a stellar event. (Special thanks to Co-Chairs Heather Sorenson - who is leading the event for the 5th year - and Co-Chairs Tonja Niemi and Dylan Johnson, along with Jennifer Bulthuis and Michelle Egertson for their leadership of this site.)

We are very happy to announce that HA's Nashville WALK will be held this year! Trisha Cooper, PA, in the Pediatric Neurosurgery Department at Vanderbilt Children's Hospital, was determined that the Nashville WALK would be held. She persevered in recruiting volunteer leadership and succeeded! HA is delighted to welcome Bunnie Damron to lead the committee, and new committee members Elizabeth "Biz" Smith, RN, (Vanderbilt) and Angela Davis, LPN, who is a research coordinator at Vanderbilt's Hydrocephalus Clinical Research Network (HCRN.) Thanks also to Chara McLaughen, HA's veteran Chattanooga WALK Chair, who will mentor the Nashville volunteers. To everyone who stepped forward to ensure the Nashville WALK continued -- thank you!

If you're participating in an HA WALK this year, we have many hints and tips to help you and your team members maximize your fundraising potential. Contact the HA national office by calling (888) 598-3789 Ext. 12 for any of these guides: HA WALKs - 12 Steps to Maximize Your Fundraising Potential, Raising Money with a Letter Writing Campaign-Top 10 Steps; HA Fundraising Ideas-A to Z or HA's Family Teams Packet.

We look forward to seeing you and the entire local hydrocephalus community at an HA WALK this year!



Never Give Up

By Ariel Yong, NEW TTC Blogger

Hello! My name is Ariel, and, yes, I was named after *The Little Mermaid*. I'm 23 years old, and I hail from Chicago, Illinois. Last June, I graduated from Northwestern University with a degree in both mathematics (eek!) and Spanish. I recently decided not to pursue a career in either of these subjects, however, so I'm currently following my other passions – reporting, writing and sports – by getting my masters in journalism at Georgetown University.

I was diagnosed with hydrocephalus three months after I was born and had my VP shunt installed shortly thereafter. My parents were (and still are) very cautious so I grew up knowing there might be things I wouldn't, and couldn't, do. But I'm here to share with you all the great and wonderful things that can be accomplished, and also the ways to handle the struggles that come with hydrocephalus. There's a whole laundry list of things I can't do.

I can't go scuba diving. I can't play a wind instrument. I can't go horseback riding. I can't hang upside down for too long. I can't play football. I can't lift heavy things. I can't do headers in soccer.

And for those of you with hydrocephalus, maybe you've heard these things, too. But I'm here to tell you that our lives are not defined by a list of "I can'ts." It's not always easy to see it this way (especially in the wake of a hydrocephalus diagnosis), and it took me a while to figure this out.

When I was younger, any time a classmate noticed my shunt protruding from my neck or the large scar on my stomach, my heart started beating one thousand miles a minute. My body temperature spiked and my palms got sweaty while I tried to think of an explanation. *Oh, it's just a vein. Appendicitis. I fell and cut myself.* Basically, I'll tell you whatever you want to hear and will believe, so we can stop discussing the main reason why I'm so different.

And for the few close friends I did share my big secret with, I didn't go into details. I didn't explain that I have hydrocephalus, an incurable neurological condition where I had surgery to have a tube put in to drain the excess fluid in my brain. I would simply describe it by reciting the list of "I can'ts" that I began this story with.

But here's the thing. We're really not that different. Looking back, I wish I wouldn't have rattled off all those "I can'ts." It was hard for me to accept my condition and still feel "normal." But I've learned. And I'm still learning. And one place that helped me see myself as just a "normal" girl is sports.

Now, you might be thinking, "Sports are definitely on the 'I can't' list!" I'd be lying if I said there isn't a risk playing sports with hydrocephalus. Both my parents and I were aware of possible head injuries, and the minor ones I received were treated with extra, over-the-top care. But I learned that there's a line between mentally pushing yourself and putting your foot down when your body – or your brain – is telling you you simply can't do it. The trick is balancing between pushing yourself, yet listening to your body and knowing how close you are to the line so that you don't cross it.

I made the sophomore basketball team when I was a freshman in high school. After serving as captain of the team my sophomore year, I decided I wanted to dance on the Pom Poms squad. So I tried out and danced on the team for two years. And my best friend made me run track, which I thought was the worst idea at the time, but couldn't thank her enough when I was named one of the captains with her my senior year. So to all the people who told me I wouldn't play sports, I did. And if you want to play, you can make it happen, too.

It wasn't always a walk in the park, however. As track captain, I wanted to lift in the heaviest lifting group for strength training because I thought that was one of the only ways to show my leadership. There came a point when the weight put too much stress on my head, and I got headaches and occasionally felt dizzy. So I dropped down to a lower weight group because, while I can lift weights, I can't lift that heavy of weights. And I figured out different ways to be a leader for my teammates – helping with core workouts and other drills. This is an example of the sometimes tricky balancing act I referred to earlier.

If you choose to play sports, there will also be some obstacles. One time, I got hit hard in the head with a basketball, and although any other athlete might not think twice about it, my parents woke me up every hour that night and quizzed me to make sure everything was okay.

So, is all the balancing and extra caution worth it? When your team or coach elects you to be captain, or you hit the winning shot, or you run that winning relay, I promise you it'll all pay off. I participated in the Doug Bruno basketball camp in Illinois one summer. I was far from the best player there, but I did win the "No Retreat, No Surrender, Never Give Up" Award out of all the girls in the camp. And if I had to choose, I would've chosen



this award over most valuable player (MVP) any day. At the bottom of my trophy, it reads, “One cannot always control circumstances...One can and must control their attitude regarding their circumstances...”

I didn't choose to live with hydrocephalus, and it still doesn't define me. It's simply a condition I'm living with, and sports helped me see this. Sports taught me mental and physical toughness to never give up when life throws obstacles and lists of “I can'ts” at you. So if you have hydrocephalus and you want to play sports, do it and do it with all your heart. Push yourself mentally, but listen to your body. Don't let fear of judgment keep you from playing the game. Because we are different. You know why? Because we never retreat. We never surrender. We never give up.

Don't miss the CONVERSATION!

#TalkTTC

TTC Has Two New Bloggers...



Madeleine Darowiche, our TTC monthly blogger for the past year, is now joined by Ariel, who you just read...and HENRY! Meet Henry Guion, 23 years old from Charleston, South Carolina. In December, he graduated from South Carolina State

University with a degree in Communications and Broadcasting. He plans to attend Coker College to major in his first love, dance, specifically performance and choreography. Some of his favorite things to do are dancing, reading, writing, hanging with friends, listening to music, cheerleading and most importantly SHOPPING. Don't miss his blogs!

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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 and renew your membership today. We promise to put your membership dollars to work. We will continue:

- Providing a source of comfort and refuge for people affected by hydrocephalus, whether it's through our toll-free hotline and email, informative publications, online resources or physician directories.
- Sponsoring educational opportunities that bring together patients, doctors, scientists and advocates to share the latest in hydrocephalus treatment and care. View our NPH Webinar on our website. Visit the Resource section on our NPH page under Education and Support.
- Advocating for public funding of hydrocephalus research by deepening our relationship with the National Institutes of Health (NIH).
- Increasing our presence on Capitol Hill. We hope to conduct another advocacy day this year to educate new members and provide an opportunity for them to engage with our community.
- Spreading the word, reaching out and building community. In 2013, we expanded our Walk program to 14,000 participants, advocated for more research funding at even more government agencies, and increased our social media presence, with over 15,000 followers on Facebook and Twitter. We will continue to use these vehicles to raise critical awareness.

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

We would like to thank our Corporate Sponsors!





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Name of person with hydrocephalus: _____

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