Hydrocephalus Association

Pathways

Hydrocephalus Association Newsletter Volume 34, Edition 1

VOLUME
34
EDITION 1

A Year of Many Firsts

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#MakeWaves for Hydrocephalus

Join our national awareness raising campaign. Flip over this newsletter and look on our back cover!

A Year of Many Firsts

As your new CEO, there have been many firsts for me this year. None have been more impactful than participating in my first National Conference on Hydrocephalus. It was a privilege to meet so many families and individuals impacted by hydrocephalus and I was honored to hear your stories and your journeys of perseverance, hope and triumph. I am privileged to lead this organization as we seek to grow our mission.

The 14th National Conference on Hydrocephalus was held in Minneapolis, June 16-19th. This was our largest group of conference participants in the history of HA, with 462 on-site delegates and 657 live-stream participants for a total of 1,119 live and virtual participants.

In case you weren't able to attend, here are some highlights:

- Our keynote address was delivered by Taurean Nixon, cornerback for the Super Bowl Champion Denver Broncos. Taurean shared the impact and inspiration he has experienced since learning of his four-year old brother T.J.'s diagnosis of hydrocephalus. Taurean and his family were warmly welcomed into the HA family.
- Scientists announced exciting developments in hydrocephalus research. For example, Dr. Yun Yung from the Scripps Research Institute has observed that LPA (lysophosphatidic acid), a compound present in blood, causes hydrocephalus. By studying the actions of LPA after a brain bleed, this research has the potential to lead to pharmacological treatment opportunities.
- We hosted seventy-two expert-led sessions focused on living with hydrocephalus and/or research developments, and twenty-three "making connections" break-out sessions. The conference was designed to create learning and interactive experiences for specific audiences like parents, teens, siblings and adults with hydrocephalus. In addition, a fabulous Kids Camp was hosted throughout the conference.
- We learned about how everyone can participate with HA in some way, whether it be as a beneficiary of our programs or through leading a Community Network, hosting a WALK, or creating a do-it-yourself fundraising event through our newest "fundraising your way" program called Make Waves for Hydrocephalus.
- We shared the new features of our HydroAssist™ app that is helping thousands of individuals to record and store their hydrocephalus treatment history and access it when they need it from a mobile device.
- We also planted the seed for our soon-to-be released patient registry, which will enable us to learn more about the broader spectrum of hydrocephalus through patient-supplied information. This data is useful for scientists conducting clinical trials and for HA to better understand the needs of our constituents.
- We danced and we laughed together at the Dinner Dance & Talent Show, boasting more acts than in any other year. This was a celebration of our unity.
- Last, but certainly not least, we experienced amazing networking opportunities. New friendships were made and old friendships rekindled.

An event of this magnitude doesn't happen without a tremendous investment of time and resources. We are so grateful to our Medical Co-Chairs, Dr. Marion "Jack" Walker and Dr. Michael A. Williams, for their program guidance and support in securing presenters. Additionally, our local host, Dr. Michael Partington, played a significant role in our success. Special thanks to all of our sponsors and exhibitors for supporting this important HA education initiative. I am grateful for the amazing staff and volunteers who contributed to the success of this incredible conference.

Warmest regards,

Diana Gray

Diana Gray, MA
Chief Executive Officer

Moving Research Forward:

Innovator Award for Investigators in Hydrocephalus Therapeutics Research

Through the HA Network for Discovery Science (HANDS), HA launched the first ever Innovator Award for Investigators in Hydrocephalus Therapeutics Research in late 2015. The goal of this award was to provide seed funding for bold and innovative research with the potential to transform the field of hydrocephalus through the understanding of disease mechanisms and the development of novel therapies.

Funding for the 2015 Innovator Awards was made possible through the support of Team Hydro and the dedicated efforts of Craig and Vicki Brown, hosts of the annual 2015 Vision Dinner.

Calling all Hydrocephalus Researchers!

Join the HA Network for Discovery Science (HANDS) to connect with other researchers, gain access to our databases and CSF Biobank, and apply for HA Grants!

Visit www.hands.hydroassoc.org

2015 Innovator Award Recipients

- $300,000 in Awarded Grants
- 7 Award Recipients
- 3 Countries Represented
- 30 Applications

Lance Lee, PhD

Faculty Member
Sanford Research

Goal: Identify Risk Modifiers in the Development of Hydrocephalus

Bonnie Blazer-Yost, PhD

Professor of Biology
Indiana University – Purdue University Indianapolis

Goal: Pharmacological Regulation of CSF
Funded by Team Hydro

Andreas Linninger, PhD

Professor of Chemical Engineering
University of Illinois at Chicago

Goal: Restore Cerebrospinal Fluid Transport
Funded by Team Hydro

Marc Del Bigio, MD, PhD, FRCPC

Professor of Pathology
University of Manitoba

Goal: Prevent Neural Damage in Hydrocephalus

Michael Piper, PhD

Australian Research Council Future Fellow
University of Queensland

Goal: Understand Brain Development and Hydrocephalus
Funded by Team Hydro

June Goto, PhD

Research Instructor
Cincinnati Children's Hospital Medical Center

Goal: Gain Insights into Fetal Onset Hydrocephalus

James 'Pat' McAllister, PhD

Professor of Neurosurgery
Washington University School of Medicine

Goal: Improve Outcomes in Post-Hemorrhagic Hydrocephalus
Funded by Team Hydro

Posthemorrhagic Hydrocephalus Workshop

On July 25 and 26, in Bethesda, MD, the HA Network for Discovery Science (HANDS) hosted an international workshop on Posthemorrhagic Hydrocephalus (PHH). The workshop brought together a diverse group of researchers including neurosurgeons, neurologists, and neuropsychologists with scientists in the fields of brain injury and development, cerebrospinal fluid dynamics, and fluid barriers in the brain. Response to the workshop has been overwhelming. Dr. Shenandoah Robinson, a pediatric neurosurgeon from Johns Hopkins University, wrote, "By getting such a variety of people together with diverse expertise in a contained environment, this workshop in two days likely advanced the science towards transforming the field more than anything else in the past 20 years."

Speakers included National Institutes of Health (NIH) supported researchers Dr. David Limbrick from the Washington University School of Medicine, an HCRN Investigator and the head of the HANDS CSF Biobank, Dr. Guohua Xi from the University of Michigan, and Dr. John Zhang from Loma Linda University.

Bringing the Patient Voice into Clinical Trial Design

The Hydrocephalus Association held the Translation to Transform Workshop on June 16th in conjunction with the National Conference on Hydrocephalus. The purpose of the workshop was to understand the patient perspective on clinical trial design. The group grappled with challenging questions. What risks are families willing to take in participating in a research study? Are there acceptable tradeoffs for non-invasive versus invasive treatments and monitoring? What are the barriers to patient enrollment and strategies to improve enrollment? What patient-centered outcomes should be explored?

The seminar series focused on three topics posed to benefit large segments of the hydrocephalus community: 1) Intracranial Pressure (ICP) monitoring, 2) Non-invasive treatments, and 3) Prevention therapies. The goals of the workshop were to start an active and on-going dialogue between patient representatives and hydrocephalus researchers while providing actionable patient-centered feedback for clinical trial design and implementation.

The workshop brought together members of the HA Patient Partner Committee with leading researchers including: Dr. Michael Williams, a neurologist and Adult Hydrocephalus Clinical Research Network (AHCRN) investigator from the University of Washington School of Medicine; Dr. Yoram Unguru, a bioethicist and pediatric hematologist-oncologist at Johns Hopkins University School of Medicine; Dr. Jessica Sun, a pediatric hematologist-oncologist at Duke University Medical Center; Dr. Norman Relkin, a retired neurologist and AHCRN investigator from Weill Cornell Medical College; and Dr. Abhay Moghekar, a neurologist and AHCRN investigator at Johns Hopkins University.

This work was supported through a Patient-Centered Outcomes Research Institute (PCORI) Program Award (EAIN-2627).

★ **Deadline Oct. 31 2016**

$100,000 Adult Hydrocephalus RESEARCH CHALLENGE

Double your impact by making a gift to further adult hydrocephalus research by **October 31, 2016**, and your gift will be matched dollar for dollar by a generous donor. The donor will give up to **$100,000 to support this effort.**

To participate, simply check the **"ADULT RESEARCH MATCH"** box on the donation envelope.

...research continued

Research in Action

HA is once again partnering with the Hydrocephalus Clinical Research Network (HCRN) to improve patient outcomes. Over the past ten years, the HCRN has worked to reduce the risk of shunt infections through the development of a 'shunt infection protocol.' Adoption of the protocol in HCRN hospitals has reduced shunt infection rates by one third. Now, HA and the HCRN are working together to increase implementation of this protocol in hospitals across the United States!

FEDERAL EMPLOYEES

We are pleased to announce that the Hydrocephalus Association has once again been qualified for inclusion in the 2016 Combined Federal Campaign, the federal government's workplace giving program. As a CFC approved Charity, HA has met all 10 accountability standards imposed by the campaign.

If you are a federal employee, please consider designating your contribution to the Hydrocephalus Association with code #10066.

Giving through the CFC is easy—you can give a little each pay period! Simply request a CFC form from you Human Resources department and designate HA with code #10066.

Every dollar counts in the fight against hydrocephalus!

Have you joined us on Social Media?

HA in Attendance

HA represents the hydrocephalus patient community at key professional meetings, keeping our agenda on the table.

NIH NINDS Advisory Council Meeting
February 4-5 | Bethesda, MD

NIH Rare Disease Day
February 29 | Bethesda, MD

Rare Disease Day on Capitol Hill
March 1 | Washington, D.C.

Navigating the Center for Drug Evaluation and Research
March 31 | Bethesda, MD

Adult Hydrocephalus Clinical Research Network
April 1-2 | Chicago, IL

American Academy of Neurology
April 15-21 | Vancouver, BC

Hydrocephalus Clinical Research Network
April 21-22 | Pittsburgh, PA

American Association of Neurological Surgeons
April 30 - May 3 | Chicago, IL

Hydrocephalus Association Posthemorrhagic Hydrocephalus Workshop
July 25-26 | Bethesda, MD

HYDROCEPHALUS ASSOCIATION

Together towards Tomorrow

Super Bowl Champ serves as our Keynote Speaker

Taurean Nixon, a cornerback for the Super Bowl Champion Denver Broncos, inspired our conference audience by sharing his family's journey with hydrocephalus. Taurean's 4 year old brother, TJ, was born with hydrocephalus. TJ inspires Taurean to be an active member of his Denver community, where he can often be found in the pediatric wing of the local hospital visiting children and their families. He was named the Denver Broncos 2015 Community Rookie of the Year for his commitment to the community.

2016 Conference Highlights

- **Live streamed breakout sessions** for those unable to attend. View the recordings on our website!
- Keynote address from **Super Bowl Champion Taurean Nixon**.
- Largest conference attendance in history! **1,119 participants** engaged in the 2016 conference onsite and through virtual participation
- Special video **message from Congressman Chris Smith** (R-NJ) encouraging our continued advocacy efforts.
- More than **70 speakers presenting in 95 sessions** addressing topics of interest to the community at large.
- Launch of our new **Do-It-Yourself Fundraising Program** - Make Waves for Hydrocephalus.
- Focus group on our **mobile app, HydroAssist**™.
- Focus group on the National Conference.
- In collaboration with Gillette Children's Specialty Healthcare, HA hosted it's **second Health Care Professional Day**.

LIVE STREAM

RECORDINGS

OF OUR CONFERENCE SESSIONS

We are happy to offer recordings of a selection of our educational sessions. The sessions we live streamed during conference are currently available on our website. We will release our additional conference session recordings within the coming months. Watch for announcements via email and social media!

www.hydrocephalusconference.org
On the main menu, select Get Involved > Conference.

THANK YOU SPONSORS!

HA would like to thank all of our 2016 conference sponsors.

FINANCIAL SPONSORS

Medtronic
Further, Together

RSRI Rudi Schulte Research Institute

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DePuy Synthes *People inspired*™
COMPANIES OF Johnson & Johnson

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At the heart of the brain

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EDUCATIONAL PARTNERS

Children's MINNESOTA

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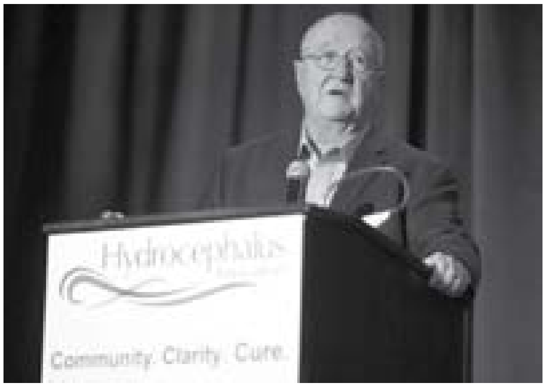
HYDROCEPHALUS ASSOCIATION

Together Towards Tomorrow *...continued*

HYDROCEPHALUS ASSOCIATION Together Towards Tomorrow *...continued*



Special Awards

The National Conference is a place to honor and recognize key volunteers and corporate partners. Katie Cook received the Vicki Brown Volunteer of the Year Award, Dr. Marion L. Walker received the Hydrocephalus Association's Distinguished Achievement Award, and Medtronic received the Hydrocephalus Association's Distinguished Corporate Partner of the Year Award.

IN APPRECIATION

We would like to thank the following individuals for contributing to our Conference Scholarship Fund that assisted members of our community to attend conference.

Anitsa Aiello
Dr. Andrew Baird
Lawrence Barron
Frederick Boop
Brian Bourne
Craig & Vicki Brown
Gary Chaffee
Lynette Chandler
Aseem Chandra
Dr. Joshua Chern
Jill Colgan
Abby Collins
Susan Contreras

Peter Cutting
Mark de Souza
Kate Dickman
Lon Diffenderfer
Betsy Dolard
Lynn Dudenhoefer
Michelle Engelman
Maribel Farish
Pam Finlayson
Patrick Gemmill
Aisha Heath
Spencer Luker
Annie Mason

Teresa Mastrangelo
Dr. Gordon McComb
Pat Moneyhan
Janyce Moroz
Sean Parker
Dr. Michael Partington
Cassandra Phillips
Jane Phillips
Kathleen Pojeta
Dr. Harold Portnoy
Larry and Michele Rivkin
Amy Rizner
AnnMarie Roth

LaVonne Senanou
Nicole and Brad Silver
Dana Sowby
Dr. Marvin Sussman
Greg Tocco Family Fund
Carolyn Van Hosen
Dr. Marion Jack Walker
Tessa van der Willgen
Dr. Yun Yung
Dr. Andrew Zabel

Sixteen States Join Congress in Declaring September Hydrocephalus Awareness Month

September is Hydrocephalus Awareness Month. Thanks to the tireless efforts of our volunteers around the country, sixteen states have joined the United States Congress in proclaiming September as Hydrocephalus Awareness Month. The Hydrocephalus Association is grateful to the Governors of Alabama, Colorado, Connecticut, Georgia, Illinois, Indiana, Kansas, Maryland, Michigan, New York, North Carolina, Pennsylvania, South Carolina, Tennessee and Virginia for working with local community leaders of the Hydrocephalus Association to bring critical attention to this challenging neurological condition. These fifteen states unite with the State of West Virginia, who once again has supported the hydrocephalus community with a proclamation. In addition to state support, the Town of Centerton, Arkansas, and Chicago, Illinois, have also proclaimed September as Hydrocephalus Awareness Month. A group of cities and towns in upstate New York have also lent their support of our community, including Erie County, Town of Grand Island, City of Rochester, City of Batavia, Town of Tonawanda, City of Niagara Falls, and City of Buffalo.

“We are so grateful that both Governor Rauner and Mayor Emanuel have shown their support in creating awareness for hydrocephalus by signing the proclamations. Spreading the truth about hydrocephalus is important to gain recognition so we can raise and receive funds for research, but the awareness also helps validate the struggles that those of us living with hydrocephalus go through on a day-to-in aday basis,” stated Sherry Reising, co-leader of the Illinois Hydrocephalus Association Community Network.

On the national level, the unwavering support of U.S. Congressman Leonard Lance (R-NJ) and U.S. Congressman Andre Carson (D-IN), Co-Chairs of the Congressional Pediatric and Adult Hydrocephalus Caucus, have allowed our community to advocate for substantive changes for hydrocephalus patients in the U.S., opening doors to new research opportunities that could result in alternative treatment options, forms of prevention, and a cure.

HydroAssist™

Hydrocephalus Association

ANDROID APP ON Google play

Download on the App Store

HydroAssist™ is the first mobile app that allows you to record and store your hydrocephalus treatment history and access it when you need it from your mobile device. Perfect for the individual living with hydrocephalus and the caregiver, alike.

Use the first hydrocephalus app created by medical experts and patients.

Enter information quickly and easily.

Get a clear and complete view of all active and inactive treatments.

Access a comprehensive treatment history documenting all procedures.

Store images of your recent scans.

Save information about yourself, doctors, and emergency contacts.

Our Community Networks

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

AL	Online	All Ages
AR	Online	All Ages
AZ	Online	All Ages
	Phoenix	All Ages
	Phoenix	NPH
CA	Online	All Ages
	Bakersfield	All Ages
	Los Angeles	All Ages
	San Diego	All Ages
CO	Online	All Ages
CT	Online	All Ages
	Hartford	All Ages
DC	Washington	All Ages
DE	Online	All Ages
	Middleton	All Ages
FL	Online	All Ages
	Central	All Ages
	South	All Ages
GA	Online	All Ages
	Atlanta	All Ages
IL	Online	All Ages
	Chicago	Adults/NPH
	Chicago	Pediatric
IN	Online	All Ages
KS	Online	All Ages
KY	Online	All Ages
MA	Online	All Ages
	Boston	All Ages
MD	Online	All Ages
	Baltimore	All Ages
MI	Online	All Ages
	Detroit	All Ages
MN	Online	All Ages
	Minneapolis	Peds/ Adolescents
MO	Online	All Ages
NC	Online	All Ages
	Charlotte	All Ages
ND	Fargo (and Moorhead)	All Ages
NY	Online	All Ages
	Buffalo	All Ages
	Long Island	All Ages
	New York City	All Ages
OH	Online	All Ages
OK	Online	All Ages
	Oklahoma City	All Ages
OR	Online	All Ages
	Portland/ Vancouver	All Ages
PA	Online	All Ages
	Eastern	All Ages
	Pittsburgh	All Ages
RI	Online	All Ages
	Providence	All Ages
SC	Online	All Ages
TN	Online	All Ages
	Chattanooga	All Ages
	Memphis	All Ages
	Nashville	All Ages
TX	Online	All Ages
	Dallas	All Ages
	Houston	Peds/ Adolescents
UT	Online	All Ages
	Salt Lake City	All Ages
VA	Online	All Ages
	Richmond	All Ages
WA	Seattle	Peds
	Bremerton	Peds
	Eastern WA	All Ages
WI	Online	All Ages
Nigeria	Lagos	Peds/ Adolescents

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

LEAVE YOUR LEGACY

The Fudge Solomon Legacy Society

Consider how you can help ensure future support of the Hydrocephalus Association by remembering HA in your long term estate plans. In doing so, you will **become a member of the *Fudge Solomon Legacy Society***, established to honor HA's pioneering founders Emily Fudge and Cynthia Solomon.

Making a bequest to HA is easy and the options are endless, including: bequests of cash, stock or other property; proceeds from a life insurance policy or retirement plan, to name a few. Giving can be customized to suit your specific situation and wishes.

To find out how you can include HA in your estate plan today, please contact the Hydrocephalus Association at (888) 598-3789 *or* giftplanning@hydroassoc.org

The Day-to-Day of Headaches and Hydrocephalus

By Dan Kricke, adult living with Hydrocephalus

When is a headache more than a headache? When do fatigue and vomiting go from a stomach bug or food poisoning to something that warrants a hospital visit?

Welcome to life with hydrocephalus. For me, more than anything else, the uncertainty around the symptoms can be the most frustrating part of the condition.

When I was younger and I would get the stomach flu, my head would eventually start hurting after a day of vomiting. And then the worry would be that the headache was the actual problem, that my shunt was malfunctioning and the vomiting was just a response. Everyone would keep a close eye on me and monitor my slightest change in temperature just to see, one way or another, whether we were going to pack a bag and head to the city to visit my neurosurgeon.

As I grow older I feel like I've become more in tune with my body, able to figure out whether an illness is just a run of the mill "everyone gets sick, sometimes" thing, or if it's hydrocephalus-related. Of course, that doesn't stop my wife from worrying and wanting to drive me to the hospital at the first sign of trouble. That said, although I'm getting better at telling the difference between sick and "hydrocephalus sick," I also believe my head has become more sensitive to certain things.

When I was a kid and everyone would get excited for that one or two days in February that would be surprisingly mild out of nowhere, I was always a little more cautious. I loved the warm weather but the sharp change in temperature would often be accompanied by a slight pressure headache. It wasn't very debilitating, but it made those surprisingly warm days just a little less fun. Now as an adult, those surprisingly warm days are sometimes even worse. Sometimes a quick change in temperature leaves me feeling like I have a terrible migraine and all I can do is lie down and either hope it passes or worry that it's something more serious.

In the time since the University of Chicago wrote their feature on me, I've had a few people reach out to discuss living with hydrocephalus. One of the people who reached out was an adult who had been just recently diagnosed. I talked him through some things and was able to help ease a lot of his fears, I think, but the one thing we both had in common were those stupid weather headaches. It was comforting to know that I wasn't the only one dealing with them, but it also made me realize that there's no easy path with hydrocephalus.

As those of us with hydrocephalus get older, we're going to have our good days and our bad days. There's no magic cure for the condition yet so we, and the people around us, need to be mindful that it doesn't take much to disrupt our equilibrium. I've been out having a perfectly nice time with friends when a headache will hit and I've had to excuse myself. I've also been at work, again, feeling perfectly fine and then suddenly my head is killing me, and the last thing I want to do is stare at a computer screen. I'm sure for some people, it seems like I'm flaking out of hanging out or that I don't want to work.

For me, more than anything else, the uncertainty around the symptoms can be the most frustrating part of the condition.

I'm of two minds on how to deal with this. On the one hand, you can't spend your whole life explaining hydrocephalus to everyone you come in contact with. It's impractical and as I've said before, many people have other conditions or issues they deal with on a daily basis, too. We're all just doing our best to live our lives. But on the other hand, it's our responsibility as people with hydrocephalus to make sure that people whose opinions matter to us know what we're dealing with. I can't just start having mysterious headaches and expect my boss to sympathize if I don't provide any context for the headaches. Similarly, my wife has experienced firsthand how hydrocephalus can bring me down. She's a life-saver when it comes to explaining my headaches to other people if I have to leave a group get-together suddenly.

We may always have hydrocephalus, and it may impact our lives in ways both subtle and much-less-so, but if we communicate how we're being impacted, it will go a long way towards making our lives easier. Easier both internally as we worry less about judgment from someone who doesn't understand what we're going through, and externally, as people around us realize we can be counted on, but occasionally may struggle with headaches and other issues beyond our control.

Visit our Ask the Expert series on our YouTube channel for segments on topics including Barometric Pressure Changes. Visit YouTube and search the Hydrocephalus Association.

The Learning Channel Airs Program on Hydrocephalus

On Monday, July 26, 2016, The Learning Channel aired an episode entitled, “My Baby’s Head Won’t Stop Growing.” The episode featured the stories of three children in different parts of the world living with hydrocephalus since infancy. Many may remember the story of Roona Begum from India who elicited an outpouring of international financial support for her impoverished family so that Roona could receive treatment. For Roona, this entailed the placement of a shunt after her head was drained from an excessive amount of fluid that had distended her skull to unlivable proportions. Across the globe in the United States, another little girl received a shunt to treat congenital hydrocephalus. Parker, now 8, is the daughter of Amy and Jeff Hendrix, two dedicated parents and sources of support not just to Parker, but to the larger hydrocephalus community. Amy is the leader of the Hydrocephalus Association (HA) Community Network in Oklahoma. The final story followed a young boy named Lyndos in Uganda who received an endoscopic third ventriculostomy with choroid plexus cauterization (ETV/CPC), a surgical technique that, if successful, can allow an individual to live without the dependency on a shunt.

“I think that it is very important to spread awareness about hydrocephalus. It’s an underfunded, under acknowledged condition,” responded Amy when asked why she felt it was so important to be a part of the show. ““I have been involved with HA at least 5 years, maybe longer, and connected with several members of our community who are adults with hydrocephalus. I have enjoyed the comradery between them and my daughter. It’s also nice to talk to adults about their challenges and gain insights from their experiences so that I can see the future for my daughter. I’ve always felt HA was a super resource from the beginning and that they are invested in anyone living with hydrocephalus across the cause and the age spectrum.”

The episode did a great job educating the general public on hydrocephalus, a condition that is slowly becoming more recognized as a significant medical condition facing over one million Americans. The Hydrocephalus Association would like to extend our sincere gratitude to Amy and Jeff for so openly sharing their family’s journey with hydrocephalus.

If you missed the episode, you can watch it on TLC’s YouTube channel. We encourage you to email our support staff if you have questions at info@hydroassoc.org. Some initial comments we received posed questions about the use of ETV and ETV/CPC to treat hydrocephalus, particularly around who are candidates for the procedures. Our website contains resources, including a very informative webinar with Dr. Jay Riva-Cambrin, that can help answer some of these questions. We would like to remind our readers that while ETV and ETV/CPC do allow an individual to live shunt-free if successful, complications can arise with the procedure, sometimes many years down the road. We ask everyone to know the signs of shunt or ETV complications and maintain a good relationship with a neurosurgeon and/or neurologist throughout their life.

PLAN NOW for TRICK OR TREAT for HA!

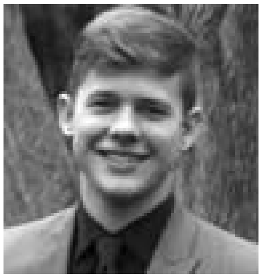
Trick or Treat for HA is a great way for your child’s school, club or organization (scout troop, 4-H, Key Club, church group) to get involved in learning more about hydrocephalus and raising money for HA and its mission. Through an educational component, elemtary-aged kids learn about how the brain works and about hydrocephalus. On Halloween night (or another date of the school or group’s choosing) kids take a collection pail with them during their Trick or Treat rounds, asking for donations.

If you’d like to get your school, club or organization involved for this fall, visit **http://www.hydroassoc.org/get-involved/making-waves/.**

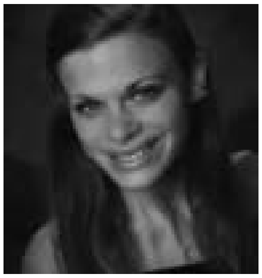
Congratulations 2016 Scholarship Recipients!

The Hydrocephalus Association (HA) is pleased to announce the 2016 Hydrocephalus Association Scholarship Award recipients. We would like to thank everyone who applied for a scholarship and congratulate those of you who were selected this year. HA's scholarship program was established in 1994 to provide financial assistance to capable and promising teens, young adults and adults who live with the ongoing challenges and complexities of hydrocephalus. Since the scholarship program was established, HA has awarded 149 scholarships to 149 deserving future leaders of our community. We are proud to honor these remarkable young adults. You can read their bios on our website under Community > Teens and Young Adults > Scholarships.

We are very grateful to the funders of our nine scholarships that sustain our program for these exceptional recipients. We would also like to thank the Scholarship Committee for their support and dedication.



David Cain
Anthony Abbene Scholarship Funds



Brittany Faitao
Morris L. and Rebecca Ziskind Memorial Scholarship

Lauren Fleck
Morris L. and Rebecca Ziskind Memorial Scholarship

Anthony Hale
Gerard Swartz Fudge Memorial Scholarship Fund

Elizabeth Heim
Justin Scot Alston Memorial Scholarship Fund

Tess Jacobsen
Gerard Swartz Fudge Memorial Scholarship Fund

Jessica Rewiski
Anthony Abbene Scholarship Funds

Dara Tannariello
Mario J. Tocco Hydrocephalus Foundation Scholarship Fund

Fiona Wilcox
Hydrocephalus Association Fund, provided by Erik and Lisa Chamberlain

Congratulations 2016 TTC Scholarship Recipients!

We are pleased and honored to announce our 2016 Hydrocephalus Association Teens Take Charge (TTC) Scholarship Awards recipients. We applaud these young adults for their academic achievements, extracurricular activities and determination. They are an inspiration to everyone at the Hydrocephalus Association and to our entire community!

Through a generous grant from the Medtronic Foundation and the Clara Rose Foundation, the Hydrocephalus Association is able to award five scholarships in the amount of $1,000 each to these extraordinary young adults.

Genna Camiolo

Taylor Dudek

Kashawn Stroman

Hannah Thornsberry

Michael Wroblewski

Break Through the Chains – Living with Anxiety and Hydrocephalus

By Madeleine Darowiche, Teens Take Charge mentor

This is the fourth installment of a series Madeleine has shared on our Teen Blog about living with anxiety and hydrocephalus. We encourage you to visit our website to read the previous installments.

I would like to use this article to let you know that things really do get better, even when you are dealing with anxiety. I know, it is a major cliché that you have all probably heard many times when you are dealing with difficulties. I've been there; that spot where you think nothing is ever going to change or improve. Though it is far from easy, you can get out of the rough spots. I want to be honest though, it does take some work.

Allow me to share an example from personal experience. I rarely spoke a word during my first year in college. I was so anxious. It seemed like everything that could go wrong, definitely did. Doesn't sound like a good start to college life, does it? It wasn't. However, there came a point after the school year had ended and I went home when I realized there were some aspects of my challenges that I could control. I was going to have to push myself harder no matter how difficult things got. Things were not going to get better if I didn't do something!

And that was how I got involved with mentoring freshmen students. Being in a leadership position on campus allowed me to gain confidence in myself and let me believe that things could start to look up. I never knew that someone like myself could become a student leader. Anxiety and leadership don't exactly go hand in hand. The best part for me is that I am doing something I love. I aspire to be an educator someday. Serving others also takes the focus off myself and allows me to lend a helping hand to students who need the assistance during their transition to college.

During my spring semester, I decided to apply for a leadership position as a freshman mentor. Prior to applying, I learned that it would be a rather social position. Normally that would have deterred me, and honestly, it really almost did. I didn't think I was capable or worthy to receive the position, so I thought, why try if the answer is probably going to be no? You see, I was quite used to hearing no, and just wasn't quite sure if I could handle more rejection. However, after some long thought and insightful conversations with members of my amazing support system, I decided to go for it. This position required a series of interviews. I figured I would have the first one and then I would not make it into the following rounds. I was so excited to be notified that I had indeed gotten a second interview! When I realized that I had gotten into the last round of interviews, I decided that no matter the outcome, I would be proud of myself for how far I had gone. After receiving notice that I had received this leadership position, I was ecstatic! To me, it was an indication that no matter the things I had been through and would probably, inevitably, continue to go through because of anxiety, it was no longer the ruler of my life. I was no longer chained to it. I could be free, despite its daily presence in my daily life.

I hope this personal story brings encouragement to those of you dealing with anxiety and hydrocephalus. I want you to know that the things you want are so worth working for. Stay the course, even when the going gets tough. It will most definitely get better. I'll end with these words of support: stay driven, remember why you started towards a goal, and never underestimate the power of a support system. They will be your biggest allies when you are striving for something difficult for you. I hope all of you remain steadfast and go for your goals.

JOIN US!

TEENS TAKE CHARGE

If you are a teen or young adult living hydrocephalus, or a sibling or friend, we encourage you to check out the Hydrocephalus Association's **Teens Take Charge (TTC)** program. You can learn more on our website under **Community > Teens**. If you would like to become more involved, please contact Megeen White at **megeen@hydroassoc.org**.

Overcoming Bullying through a Passion for Sports

By Bryant Williams, adult living with hydrocephalus

I'm not sure how many of you out there living with hydrocephalus have been bullied, but in my younger days, and in certain ways as an adult, I have. When I was in high school, I was called anything that anyone could think of when it came to my scars or my lazy eye. Not to mention the beautifully drawn pictures of tubes running through my body. It happened day after day, year after year.

We went to those in charge and, of course, they weren't able to fix anything. Kids will be kids, right? My mother begged for a resolution but none was ever found. She warned the faculty that one day I was going to fight. She wasn't wrong. I did. I look back on it now and I know that what I did didn't solve any problems at all; it only created more.

For many years, I came home depressed and didn't want to go back to school the next day. I was tired of dealing with it and was even more tired of no one else dealing with it. I was alone. Of course, I had a loving family and good friends who stood up for me and even supported me when I stood up for myself. But I still had to deal with it.

All through my life I have done one thing and that's play sports. I always had a lot of determination and was very competitive. I soon learned that I could use this to my advantage. It was one way that I could drown out the name calling and avoid any confrontation.

So I took to the basketball court and practiced every spare second I had. I became pretty good. I went on to play basketball up until tenth grade. I won awards and contests and, most importantly, I gained confidence in myself. Not to mention, playing basketball really helped with my balance and coordination. Something that many people with hydrocephalus struggle with.

As the seasons went on, I wouldn't say that the bullying completely stopped, but I heard a lot more about how well my team and I played and a lot less of how my eye looked. Plus, if you stepped out on the basketball court with me, you were going to get everything I had for every minute of that game. It was where I felt free. Where I couldn't be judged for my scars or anything else.

If anyone did have anything to say, well, I found a way to quiet them. Basketball, and all the sports I played, were truly a blessing. They saved my balance, my coordination and, most importantly, my confidence.

Beating Bullying

I found myself eventually walking away from basketball to pursue track and cross country. Unfortunately, my high school didn't have a cross country team, so I had to practice on my own. A wonderful teacher at the time volunteered to take me to a few meets that the school would allow her to take me to. She was very supportive and always made sure I was prepared.

The beautiful part about this sport was that I was alone. I had every team, every runner, every coach hoping that I wouldn't succeed because I didn't have a team; but I did succeed. I went on to have two very good seasons as the only athlete without any help when it came to training. I did it all on my own.

This had the greatest reward, which came in the morning announcements the day after a meet where they would state the position I finished in, out of how many runners. I was doing something that no one else in the school was doing and it made me feel great. It relieved so much pressure and, yes, the pun is intended.

What's Your Passion?

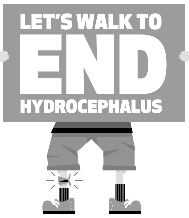
I'm sharing this with you because if you are living with hydrocephalus and you have dealt with being bullied, I encourage you – with everything in me – to find your passion and run with it. You're already unique, you might as well continue to set yourself apart. Do not allow people to bring you down.

When I found my passions, it helped prepare me for the future. Now when someone asks me about my scars or makes any negative comment, it doesn't ruin my entire day. It may ruin that moment, but I leave it at that moment and move on. My passions, such as my passion for writing these words, have helped me move through life with my head high and a heart filled with determination.

Please, go out and find your passion and you will thank yourself for finding it when you look back and realize what it has done for you.

October is Bullying Prevention Month. Visit the Teen Portal on our website for resources about bullying. Share how you can make a difference in October on our Teens Take Charge Facebook page.

HA WALK Site Projected to Top $200,000 in 2016!



HA is projecting that one of its WALK sites will top the $200,000 mark for its 2016 event – Los Angeles! Led by volunteer Co-Chairs Jennifer Pope, Cortney Pellettieri, Tania Heise and Dan Solchanyk, Los Angeles has broken all records since its inception in 2013, raising more than $129,000 in its first year, $150,000 in its second year and $196,000 in 2015! If this projection comes to fruition, this will be HA's only WALK site to achieve $200,000 in a single year.

The Los Angeles WALK is sponsored by the LA Kings and the Kings Care Foundation, with many of the team's players and staff assisting with the annual event in Redondo Beach, CA. In 2015, other sponsors for the Los Angeles HA WALK included the Children's' Hospital of Los Angeles, Premiere Sports Medicine Medical Group and Turner Broadcasting System. Also supporting the event once again are HA's national WALK partners: Aesculap, Codman, Medtronic and Sophysa.

The money raised with the HA WALK program is used to support HA's mission: to promote a cure for hydrocephalus and improve the lives of those affected by the condition. This includes HA's world-class support and education program, quality of life developments like the HydroAssist^{TM} application and critically needed research (clinical, basic and translational). All HA WALKS currently raise almost half of HA's total annual revenue.

For more information on the Los Angeles WALK or an HA WALK near you, please contact walk@hydroassoc.org.

The Race is on to Promote Hydrocephalus Awareness

Hayden Mellross is an Australian Supercross and Motocross rider. At only 20 years old, he has already accomplished so much. Hayden has taken multiple podium finishes in both Australia and in the United States, and has his sights set on many more wins.

Steve Reis is one of Hayden's sponsors. Sponsor benefits include having his company's logo placed on Hayden's bike, jersey, tent, and other promotional materials. Instead of having Hayden promote his company, Reis Auto Service, he decided to have Hayden promote the Hydrocephalus Association. Steve was first introduced to hydrocephalus when his granddaughter was diagnosed shortly after her birth in 2008. She has endured 13 brain surgeries in her 8 years of life.

"Kayleigh, and so many others with hydrocephalus, have had more brain surgeries than birthdays. That's not okay," said Steve. "There needs to be more awareness about hydrocephalus to drive more funding for better treatment options, and ultimately a cure." As Steve has shared his granddaughter's story, he has discovered that not many people know what hydrocephalus is. "Motocross is a great platform to promote HA and hydrocephalus awareness. It's a national sport, putting many eyes on the word 'hydrocephalus'."

Hayden was more than happy to jump in and help spread awareness. "After I heard Steve's granddaughter's story, I felt like this is something so important to promote. So many people have never heard of hydrocephalus, yet it affects more than 1 million Americans. I'm proud to ride with the Hydrocephalus Association logo on my gear."

Hayden rode in three national races this August to promote hydrocephalus (August 13 – New Berlin, NY. August 20 – Mechanicville, MD. August 27 – Crawfordsville, IN). We extend our deep gratitude to Hayden and to Steve for raising hydrocephalus awareness through Supercross and Motorcross.

2016 HA Walks

We have WALKS through October and November! Whether you've participated in one of HA's WALKS before or you're new to the event, we invite you to join us for a great day of fun for the whole family. The money raised with HA WALKS is used to fund HA's program services (support, education and advocacy) as well as cutting edge research to find the answers to this complex and complicated condition. We hope to see you there!

State	Market	2016 Event Date	Web site	Email
AL	Central AL	11/13/16	http://HAwalk.kintera.org/alabama	centralALWALK@hydroassoc.org
FL	Orlando	10/15/16	http://HAwalk.kintera.org/orlando	orlandoWALK@hydroassoc.org
FL	South Florida	10/22/16	http://HAwalk.kintera.org/southflorida	southFLWALK@hydroassoc.org
IN	Indianapolis	10/01/16	http://HAwalk.kintera.org/indianapolis	indianapolisWALK@hydroassoc.org
KS	Wichita	10/08/16	http://HAwalk.kintera.org/wichita	wichitaWALK@hydroassoc.org
KY	Louisville	09/24/16	http://HAwalk.kintera.org/louisville	louisvilleWALK@hydroassoc.org
MA	New England/Boston	10/02/16	http://HAwalk.kintera.org/newengland	newenglandWALK@hydroassoc.org
MA	Fitchburg - Road Race	11/24/16	http://HAwalk.kintera.org/thanksforrunning	thanksforruning@hydroassoc.org
MO	St. Louis	10/22/16	http://HAwalk.kintera.org/stlouis	stlouisWALK@hydroassoc.org
NC	Eastern Carolina	11/05/16	http://HAwalk.kintera.org/charlotte	charlotteWALK@hydroassoc.org
NJ	Basking Ridge	09/25/16	http://HAwalk.kintera.org/westernny	westernNYWALK@hydroassoc.org
PA	Western PA	09/24/16	http://HAwalk.kintera.org/centralpa	centralPAWALK@hydroassoc.org
TN	Chattanooga	10/22/16	http://HAwalk.kintera.org/chattanooga	chattanoogaWALK@hydroassoc.org
TX	Dallas/Fort Worth	10/01/16	http://HAwalk.kintera.org/dfw	dfwWALK@hydroassoc.org
TX	Houston	11/05/16	http://HAwalk.kintera.org/houston	houstonWALK@hydroassoc.org
	Virtual WALK		http://HAvirtualwalk.kintera.org	walk@hydroassoc.org

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Together Towards Tomorrow

By Susan Fiorella, HA Board Member

As a part of this year's member campaign, ***Together Towards Tomorrow***, I wanted to share my story and why I believe every family affected by **hydrocephalus** must help further the critical work of the Hydrocephalus Association.

We started our journey three years ago bent over our beautiful son lying unconscious on a table in the emergency room. We had **never before heard of hydrocephalus**, but we were told that our son would die of it if he did not have **immediate brain surgery**. We handed our beloved, dying two-year-old to unknown surgeons, and prayed that he survive.

We got lucky. When Jacob came out of his coma days after surgery, he woke up laughing – the sweetest sound we have ever heard. But the strokes he had endured during his diagnosis had taken their toll. He lost the ability to move his arms and legs. Since then, he has been on a long but determined path to recovery, which he continues to undertake with a grace that never ceases to amaze us.

Like all who live with hydrocephalus, we learned that we face a lifetime of vigilance. At any time, with little warning, Jacob could be faced with a **hydrocephalus-related emergency** requiring immediate neurosurgery.

We've been very fortunate. To date, Jacob has needed only one additional emergency surgery. When I tell most other parents how 'lucky' we are to have 'only' needed two neurosurgeries thus far, they look at me with shock. Of course, I understand their surprise. One experience with brain surgery is traumatic enough, let alone repeated neurosurgeries.

Jacob's diagnosis was understandably very traumatizing for our whole family. We live with the constant anxiety that another surgery is around the corner, and that his next incident could take our dear Jacob from us forever. The scars on my son's head, the limp in his gait, and the difficulty he has identifying letters and numbers are all constant reminders that more needs to be done.

As I researched other diseases that have experienced major improvements in treatments (e.g., HIV and Cystic Fibrosis), there was a common thread: Activist parents, friends, families, and patients, working together, make all the difference in the world.

If we don't act with a collective sense of urgency, nobody else will. It's been more than 50 years since a significant improvement has occurred in the treatment of hydrocephalus. We cannot allow such a glacial pace to continue when the lives of our loved ones are at stake.

But the only way that we can make a difference is to work together. Together, we can help ensure that **clinical research for hydrocephalus** happens on a much larger scale. We need to **advocate on behalf of hydrocephalus** to our legislators, contribute what we can financially, and help raise awareness and funds for clinical research.

During our journey, I have spent a lot of time googling hydrocephalus and stumbled upon the Hydrocephalus Association (HA). I contacted the HA office and asked if they could connect me with other moms who had older children who had hydrocephalus. Talking with those moms helped me get through the early days in the hospital. I stayed in touch with HA, and soon joined the advocacy committee. I was so impressed by the committee members; not only did the committee share my passion for a better future, but they also possessed real world advocacy expertise. The more I learned about HA, the more I saw how HA is aligned with the interests I have for my family and for all the families living with hydrocephalus. This should come as no surprise since HA was founded by parents of a child with hydrocephalus. I know you share my hope for a better future, and that's why I ask you to send a generous membership gift to ensure that the Hydrocephalus Association continues to galvanize research, advocacy and community for hydrocephalus. Our best chance for a better future is by working together.

I hope you will stand with us and send your annual membership gift today!

We would like to thank all of our loyal donors who join us each year to support HA's agenda to end hydrocephalus. You can send your member gift by completing the member form on the enclosed envelope or by going online to our Donate page.

Hydrocephalus
Association

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NEWSLETTER
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34
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Make Waves
for Hydrocephalus

JOIN US AND #MAKEWAVES!

We need your help to raise awareness and improve the lives of those affected by this condition. We're asking you to show us how you #MakeWaves for Hydrocephalus.

Post a picture or a video on your Twitter, Facebook, or Instagram of how you #MakeWaves. Make sure you use #MakeWaves when posting your video or photo!

Be creative. Be funny. Be INSPIRATIONAL!
Let's #MakeWaves for Hydrocephalus!

www.hydroassoc.org/makewaves