HA has accomplished so much, and in 2014 we experienced significant breakthroughs in every aspect of our key strategic areas.

Dear Friends,

Thank you for your support of the Hydrocephalus Association (HA) in 2014. As the Chairwoman of HA, it gives me great pleasure to share this report detailing yet another banner year for the association. Thanks to your outpouring of support, we have truly become a stronger community with a more prominent voice United for A Cure. I can’t tell you how proud I am of the progress that HA has made within just a few short years, and the future of HA looks even more promising than ever before. As you review this report of what you have helped to accomplish, I hope you feel proud and just as hopeful.

We have experienced significant breakthroughs in every aspect of our key strategic areas. On the advocacy front, we fought to ensure hydrocephalus researchers were able to compete for federal dollars allocated through the Congressionally Directed Medical Research Program of the Department of Defense (DOD). For the first time in the history of the association, hydrocephalus will be listed as a medical condition eligible for pursuing $247M in DOD research funding.

Our Research Initiative continues to advance. In 2014, we planted the seed to launch a third research network that will focus on accelerating cure-based outcomes through a virtual lab called HANDS — the Hydrocephalus Association Network for Discovery Science. This report includes a special research update on current grantees and the progress of the Hydrocephalus Clinical Research Network and the Adult Hydrocephalus Clinical Research Network, funded through your support.

Finally, our Support and Education programs continue to expand, reaching record numbers of patients through social media, educational webinars and local education days. We focused our efforts in 2014 on hosting the 13th National Conference on Hydrocephalus, uniting hundreds of families, researchers, neurosurgeons and advocates together in Portland, Oregon. The next conference is scheduled for June 16–19, 2016, in Minneapolis, Minnesota, and will be an event you will not want to miss.

We ended the year finalizing HA’s five-year strategic plan to implement our mission of promoting a cure for hydrocephalus and improving the lives of those affected. The strategic objectives moving forward include: increasing the amount of high-quality, high impact research being conducted on hydrocephalus; enhancing patient outcomes through education and the improvement of treatments and enhanced services; launching a national Advocacy Campaign; developing and implementing a national Awareness Campaign; and, expanding HA’s focus on adult hydrocephalus.

I am confident that through the Hydrocephalus Association’s persistence, the power of our collective voice, and your continued support, we will pave the way to medical breakthroughs that will dramatically improve lives. Thank you for your commitment.

United I Stand,

Barrett O’Connor
Support and Education

The Hydrocephalus Association is committed to providing innovative programs to meet the diverse needs of the community.

Our services ensure that patients living with hydrocephalus have a place to turn for resources and peer-to-peer support. In 2014, we published several new educational materials, provided thousands of hours of one-on-one support through phone, mail, email, and social media to help patients and their families, and expanded our reach by restructuring the Hydrocephalus Community Networks.

The 13th National Conference on Hydrocephalus was held in Portland, Oregon, on July 9-11, 2014. The National Conference addresses the medical, educational and social complexities of living with hydrocephalus. The extensive program included 44 speakers who presented over 65 interactive sessions, research updates, and educational seminars addressing a variety of topics. The conference was attended by 330 individuals from all over the world, including physicians, researchers, individuals living with hydrocephalus, caregivers, and others. It was a powerful time of connection, education, and friendship.

Webinar Series

We continued our Support and Education Webinar Series, designed to deliver vital information to our community. These interactive, free sessions featured presentations from medical professionals, researchers, and other experts working in the field of hydrocephalus. In 2014, the Hydrocephalus Association (HA) hosted five webinars, which included three webinars that were open to the public and two private training sessions. As part of a capacity-building strategy for our volunteer Community Network leaders, HA staff held a Community Network Chair Training which provided an overview of the Community Networks, the role of the chair, preparing for a meeting, and leading and facilitating a meeting or event. This is the first in a series of Training Webinars for HA Community Network Chairs that will strengthen our ability to provide in-person services across the country.

UNITED FOR A CURE Webinar Series

“Research Update: Delivering on a Promise”
Presented by Dr. John Kestle, Dr. Mark Hamilton, and past HA Board Chairman, Paul Gross

This research webinar included updates on the current work of the Hydrocephalus Clinical Research Network (HCRN), the formation of the Adult Hydrocephalus Clinical Research Network (AHCNRN), and other HA funded research.

“Preparing for Rally Day: Hydrocephalus Talking Points”
Presented by Shawn Daugherty and Dawn Mancuso

The webinar engaged the Hydrocephalus Action Network to prepare for Congressional Office visits at the 2014 Rally for Medical Research and to conduct local state visits with representatives.

“Hope in Progress: Research Update”
Presented by Dr. Timothy Vogel, Dr. James “Pat” McAllister, Dr. Norman Relkin, and past HA Board Chairman, Paul Gross

The webinar showcased several exciting studies being conducted, explained how basic, translational, and clinical research can all impact the management and treatment of hydrocephalus, and provided an update on the newly launched Adult Hydrocephalus Clinical Research Network.
Local and Online Community Networks

There are over one million people affected by hydrocephalus in the United States alone. Expanding our ability to reach more individuals and families impacted by the condition is critical to ensure we meet the demands of our community.

In 2014, HA’s Community Networks continued to strengthen and expand across the United States. The Community Networks provide localized support, education and empowerment by hosting educational events, support group meetings, advocacy activities and other gatherings that enable individuals and families to connect and thrive.

HA’s Community Network consists of 42 networks, which have held 81 events hosting nearly 1,500 individuals. In addition, we have 23 active virtual networks with online Facebook Groups consisting of more than 2,500 members. These closed groups allow those living with hydrocephalus, and their loved ones, to connect and share in a private forum in their own region. We are grateful to our many volunteers who are involved in raising local awareness and facilitating community gatherings, and to the Theodore Batterman Foundation for providing a grant to build the capacity of the network.

Resident’s Prize

Each year the Hydrocephalus Association presents a Resident’s Prize award to the most promising hydrocephalus-related research paper presented by a neurosurgical resident at the Pediatric Section Meeting of the American Association of Neurological Surgeons/Congress of Neurological Surgeons. The prize is designed to encourage young doctors to focus their research efforts on advancing the treatment and care of individuals with hydrocephalus. The 2014 recipient will be selected at the Pediatric Section Meeting in December 2015, in Seattle, Washington.

Scholarships

Since the Hydrocephalus Association’s (HA) scholarship program was established in 1994, we have awarded 111 scholarships to deserving future leaders of our community. This year, we were able to offer eight educational scholarships to young adults living with hydrocephalus who have exhibited promising leadership skills and are involved in their communities. Despite the tremendous challenges and obstacles they face, these students continue to excel in the classroom, volunteer and give back to their communities, and inspire their peers and all of us. These awards were made possible through the support of the following endowed scholarship funds: Gerard Swartz Fudge Memorial Scholarship Fund, Morris L. and Rebecca Ziskind Memorial Scholarship Fund, Anthony Abbene Scholarship Fund, the Justin Scot Alston Memorial Scholarship Fund, and the Mario J. Tocco Hydrocephalus Foundation Scholarship Fund.

For the second year, we also awarded five additional scholarships through our Teens Take Charge (TTC) Program. TTC’s scholarship awards were made possible through the continued support of the Clare Rose Foundation, and all the individuals who held events and contributed to the program.
Teens Take Charge

The Teens Take Charge (TTC) program continues to facilitate an active online community of more than 1,500 teens and young adults affected by hydrocephalus, and their siblings.

This forum provides an opportunity for young adults to openly share their journey and provide peer-to-peer support, encouragement and advice. TTC members are involved in various fundraising and awareness activities - from presenting at school assemblies and in HA webinars, to taking part in local parades, and representing the program at our WALK events. In addition, TTC’s advisory council and members publish articles and share their personal stories of encouragement that are posted on our website and various social media platforms to inspire youth living with this condition.
Research Update

Creating a Cure-Focused Research Ecosystem

Since the start of the Research Initiative in 2009, the Hydrocephalus Association (HA) has committed over $3.5 million to create a research ecosystem primed to find a cure for hydrocephalus. Through conferences and workshops, individual grant awards, and the Mentored Young Investigator program, HA has supported the research ecosystem and basic science efforts while the Hydrocephalus Clinical Research Network (HCRN) and Adult Hydrocephalus Clinical Research Network (AHCRN) provide the structure and expertise necessary to efficiently and thoroughly test new technology, therapies, and preventions with the highest clinical standards. What we are still missing is a unified basic science research community committed to developing these breakthroughs. To fill this gap, the Board of Directors approved funding in 2014 for the Hydrocephalus Association Network for Discovery Science (HANDS).

HA Network for Discovery Science (HANDS)

Developed out of discussions from HA and National Institutes of Health (NIH) sponsored workshops, HANDS will be a platform for both communication and collaboration among hydrocephalus basic and translational researchers with a focus on mentorship, innovation, and shared infrastructure to support high-quality, high impact research.

To accelerate the development and implementation of innovative, cure-focused ideas, researchers need access to the tools, the specimens, and the expertise of scientists and clinicians around the globe. In its current state, the field of hydrocephalus research is small and scattered. Ideas with potentially field-altering implications are being left on the table because researchers do not have the necessary tools to perform the studies and collaborations are slow to form. HA is centralizing and solidifying the field by bringing together the brightest minds into a single virtual center – Hydrocephalus Association Network for Discovery Science. Utilizing shared infrastructure from top institutions around the country, forward-thinking researchers will be able to test their hypotheses at an accelerated pace and bring new therapies, prevents, and hopefully cures to the hydrocephalus community.
TIMOTHY VOGEL, MD
HOPE: Discover Root Cause of Hydrocephalus

Tim Vogel, MD, is an Assistant Professor of Pediatric Neurosurgery at Cincinnati Children’s Hospital Medical Center. In December 2012, a study published in Nature Medicine gave new insight into the role of cell signaling defects in the development of neonatal hydrocephalus. In 2013, Dr. Vogel received the Hydrocephalus Association Award in Cerebrospinal Fluid (CSF) Production, Regulation and Flow, Therapeutics and Diagnostics. His study, “Role of Neural Progenitor Cells in the Development of Neonatal Hydrocephalus,” is focused on the cilia, or hair-like structures on the surface of neural progenitor cells in the brain. He is exploring whether or not abnormal signaling through the cilia contributes to the development of neonatal hydrocephalus. Identification of these key signaling pathways could lead to preventative therapies.

YUN YUNG, PHD
HOPE: Prevent the Development of Fetal Hydrocephalus

Yun Yung, PhD, is a neuroscientist and Research Associate at The Scripps Research Institute in San Diego, California. Since being awarded the Hydrocephalus Association Mentored Young Investigator Award in 2009, Dr. Yung has made tremendous strides in uncovering one cause of fetal hydrocephalus. In 2011, Dr. Yung, along with mentor Dr. Jerold Chun, published a study in the journal Science Translational Medicine which showed that a fatty acid found in blood could induce fetal onset hydrocephalus. An even more exciting discovery was that blocking the action of this protein prevented hydrocephalus from developing. This research is being carried on through a large NIH grant and could have a significant impact on preventing the development of hydrocephalus after a brain bleed.

HEATHER KATZEN, PHD
HOPE: Improve the Psychological Health of Adult Hydrocephalus Patients

Heather Katzen, PhD, University of Miami Health System, is a neuropsychologist and principal investigator for the Adult Hydrocephalus Clinical Research Network (AHCNRN). Dr. Katzen has been instrumental in the development of the AHCNRN Neuropsychological Core Battery. The neuropsychological core tracks cognition and psychological health. The neuropsychological battery includes the Montreal Cognitive Assessment (MOCA), the Symbol Digit Modalities Test (SDMT), the Lawton Instrument of Daily Living Scale (ADL/IADL), and the Beck Depression Inventory-II (BDI-II). These tests are designed to assess various forms of cognitive impairment and the psychological health of adults with hydrocephalus. This data will be used to assess how interventions such as a lumbar puncture or external lumbar drainage affect neuropsychological outcomes.
Pediatric Hydrocephalus Guidelines on Treatment and Management


The report provides an in-depth analysis of current hydrocephalus treatment practices and the level of evidence supporting each in a series of ten articles with nine areas of recommendations. Nineteen treatment recommendations are given along with the evidence-based strength of each recommendation. The recommendations address topics ranging from the treatment of children with intraventricular hemorrhage (IVH), infection protection and treatment, technical advances in catheter placement, assessment of one valve over another, to defining how to judge the success of treatments. The goal is to guide clinical practice by identifying the best ways to treat and manage pediatric hydrocephalus and could have both commercial and clinical practice implications.

The publication was authored by a volunteer task force under the auspices of the American Association of Neurological Surgeons (AANS) and the Congress of Neurological Surgeons (CNS). HA played an integral role in both the development and publication of the guidelines by serving as the patient voice in the development of the report and providing funding to publish the report. Dr. Ann Marie Flannery, corresponding author and member of the HA Medical Advisory Board, said “The Hydrocephalus Association was with us at the beginning and came through in a huge way at the end.”
Adult Hydrocephalus Clinical Research Network (AHCRN)

In late 2014, the Adult Hydrocephalus Clinical Research Network (AHCRN) began enrolling patients at five participating sites located throughout the United States and Canada.

The Registry is open to adult hydrocephalus patients who have been newly diagnosed with an acquired form of hydrocephalus or Normal Pressure Hydrocephalus, patients with arrested hydrocephalus, and pediatric patients who are transitioning into adulthood.

Led by Dr. Mark Hamilton from the University of Calgary, the initial focus is on a core data project that will collect patient demographics, hydrocephalus cause, diagnosis information, surgical and medical management information, images, and cerebrospinal fluid (CSF) samples for biobanking. This initial data will be used to understand the variability, progression, and current treatment practices and inform the development of hypothesis-driven research. The creation of a CSF biobank and image database will help fast track research enabling basic, translational, and clinical research to move forward in parallel.

Hydrocephalus Clinical Research Network (HCRN)

Founded in 2006, the Hydrocephalus Clinical Research Network (HCRN) has developed a rich registry of pediatric patient data and, through the hard work and dedication of its physicians, research coordinators, and the data coordinating center, has been prolific in publishing high quality, high impact articles aimed at improving the outcomes for children with hydrocephalus.

HCRN has not only raised the standard for clinical research in hydrocephalus, but has already made significant contributions to the hydrocephalus community by developing protocols that reduce the risk of shunt infections and determining if visual guidance improves shunt placement and subsequent outcomes. HCRN is currently operating at full speed, comparing the outcomes of shunting versus ETV and ETV-CPC, unraveling the causes of recurrent shunt infections, and starting a randomized clinical trial to determine if shunt entry site affects revision rates.
HA WALKS and Special Events

It was another record-breaking year for HA WALKS and Special Events, raising more than $1.5 million, achieving a 28% increase over 2013. This represents almost half of HA’s total annual revenue; an impressive result since all HA WALKS and Special Events are volunteer initiated and volunteer coordinated.

HA WALKS

Thirty-five WALKS were held across the U.S. with more than 15,000 participants and over 1,000 event day volunteers. HA is pleased to announce that three WALKS exceeded six figures: Los Angeles, Chicago and Long Island. Five WALKS raised more than $70,000, closing in on that $100,000 benchmark: Seattle, Greater New England, South Florida, Twin Cities (Minneapolis/St. Paul) and Denver. The Twin Cities posted one of HA’s most impressive increases, raising $74,000 – a 104% increase over the prior year.

HA held five new WALKS in 2014: Cleveland, Dallas/Fort Worth, Indianapolis, Las Vegas and Memphis. Although not technically a new WALK, but returning after a two-year hiatus, the Phoenix WALK returned in 2014, with a 95.6% increase over its former total.

Kids to Cure Hydrocephalus

Two schools held very successful “Kids to Cure Hydrocephalus” events: the Jennie E. Hewitt Elementary School in Rockville, New York, and the Silverdale Baptist Academy and Preschool in Chattanooga, Tennessee. The Hewitt School event, chaired by Andrea Moore, raised $10,400 for HA’s mission. The Silverdale Baptist Academy event, chaired by Chara McLaughen, raised $13,000. An amazing achievement – congratulations to these two schools.
HA Special Events

HA was very grateful to be the beneficiary of several special event fundraisers held throughout the year.

Returning for its seventh year was Team Hydro— a team of swimmers who compete in the San Francisco and Boston Sharkfest® events. Team Hydro is chaired by Pam, Peter and Sam Finlayson, in memory of their daughter and sister, Kate, who passed away due to complications from hydrocephalus in 2010. The 2014 Team Hydro (with the support of the Little Falls Swim Club in Potomac, Maryland) raised $64,000 for hydrocephalus research. Special thanks to the entire Finlayson family for this outstanding achievement.

Another long-term special event, “Thanks for Running,” raised more than $11,000, almost doubling its previous total, thanks in part to a generous donation from the Schwartz Charitable Foundation. The event, strictly a volunteer-led initiative, is a 5K Run held in Fitchburg, Massachusetts, on Thanksgiving Day morning. Kudos to the “Thanks for Running” Chair, Amy Maynard, and special thanks for serving in that capacity for 17 consecutive years. During her tenure, “Thanks for Running” has grown from a small, neighborhood run with 28 participants to almost 200 participating, despite a surprise snowfall making the set up for the race incredibly difficult.

Trick or Treat for Hydrocephalus, an effort for children to collect donations during Halloween, had another amazing year, raising over $25,000. Trick or Treat for Hydrocephalus was initially developed by Orange County, California, volunteer, Heather Kluter. Now in its third year, Heather continues to lead this annual event, serving as nationwide volunteer Chair.

Finally, MX for Children (and the MX Jackpot Challenge) is a fundraising effort to support hydrocephalus research at children’s hospitals across the U.S. raising money from motocross enthusiasts. Chaired by Brett Wise, the 2014 MX for Children raised more than $21,000 for hydrocephalus research.

* Third party events are events which are not sponsored by the Hydrocephalus Association but are conducted by local volunteers to benefit the Hydrocephalus Association and its mission.
### 2014 Hydrocephalus Association WALKS Top Five!

<table>
<thead>
<tr>
<th>Walk Site</th>
<th>Walk/Chair/Co-Chairs</th>
<th>#Registered Participants</th>
<th>Total Raised</th>
<th>% of Increase Over Previous Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Los Angeles</td>
<td>Tania Heise, Cortney Pelletti, Jennifer Pope, Dan Solchanyk</td>
<td>700</td>
<td>$150,100</td>
<td>16.1%</td>
</tr>
<tr>
<td>Chicago</td>
<td>Stacy Buckner, Katie Cook, Zahadita Kudrna, Andrea O’Shea</td>
<td>610</td>
<td>$114,250</td>
<td>25.7%</td>
</tr>
<tr>
<td>Long Island</td>
<td>Jackie Davidson, Mia Padron</td>
<td>712</td>
<td>$100,050</td>
<td>23.5%</td>
</tr>
<tr>
<td>Seattle</td>
<td>Dawn Adix, Jenifer Petersen</td>
<td>421</td>
<td>$84,000</td>
<td>6.0%</td>
</tr>
<tr>
<td>Greater New England</td>
<td>Jennifer Martinage, Georgana Tocco</td>
<td>325</td>
<td>$83,750</td>
<td>86.0%</td>
</tr>
</tbody>
</table>
Second Annual Vision Dinner

The Hydrocephalus Association’s Second Annual Vision Dinner, “A Time for Awareness. The Hope of a Cure,” was held on October 16, 2014, in New York City, at the Apella Alexandria Center.

The event brought together existing and prospective members of the hydrocephalus community – patients and their families, clinicians, researchers, scientists, philanthropists, business leaders and advocates – to share information, spotlight progress and chart a course for the future.

The evening program featured several individuals working tirelessly to help people living with hydrocephalus survive and thrive. Speakers shared important information about the lives of patients – their struggles at various life stages - and spotlighted a specific form of the condition known as Normal Pressure Hydrocephalus (NPH).

NPH affects the baby boomer population, occurring largely in adults 55 years and older. Alarminglly, NPH is often misdiagnosed as dementia, Alzheimer’s and Parkinson’s disease. With an estimated 700,000 sufferers in the United States, it is critical that we educate the public about NPH and encourage healthcare providers to be more aggressive about screening. While the impact of various forms of hydrocephalus in infants and children can be devastating, miraculously, the symptoms of NPH can often be reversed with early intervention and appropriate treatment. But, first, NPH must be correctly diagnosed.

Guests had the opportunity to experience the journey of misdiagnosis to diagnosis through a video presentation featuring Dr. Milton Newman, who got his life back after 15 years of misdiagnosis and progressive dementia caused by NPH. The evening also highlighted the 50th anniversary of the definition of NPH as a distinct medical condition by the late Dr. Salomón Hakim. Dr. Michael Williams was the keynote speaker and detailed the challenges of treating patients with hydrocephalus as they transition from childhood to adulthood. And, from a supporter and member of the HA Board of Directors, Cliff Goldman, guests experienced a first-hand account of a father’s personal story of hope and perseverance. The Vision Dinner plays a critical role in the awareness and fundraising efforts of HA and it is through events like this that we will continue to make significant strides in pursuing a cure for hydrocephalus.

The Hydrocephalus Association is very grateful for the leadership and support of Craig and Vicki Brown for hosting this event to move HA’s mission forward.
Advocacy in Action

HA’s national advocacy efforts started in May 2006, when we organized our first National Hydrocephalus Awareness and Advocacy Day on Capitol Hill.

We were a small but mighty voice sharing our collective story throughout the halls of Congress. In 2012, recognizing the importance and need for more federal dollars to advance our research agenda, the board relocated the association to the Washington, D.C. area, in close proximity to the National Institutes of Health and Capitol Hill. As part of our advocacy efforts, we launched the Hydrocephalus Action Network (HAN) to identify and train our members on effective advocacy techniques for meeting with elected officials. This included building an area of our website that contains an Advocacy Toolkit to empower our advocates to ask for change.

Advocacy Steering Committee

To help develop and drive the association’s advocacy strategy, a community-led Advocacy Steering Committee was established. The committee will develop tactics each year to ultimately achieve our primary advocacy goal to ensure the federal government invests adequate funds to support our community. Specifically, the committee will ensure that Congress: understands the breadth and depth of the impact of hydrocephalus on our people; prioritizes funding hydrocephalus research for improved treatments and cures; and supports those affected by hydrocephalus with appropriate programs. These goals require targeted awareness campaigns to assure that decision-makers understand that hydrocephalus is a condition that affects a broad array of people, is not cured with the insertion of a shunt and is a growing problem with significant burden on our people and the economy.
Coalition Building

HA works with a number of national health advocacy groups to promote the importance of federally-sponsored research. We joined Research!America, the nation’s largest not-for-profit public education and advocacy alliance working to make research to improve health a higher national priority at the 2014 Rally for Medical Research and Capitol Hill Day as a Gold level sponsor. Through this coalition, we urged Congress and the Administration to increase funding for the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), Agency for Healthcare Research and Quality (AHRQ), Food and Drug Administration (FDA) and National Science Foundation (NSF) at levels that keep pace with scientific opportunity. We also advocated for federal funding for global health research and a legislative and regulatory climate that stimulates growth in industry research and development. In addition, HA was active in advocacy meetings and sign-on letters put together as part of the National Health Council (NHC), the American Brain Coalition (ABC), the Rare Disease Legislative Advocates (RDLA), and the National Organization for Rare Disorders (NORD). Topics have included the implementation of the Affordable Care Act, the effects of sequestration on research funding and the Orphan Drug Act.

National Institutes of Health Partnership

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

On Monday, December 19, 2014, President Obama signed into law H.R. 83, the Omnibus and Continuing Resolution Appropriations Act of 2015, which for the first time, made hydrocephalus a condition eligible to receive funding through the Congressionally Directed Medical Research Programs (CDMRP) administered by the Department of Defense (DOD). The Hydrocephalus Association (HA), working in conjunction with its allies on Capitol Hill, celebrated this victory for the patient community, as it provides new opportunities to obtain much needed research funding which could result in better treatment options for the many children, veterans, and elderly living with hydrocephalus. The CDMRP has appropriations of over $247 million, which are used to fund the best scientific and medical research aimed at preventing, controlling, and curing disease.
## In the News

<table>
<thead>
<tr>
<th>The Saturday Evening Post Spotlights Normal Pressure Hydrocephalus</th>
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<tbody>
<tr>
<td>The Saturday Evening Post spotlights Normal Pressure Hydrocephalus (NPH), an often misdiagnosed condition that affects approximately 375,000 individuals in the U.S.</td>
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<table>
<thead>
<tr>
<th>Famous Rock Star Treated for NPH</th>
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<tbody>
<tr>
<td>ABC News features a story about rock legend, Dick Wagner (lead guitarist for Alice Cooper, Aerosmith and KISS) and his journey with Normal Pressure Hydrocephalus. After receiving a shunt, he was back on the road making music.</td>
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<tr>
<th>NPH Featured on Boston National Public Radio Show</th>
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<tbody>
<tr>
<td>National Public Radio Boston affiliate WBUR’s Here and Now host, Robin Young, interviews Dr. Mark Johnson, neurosurgeon and head of the Adult Hydrocephalus Program at Brigham and Women’s Hospital, about Normal Pressure Hydrocephalus (NPH).</td>
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<table>
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<tr>
<th>South Florida Radio Program Delves into Hydrocephalus</th>
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</thead>
<tbody>
<tr>
<td>South Florida Medical Insider radio show on 1230 WBZT interviews pediatric neurosurgeon Dr. Neil Patel and Hydrocephalus Association South Florida WALK Chair Eileen Rodger for an in-depth story about hydrocephalus.</td>
</tr>
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<thead>
<tr>
<th>Olivia Maccoux Dubbed ‘Iron Athlete’ By High School Teammates</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Minneapolis Star Tribune reports on our very own Olivia Maccoux who has shone as a star athlete, despite having endured over 100 brain surgeries to manage her hydrocephalus.</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>The Right Questions to Ask When Caring for a Parent with Hydrocephalus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jillian Keenan of The New York Times puts together a list of questions all adult children need to ask of their parents before a critical medical emergency takes place. In her case, her father had Normal Pressure Hydrocephalus.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Cynthia Solomon Receives Spirit of Excellence Award</th>
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</thead>
<tbody>
<tr>
<td>Cynthia Solomon, a founding member of HA for which she won the Distinguished Achievement Award, is awarded the Spirit of Excellence Award by the California Office of Health Information Integrity (CalOHII) for founding FollowMe, a web-based personal health record company.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Leadership Award for Two Founding Members of the Hydrocephalus Association</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long Island Newsday reports on Emily and Russell Fudge, recipients of the Vision Award for Leadership, for being part of the initial group of founding members of the Hydrocephalus Association. They received the award at the Hydrocephalus Association’s First Annual Vision Dinner held in New York City on October 10, 2013.</td>
</tr>
</tbody>
</table>
# 2014 Audited Financial Statement

## Statement of Financial Position

**At December 31, 2014**

### ASSETS

**Current Assets:**

<table>
<thead>
<tr>
<th>Asset</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$2,357,827</td>
</tr>
<tr>
<td>Investments</td>
<td>$236,762</td>
</tr>
<tr>
<td>Pledges receivable, current portion</td>
<td>$128,129</td>
</tr>
<tr>
<td>Grants receivable</td>
<td>$232,500</td>
</tr>
<tr>
<td>Other receivables</td>
<td>$10,020</td>
</tr>
<tr>
<td>Prepaid expenses</td>
<td>$34,441</td>
</tr>
<tr>
<td>Inventory</td>
<td>$5,307</td>
</tr>
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</table>

**TOTAL CURRENT ASSETS** $3,004,986

<table>
<thead>
<tr>
<th>Asset</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Investments</td>
<td>$80,718</td>
</tr>
<tr>
<td>Property and equipment, net</td>
<td>$34,384</td>
</tr>
<tr>
<td>Pledge receivable, less current portion, net</td>
<td>$94,359</td>
</tr>
<tr>
<td>Deposits</td>
<td>$10,308</td>
</tr>
</tbody>
</table>

**TOTAL ASSETS** $3,224,755

### LIABILITIES AND NET ASSETS

**Current Liabilities:**

<table>
<thead>
<tr>
<th>Liability</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts payable and accrued expenses</td>
<td>$320,417</td>
</tr>
<tr>
<td>Capital lease payable, current</td>
<td>$3,980</td>
</tr>
</tbody>
</table>

**TOTAL CURRENT LIABILITIES** $324,397

**Long term Liabilities:**

<table>
<thead>
<tr>
<th>Liability</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accrued rent expense</td>
<td>$23,169</td>
</tr>
<tr>
<td>Capital lease payable, non-current</td>
<td>$10,020</td>
</tr>
</tbody>
</table>

**TOTAL LIABILITIES** $349,413

### NET ASSETS

<table>
<thead>
<tr>
<th>Asset</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unrestricted net assets</td>
<td>$2,269,865</td>
</tr>
<tr>
<td>Temporarily restricted net assets</td>
<td>$524,359</td>
</tr>
<tr>
<td>Permanently restricted net assets</td>
<td>$81,118</td>
</tr>
</tbody>
</table>

**TOTAL NET ASSETS** $2,875,342

**TOTAL NET ASSETS AND LIABILITIES** $3,224,755

## Statement of Activities

**For the year ended December 31, 2014**

### SUPPORT AND REVENUE

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Restricted grants and donations</td>
<td>$891,100</td>
</tr>
<tr>
<td>Unrestricted contributions</td>
<td>$982,589</td>
</tr>
<tr>
<td>Fundraising</td>
<td>$1,210,579</td>
</tr>
<tr>
<td>(net of expenses of $313,543)</td>
<td></td>
</tr>
<tr>
<td>Sale of books, publications and other items</td>
<td>$9,639</td>
</tr>
<tr>
<td>Conference Fees</td>
<td>$54,031</td>
</tr>
<tr>
<td>Interest and dividends</td>
<td>$10,889</td>
</tr>
<tr>
<td>Net investment gain (loss)</td>
<td>($8,942)</td>
</tr>
<tr>
<td>Other income</td>
<td>$8,245</td>
</tr>
</tbody>
</table>

**TOTAL SUPPORT AND REVENUE** $3,158,130

### EXPENSES

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
<td>$803,048</td>
</tr>
<tr>
<td>Public support and education</td>
<td>$640,895</td>
</tr>
<tr>
<td>Advocacy</td>
<td>$108,666</td>
</tr>
<tr>
<td>Conferences</td>
<td>$270,814</td>
</tr>
<tr>
<td>Total Program Expenses</td>
<td>$1,823,423</td>
</tr>
<tr>
<td>Walks</td>
<td>$237,717</td>
</tr>
<tr>
<td>Fund Development</td>
<td>$366,325</td>
</tr>
<tr>
<td>Administration</td>
<td>$351,542</td>
</tr>
</tbody>
</table>

**TOTAL FUNDRAISING & ADMINISTRATION** $955,584

**TOTAL EXPENSES** $2,779,007

<table>
<thead>
<tr>
<th>Change in net assets</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in net assets</td>
<td>$379,123</td>
</tr>
<tr>
<td>Net assets at beginning of period</td>
<td>$2,496,219</td>
</tr>
</tbody>
</table>

**NET ASSETS AT END OF PERIOD** $2,875,342

## EXPENSE ALLOCATION

- Research: 29%
- Public Support and Education: 13%
- Advocacy: 13%
- Walks: 9%
- Fundraising: 4%
- Administration: 33%

---

*Data compiled from the Hydrocephalus Association Annual Report 2014.*
## 2014 Donor List

**$100,000 or more**
- Paul and Debbi Brainerd
- Craig and Vicki Brown
- Hugh and Nancy Devlin
- Theodore W. Batterman Family Foundation, Inc.
- Jay and Carrie Weaver

**$50,000 - $99,999**
- Clare Rose Foundation
- Herman E. and Estelle Goodman Foundation
- Frank Clinton Estate
- Jan Churchill and Randy Kell
- LA Kings Care Foundation
- Medtronic Neurosurgery

**$25,000 - $49,999**
- Alpern Family Foundation
- Richard H. Goldman Memorial Foundation
- Cliff and Amy Goldman
- Ines Kingsley
- Rudi Schulte Research Institute
- Jennifer and Jonathan Soros Foundation

**$10,000 - $24,999**
- Adobe Inc.
- Adobe Foundation
- Aesculap
- Ahn Family Foundation
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- Aseem and Amita Chandra
- John and Elizabeth Devlin
- Toni Haselton
- Hydrocephalus Foundation
- Marie Larm from Charitable Foundation
- Ray and June Moser
- Paul Gross and Lori Poliski
- Barrett O’Connor and Paul V. Rogers
- Paul Raether
- Schwartz Charitable Foundation
- Howard Solomon and Sarah Billinghurst

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- Fernando Anon
- Bassett Family Fund
- Delta Airlines
- DePuy Synthes, Codman Neuro
- Kelly Donovan
- Barbara Dorsey
- Fantich Media
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- Susan and David Fowler Charitable Gift Foundation
- Gold Coast Beverage Distributors
- The Gansett Foundation
- Timothy Harris
- Reedy and Philip Hickey
- John and Ann Hirshey
- Beatrice Jaffe Estate
- William Janetschek
- Stephen Keane
- Kohls Cares
- Patty McCallister
- Mesko Restaurant Group, LLC
- Michael Thompson Golf LLC
- Alfred Moses
- Navesink Foundation, The Marion Osborne Estate
- Providence Health and Services
- Michael Riordan
- Seattle Children’s Research Institute - Integrative Brain Research
- Shepherd Kalan LLC
- SOPHYS, USA, Inc.
- Stateline Community Foundation
- Peter and Anna Stonefield
- Thomas Title & Escrow
- Scott Voulgaris
- Wettermark & Keith, LLC
- Todd and Stacy Wolter

**$2,500 - $4,999**
- Anthem Contracting
- Robert Beardslee
- Bell-Anderson Insurance
- Children’s Memorial Hermann Hospital
- Lorraine Cogan
- COMED
- Davis & Gilbert LLP
- Glenn and Michelle Engelman
- Eye Surgical & Medical Associates
- Susan Fiorella
- FMC Ice Sports
- Ishare/Image Outfitters
- J L Wilson & Associates
- Jackson and Coker LocumTenens
- JALS Foundation
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- OnPoint Community Credit Union
- Opalack Foundation
- Greg and Candace Osborn
- Portland Firefighters Association Local 43
- Kelly Smith
- Sunrider International
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- Van Nest Recreation Center
- W. West Equipment
- Bernie and Nancy Wendler

**$1,000 – $2,499**
- Absolutdata Technologies, Inc.
- Gary and Pennie Abramson Charitable Foundation
- Adix’s Bed and Bath for Dogs and Cats
- AmazonSmile
- Joanne Anderson
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- Bank of America Charitable Foundation
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Marian Gabonik
Gelco Philanthropic Foundation
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Manny and Marti Gonzalez
Goodman Campbell Brain and Spine
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Carolyn Hill
Robert Hoak
Richard Hopple
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The Selander Foundation
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Lisa Stark
James and Barbara Stenson
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Lynnea St John
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TDK
Tenet Florida Physician Services
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TPC
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VMG Administration
Barbara and Charles Wade
Marion Walker
Anton Weinberg
Heather Weitz
Williams Brothers Construction
Erika and Ken Witover
Calle Wolski
Dakota Yaskow
Quinten Zalesky

$500 – $999
Abay Neuroscience Center, LLC
America’s Backyard
Ashley Adebowo
Affiliated Control
Ahsirt Fitness & Nail SPA LLC
Gary and Sheri Albertson
David Ambach
Amerisource Funding, Inc.
Ancient Art Stone
John and Hilary Ancona
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