

Your Voice in Washington

2012 Annual Report



Hydrocephalus
Association

A Letter from Our Chairman

Dear Friends,

As I look back over my chairmanship of the past four years, I am amazed by the rate of change and the trajectory of the **Hydrocephalus Association's** (HA) future. In 2009, we held a retreat to kick off what was a very ambitious five-year plan. We adopted the more aspirational, "to eliminate the challenges of hydrocephalus," as our mission statement. This change embodied our desire to improve treatments and outcomes, and eventually develop cures and preventions for those with hydrocephalus. Our strategic plan put forth bold goals, to not only build a research funding and advocacy capability, but also to dramatically increase the breadth and depth of our support program. The funding required to support these goals would require substantial growth in the capacity of HA, which was then a \$1.2 million per year organization.

Implementing these bold new goals served to stretch the organization in new directions. We modified our bylaws to allow us to fund disease research, and we engaged the biomedical research community in a dialogue on moving it forward. The Research Initiative that was borne of these discussions has guided our funding decisions and partnerships to \$2.2 million since 2009. Our funded research is being published, changing treatment practices, and reinvigorating a previously anemic research ecosystem.

Our ambitions led us to move our headquarters close to Washington, D.C., in order to build awareness for hydrocephalus in our nation's capital, influence public

policy, and advocate for increased research emphasis at the National Institutes of Health (NIH). We completed the move in the fall of 2012, and find ourselves regularly involved in meetings with Congress, the NIH, FDA, DoD, and other governmental organizations with the power to change the course of hydrocephalus research. We have been appointed to an NIH Advisory Council and established hydrocephalus as an officially tracked disease by the NIH. We have influenced report language for appropriations. We have raised visibility around hydrocephalus with our armed forces and connected with the governmental efforts around traumatic brain injury.

These efforts and more have been supported by you – our members, professionals, donors, corporate sponsors, and volunteers. We ended 2012 having raised \$1 million more than in 2008, with significant increases in support, research, and advocacy programs, not to mention broader communication capability to build awareness about hydrocephalus. The growth of volunteer-led WALKs has been a critical part of this expansion. Our network of volunteers in both support and events has been an invaluable extension of our mission. As we set out to update our strategic plan and undergo a change in leadership with Barrett O'Connor heading our board and Dawn Mancuso leading the staff, I am confident that the next five years will yield an even greater impact on the future of those affected by hydrocephalus. I'm honored to have held the role of board chair, and am excited for the future of HA under our new leadership.

Sincerely,



Paul H. Gross

*Chairman, Board of Directors
Hydrocephalus Association*



Commitment to Support and Education

The Hydrocephalus Association began as an organization dedicated to helping families affected by hydrocephalus, and has grown to become the preeminent organization of its kind. Our services ensure that patients battling hydrocephalus have a place to turn to for support and education. In 2012, we reached more than 170,000 individuals in all 50 states and more than 180 countries through our educational website, social media platforms, and our many support and education programs.

12th Biennial National Conference: Getting to the Heart of Hydrocephalus

In June, we held our 12th Biennial National Conference, "Getting to the Heart of Hydrocephalus," in Bethesda, Maryland, to provide community and support, and to educate attendees about advances in hydrocephalus research, care, and treatment. Nearly 400 constituents were in attendance, representing more than 32 states and countries as far away as Nigeria and Australia. The conference hosted approximately 40 breakout sessions on topics ranging from the latest hydrocephalus research findings to innovative treatment options, and resources for addressing typical work-life challenges for patients and families. The response to the conference was very positive, with many attendees already planning to attend the next conference in 2014.

Motivational Keynote Speaker



Captain Mark Kelly, Commander of the final mission of the Space Shuttle Endeavor, delivered a rousing talk, which challenged participants to dream big and not let obstacles stop them from pursuing their goals. Captain Kelly brought a special hand-written message from his wife, former Congresswoman Gabrielle Giffords, encouraging our members to "Fight! Fight! Fight!" Congresswoman Giffords was diagnosed with hydrocephalus after the tragic shooting on January 8, 2011, in Casas Adobes, Arizona. She received a ventriculoperitoneal (VP) shunt in 2011 and is committed to helping HA raise awareness.

Inspirational Keynote Speaker



Benjamin Warf, MD, delivered his keynote address to a rapt audience, as he introduced a new surgical technique in infants that potentially eliminates the need for a shunt. Dr. Warf is an Associate in Neurosurgery and the Director of Neonatal and Congenital Anomaly Neurosurgery at Boston Children's Hospital. His talk centered on his ground-breaking surgical treatment that combines the Endoscopic Third Ventriculostomy (ETV) with Choroid Plexus Cauterization (CPC), allowing infants previously not candidates for an ETV to experience a 70 percent success rate in treating their hydrocephalus without a shunt. Dr. Warf developed the procedure while working in Sub-Saharan Africa and was awarded the prestigious John D. and Catherine T. MacArthur Foundation Genius Grant as a result of his ground-breaking work.

Scientific Keynote Speaker: Robert Pudenz Lectureship



Story C. Landis, PhD, Director of the National Institute for Neurological Disorders and Stroke (NINDS), part of the National Institutes of Health, was the Scientific Keynote Speaker at our conference. Dr. Landis addressed the importance of hydrocephalus research and how this research fits into NINDS' mission to reduce the burden of neurological disease. It has been under Dr. Landis' watch that HA Chairman Paul Gross was named to the NINDS Advisory Council, and as a result, has lead her staff to take a more concerted look at hydrocephalus research.



Commitment to Support and Education

Local and Online Support Network

The Hydrocephalus Association strives to meet the education and support needs of everyone affected by hydrocephalus, regardless of their location. In 2012, we grew our support network to 31 groups that meet regularly and expanded our virtual support group community through closed groups on Facebook. These closed groups allow those living with hydrocephalus to connect and share in a private forum in their own region and throughout the world. Combined, these online networks have more than 700 members. We are grateful to our many volunteers who are involved in raising local awareness and facilitating gatherings in their community.

Awards and Scholarships

HA awarded \$14,000 in scholarships to youth living with hydrocephalus who have exhibited promising leadership skills and are involved in the community. The scholarships are used to help support the recipients' educational pursuits and celebrate their ability to overcome challenging odds. The 2012 scholarship recipients are: Carly Bowles, Amanda Bream, Mary Conyard, David Kenneth Creighton, Molly Fuchs, Elizabeth Ann Norris, Lindsey Pampanye, Ashley Reber, and Maria Wiggins. The awards were made possible through the support of the following endowed scholarship funds: Gerard Swartz Fudge Memorial Fund, Morris L. and Rebecca Ziskind Memorial Fund, Anthony Abbene Fund, the Justin Scot Alston Memorial Fund, the Mario J. Tocco Hydrocephalus Foundation Fund, and the Giavana Marie Melomo Memorial Fund.

“Teens Take Charge has truly changed my life. I have gained more confidence and I know others go through the same things I do. It has helped me feel less alone.”
– Madeleine Darowiche,
Margate, Florida

For the first time, we also awarded five additional scholarships through our Teens Take Charge (TTC) Program to Shawn Berg, Jamie Hill, Prisca Patrick, Siobhan Powell, and Lucas Russell.

The Hydrocephalus Association Resident's Prize was presented to Jayant Prasanna Menon, MD, for his paper on "Significant Shunt Obstruction Caused by Parenchymal Tissue Shearing During Ventricular Catheter Implantation," which was presented at the 2012 Pediatric Section meeting of the American Association of Neurological Surgeons/ Congress of Neurological Surgeons (AANS/CNS) in St. Louis, Missouri. This prize is awarded each year to the most promising hydrocephalus-related research paper presented by a neurosurgical resident at the Pediatric Section meeting of the AANS/CNS. The prize is designed to encourage young doctors to focus their research efforts on advancing treatment and care of individuals with hydrocephalus.

Teens Take Charge Highlights

The Teens Take Charge (TTC) program continues to facilitate an active online community of more than 1,000 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 advice. TTC members are also involved in a number of fundraising and awareness activities, from presenting at school assemblies to running marathons and taking part in local parades. In addition, TTC members publish articles and share personal stories of encouragement that are posted on the HA website and on various social media platforms to inspire youth living with this condition. Seven members of the TTC Advisory Council attended and presented at the 2012 National Conference on Hydrocephalus and met with their Congressional representatives to advocate for increased funding for hydrocephalus research. HA is extremely proud of this program and the zeal of the young people involved who are dedicated to making a difference.





“Thank you so much for being here! I had not realized just how profound an impact the information you provide has until talking to someone diagnosed just a few years before me. It is great to see how HA has grown and I am very excited about where your research, support, and advocacy efforts will take us!”

– Jamie Wright, Houston, Texas

Commitment to Research

The Hydrocephalus Association will secure over \$3 million by the end of 2013 to advance our three-pronged research initiative that seeks to: stimulate the research ecosystem, identify and improve clinical practices, and improve the understanding of the root causes of hydrocephalus. In 2012, we made significant progress and invested resources to maintain our internal research capacity by continuing to fund a dedicated Research Program Manager who will help strengthen the hydrocephalus research community and forge partnerships with academic and research institutes.

Our Grantees

As of 2012, HA has funded nine grantees, including seven mentored young investigators (MYI) and two experienced investigators. The MYIs have been very successful with their research, with seven publications in peer-reviewed journals and numerous presentations at scientific conferences. In 2012, we also funded two experienced researchers, James P. McAllister, PhD, and Miles Johnston, PhD, with grants for research focused on cerebrospinal fluid production, flow, and regulation, in order to increase our understanding of the fundamental mechanisms of hydrocephalus. These studies have provided significant insight into the root causes of hydrocephalus and the dynamics of cerebrospinal fluid that may eventually prevent or ameliorate the effects of the condition.

In November 2012, HA announced a new research grant, to be awarded in 2013, for the study of Cerebrospinal Fluid Production, Flow and Regulation Therapeutics and Diagnostics in partnership with the Rudi Schulte Research Institute (RSRI). Through this partnership, we will continue to stimulate novel and groundbreaking research, investing \$1 million of funding from 2013 to 2016.

The Hydrocephalus Clinical Research Network

HA continues to pursue and encourage strategic partnerships, which will further advance the research ecosystem. In the summer of 2012, we signed a 3-year partnership agreement with the Hydrocephalus Clinical Research Network (HCRN) and committed to funding the network of nine children's hospitals that are conducting clinical research on hydrocephalus.

The mission of HCRN is to dramatically improve the lives of kids suffering from hydrocephalus by conducting important and field-changing, multicenter clinical research. The Network seeks to focus on areas such as reducing the incidence of shunt infection, improving the treatment of shunt infection, compiling a comprehensive patient registry, and improving the management of hydrocephalus in premature children.

Through the sharing of patient data and the collaboration across sites, HCRN is able to conduct multiple simultaneous studies, thereby advancing research more quickly than traditional clinical studies. Through this partnership, HA will promote HCRN's research and funding needs to its members. Our funding commitment is substantial – more than \$1M over the next three years – to support the shared data coordinating center located at the University of Utah (which pools patient populations and allows them to be studied more rapidly), as well as the research site coordinators at each center. HA also participates in the advisory board, executive committee and scientific meetings of the HCRN. HCRN Chairman John Kestle, MD, sits on the HA board of directors and serves on our medical advisory board.

Expanding HCRN's Impact in the Adult Population

The Hydrocephalus Association is dedicated to improving the lives of patients with hydrocephalus in all life stages. In the past year, HA has worked with distinguished adult hydrocephalus researchers, including neurosurgeons, neurologists and neuropsychologists, to establish an adult-focused hydrocephalus research network modeled after the HCRN. This group desires to improve the lives of adults with hydrocephalus, raise awareness of the disease, and cover issues related to transitional patients, congenital adults, Normal Pressure Hydrocephalus (NPH) and other adult-onset cases. Seven sites were initially selected, and progress was made throughout 2012 to develop essential data elements and protocols for the network.

We are proud to be funding research through HCRN and sponsoring an adult study group to better understand this complex and complicated condition. The collaboration that takes place within these research networks has already made a significant difference in improving the outcomes for hydrocephalus patients, including decreasing the shunt infection rate by more than 35% at participating hospitals. Future research will continue to seek better treatment methods and ways to improve the quality of life for those living with hydrocephalus.

NIH Public Funding Paper and Conclusions

In 2012, HA Chairman Paul Gross and the HA research staff conducted a comprehensive search to identify the amount of public (government) funds being dedicated to hydrocephalus research. Using the National Institutes of Health (NIH) Research Portfolio Online Reporting Tool (RePORTER) database, all NIH funding related to hydrocephalus was identified for the years 2002 through 2011. The relevant studies were categorized based on the scientific approach, and an in-depth analysis was done to visually display the trends of funding for hydrocephalus research.

The results of the paper have been submitted for publication. In review, there is a discrepancy between hydrocephalus and diseases with a similar health care burden. Between 2002 and 2011, \$51 million has been spent on hydrocephalus research, primarily on clinical, patient-based research. This is considerably lower than other conditions with the same disease burden, such as cystic fibrosis (\$341 million in 3 years) and Parkinson's disease (\$629 million in 3 years). The limited resources in hydrocephalus research funding indicate the need for both an increase in the number of researchers as well as additional sources of funding. Within that same time period, the Hydrocephalus Association has made significant changes to address the need for additional private funding resources for research, and has initiated an advocacy program to support an increase in public research funding. HA has funded \$2.2 million in hydrocephalus research since 2009, and will continue to sponsor innovative and promising research in hydrocephalus for years to come.

2012 Research Conference

In July 2012, the Hydrocephalus Association played a significant role in organizing the third NIH-sponsored conference on hydrocephalus, "Opportunities for Hydrocephalus Research: Pathways to Better Outcomes," in Seattle, Washington. The conference focused on the state of clinical and basic research efforts in hydrocephalus. More than 120 people attended, including neurosurgeons, scientists/researchers, neurologists, engineers, neuropsychologists, and patient advocates. The conference built upon the impressive success of the NIH-sponsored workshops: "Hydrocephalus Myths, New Facts and Clear Directions" in 2005, and "Improving Outcomes in Hydrocephalus:

Bridging the Gap between Basic Science and Clinical Management" in 2009. Four major areas of hydrocephalus research were discussed, including: causes of hydrocephalus (genetic and pathophysiological); diagnosis of hydrocephalus (biomarkers and neuroimaging); treatment of hydrocephalus (bioengineering advances and neurosurgical treatments); and outcomes in hydrocephalus (neuropsychological and neurological). As a result of the conference, consensus priorities were developed, and areas of promise for future hydrocephalus research were identified. A paper detailing the conference and the priorities will be submitted to the *Journal of Neurosurgery, Pediatrics*.





Commitment to Awareness and Advocacy

WALKs

2012 was another record breaking year for HA WALKs and Special Events, raising critical awareness and \$1.1 million with 10,000 participants across the United States. HA WALKs and Special Events would not exist without the hard work of our 66 dedicated volunteer chairs. We cannot thank them enough for all they do on behalf of HA and its mission.

In the past year, HA held WALKs in 32 sites across the United States, and for the first time, raised over \$1 million. HA WALKs are growing in size, too. For example, thanks to additional volunteer leadership and a new venue, the Chicago WALK flourished, experiencing a 112 percent increase in revenue over the previous year. Both the Seattle and the South Florida WALKs' revenues grew by 41 percent from the previous year. The Central Pennsylvania WALK showed a revenue increase of 77 percent, Portland's WALK had an increase topping 45 percent, and Fresno's WALK attained a revenue increase of almost 34 percent.

The Birmingham, Alabama WALK was very successful in expanding its geographic range this year by taking a new approach. WALK Co-Chair Nalini Patel recruited a Regional Team Captain for an area covering approximately 150 miles from the WALK site. When the Regional Team Captain, Britley Parker, recruited more than 50 registered participants who raised more than \$4,000, HA chartered a bus to transport the participants to and from the WALK. This is a model that could be easily replicated in other WALK sites in 2013.

Special Events

Although the WALKs raise a large part of HA's annual revenue, HA's Special Events also contribute to the organization's overall revenue, raising more than \$153,000 in 2012. Every year, HA is the recipient of money raised by third-party fundraising events. These events are run totally by the volunteer coordinator who collects the revenue, pays any expenses and then sends the net proceeds to HA. This year's HA Special Events included:

- [15th Annual Thanks for Running 5K \(Fitchburg, MA\)](#) – a Thanksgiving 5K race, chaired and coordinated by Amy Maynard.
- [5th Annual Team Hydro Swims for a Cure](#) – participating in the San Francisco and Potomac River Sharkfest events, led by Peter, Sam and Pam Finlayson in memory of their sister and daughter, Kate.
- [Annual MX for Children Jackpot Challenge](#) – a motocross event held in multiple cities across the United States. This fundraising activity is led by the Chairman of HA's Board of Directors, Paul Gross.
- [HA's Extreme Athletes](#) – multiple volunteers who participate in a marathon or other sporting event, making participation in the event a vehicle for raising money for HA.
- [Spirit of America Ride](#) – a cross-country bicycle ride from Tampa, Florida to Denver, Colorado, led by Mark Paulissen and Mary Sodano, who rode to raise awareness for hydrocephalus and to raise money for HA.

These events and many others are vital to HA's overall success. We greatly appreciate the volunteers who coordinate them, as well as all those who come out and participate.



Record Awareness Raised – HA in the News

South Florida Radio Program Delves into Hydrocephalus. 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.

12-Year-Old Girl Interviewed by NBC on Her Journey with Hydrocephalus. 12-year-old Gabriela Montes Garzón is interviewed with her mother, HA's own Amanda Garzón, about her journey with hydrocephalus, from being a preemie in the NICU to a 6th grader at The Diener School by **NBC Washington Channel 4 News** reporter Seth Lemon.

Local ABC Affiliate Airs Announcement for the Birmingham WALK. The local **ABC 33/40 news** station in Birmingham, Alabama, aired a public service announcement, hosted by Charles Daniel, meteorologist, for the 5th Annual Birmingham Hydrocephalus WALK.

Birmingham Reporter Finds a New Hero. James Phillips of the **Daily Mountain Eagle** shares a moving story of support for 5-year-old Addox Morrow as Addox's team prepares to walk in the 5th Annual Alabama Hydrocephalus Association WALK.

The Hanford Sentinel Shares the Story of the Zepeda Family. The **Hanford Sentinel**, out of Hanford, California, a small town in California's Central Valley, shares the story of the Zepedas and their twin daughters, Brenda and Dani, born prematurely and diagnosed with hydrocephalus.

WRCB TV in Chattanooga Reports on the Chattanooga WALK, Saturday, October 27th. Highlighting Emalinn McLaughen and her mom, Chara, **WRCB TV** out of Chattanooga, Tennessee, reports on the Chattanooga WALK for Hydrocephalus.

KMPH News Features Fresno WALK. **KMPH** news station features the Fresno WALK.

Chicago WALK Appears in Chicago Sun-Times.

The 2012 Chicago, Illinois WALK was featured in the online edition of the **Chicago Sun-Times**.

Chattanooga, Tennessee WALK Featured in Local timesfreepress.com. The **timesfreepress.com**, a local news outlet, features the story of Chara McLaughen and Emalinn, her three-year-old daughter living with hydrocephalus, and how they hope to make a difference in the Chattanooga, Tennessee WALK.

Article about Hydrocephalus Published in The Hartford Courant. Tracy Taback raises awareness about hydrocephalus, shares her personal journey, and announces the Middlebury, Connecticut WALK.

Chicago's Upcoming WALK Appears in the Chicago Sun Times Online. Local reporter, Matthew Schwerha, highlights the 2012 Chicago WALK.

Hershey Park/Harrisburg WALK Featured on Pennlive.com. The Hershey/Harrisburg, Pennsylvania WALK is featured on **Pennlive.com**.

St. Louis WALK Appears on Show Me St. Louis and in Local Newspaper. **STLtoday.com** featured the Annual St. Louis WALK at Queeny Park. The WALK was also featured on Show Me St. Louis in September during Hydrocephalus Awareness Month.

WALK Chair and TTC Council Member Featured in their Local Paper. Mother and daughter team, Miaja and Alexis Rocciola of Petaluma, California were featured in their local online magazine, **petaluma360.com**. The article talks about their struggles with hydrocephalus, as well as their participation in HA's "Day of Advocacy" on Capitol Hill.

Phoenix, Arizona WALK Featured in Local Paper. Mike and Mindy Weinstein were featured in the **Ahwatukee Foothills News**. The article tells Mindy's story of living with hydrocephalus and their participation in the Phoenix, Arizona WALK.

WALK EVENTS IN 2012

Top Five

Seattle, WA WALK

– 700 participants – \$95,500

(Paul Gross and Gena Azar, Co-Chairs)

Long Island, NY WALK

– 800 Participants - \$77,000

(Mia Padron and Jackie Davidson, Co-Chairs)

Chicago, IL WALK

– 700 Participants - \$68,300

(Katie Cook, Zahadita Kudrna, Andrea O'Shea and Stacy Buckner, Co-Chairs)

South Florida WALK

–600 Participants \$57,250

(Eileen Rodger, Chair)

Washington, DC 5K RUN/WALK

– 800 Participants - \$56,700

(Barrett O'Connor and Martha Fleury, Co-Chairs)

New WALKS Join the Network

Northern KY/Cincinnati (Shawn and Julie Robinson, Co-Chairs)

Houston, TX (Margaret Powers, Chair)

Smyrna, DE (Katie Wilbur and Kelly Mereider, Co-Chairs)

Nashville, TN (Melissa Arsenault and Genia Hastings, Co-Chairs)

Milwaukee (which rejoined HA's WALK program after holding its most recent event in 2010, Patti Lampien and Cassie Siebenlist, Co-Chairs)

Advocacy in Action

HA's advocacy strategy spans a broad range of activities, from local grassroots awareness efforts to federal efforts in order to ensure that the U.S. government is investing adequate funds towards improved treatment options and a cure for hydrocephalus. The bold decision by the HA board to move the association headquarters to the Washington, D.C. area positions the association to be a strong presence in our nation's capital, home of the U.S. Congress and offices of the National Institutes of Health (NIH). In 2012, we have taken advantage of this move, bringing our voices to the halls of government in full force.

Advocacy Day

As part of the National Conference on Hydrocephalus in June, more than 200 members of our community visited approximately 100 Congressional members to advocate for expanded funding for hydrocephalus research. HA Board of Directors Chairman Paul Gross gave out our first ever Public Service Awards to Representatives Robert Andrews (D-NJ), Leonard Lance (R-NJ) and Rosa DeLauro (D-CT) to recognize their important contributions to the hydrocephalus community.

Our Advocacy Day came on the heels of a letter written by Representative Robert Andrews (D-NJ), a senior member of the House Armed Services Committee, in coordination with the Hydrocephalus Association, to Defense Secretary Leon Panetta, regarding the incidence of hydrocephalus in the military. This important letter opened a dialogue on the floor of the U.S. House of Representatives about the difficulties veterans will face without proper screening and diagnosis. HA also met with the Department of Defense and the Veterans Administration and will continue to work with them to address this issue.

NIH Partnership

We had the great honor of having our own Paul Gross join the 18 member National Advisory Neurological Disorders and Stroke Council, the major advisory panel for funding of government grants to the NIH National Institute of Neurological Disorders and Stroke (NINDS). Mr. Gross was also the impetus behind a meeting of the Trans-NIH Hydrocephalus Working Group in November 2012 to discuss the future of hydrocephalus research funding. This Working Group brought together a broad array of representatives, including leadership from NINDS as well as from four additional Institutes within NIH to learn about the work HA is doing to advance hydrocephalus research in the private arena, and to discuss what it would take to increase the amount of public funding going to hydrocephalus research.

Hydrocephalus included in NIH REPORT

In 2012, the NIH agreed to add hydrocephalus as a new research category in the Research, Condition, and Disease Categorization reports (which are published on NIH's RePORT web site) for FY2012. RCDC provides consistent and transparent information to the public about NIH-funded research, providing a complete list of all NIH-funded projects related to each category. By clicking on each of the categories, the public can access full project listings

for that category and view, print, or download the detailed report. With the agreement to include hydrocephalus as a category, the amount of money that the NIH spends each year on hydrocephalus-related research, and the nature of the research projects being funded that deal with hydrocephalus, will now be reported to the public in a very transparent and easily traceable way, beginning in early 2013. Accounting for hydrocephalus funding will help us to make the case for additional funding in the future. This change in procedure within the NIH came about in response to two letters the HA coordinated and sent to the NIH from Rep. DeLauro (D-CT) regarding hydrocephalus.

Local Advocacy in Action

While HA is busy in Washington, D.C., a number of our members continue to advocate and raise awareness at the state and local levels. State-level Hydrocephalus Awareness Month proclamations were attained in New York and Arkansas, thanks to Mia Padron and Jackie Davidson, and Cessilye Lawson, respectively. To assist members with continued engagement with elected officials, HA launched its online Advocacy Toolkit. Many members within our community bravely shared their personal stories with major press outlets, including the *Washington Post*, the *Chicago Sun Times*, and the *Hartford Courant*.

The future of the Hydrocephalus Association is much brighter thanks to the growing level of support from members, donors and volunteers who are eager to help fulfill our mission of eliminating the challenges of hydrocephalus. We have so much more to do and are uniquely positioned to make major advancements in hydrocephalus research, provide increased support and education to patients and their families, and mobilize a global movement through greater awareness and advocacy that will help to eradicate this condition.



2012 Donor List

Thank you for your support of the hydrocephalus community.
Your contributions allow us to move one step closer to fulfilling
our mission of eliminating the challenges of hydrocephalus.

\$100,000 or more

Theodore W. Batterman
Family Foundation
Nancy and Hugh Devlin
Paul Gross and Lori Poliski
Medtronic Foundation and
Medtronic Neurologic
Technologies

\$50,000 - \$99,999

Craig and Vicki Brown
Jan Churchill and Randy Kell
Seattle Children's
Research Institute

\$25,000 - \$49,999

Paul and Debbi Brainerd
Codman and Shurtleff, Inc.
John and Liz Devlin
Cliff and Amy Goldmann
John and Ines Kingsley
Rudi Schulte
Research Institute

\$10,000 - \$24,999

Adobe Foundation, Inc.
Aesculap, Inc.
Ahn Family Foundation
Alpern Family Foundation
Howard Solomon and
Sarah Billinghurst
Clare Rose Foundation
Eagle Quest Investment
Herman and Estelle
Goodman Foundation
Kohl's
June and Ray Moser
Alfred Moses
Barrett O'Connor and
Paul V. Rogers
SeeYourImpact

\$5,000 - \$9,999

Bank of America
Angela and Christopher
Batterman
Theodore Batterman
Travis Byrom
California Choice
Helen and Paul Fiedler
Filament Advisors
Gansett Foundation
Gold Coast
Beverage Distributors
Mary Beth and Tim Harris
Hydrocephalus Foundation
Integra Foundation
Integra Life Sciences
Stephen and Winifred Keane

Larry and Patti Kenyon
Frank Kolodziej
Hannah McCrory
SOPHYSA USA
Carrie and Jay Weaver

\$2,500 - \$4,499

Sukhi Basati
Bell Anderson Insurance
Center for Diagnostic Imaging
Amita and Aseem Chandra
Children's Hospital of Wisconsin
Computers and Structures
Michael and Sara
Craig-Scheckman
M. Daigle Custom Homes
Amos Dare
DC Power and
Industrial Projects LLC
Deutsche Bank
Americas Foundation
Michelle Engelmann
Cathie and Andres Fanjul
Grant and Pam Finlayson
FMC Ice Sports
Fresh Swagg
Julie and Douglas Garn
Motorcycle Superstore, Inc.
Greg and Candace Osborn
Diana Peterson
Portland Firefighters
Association Local 43
Richardson Farms
Romney Family Foundation
Tara and Mike Schwab
Van Nest Recreation Center
Noah Whittington

\$1,000 - \$2,499

Adix's Bed and Bath
for Dogs and Cats
American Family
Children's Hospital
Arapahoe Park Pediatrics
Autodesk, Inc.
Bank of America
Charitable Foundation
Pat E. Belcher
Sarah Billman
Boeing Company
Johanna Bon
Gary Bonde
Nate Bonde
Oliver and Dawn Bowen
Jerad and Barbara Browdy
Christopher Brown
Michael Capone
Andy Carothers
Celsius, Inc.

Ned Chapin
John Childers
Children's Hospital at Vanderbilt
Randi Corey
Corey Steel Company
Ty Curry
Tonja and Paul Darling
Don and Sandra Davis
Mark Denzler
Gary East
Glenn Ebert
Robyn Ewing
Exxon Mobil Foundation
Roger and Kathy Farmer
Fidelity Charitable Gift Fund
Norris and Mary Finlayson
Florida Panthers Foundation
Marilyn and John Floyd
Foods Co. Foundation
Andy and Sarah Fuccillo
Emily and Russell Fudge
Farrah Fure
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GEICO Philanthropic Foundation
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Emily Gladden
Amy and John Glover
Graham Fire Department
Ladies Auxiliary
Joyce and Daniel Gregonis
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Guardian Energy
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JALS Foundation
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David Loewenstein
Dawn Mancuso
Jason Martinage
Mayesh Wholesale
Richard McClain
Geoffrey McCurdy
Nancy Mejia

Michael Baker
Corporation Foundation
Gloria Miesner
Jerrold Miller
Lisa Mooney
James Morton
Nibbi Brothers Construction
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Premier Landscape Contractors
Prodigy Contracting Group
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Sue Riebe
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Boyd Smith
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John Smith
Hari Srinivasan
Stanley Convergent Security
Systems, Inc
Susan Sticha
Russell Stockdale
Wilson Meany Sullivan
Arielle Sutton
Denny and Joy Swanson
Team Evergreen Bicycle Club, Inc.
Keith and Pam Thomas
Noel Tulipan, MD
UBM Tech Web
United Business Media
University of Wisconsin Hospital
and Clinics Authority
UPS Foundation, Inc.
Sue Ann and
Marion Walker, MD
Wal-Mart Foundation
Rogers and Julie Weed
Tyler Weichert
Wells Fargo
Bernie and Nancy Wendler
Anna Wicks

Michael Williams, MD
Elizabeth and James Wilson
Todd and Stacy Wolter

\$500 - \$999

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Ancient Art Stone
Joanne Anderson
Jane Andren
Daniel and Maria Andrzejek
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Arizona Lottery
Arizona State
John and Christine Augustine
Vann Avedisian
Matt Barnes
Barrow Neurosurgical
Associates Ltd
Susanne Beck
Paul Behrman
Aimee Benson
John and Sarah Besuegli
Big Head Caps
James Bishop
William H. Blackmer
Bradley Blake
Boca Raton Little League
Anthony Bonanzinga
Michael Brand
Samuel Browd
David and Lisa Browdy
George and Julie Bullock
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Ellen Burns
Frank Burns
David Buzby
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Joe Carothers
Kathryn Carr
Casino Aztar
Centennial Medical Center
Claudia Cervantes
Kent Chaplin
Chattanooga GYN-Oncology
Jeff Chen
Chee and Christine Chew
Chicagoland Italian American
Charitable Organization
Children's Health System
of Alabama
Grace Christ
Samuel Ciricillo
Tom Clement
Frank Clinton
CN Employees and Pensioners

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Mike Collins
Elizabeth Conyard
Megan Cornelius
Steven Crabtree
Thalia Crooks
Cruise Authority
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Linda Keeney
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Jeff Ojemann

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Anonymous	June and Raymond Moser
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David and Lisa Browdy	Shannon O'Connor
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Amita and Aseem Chandra Family Trust	Barrett O'Connor and Paul Rogers
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Edith B. Gross, PhD	Marion L. Walker, MD
Lori Poliski and Paul Gross	

For more information about how to leave a legacy,
please call **1-888-598-3789 ext. 17** or e-mail giftplanning@hydroassoc.org

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Mia and Henry Padron
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Jennifer Panasko
Cheryl Papciak-Brooks
Nancy Paris
Britley Parker
Pediatric Therapy Services
Pepsi Co.
Lori Lynn Phillips
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PowerReviews, Inc.
Prinova
R.L. Vallee, Inc.
Dave Rasmussen
Michael Rauzzino

\$500 - \$999 (Continued)

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Michelle and Larry Rivkin
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Saint Joseph's School
Thomas Sanders
Carrie Scalzo
Sandy Schmidt
Rodney Scott
Sea Truck Inc.
Seaboard Corporation
Robin and Jill Selati
Mike Sherman
Jeff Shern
Sherwin Williams
Neil Shifrin
Edward Shugrue
Sinners Hope Baptist Church
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Physical Rehabilitation
Kristina Skubon
Joseph Slattery
Jennifer Sluiter
Rick Smith
Terence Smolev
Robert Spencer
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Micki Stewart
Sonja Stewart
Strong Insurance Agency, Inc.
Marvin Sussman
Betty Swarens
June Sweeny
Ellen Swyler
Jon Taggart
Ron and Tina Tanemura
Mike Sherman
Charles Tarino
Robert Taylor
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John Tegeler
Dennis Theis
Trevor Thompson
Christine Tidmore
Todd Companies
Scott and Pam Tompkins
Toyota Material Handling
Trans Canada Pipeline USA, Ltd
Tristar Centennial
Trombetta
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Paul Turnbull

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Management, LLP
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Kyle Voulgaris
Herb Wagner
Stephan Wakefield
Sally and Ken Walker
Rachel Walls
John Warmerdam
Waterfront Development
Corporation
Judy Waterhouse
WFHM
Monte Whitefield
Richard Whiting
George Wicks
Richard Wicks
Kate Wilber
Jackson Williams
Yampa Valley Bank
Monica Young
Laura Zellers



In Honor Of

Connor Aaronson
Clayton Allen
Ryan Allen
Brynn Anduss
Antoine Aparicio
Mary E. Augustine
Nathan Baer
Gavin Baldes
Kori Tully Barnes
Michael Bauer
Jennifer Bechard
Theresa Bechard
Lilly Beck

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Beth Leigh Boberg
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Mairin Fallon
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Phyllis Fineman
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Jessica Fiser
Oliver Fjelstrom
Dina Frank
William Fraser
Troy Frisbee
Gerard Fudge
Taryn Garn
Robert Gaylord-Ross
Drew Geloni
George Carey Gildersleeve
Amy Glover
Adelyn Rose Godowns
Emmalia Goemmer
Jayden Gohl
Katie Goldman
Pier Goldreich
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Noah Goralski
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Lucas Graves
Jenny Grinnip
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Laura Mick

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Mildred Natale
Philip Nelson
Kahlia Newton
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Sara Nieves
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Elizabeth Norris
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Brady O'Connell
Emily O'Conner
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Molly Parker
Kelli Fort Pasierb
Aaron Patel
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Taylor Perez
Svend Lundsgaard Phillips
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Jake Pitts
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Evan Plucker
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Nathaniel Popat
Stephen Popnick
Devin Patrick Postullo
Ashlyn Marie Powell
Madeline Powell
James Rahal
Christopher Range
Sreya Rao
Siobhan Reardon
Dennis Rich
Everett Riser
Alexis Rocciola
Emily Rogers
Zach Romig
Kyla Mantilla Ross
Amber Rowen
Theresa and David Russel
Jacqueline and Joe Santamaria
Matthew V. Santamaria
Thomas Santamaria
Henry Schmit
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Katie Schuderer
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Harrison Silver
Sara Simonsen
Alex Smith
Breanna Smith
Levi Smith
Griffin Snyder
Luke Soukup
Konnor Stellhorn
Elliot Carns Straw
Marissa Sullivan
Ethan Sweeny
Tracy Taback
Aiden Tanz
Matthew and
Kathleen Tegeler
Karson Thomas
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Tiffanie Thomas
Hayley Thorpe
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Mac Tronsdal
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Julia Weiner
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Molly Kate Wilkinson
Macey Williams
Shelley A. Williams
Karen Wilson
Kenadee Winsett
Konnor Wojcik
Humera Yusuf
Quinten Zalesky





In Memory

Bruce John Alexander

Justin Scot Alston

Jobe Arceneaux

Rebecca Barlow

Harry Bither

Michael Blake

Kaitlyn Bodeker

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Mary Louise Duffy

John Emrey

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Gerard Fudge

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Gloria A. Gentile

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Nancy Harvey

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Katheryn Blalock McKenzie

Mary Adele Medeles

Nancy Mella

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Margaret Murphy

Mildred Natale

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Jane E. Rogers

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Ellie Tscouleas

Virgil Weichert

Marjorie Werry

Amy Wiczorek

Sharay Andrea Williams

Dalee Wilson

Annette Woodson

Humera Yusuf

Morris and Rebecca Ziskind

2012 Audited Financial Statement

Statement of Financial Position

At December 31, 2012

ASSETS

Current Assets:

Cash and cash equivalents	\$1,132,500
Accounts receivable	38,834
Unconditional promises to give	76,500
Investment in low duration bond fund	312,216
Prepaid expenses	12,760
Inventory	16,525

Total Current Assets \$1,589,335

Property and equipment	52,617
Deposits	10,108

Total Assets \$1,652,060

LIABILITIES

Current Liabilities:

Accounts payable and accrued expenses	\$160,782
Lease payable, current	4,734
Total Current Liabilities	165,516

Long term Liabilities:

Accrued rent expense	16,984
Capital lease payable, non-current	12,108

Total Liabilities \$194,608

NET ASSETS

Unrestricted net assets	900,003
Temporarily restricted net assets	476,331
Permanently restricted net assets	81,118

Total Net Assets 1,457,452

Total Net Assets and Liabilities \$1,652,060

Statement of Activities

For the year ended December 31, 2012

SUPPORT AND REVENUE

Restricted grants and donations	\$488,729
Unrestricted contributions	690,464
Fundraising (\$1,054,912 revenues less \$138,903 expenses)	916,009
Government contracts and grants	13,425
Sale of books, publications and other items	16,647
Conference fees	76,921
Interest and dividends	13,640
Net investment gain (loss)	6,823
Other income	5,867

Total Support and Revenue \$2,228,525

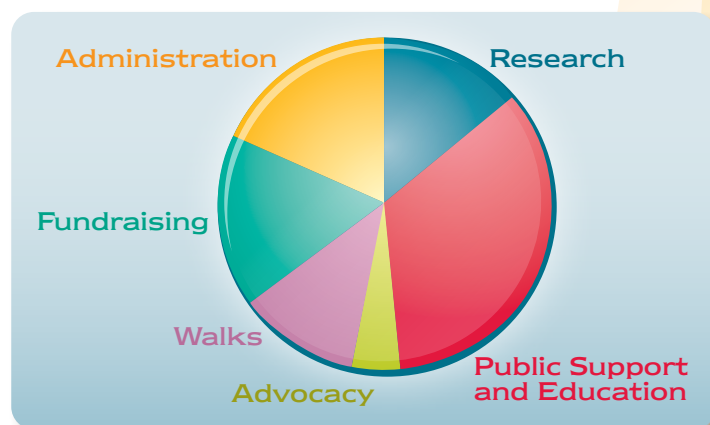
EXPENSES

Research	226,673
Public support and education	283,391
Advocacy	104,959
Hydrocephalus conference	377,666
Total Program Expenses	992,689
Walks	235,675
Fund Development	290,983
Administration	324,122

Total Expenses \$1,843,469

Change in net assets	385,056
Net assets at beginning of period	1,072,396

Net assets at End of period \$1,457,452



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Barrett O'Connor, *Vice Chairwoman*
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