



# Looking Back... Moving Forward

2013 ANNUAL REPORT

## A Letter from Our Chairwoman

Dear Friends,

This year marked the 30th anniversary of the Hydrocephalus Association (HA). What began in 1983 by a small network of concerned parents has blossomed into the nation's largest and most widely respected health advocacy organization devoted to meeting the needs of families affected by hydrocephalus. Thanks to your support, we were able to have another banner year, bringing the association one step closer to fulfilling its mission of eliminating the challenges of hydrocephalus.

As a mom of a daughter with the condition, I can't tell you how proud I am to share the organization's achievements in 2013. In many regards, it was a year of *firsts*, paving the way for a promising future for our loved ones affected by the condition. We celebrated the 30th anniversary by honoring our founders, Russell and Emily Fudge and Cynthia Solomon, during the inaugural Vision Dinner held in New York City. This intimate event was designed to raise national awareness and encourage new partners to join us on our journey to find a cure. In addition, commemorative events were held in conjunction with our WALKs, engaging 14,000 participants across the nation. We are grateful to the many volunteers for hosting these special gatherings.

We surpassed our Reason for Hope campaign goal, securing our first \$3 million to advance HA's research agenda. Because of the generous support of our many donors, HA was able to fund an additional \$1 million in new research this year. This included the launch of the Adult Hydrocephalus Clinical Research Network (AHCRN), a network of six hospitals and institutes that will focus research on adult forms of hydrocephalus and address the diverse needs of our community across the age spectrum.

Committed to our roots, support and education continue to be important focal points in the work of HA—they are how my family found the organization 10 years ago. HA added webinars to our extensive support publications and products. Our first webinar entitled, "What if It Isn't Alzheimer's or Parkinson's?" was conducted by Dr. Michael Williams and received great reviews. In addition, HA provided over 1,750 hours in direct patient support and continues to leverage a vibrant presence on social media to engage the community.

I hope you feel proud of what you helped to build and all that HA has accomplished. Without your support, HA would not have been able to achieve many of the successes shared in this report. We look forward to your continued involvement as we seek to fulfill our mission of eliminating the challenges of hydrocephalus.

Sincerely,



**Barrett O'Connor**  
Chairwoman, Board of Directors  
Hydrocephalus Association



## 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 to for resources and peer-to-peer support. In 2013, we published several new educational materials, provided 1,750 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.

### Webinar Series

We launched a new webinar series designed to deliver vital information to our community. These interactive, free sessions feature presentations from medical professionals, researchers, and other experts working in the field of hydrocephalus.

We hosted our first webinar, "What if it isn't Alzheimer's or Parkinson's?" presented by Dr. Michael Williams, director of The Sandra and Malcolm Berman Brain & Spine Institute, Sinai Hospital of Baltimore, during Hydrocephalus Awareness month in September. This webinar was targeted to individuals who have been diagnosed with Normal Pressure Hydrocephalus, caregivers of older adults, medical professionals, nursing home staff and those who have been treated for Parkinson's, Alzheimer's or dementia.

### Local and Online Community Networks

There are 1 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 ensuring that we meet the demands of our community. In 2013, we restructured our support groups to serve as broader-based Community Networks. The 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 thrive.

HA's Community Network consists of 39 networks, which have held 80 events hosting nearly 1,500 individuals. In addition, we have 25 active virtual networks with online Facebook Groups consisting of more than 1,200 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 as well as throughout the world. We are grateful to our many volunteers who are involved in raising local awareness and facilitating community gatherings.



## Awards and Scholarships

### Resident's Prize

The Hydrocephalus Association Resident's Prize was awarded to Jennifer Strahle, MD, for her paper, "Early Treatment of Neonatal Intraventricular Hemorrhage-Associated Hydrocephalus with Systemic Deferoxamine," which was presented at the 2013 Pediatric Section meeting of the American Association of Neurological Surgeons (AANS)/Congress of Neurological Surgeons (CNS) in Toronto, Canada.

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 the treatment and care of individuals with hydrocephalus.

### Scholarships

Since the Hydrocephalus Association's scholarship program was established in 1994, we have awarded 103 scholarships to deserving future leaders of our community. This year, we were able to offer nine 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. The 2013 recipients are Anna Elise Jones, Juliette Ohan, Ana L. Ubierna, Melissa Bruebach, Jordan Rogers, Timothy Beighley, Emma Jane Maurer, Abigail Fazelat and Lindsay Kerr. 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, Justin Scot Alston Memorial Scholarship Fund, Mario J. Tocco Hydrocephalus Foundation Scholarship Fund and Giavanna Marie Melomo Memorial Scholarship Fund.

For the second year, we also awarded five additional scholarships through our Teens Take Charge (TTC) Program to Amanda Korcal, Emily Reed, Ruby Poole, Danielle Denise Kulowitch and Samantha Richardson. TTC's scholarship awards were made possible through the continued support of the Medtronic Foundation and all the individuals who held events and contributed to the program.

### Looking Back...1986

Our **first educational booklet**, *About Hydrocephalus — A Book for Parents*, is published. This is our first publication in a line of numerous publications that have become mainstays for individuals and families.



### 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 holding classroom discussions on hydrocephalus, 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 youths living with this condition.

## Research Update

This year marked the end of phase one of our Reason for Hope research funding campaign, which started in 2009 to fund the Hydrocephalus Association's (HA) Research Initiative.

We are proud to report that as a community we surpassed our \$3 million funding goal, raising a total of \$3,065,046 for hydrocephalus research. Over the past five years, HA has funded a total of \$2.7 million in both basic and clinical hydrocephalus research. These research projects are focused on understanding the causes of hydrocephalus and developing better treatments in order to, ultimately, find a cure.

In 2013, we partnered with the Rudi Schulte Research Institute (RSRI) to fund a new research venture. RSRI chose Mark Wagshul, PhD, for his proposal, "MR Elastography: A noninvasive tool for the management of shunted pediatric hydrocephalus." Dr. Wagshul will utilize this noninvasive MRI-based technique to see if brain compliance can help determine the best treatment option for pediatric hydrocephalic patients.



Dr. Wagshul is an Associate Professor in the department of radiology at Albert Einstein College of Medicine. He received a BA in physics from Rutgers University and a PhD in physics from Harvard University. He completed a postdoctoral fellowship at the National Institute for Standards and Technology.

HA awarded a second grant to Timothy Vogel, MD, of Cincinnati Children's Hospital. Dr. Vogel's proposal, "The role of neural progenitor cells in neonatal hydrocephalus," focuses on cilia, hair-like structures on the surface of neuron progenitor cells (NPCs) in the brain that contribute to CSF movement. He will be exploring how defects in cilia motility contribute to the development of neonatal hydrocephalus.



Dr. Vogel is a pediatric neurosurgeon and Assistant Professor of pediatric neurosurgery and developmental biology at Cincinnati Children's Hospital Medical Center. He holds a BA in chemistry from Princeton University and a MD from Columbia University College of Physicians and Surgeons.

### Looking Back...2009

#### Mentored Young Investigator

(MYI) program is started, with 5 awards made to new researchers interested in hydrocephalus. The MYI program intends to stimulate innovative research such that scientists go on to apply to various programs at the NIH for further grant funding.

## Hope in Progress

### SONIA PODVIN, PhD

#### HOPE: Develop Pharmacological Agent to Treat Hydrocephalus

Sonia Podvin, PhD, is a post-doctoral fellow at the University of California, San Diego. Dr. Podvin was a recipient of one of HA's Mentored Young Investigator (MYI) Awards. Her MYI grant funded her research as a molecular pharmacologist aiming to develop safe, specific drugs to treat hydrocephalus. Her study investigates an anti-inflammatory hormone called augurin that circulates in CSF. Augurin may be able to control brain hydrodynamics and ultimately may be pharmacologically manipulated to treat hydrocephalus non-invasively.

### JOHN KESTLE, MD, FRCSC, FACS

#### HOPE: Reduce Shunt Infections

John Kestle, MD, FRCSC, FACS, is a Professor and Vice Chair of Clinical Research in the Department of Neurosurgery at the University of Utah, Salt Lake City, Utah. His clinical practice specializes exclusively in pediatric neurosurgery, with a specific interest in pediatric epilepsy surgery. Dr. Kestle has developed a clinical protocol for treating hydrocephalus that has helped reduce post-operative infection rates for shunt surgery by more than 35%. He co-founded and chairs the Hydrocephalus Clinical Research Network, which is supported with funds from the Hydrocephalus Association.

### MARK HAMILTON, MD, FRCSC

#### HOPE: Improve Treatment and Diagnostic Methods for NPH

Mark Hamilton, MD is a neurosurgeon and director of the Adult Hydrocephalus Program at the University of Calgary. Dr. Hamilton is currently the chair of the Adult Hydrocephalus Clinical Research Network (AHCRN). AHCRN is focused on addressing the needs of both transitional patients and adults that acquire hydrocephalus and is being funded by HA. AHCRN will conduct multisite research while developing an electronic image database and cerebrospinal fluid (CSF) biobank. These research efforts are focused on finding better treatments for hydrocephalus and identifying new diagnostic methods for normal pressure hydrocephalus (NPH).



## HA Publishing: Hydrocephalus Funding Landscape

HA is committed to advancing hydrocephalus-focused research but little is known about past hydrocephalus funding.

To understand the past funding environment, to create benchmarks to measure against future progress and to quantitatively bolster the case for increased hydrocephalus funding, HA analyzed the amount of funding allotted for hydrocephalus research by the National Institutes of Health (NIH).

The resulting paper, "Hydrocephalus research funding from the National Institutes of Health: a 10-year perspective," was published online in the *Journal of Neurosurgery Pediatrics* in December 2013. The study analyzed public funding for hydrocephalus research during the 10-year period between 2002 and 2011. It concluded that hydrocephalus needs more researchers conducting high impact, innovative research and alternative funding is very important given the challenging public funding environment.

## Adult Hydrocephalus Clinical Research Network (AHCRN)

The success of the HCRN provided the catalyst for establishing an Adult Hydrocephalus Clinical Research Network (AHCRN).

In 2012, HA began working with distinguished adult hydrocephalus researchers including, neurosurgeons, neurologists, and neuropsychologists to establish an adult research network. The goals of the network are to improve the lives of adults with hydrocephalus, raise awareness of the condition and tackle the unique issues transitional patients, adult congenital patients and other adult-onset patients face. Six sites were selected and progress was made throughout 2013 developing essential data elements and protocols for the network. The six participating researchers and sites in the network include:

- Mark Hamilton, MD, University of Calgary
- Heather Katzen, PhD, University of Miami
- Petra Klinge, MD, Brown University
- Mark Luciano, MD, PhD, Cleveland Clinic
- Norman Relkin, MD, PhD, Weill Cornell Medical College
- Michael Williams, MD, Sandra and Malcolm Berman Brain & Spine Institute, Sinai Hospital of Baltimore

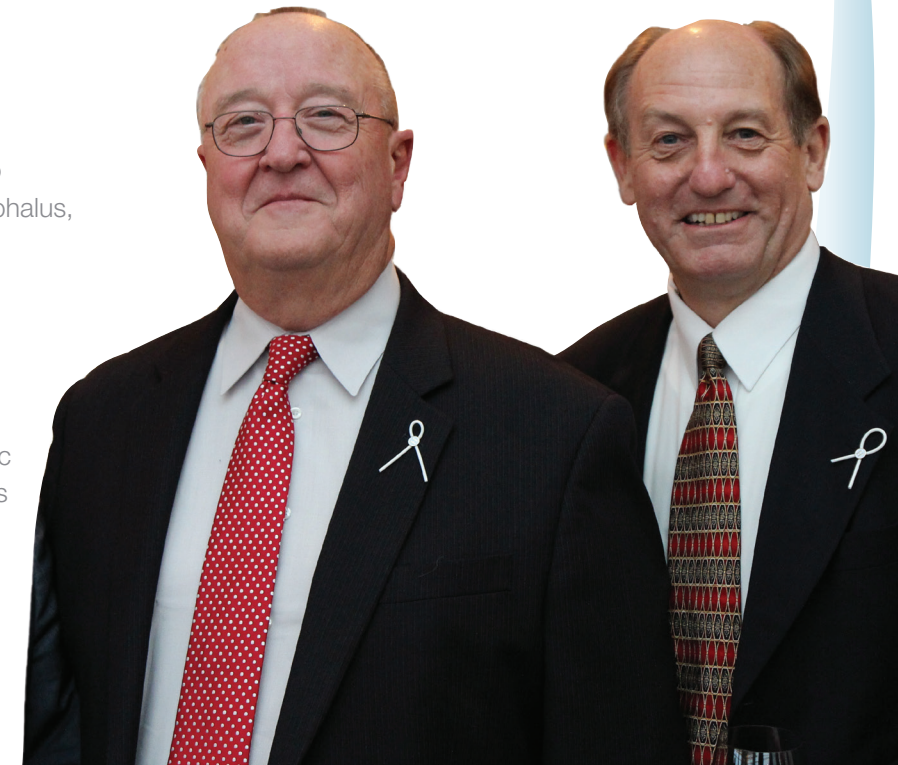
Dr. John Kestle, co-founder of the HCRN, also joined this group effort to study adult hydrocephalus, bringing his rich history in hydrocephalus research to benefit the collaboration.

The development of the adult network is essential for HA's mission to improve the lives of all people with hydrocephalus. The adult network will increase in importance as pediatric patients transition to adulthood and awareness of adult-onset hydrocephalus increases.

## Hydrocephalus Clinical Research Network (HCRN)

The HCRN expanded its network from seven to nine centers with the additions of Vanderbilt University and the University of British Columbia.

Initially, the two centers focused on adding patients to the HCRN registry and participating in the HCRN Quality Improvement Study for post-surgical infections. They are now completely incorporated into the HCRN. Dr. Wellons is heading the center at Vanderbilt and continues to be the lead Principal Investigator on the study of post-hemorrhagic hydrocephalus, which is nearing the completion of its accrual of patients. Dr. Doug Cochrane is heading the center at the University of British Columbia. In addition to expanding to nine centers, the HCRN has been busy publishing three papers in 2013.



## Annual Report: WALK/Special Events

The Hydrocephalus Association's (HA) WALKs and Special Events had another record-breaking year, raising close to \$1.3 million towards our mission.

With 32 local events across the country and more than 15,000 participants, our volunteer-coordinated WALKs grew by ten percent, raising over \$1.1 million. Special events, primarily "third party events," raised more than \$168,000 – a 13 percent increase over last year. This was only possible due to the hard work and hundreds of hours of time expended by our wonderful volunteer network – WALK Chairs, Special Events leaders and participants, sponsors and donors. THANK YOU!

The inaugural Los Angeles WALK raised more than \$130,000 – the largest first year event in HA history. Chicago's WALK ranked as the second largest WALK in the country, posting a 33 percent increase from the prior year by raising more than \$90,000. The Seattle WALK continued its success, finishing in third place with \$85,000.

The Hydrocephalus Association's special events also demonstrated great results. Team Hydro, participating in Sharkfest for the sixth year, raised \$53,000 for hydrocephalus research. Other events included a holiday concert organized by (and starring) Lyn Leach from Lucas, Kentucky, raising \$4,000. The 17th annual "Thanks for Running 5K" in Fitchburg, Massachusetts, (held Thanksgiving Day morning) raised more than \$6,700. "MX for Children," an annual motocross event, had another great year by raising more than \$43,000. One of our newer events, "Trick or Treat for Hydrocephalus," showed incredible growth by raising more than \$30,000 from a small group of schools. The Hydrocephalus Association was the charity of choice for Atlanta's Manheim Company, which held a golf tournament that raised over \$30,000.

*\* 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.*

### Looking Back...1994

**TEAM I Hydrocephalus** walks the Bay Bridge and raises \$5,000, launching our TEAM Hydrocephalus program, later to be renamed our Hydrocephalus WALK program.



### Top WALKs for 2013

- 1. LOS ANGELES HYDROCEPHALUS ASSOCIATION WALK**  
\$129,230 – 770 participants  
*Co-Chairs: Tania Heise, Amber Milliken, Cortney Pelletieri, Jennifer Pope and Dan Solchanyk*
- 2. CHICAGO HYDROCEPHALUS ASSOCIATION WALK**  
\$90,900 – 754 participants  
*Co-Chairs: Stacy Buckner, Katie Cook, Zahadita Kudrna and Andrea O'Shea*
- 3. SEATTLE HYDROCEPHALUS ASSOCIATION & CHILDREN'S HOSPITAL WALK**  
\$89,428 – 528 participants  
*Co-Chairs: Dawn Adix and Jenifer Petersen*
- 4. LONG ISLAND HYDROCEPHALUS ASSOCIATION WALK**  
\$81,004 – 735 participants  
*Co-Chairs: Jackie Davidson and Mia Padron*
- 5. NATIONAL CAPITAL 5K RUN/WALK FOR HYDROCEPHALUS (WASHINGTON, DC)**  
\$70,005 – 579 participants  
*Chair: Amanda Garzon*

# HYDROCEPHALUS ASSOCIATION AT 30

## A History Rooted in Community

In 1983, a small group of parents of children with hydrocephalus living in the San Francisco Bay area came together seeking community and support. They were all patients of Dr. Michael Edwards at the University of California, San Francisco Medical Center. Dr. Edwards and Lori Howell, his neurosurgical nurse, graciously hosted a few small, informal gatherings after Emily and Russell Fudge expressed their feelings of isolation and frustration when their son, Gerard, had his second shunt revision. This was a time very different from today. In the early 80s there was no widespread public acknowledgement that the majority of shunts would need to be revised multiple times during a lifetime. There were no programmable or adjustable valves. There were no MRIs. There were no such people as Board certified pediatric neurosurgeons and no Patient's Bill of Rights. This was a time before the internet, leaving parents, patients, and loved ones to seek out the scant information available in libraries and from their doctors. And there was nowhere to turn for support and guidance.

In 1984, Emily and Russell decided to host a more formal meeting, asking Dr. Edwards to speak about hydrocephalus and inviting a large number of his patients. At that meeting, they proposed the idea to create an organization. With a \$1,000 grant from UCSF and Dr. Edwards, the Hydrocephalus Foundation of Northern California was formed, later to be renamed the Hydrocephalus Association. The association was initially organized out of the basement of the Fudge home by a dedicated core group of individuals that included Emily and Russell Fudge, Jennifer Henerlau, Pip Marks, and Cynthia Solomon.

This year we commemorate the 30 year anniversary of the Hydrocephalus Association. We honor the resolve of this dedicated group of parents who recognized the need for an independent, patient-focused organization to support individuals affected by hydrocephalus and to provide their families and friends, who were desperate for information, with life-changing educational materials and group interactions. Thirty years ago this determined group could never have imagined that the Hydrocephalus Association would become the nation's largest and most widely respected provider of information, support services, advocacy initiatives and private research funding for hydrocephalus.

It is this rich history rooted in our community that drives our core values and mission today.



# FIRST ANNUAL VISION DINNER

## A Time for Awareness. The Hope for a Cure.

The Hydrocephalus Association's first annual Vision Dinner, "A Time for Awareness; The Hope for a Cure," was held on October 11, 2013, at the Apella Alexandria Center in New York City. Generously hosted by Vicki and Craig Brown, major benefactors of the Hydrocephalus Association (HA), the evening united patients, neurosurgeons, scientists, advocates and business leaders to raise the public profile of hydrocephalus and to share the need for greater research funding to cure the condition.

The evening debuted HA's Reason for Hope video that profiled the unique stories of members in our community. Attendees also had the opportunity to hear from two parents leading the way to further HA's research initiative and learn about the hope in progress, currently funded by the association. Renowned pediatric neurosurgeon and 2012 MacArthur Foundation Fellow, Dr. Benjamin Warf, was the keynote speaker, sharing his revolutionary new surgical procedure to treat hydrocephalus in the infant population.

The evening also honored three individuals for their tireless dedication to eliminate the challenges of hydrocephalus through their affiliation with the Hydrocephalus Association. Paul Gross, Co-Founder, Hydrocephalus Clinical Research Network, received the Inspiration Award; Marion Walker, MD, Professor, Neurosurgery, Primary Children's Medical Center, received the Service Award; and Emily and Russell Fudge, Co-Founders, Hydrocephalus Association, received the Leadership Award. United States Senator Charles E. Schumer and New York State Senator John J. Flanagan provided congratulatory letters praising the dedication of the awardees and the progress of the Hydrocephalus Association.



## Advocacy in Action

### Your Voice in Washington

HA's national advocacy efforts started in May 2006, when we first organized the 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, minutes away from the National Institutes of Health and Capitol Hill. As part of our advocacy efforts, we have trained thousands of members and arranged visits with elected officials to inform them about the impact this condition has on families across the nation.

### Advocacy Steering Committee

To help develop and drive the association's advocacy strategy, a community-led Advocacy Steering Committee was established in 2013. 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; 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. 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.

### Congressional Directed Medical Research

HA advocated for the inclusion of hydrocephalus on the list of conditions eligible for funding under the Department of Defense's Congressionally Directed Medical Research Programs (CDMRP). Great strides were made to educate the House and Senate spending and authorizing committees that allocate money for federal health care research. HA reached out to health and defense appropriators and authorizers to help increase funding for hydrocephalus research at NIH and to create a new funding stream for hydrocephalus research through the Department of Defense's Peer Reviewed Medical Research Program (PRMRP). We were successful in gaining support on the Senate appropriations side for the hydrocephalus-specific language that Representative Andrews included in the National Defense Authorization Act. Unfortunately, due to partisan battles within Congress over other issues, the language included in a bill passed by the House of Representatives was not included in the final DOD Appropriations bill passed by a conference committee of both the House and Senate.

### 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, HA board member 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.

### Looking Back...2006

We hold our **FIRST National Advocacy Day** in Washington, D.C. More than 120 individuals personally touched by hydrocephalus meet with 48 Senators and 51 Congressional Representatives.





## In the News

### *AARP Informs Members About Normal Pressure Hydrocephalus*

Dr. Michael Turner, neurosurgeon, talks about Normal Pressure Hydrocephalus on AARP Radio.

### *HCRN Included in US News & World Report 2013 Children's Hospital Rankings*

US News & World Report acknowledges the importance of HCRN's role in the hospitals ranked in the 2013 Best Children's Hospitals, which includes stronger treatment protocols and research around the causes and treatment of hydrocephalus.

### *Famous Rock Star Treated for NPH*

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.

### *The Saturday Evening Post Spotlights Normal Pressure Hydrocephalus*

The Saturday Evening Post spotlights Normal Pressure Hydrocephalus (NPH), an often misdiagnosed condition that affects approximately 375,000 individuals in the U.S.

### *NPH Featured on Boston National Public Radio Show*

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).

### *Leadership Award for Two Founding Members of the Hydrocephalus Association*

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.

### *Cynthia Solomon Receives Spirit of Excellence Award*

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.

### *South Florida Radio Program Delves into Hydrocephalus*

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.

### *The Right Questions to Ask When Caring for a Parent with Hydrocephalus*

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.

### *Olivia Maccoux Dubbed 'Iron Athlete' By High School Teammates*

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.

## 2013 Audited Financial Statement

### Statement of Financial Position

At December 31, 2013

#### ASSETS

<i>Current Assets:</i>	
Cash and cash equivalents	\$1,952,896
Other receivable	392
Grants receivable, current portion	232,500
Prepaid expenses	50,769
Inventory	9,151
<b>Total Current Assets</b>	<b>\$2,245,708</b>
Investments	303,498
Property and equipment, net	39,528
Grants receivable, less current portion, net	171,217
Deposits	11,108
<b>TOTAL ASSETS</b>	<b>\$2,771,059</b>

#### LIABILITIES AND NET ASSETS

<i>Current Liabilities:</i>	
Accounts payable and accrued expenses	\$238,649
Capital lease payable, current	2,713
<b>Total Current Liabilities</b>	<b>241,362</b>
<i>Long term Liabilities:</i>	
Accrued rent expense	25,762
Capital lease payable, non-current	7,716
<b>TOTAL LIABILITIES</b>	<b>\$274,840</b>

#### NET ASSETS

Unrestricted net assets	1,840,303
Temporarily restricted net assets	574,798
Permanently restricted net assets	81,118
<b>Total Net Assets</b>	<b>2,469,219</b>
<b>TOTAL NET ASSETS &amp; LIABILITIES</b>	<b>\$2,771,059</b>

### Statement of Activities

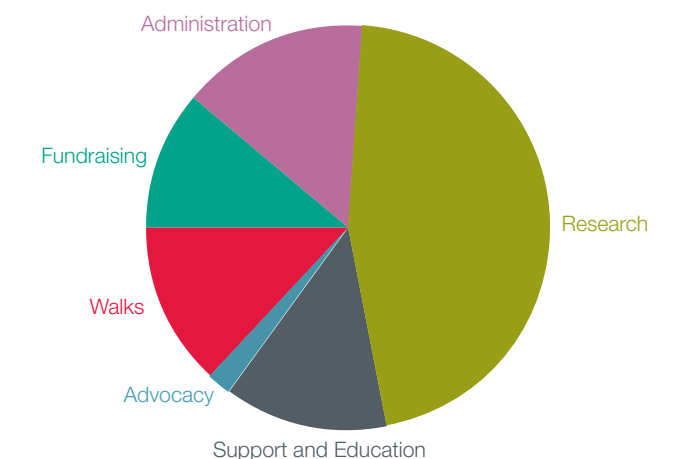
For the year ended December 31, 2013

#### SUPPORT AND REVENUE

Restricted grants and donations	\$1,400,688
Unrestricted contributions	1,004,492
Fundraising	1,032,234
(net of expenses of \$157,772)	
Sale of books, publications and other items	5,605
Interest and dividends	5,502
Net investment gain (loss)	(7,675)
Other income	15,353
<b>TOTAL SUPPORT &amp; REVENUE</b>	<b>\$3,456,304</b>

#### EXPENSES

Research	\$1,120,776
Public support and education	282,200
Advocacy	41,721
Conferences	24,541
<b>Total Program Expenses</b>	<b>1,469,238</b>
Walks	315,737
Fund Development	277,016
Administration	355,546
<b>Total Fundraising &amp; Administration</b>	<b>948,299</b>
<b>TOTAL EXPENSES</b>	<b>\$2,417,537</b>
Change in net assets	1,038,767
Net assets at beginning of period	1,457,452
<b>Net assets at End of period</b>	<b>\$2,496,219</b>



## Looking Back...2003

The **Visionaries** documentary series season 10 spotlights HA on PBS stations across the country.

# 2013 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  
Craig and Vicki Brown Estate of Frank Clinton Nancy and Hugh Devlin Paul Gross and Lori Poliski

## \$50,000 - \$99,999

Clare Rose Foundation Jan Churchill and Randy Kell Medtronic Foundation Medtronic Neurosurgery

## \$25,000 - \$49,999

Alpern Family Foundation, Inc. John and Liz Devlin Cliff and Amy Goldman Richard H. Goldman Memorial Foundation Rudi Schulte Research Institute

## \$10,000 - \$24,999

Adobe Foundation Aesculap Ahn Family Foundation Anonymous Howard Solomon and Sarah Billinghurst Bostock Family Foundation Aseem and Amita Chandra Herman E. and Estelle Goodman Foundation Hydrocephalus Foundation, Inc. William Janetschek Kings Care Foundation Ray and June Moser Paul Raether Barrett O'Connor and Paul V. Rogers Brad and Nikki Silver Jay and Carrie Weaver

## \$5,000 - \$9,999

Active Network, Inc. Anderson and Chamberlain Families Depuy Synthes Donnelly, Lipinski and Harris

Gansett Foundation Gold Coast Beverage Distributors, Inc. Henry and Lucy Moses Fund, Inc. Stephen and Winifred Keane Larry and Patti Kenyon Krajecki Family Alfred Moses Michael Riordan James Schuler Seattle Children's Research Institute SOPHYSA, USA, Inc. Beth and Tom Volpe Todd and Stacy Wolter

## \$2,500 - \$4,999

Adobe Systems Inc. Matt Barton Angela and Christopher Batterman Brock's Gap Intermediate School John R. and Dorothy D. Caples Andrew Carothers Michelle and Glenn Engelmann Norris and Mary Finlayson Susan Fiorella FMC Ice Sports Jolene Grau Vera and Paul Guerin Lyn Leach and Stephanie Oltean Madison Dearborn Partners Majestic Realty Co. Koen and Raea McLeod Memorial Hermann - Mischer Neuroscience Institute Motorcycle Superstore Pam Murphy Opalack Foundation Kevin O'Shea Diana Peterson Portland Firefighter Association Tracy Taback Annie Vongkham Scott Voulgaris Bernie and Nancy Wendler Garland and Suzanne Wood

## \$1,000 - 2,499

AbsolutData Active Network, Inc. AEG Bruce Allbright Joanne Anderson Automatic Data Processing, Inc Bank of America United Way Campaign Frank Baron Tracey Barone Alex Becker Rebecca and Bill Benson Best Buy John Besuegli John Bragczewski Bristol-Myers Squibb Giving Program David and Lisa Browdy Richard Bruening Linda Burk BYB Brands, Inc. Joel and Joy Campbell Sean Carney Joseph Carothers Jef Carter Robert and Josephine Caruso Robert and Rosemary Caruso Celgene Cellular Therapeutics Chattanooga GYN-Oncology Children's Hospital at Vanderbilt Coca-Cola Bottling Co. Consolidated David Cole Randi Corey Corey Steel Company Steve Crabtree Milan Damjanovic Tonja and Paul Darling Dave's Last Resort and Raw Bar Davis and Gilbert LLP Mark Denzler Glenn Desimone Gary East EMS Enterprise Products Operating LLC

Enterprise Products Partners L.P. Express Rail, LLC Eye Surgical and Medical Associates, Inc Lauren Famularo Kathy and Roger Farmer Frederick Felman Donald and Joanne Ferrara Pam and Grant Finlayson Florida Panthers Foundation Russell and Emily Fudge Genesis Automation, Inc. Steven and Ruth Glazer Global Six Goddard School (TME Preschool) Adam Goldberg Goodrich Foundation Anshu Goyal and Shilpi Chandra Dave Graves Joyce and Daniel Gregonis Edith Gross Guardian Energy, LLC Scott and Sheryl Haberman Hawkins Commercial Appliance Service Paul Heilman Carolyn Hill HLI Construction Richard Hopple Robert Hughes Mary Hutchcraft Image Outfitters Integra LifeScience JALS Foundation JDA Software Kristin Kehrberg John and Tina Keker Kenyonia Corp Kern Electric Distributors Kleper Donor Advised Fund Heather Kluter Kohl's Associates in Action Kohl's Cares Matching Gift Program John Lawrence and Deborah Phillips Ross Levin Davida and Matt Loewenstein Los Angeles Lakers Olivia and Molly Mandelblatt Mayesh Wholesale Flowers Richard McClain J. Gordon McComb, MD Mel Hamblen Ford, Inc. Microsoft Matching Gifts Program Dale Miesner National Basketball Association Neurosurgeons for

Children, P.A. Nibbi Brothers Construction Christine and Daniel O'Connor Octopus Car Wash Ilana and Emeka Okafor Onpoint Union Alan Ostendorp Pediatric Dentistry of Cleveland and Ooltewah, PLLC Pelco by Schneider Jim Perry Pfizer Foundation Matching Gift Program Jenny Piccola Picket Construction Company, Inc. Plateau Mary Louise Quinlan R and R Millwork, Inc. R.L. Valley, Inc. Recromax, LLC Norm Richards Marisa and Alfonso Rocciola Andrew Rosenbaum Roxbury PBA Lewis Rubin Isak and Maria Rusinek Schneider Electric Steven Schneider, MD Mike and Tara Schwab Alex and Dawn Seaman Arthur Selkowitz Siskin Hospital for Physical Rehabilitation St. Louis Children's Hospital Jenna Stanley Steve Stratton Francis and Vicki Sweeney Tom Sweeney TDK The Redstone Group Pam and Keith Thomas TIRR Memorial Hermann Joseph Tomasulo Van Nest Recreation Center Vanderbilt Neurosciences Department Veted Solutions Karen Wake Rogers and Julie Weed Mike Westberg Susan Whitefield Noah Whittington Michael Williams, MD Pauline Wilsbach Dwayne Wilson Elizabeth and James Wilson Dakota Yaskow

## \$500 - \$999

Abay Neuroscience Center Abbott Middle School Ancient Art Stone Elvira Andrade Andrews Consulting Lorraine and Sid Applebaum Arapahoe Park Pediatrics Art Stone Employees Betsy Bacot-Aigner Lissa Baird, MD Steve Baker Randall Baskin Robert and Susan Baxter Anna Beck Paul Behrman Peter Bjork Chris Bleau Robert Blomgren Robert Bone Boonslick Medical Group Steve Borow Dawn and Oliver Bowen BP Foundation, Inc. Bravo Mexico Inc. Michael Brenner Samuel Browd Nicole Brown Harrison Burnham Michael Bury Michael and Sarah Byars Debra Caldwell James Caltagirone Michael Campbell Canning Foundation Julie Cano Tim Carlberg and Clay Scarzella Teena Carmichael Carolina Neurosurgery and Spine Associates Sandy Cecil Cedars-Sinai Medical Center June Chapin Charleston Invitational Cup Chemsil Silicones, Inc. Jeff Chen W. Cheng Chee and Christine Chew Children's Hospital of Alabama Chris Hays and David Slater Kyle and Paige Clifford Clifton Larson Allen Tammy and Kelly Clinch Community Health Charities Stephen Constantinou Betsy Conyard Katie Cook Renee Cook

Margaret Cooper Corwin Family Coydog Foundation Coyote Insight, LLC Blake Crousore James and Pamela Crouthamel Crown Imports Ty Curry David Daniel Dark Millennia Tattoo Studios Darlington Family Carlton Deaton Richard and Marilyn Dickstein DigiCert Inc. Pat Donnelly Sue Duda Todd Dunn Ann Edlen Elevation Reps of the Rockies Inc. Richard Ellenbogen, MD Jonathan Ellichman Jill Elrod Shannon Ehloe Janice Ethington Stefanie Fair Krystal Fay Samuel Finlayson Mary and Paul Finnegan Judy and Kenneth Fischer Michael and Kristin Fiser Mary Fleming Food Services, Inc. James Garrity Gavin Garzee GFDS Engineers Anthony Giardina Holly Gilmer-Hill, MD Global Impact Maud Carol Goldfield Alyssa Greene Doug Grissom Dana Guerin Lisa Guerin Mike, Rachelle and Lilah Guerin Rummy and Nitin Gupta Gregory Gursky H. Pearce Real Estate Stephen Haines, MD Thomas and Linda Hale Michael Handler, MD Deborah Harrison April Hart Devin Harwell Jessica Hatch Hearth Designs Hecker Wakefield and Fielberg Jonathan and Sarah Hodges

## Looking Back...2010

The **Fudge Solomon Legacy Society** is established to encourage and recognize all those leaving a legacy gift to HA.

Sharon Hollon  
Margaret Hung  
Penny Isaacson  
Ruby James  
Monty January  
Cameron Javdani  
Jewish Federation of Cleveland  
Jewish Federation of Metropolitan Chicago  
Legacies and Endowments  
Dylan Johnson  
Richard Johnson  
Laurine Jones  
JP Morgan Charitable Giving Program  
John Julius  
Ronald and Susan Kaplan  
Jeanne Kennedy  
Ron Keys  
Roger and Eileen Kimber  
King Street Capital Management, LP  
Shane Kisner  
Ralph and Dale Kistler  
Jennifer Klopp  
Travus Knotts  
Lana Krombein  
R. Harry Krombein  
Kodette LaBarbera  
Le, Arnold and Associates, LLC  
Brenda Lee  
Amy Lee  
Susan Lemieux  
Jody Leonardo, MD  
Eric Levin  
Rachel Lewis  
Lindmour Foundation Fund  
Betty Logoluso  
Loyal Order of Moose - Point Pleasant Lodge #1549  
David Lundsgaard  
Mark and Lisa Lundy  
Mary Ann Madura  
Dawn Mancuso

Anne and Tony Marci  
Market System Payroll  
Melvin Marmer  
Jason Martinage  
Philip R. Mascia  
Jennifer Matheis  
Pamela Mathews  
Jason McClure  
Patti McCullum  
Laura and Brent McIntosh  
Scott McLanahan, MD  
MedImmune LLC (Matching Gift)  
Menasha Corporation  
Samuel Menco  
Method 360  
Mike Collins and Associates  
Anna Minarik  
Marisol Miranda  
Mark Mittler  
Michael Moland  
Kimiko Nakatake  
Aimee Nall  
Tracy Naragon  
Northrop Grumman Corporation  
Cody O'Brien  
Jeff Ojemann  
Clare O'Neil  
Oppenheimer Funds  
Oracle Corporation  
Kinley Parker  
Pediatric Care Nightly  
Pediatric Neurosurgical Associates  
Johnson Peil  
George Pellettieri  
Joseph Piatt, MD  
Pilgrim Urological Associates  
Pittsburgh Foundation  
Plastic Products, Inc.  
Port City Air, Inc.  
Portland French Bakery  
Dale and Karen Powell  
Power and Communications

Professional Video Technology  
Progressive Waste Solutions of Florida, Inc.  
Pulaski Road School  
Teddy Purcell  
Madison and Carter Quick  
Ray Rasmussen  
Harold Rekate, MD  
Sophia Ribeiro  
RILCO Manufacturing Co., Inc.  
Michele and Larry Rivkin  
Michael and Kristin Rogers  
Phyllis Rogers  
Robin Rogers  
Sally Rogers  
Edward Rosenbaum  
Rhonda Salveski  
Bonnie Savage  
Linda Schimberg  
Liz Schumacher  
J. Michael Schwab  
Schwab Charitable Foundation  
Robin and Jill Selati  
Nathan Selden, MD  
Sensors and Integrated Systems  
Neil Shifrin  
Lance Shores  
Brad Silverberg  
Stanley Skarli  
Michael Slattery  
Rick and Amal Smith  
Kelly Smith  
Ryan and Stacey Smyth  
Souleles Family Charitable Fund  
Leonard Spoto  
Spring Creek Pediatrics  
St. Anthony of The Woodlands Knights of Columbus  
St. Joseph Parish Oakley, Inc.  
State of Maryland  
Calvin Stewart  
Sonja Stewart  
Maddie Mae Stone

Kevin Sullivan  
Chad Sullivan  
Gary Swerling  
Mary Susan Talarico  
John and Regina Tegeler  
Tenet Florida Physician Services  
The Egg and I Restaurant  
Dennis Thies  
Donald and Jeanne Thompson  
Todd Companies  
Torrey Company, Inc.  
TRUISt  
Noel Tulipan, MD  
Uniform Advantage  
United Health Group  
United Way  
Deborah and Jay Van Der Sanden  
James and Lorelee Vassar  
Karen Vesely  
Vetted Solutions  
William and Amy Vincent  
W. West Equipment  
Sally Walker  
Marion Walker, MD  
Nancy Wall  
Jason Wallace  
Simon Walling  
Jay Wellons, MD  
Wells Fargo Community Support  
West Islip Country Fair Committee  
Danae Whitaker  
Whitinsville Christian School  
Debbie Wicks  
Williams Company  
Michael Wilson  
F. Wise  
Jeffrey Wise  
Ken and Erika Witover  
Ben and Rachel Zeidman

## In Honor

Connor Aaronson  
Tony Alvarado  
Nicholas G. Banks  
Joseph Batterman  
Lilly Beck  
Lynn Beirl  
Sally Bell  
Desiree Bellman  
Katherine Benson  
Bert Berkowitz  
Tommy Bolz  
Andrew Bonazinga  
Dawn Bowen  
Elena and James Bowles  
Riley Braun  
Justin Braunscheidel  
Lexi Brown  
Wells Brown  
Vicki and Craig Brown  
Lucy Bryant  
Allison Caffey  
Christopher Candy  
Kate Cascio  
Emma Caulder  
Myles Chamberlain  
Aaron Chapple  
Juliana Chavez  
Reece Christian  
Gianfranco Ciampi  
Jonah Cook  
Rosemarie Corsi  
Henry Cozzolino  
Victoria Crawford  
Patricia Cunniff  
Lara Dahlstet  
Avery Dalbey  
Miss Brooke Daniel  
Ellie Davis  
Timothy Delahousse  
James DelGiudice  
Samuel Denney  
Tenleigh Dietz  
Elizabeth DiPietro  
Jerry Dorn  
Harold Douville  
Adam Dunn  
Burt Eaton  
Stanley Ellis  
Rachel Engelman  
Mairin Fallon  
Sam Fine  
Jessica Fiser  
Kevin Flynn

Dina Frank  
Emily Fudge  
JR Garcia  
Gabriela Garzon  
Robert Gaylord-Ross  
Nora Geasler  
Kyle Gospodarek  
The Gross Family  
William Gross  
Max Hanson  
Siena Hardy  
Titus Haymore  
Brianna Hicks  
Gail Highberg  
Sarah and Jonathan Hodges  
Wade Huwar  
Hydrocephalus Patients  
Carter Hyland  
Carolyn Hyman  
Matthew Jameson  
Jordyn Jannicelli  
Ben Kaplan  
Glenn Karahadian  
Sofia Karch  
Brinkley Kasper  
Jocelyn Keat  
Sarah Kell  
Katie Kelsch  
John Kerkhoff  
Griffin Kidd  
Asher King  
Hilda Klein  
Gavin Lambdin  
Emma Lane  
Matthew and Tracey Larson  
Johnathan Larson  
Elijah Lawrence  
Delaney Lee  
Brooke Leffler  
Matthew Legates  
Max Lehnert  
Audrey Lintott  
Christopher Logan  
Veronica Lopez  
Svend Lundsgaard  
Jaxson Lyon  
Isabella Mallozzi  
Philip Manning  
Natalie Marcellus  
Vincent Maresco  
Sam Marks  
Linda Marshall

Henry Marshall Schmit  
Patrick Martinage  
Thomas Martinez  
Tyler Matlock  
Emma Maurer  
Amanda McCallister  
Molly McEnroe  
Scott and Betsy McGriff  
John McNulty  
Jack Messick  
Evan Miles  
The Miles-Denney Family  
Jameson Miller  
Grant Miller  
Robert Mosby  
Anne T. Murphy  
Paxton Naragon  
Avery Nicole Wright  
Sara Nieves  
Adora Norris  
Dylan Nowacki  
Barrett O'Connor  
Nicole Ohr  
Kenton Osborne  
Jesiah Lee Page  
Madison Pardi  
Katie Penasko  
Tom Penman  
Molly Perdek  
Rebekah Perkins  
Deborah Phillips  
Sarah Plank  
Charlie Pope  
Kylie Rager  
Hailey Rankin  
Hope Ridgle  
Brady Rivkin  
Joey Rivkin's Bar Mitzvah  
Lara Christy Roberts  
Conley Robinson  
Lily Robyn  
Alexis Rocciola  
Emily Rogers  
Amy Romanoski  
Isaiah Romo  
Amber D. Rowen  
Alex Russell

Eliana Russo  
James Savage  
Ross Savo  
Joe Schwab  
Samantha Shales  
Isabella Shane  
Levi Shull  
Griffin Snyder  
Felipe Souza  
Pamela Stanton  
Konnor Stellhorn  
Loretta Strohm  
Nolan Stuart  
Marissa Sullivan  
Matt Tegeler  
Michael Tozzi  
McCallister Tronsdal  
Nicole Tscouleas  
Susan and Stephen Tscouleas  
Hero Tsukushi  
Team Tyler  
Erin J. Uyeda  
Gracie Vargas  
Marion Walker  
Alec Warner  
Elaine K. Weiner  
Sarah Ann Whitbeck  
Paige Whitefield  
Julia Wiener  
Laura Ann Wiersteiner  
Fiona Wilcox  
Haley Williams  
Shelley Williams  
Karen Wilson  
Ryan Winchell  
Abby Wood  
Anton Young

## Fudge Solomon Legacy Society

Anonymous	Amita & Aseem Chandra Family Trust	Shannon O'Connor
Shirley B. Adams	Edith B. Gross, PhD	Barrett O'Connor & Paul Rogers
Jan H Adams, PhD, DNP	Lori Poliski & Paul Gross	Christine & Daniel O'Connor
Sally Baldus	Pip Marks	Michele & Larry Rivkin
David & Lisa Browdy	J. Pat McAllister III, Ph.D	Cynthia Solomon
Buffa Family Trust	June & Raymond Moser	Marion L. Walker, MD

For more information about how to leave a legacy, please call 1-888-598-3789 ext. 17 or e-mail [giftplanning@hydroassoc.org](mailto:giftplanning@hydroassoc.org)



## In Memory

Jacob Woodward-Adams	Frank Heery	Lee Sager
Betty Beardsley	Conley David Heidenreich	Alex Salchow
Yvette B. Bialko	Sean Helsil	Stephen Sciantarelli
Nicholas Brinkley	Harold C. Karsten	Maureen Smiley Gross
Chin Chang	Mary Louise Larr Duffy	Laurene Sowby
Leslie Colburn	Ellie Mackiewicz	Norman Andrew Stephenson
Peter Coppola	Miriam McCollom Prouty	Eugene E. Stevens, III
Gerald C. Dorn	Joan Mileski	Mrs. Elvera Marie Sticker
Burt Eaton	Mildred Natale	Jeffrey Stunkard
Jack Gallanis	Caleb Nelson	Jeanne Thompson
Kate Finlayson	Brian Newcomer	Michael Tozzi
Gerard Fudge	Sam Perkins	Gertrude Wallis
Marvin Israel Goldman	Miriam Prouty	John Walters
Jean Alice Gorisek	William and Judy Rogers	Clesson H. Washburn
David H. Swanson	Ashley Ruth	Haley Williams

## The Legacy of Frank L. Clinton

Frank Clinton was a pillar in the community of Paris, Illinois. He served as the town mayor for 16 years, and there was not a person or family in the area that he didn't know. Mr. Clinton was introduced to HA shortly after being diagnosed with Normal Pressure Hydrocephalus (NPH). He received treatment and blossomed after the surgery with no complication. In appreciation for HA's services during this difficult time and eagerness to see the organization's mission fulfilled, Mr. Clinton placed HA in his will. He continued to engage with the association for many years. On April 1, 2013, Mr. Clinton died from other health challenges. HA received notification that he selected the organization to be the sole beneficiary of his estate. His confidence in HA's direction and loyalty to see our work advance is evident in his final gift that will ensure his legacy continues.



## Hydrocephalus Association

### Officers of the Board

Barrett O'Connor, *Chair*  
 Craig Brown,  
*Senior Vice Chair*  
 David Browdy,  
*Vice Chair*  
 Aseem Chandra,  
*Vice Chair*  
 Rick Smith,  
*Treasurer*  
 Paul Gross,  
*Secretary and Past Chair*

### Directors

Debby Buffa  
 Laurel E. (Lolli) Fleming  
 Cliff Goldman  
 John Kestle, MD, FRCSC, FACS  
 Ralph A. Kistler  
 John Lawrence  
 Raymond R. Moser, Jr.  
 Shannon O'Connor  
 Mike Schwab  
 Marion L. Walker, MD

### Medical Advisory Board

Rick Abbott, MD  
 Marvin Bergsneider, MD  
 James M. Drake, MD  
 Michael Egnor, MD  
 Richard G. Ellenbogen, MD  
 Ann Marie Flannery, MD  
 Bruce A. Kaufman, MD  
 John R. Kestle, MD, FRCSC, FACS  
 Mark Luciano, MD, PhD  
 Joseph R. Madsen, MD  
 J. P. (Pat) McAllister II, PhD  
 J. Gordon McComb, MD  
 C. Scott McLanahan, MD  
 Joseph H. Piatt, Jr., MD  
 Marion L. Walker, MD  
 Michael A. Williams, MD  
 Jeffrey H. Wissoff, MD

### EMERITUS:

Michael Edwards, MD

### Staff

Dawn M. Mancuso, MAM, CAE, FASAE,  
*Chief Executive Officer*  
 Jennifer Bechard,  
*Support and Education Manager*  
 Randi Corey,  
*Director of Special Events*  
 Amanda Garzón, MIA,  
*Communications and Marketing Manager*  
 Aisha Heath, CFRE, MPA  
*Director of Development*  
 Marisol Ortiz,  
*Donor Relations and Database Manager*  
 Karima Roumila, MPH,  
*Director of Support and Education*  
 Michael Ticzon,  
*Special Events Coordinator*  
 Amy Weist,  
*Business Manager*  
 Ashly Westrick, MPH,  
*Research Programs Manager*



4340 East West Highway, Suite 905  
Bethesda, MD 20814-4447  
Toll-free: (888) 598-3789  
E-mail: [Info@HydroAssoc.org](mailto:Info@HydroAssoc.org)  
[www.hydroassoc.org](http://www.hydroassoc.org)