A Time for Awareness The Hope of a Cure

Hydrocephalus Association

2015 ANNUAL REPORT

A LETTER FROM OUR CHAIRMAN & CEO

Dear Friends,

Thank you for your support of the Hydrocephalus Association (HA) in 2015. Through the generosity of donors like you, we achieved new heights, positioning the organization one step closer to fulfilling its vision of a world without hydrocephalus. HA continues to make significant strides in advancing the mission to promote a cure for hydrocephalus and to improve the lives of our diverse patient base. The organization remains 100% funded by the generosity of individuals, corporations and foundations, and it is only through this continued support that we have been able to achieve the progress we have made to date.

In 2015, we finalized the organization's five-year strategic plan, developing a roadmap to dramatically increase awareness of the condition and invest in a bolder research strategy. This strategy necessitated an unprecedented growth of the Hydrocephalus Association by 2020 to fund our objectives. The Hydrocephalus Association Board took the opportunity to recruit a new leader who has substantial experience in fundraising and in the implementation of transformational growth plans for national health organizations. Diana Gray stepped into the role of Chief Executive Officer for the Hydrocephalus Association to lead this critical effort and is now supported by a staff of 17 full-time employees. Ms. Gray has worked as a nonprofit executive for 28 years and is passionate about HA's mission.

We are also very excited about our recent endeavor to launch the Hydrocephalus Association Network for Discovery Science, HANDS, featured on page 7, which will help accelerate cure-based research through a virtual lab. We continue to heavily invest in the research pipeline of our two clinical networks that seek to improve the treatment outcomes and quality of life for adults and children with hydrocephalus. To date, HA has supported 18 investigators, committing and leveraging more than $4.5 million in resources since the start of the research initiative in 2009. In 2016, we will launch a $3,000,000 three-year campaign to raise crucial funds to direct the association's extensive research capabilities to find a cure for PHH.

Community support and education remain a top priority for the organization. This includes, providing over 2,400 hours of one-to-one support, conducting live educational webinars led by experts in the community on topics ranging from understanding the Health Insurance Exchange to updates on the Adult Hydrocephalus Clinical Research Network, and advocacy training for youth. Hundreds of families have participated in the webinars, and this has been a rich addition to the educational resources provided by HA. In addition, HA created a new mobile application, HydroAssist™, that allows patients to record and store their hydrocephalus treatment history and access it when needed from their mobile device. The app has received very positive reviews and has over 1,300 users.

You will find many more examples of our progress outlined in this report. We are confident that through the Hydrocephalus Association's continued persistence, the power of our collective voice, and your continued support, we will continue to pave the way to medical breakthroughs that will dramatically improve lives. Thank you for your continued commitment.

Sincerely,

Aseem Chandra
Chairman, Board of Directors, Hydrocephalus Association

SUPPORT AND EDUCATION

The Hydrocephalus Association is deeply committed to providing innovative programs and comprehensive resources to meet the diverse needs of our community.

In 2015, over 7,000 patients and caregivers benefited from the services provided by the Hydrocephalus Association. The organization continues to serve as the go-to source for the latest and most accurate information about research, medical technologies and protocols, and educational resources. Whether someone is newly diagnosed, living with the condition for many years, or a loved one, HA's resources empower patients and caregivers to make informed decisions about their care, provide answers, and address a range of concerns that are specific to the needs of our diverse community.

In an effort to support and reach more patients and caregivers impacted by hydrocephalus , HA believes it is imperative to increase and enhance its collaboration with healthcare professionals and hospitals. To accomplish this, HA developed new, free publications and conducted hospital and patient outreach at community and professional events. As a result, HA connected with over 550 new medical professionals in 2015. We also made significant strides in leveraging these new relationships to host Hydrocephalus Education Days at local hospitals.

The Hydrocephalus Association's free webinar series delivered seven informative, wide-ranging sessions on topics including the affordable care act, advocacy and the latest treatment methods and pursuits to cure hydrocephalus. These interactive sessions were viewed by over 1,000 people and featured presentations from renowned experts working in the field of hydrocephalus.

In addition, to enhance the online resources readily available to patients and caregivers, HA has continued its video series, *Through a Mother's Eyes: A Journey with Hydrocephalus*. Viewed by nearly 3,000 individuals, the series answered questions and offered valuable tips, tools, and knowledge shared from personal experiences.

The Hydrocephalus Association's new mobile app, HydroAssist™, is the first mobile app that allows patients and caregivers to immediately access their entire hydrocephalus treatment history through a mobile device. Collaboratively developed by a neurologist, pediatric neurosurgeon, medical app developer and a representative from the Hydrocephalus Association, HydroAssist is being utilized by over 1,000 people to track treatment methods, operations, and shunt setting adjustments overtime.

HA's Community Networks continued to strengthen and expand across the United States, enabling individuals and families to connect and thrive through educational events, support group meetings, advocacy activities and other gatherings. In 2015, HA's 46 Community Networks increased patient engagement by hosting 74 events throughout the country with over 1,000 individuals in attendance. In addition, our 23 active virtual networks using Facebook groups connected over 2,500 members through online discussions and interactions. 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.

Expanding our ability to reach more individuals and families impacted by hydrocephalus is critical to ensure we meet the demands of the entire community. To build the capacity of our volunteer Community Network leaders, in 2015, HA held a two-day training. Attendees received guidance from HA staff, medical professionals and other experts in the field regarding peer support, practical aspects of hosting local events, advocacy, and hydrocephalus research.

We are grateful to our many volunteers who are involved in raising local awareness and facilitating community gatherings, and to the Theodore Batterman Foundation for providing a grant to build the capacity of the network.

AWARDS AND SCHOLARSHIPS

RESIDENT'S PRIZE

Each year the Hydrocephalus Association presents the Resident's Prize to the most promising hydrocephalus-related research paper presented by a neurosurgical resident at the Pediatric Section Meeting of the American Association of Neurological Surgeons/Congress of Neurological Surgeons. This prize is designed to encourage young doctors to focus their research efforts on advancing the treatment and care of individuals with hydrocephalus. This year, Brian William Hanak, MD, a resident at University of Washington School of Medicine, was awarded for his paper, entitled "The Cellular Basis for Cerebrospinal Fluid Shunt Obstruction: Construction of an Explanted Hydrocephalus Device Bank."

SCHOLARSHIPS

Since the Hydrocephalus Association's (HA) scholarship program was established in 1994, HA has awarded 135 scholarships to deserving future leaders of the hydrocephalus community.

In 2015, HA offered 14 educational scholarships to young adults living with hydrocephalus who exhibit 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 inspire their peers. These awards were made possible through the support of the Clare Rose Foundation and the following endowed scholarship funds: Gerard Schwartz Fudge Memorial Scholarship Fund, Morris L. and Rebecca Ziskind Memorial Scholarship Fund, Anthony Abbene Scholarship Fund, the Justin Scot Alston Memorial Scholarship Fund, the Mario J. Tocco Hydrocephalus Foundation Scholarship Fund and the Hydrocephalus Association Scholarship which is provided by Erik and Lisa Chamberlain.

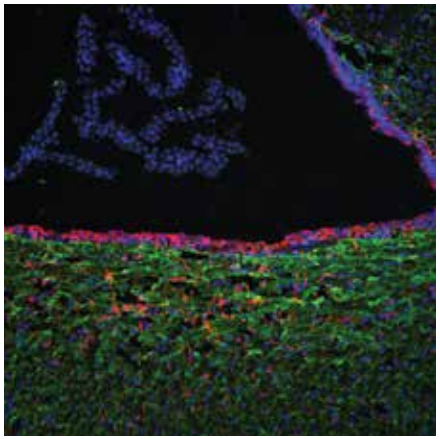
TEENS TAKE CHARGE

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 high school and college assemblies and in HA webinars, to taking part in local health fairs, and representing the program at our WALK events. In addition, TTC's advisory council and members publish articles and share their personal stories of inspiration on our website and various social media platforms to encourage youth living with this condition.

RESEARCH UPDATE

ACCELERATING CURE-FOCUSED RESEARCH

The Hydrocephalus Association (HA) remains dedicated to supporting high quality, high-impact research through continued support of the HA Network for Discovery Science (HANDS), Hydrocephalus Clinical Research Network (HCRN), and Adult HCRN (AHCRN). HANDS provides the connections, technology, and tools needed to spur and support innovative basic and translational research. The pediatric focused HCRN and adult focused AHCRN provide the structure and expertise necessary to efficiently and thoroughly test these new technologies and clinical therapies (with or implementing) the highest clinical standards. By linking basic, translational, and clinical researchers, HA has created a pipeline to move research from the bench to the bedside.



HA NETWORK FOR DISCOVERY SCIENCE (HANDS)

Work on the HA Network for Discovery Science (HANDS) began in 2015. Developed out of discussions during HA and National Institutes of Health (NIH) sponsored workshops, HANDS is a platform for both communication and collaboration among hydrocephalus basic, translational, and clinical researchers with a focus on mentorship, innovation, and shared infrastructure to support high-quality, high-impact research. HANDS membership already extends to 18 countries and is (noticeably or positively) impacting the collaborative efforts in hydrocephalus research.

The HANDS cerebrospinal fluid (CSF) repository was created at Washington University School of Medicine in St. Louis, Missouri. This repository operates within the Washington University Tissue Procurement Center, which also hosts the Central Specimen Bank for the American College of Surgeons Oncology Group, the Neurologic AIDS Research Consortium, the Hydrocephalus Clinical Research Network, and other major multi-institutional studies and contains over 400,000 biospecimens. By building shared infrastructure, such as the CSF repository, forward-thinking researchers will be able to test their hypotheses at an accelerated pace and bring new therapies, preventions, and cures to the hydrocephalus community.

On-going efforts will be focused on expanding the network, developing additional shared infrastructure, and supporting new collaborative efforts and research studies. In 2016, HANDS will focus on spurring research efforts in posthemorrhagic hydrocephalus, the most prevalent form of pediatric hydrocephalus in the United States.

2015 INNOVATOR AWARDS

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

June Goto, PhD
Research Instructor
Cincinnati Children's Hospital Medical Center
Goal: Gain Insights into Fetal Onset Hydrocephalus

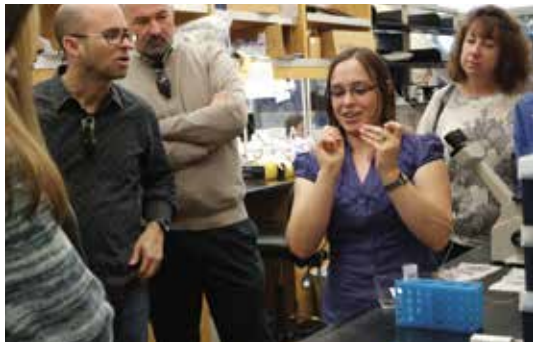
Lance Lee, PhD
Faculty Member
Sanford Research
Goal: Identify Risk Modifiers in the Development of Hydrocephalus

Andreas Linninger, PhD
Professor of Chemical Engineering
University of Illinois at Chicago
Goal: Restore Cerebrospinal Fluid Transport
Funded by Team Hydro

James P. (Pat) McAllister, PhD
Professor of Neurosurgery
Washington University School of Medicine
Goal: Improve Outcomes in Post-Hemorrhagic Hydrocephalus
Funded by Team Hydro

Michael Piper, PhD
Australian Research Council Future Fellow
University of Queensland
Goal: Understand Brain Development and Hydrocephalus
Funded by Team Hydro

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



HYDROCEPHALUS CLINICAL RESEARCH NETWORK (HCRN)

In late October, the Hydrocephalus Clinical Research Network (HCRN) principal investigators and clinical research coordinators met in Deer Valley, Utah, to discuss study progress in the network.

Significant milestones were reached in a number of studies. The Quality Improvement (QI) shunt surgery protocol, aimed at reducing rates of surgery complications such as shunt infection, was discussed and plans were made to evaluate modifications for the third iteration of the protocol. A related study focused on implementation of the QI protocol in non-HCRN hospitals. The survey revealed significant practice variation among neurosurgeons, but a unanimous interest in an HCRN-driven implementation study. Mandeep Tamber, MD, with the Hydrocephalus Association's Research Department and Support and Education Department, is developing such an initiative.

The study, "Ventricular Involvement in Neuropsychological Outcomes for Hydrocephalus (VINOH)," funded by the Hydrocephalus Association, has completed patient accrual. Analysis of the VINOH study will begin after neuropsychological testing follow-ups are completed. In addition, the pilot study, "Endoscopic Third Ventriculostomy with Choroid Plexus Coagulation (ETV/CPC)," has been completed and results are currently being evaluated to determine if a randomized control trial is warranted.

Other active study topics included accrual for the Patient Centered Outcomes Research Institute (PCORI) funded Shunt Entry Site Trial and preliminary findings from the Biomarkers in Post Hemorrhagic Hydrocephalus study. HA's own, Jenna Koschnitzky, PhD, Director of Research Programs, presented updates on Hydrocephalus Association initiatives, including the Department of Defense Congressionally Directed Medical Research Programs and a PCORI-funded workshop. Mark Hamilton, MDCM, FRCSC, Chair of the Adult Hydrocephalus Clinical Research Network (AHCRN), presented an update on network progress and next steps.

ADULT HYDROCEPHALUS CLINICAL RESEARCH NETWORK (AHCRN)

In November 2015, the Adult Hydrocephalus Clinical Research Network (AHCRN) met in Salt Lake City, Utah, to discuss the progress and next steps for the network. Since the beginning of the Core Data Project in late 2014, the AHCRN has enrolled nearly 200 patients.

The Core Data Project collects patient demographics, hydrocephalus etiology, diagnostic information, and surgical and medical management information. This initial data will be used to understand the variability, progression, and current treatment practices for hydrocephalus in adults and inform the development of hypothesis-driven research.

This year, the AHCRN expanded to two additional centers, University of Washington in Seattle and Johns Hopkins Hospital in Baltimore. By building a larger network, the AHCRN will be able to conduct high-quality, high impact research more quickly, leading to improvement in the lives of those living with the condition. The AHCRN is chaired by Mark Hamilton, MD, PhD, Director of the Adult Hydrocephalus Program at the University of Calgary. He is joined by an exceptionally dedicated group of neurosurgeons, neurologists, and a neuropsychologist.

HA PUBLISHING

In 2012, the Hydrocephalus Association and the National Institutes of Health (NIH) sponsored a symposium on hydrocephalus research, "Opportunities for Hydrocephalus Research: Pathways to Better Outcomes." The primary goal of this conference was to collectively identify hydrocephalus research priorities that held early promise for improving patient care. Recognized experts provided educated guidance on areas of research that hold the most promise for early "winnable" achievements in improving patient care. The gathered experts also identified long-term goals that may lead to advanced treatment options or potential cures for hydrocephalus.

In late 2015, the priorities and recommendations identified during this conference were published in the Journal of Neurosurgery. The paper, "An Update on Research Priorities in Hydrocephalus: Overview of the Third National Institutes of Health-Sponsored Symposium 'Opportunities for Hydrocephalus Research: Pathways to Better Outcomes'," outlines hydrocephalus research priorities that have the potential to impact patient care in the next five years. The priorities are divided into four themes: (1) Causes of Hydrocephalus, (2) Diagnosis of Hydrocephalus, (3) Treatment of Hydrocephalus, and (4) Outcomes in Hydrocephalus.

The research priorities related to the Causes of Hydrocephalus theme include obtaining a greater understanding of how the condition develops in conjunction with developing better research models. Normal Pressure Hydrocephalus (NPH) was the main focus for the second theme Diagnosis of Hydrocephalus. Priorities included implementation of standardized protocols, development of shared repositories, and implementation of prospective studies related to biomarker identification and new imaging techniques. Priorities under the third theme, Treatment of Hydrocephalus, focused on improving shunt technology and preventing shunt obstruction through advances in bioengineering as well as clinical testing of alternative interventions such as endoscopic third ventriculostomies with choroid plexus cauterization (ETV/CPC). Finally, priorities for Outcomes in Hydrocephalus pinpointed the need for outcome measures specific to the hydrocephalus community, the need for better long term neuropsychological and neurocognitive studies, and better understanding of the prevalence and incidence of hydrocephalus across our diverse population.

The paper was written by the Hydrocephalus Symposium Expert Panel led by James 'Pat' McAllister, PhD and Samuel Browd, MD, PhD. Dr. McAllister is a Professor of Neurosurgery at Washington University in St. Louis. Dr. McAllister is a member of the HA Medical Advisory Board and this year received a HANDS Innovator Award for his research, Therapeutic Modulation of Posthemorrhagic Hydrocephalus. Dr. Browd is a neurosurgeon and Director of the Hydrocephalus Program at Seattle Children's Hospital. Dr. Browd is also a principal investigator for the Hydrocephalus Clinical Research Network (HCRN).

ANNUAL REPORT: WALK/SPECIAL EVENTS

HA WALKS AND SPECIAL EVENTS

It was another record-breaking year for HA WALKS and Special Events, raising almost $1.6 million -- approximately half of the Association's total annual revenue. As in the past, HA WALKS continue to be volunteer initiated and volunteer coordinated. Over 100 volunteer leaders from across the country are the foundation of these fundraising initiatives. Most have full time jobs outside the home, families, multiple priorities and a passion to make a difference. As one volunteer leader said "I may not be able to put on a lab coat and conduct research to make life better for my child but I can help raise the money to buy the best science available. My job is to raise the money, to fund the research, to improve the lives of everyone with hydrocephalus." The Hydrocephalus Association salutes these intrepid volunteers for their dedication and the countless hours they devote to raising the resources needed for HA to fulfill its mission.

HA WALKS

Thirty-five WALKS were held across the U.S. with more than 12,000 participants and over 1,000 event day volunteers. HA proudly added the Seattle WALK, chaired by Betsy Conyard and Lori Poliski, to the list of HA WALKS raising over $100,000. We also welcomed a new WALK site in Baltimore, co-chaired by David Brucker and Jaclyn Gover. Thank you to all of the volunteer leaders, participants, donors and sponsors who made the 2015 WALK program such an outstanding success.

KIDS TO CURE HYDROCEPHALUS

HA's school WALK program continued quite successfully in Chattanooga, Tennessee, with the Silverdale Baptist Academy and Preschool posting an outstanding total of $10,700 raised for HA and its mission. Congratulations to event Chair, Chara McLaughen, and the students of Silverdale Baptist Academy for their great work.

2015 Hydrocephalus Association WALKS TOP FIVE!

Walk Site	Walk Chair/ Co-Chairs	# Registered Participants	Total Raised
Los Angeles	Tania Heise, Cortney Pellettieri, Jennifer Pope, Dan Solchanyk	700	$184,800
Chicago	Stacy Buckner, Katie Cook, Zahadita Kudrna, Andrea O'Shea	650	$118,250
Seattle	Betsy Conyard, Lori Poliski	475	$110,200
Long Island	Jackie Davidson, Mia Padron	575	$102,000
South Florida	Eileen Rodger, Angelica Haymore, Lisa Piazzese	518	$83,750

If there is no HA WALK in your community and you would like to explore the idea of starting and leading one, please contact the WALK/Special Events department at walk@hydroassoc.org. HA staff is eager to help you!

Hydrocephalus raises awareness on The Today Show

Our New York City advocates arrived early to Rockefeller Center in New York City on the morning of September 16th to secure their spot on The Today Show plaza. Serving as the backdrop for the weather report, our volunteers wore special t-shirts and held signs with clear messaging, which was visible to a television audience of 4.756 million viewers.

HA SPECIAL EVENTS

HA is very grateful to have been the beneficiary of several special event fundraisers held throughout the year.

Returning for its 8th year was **Team Hydro**—a team of swimmers who competes in the San Francisco and Boston Sharkfest® events. The 2015 Team Hydro (with the support of the Little Falls Swim Club in Potomac, Maryland) raised $57,000 for hydrocephalus research. Team Hydro is chaired by Pam, Peter and Sam Finlayson, in memory of their daughter and sister, Kate, who passed away due to complications of hydrocephalus in 2010. Special thanks to the entire Finlayson family for another great result.

HA was honored to once again be the recipient of the Thanks for Giving 5K, held in Fitchburg, MA on Thanksgiving Day morning. **Thanks for Giving 5K** is now in its 18th consecutive year. Special thanks to event Chair, Amy Maynard, for making this possible.

Trick or Treat for HA encourages children to collect donations to support HA and its mission during their Halloween rounds. The program had another amazing year, raising over $25,000. Trick or Treat for HA was initially developed by Orange County, California, volunteer, Heather Kluter. Now in its third year, Heather continues to lead this annual event, serving as nationwide volunteer Chair.

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

IN THE NEWS

In 2015, the Hydrocephalus Association expanded awareness of the many forms of hydrocephalus and strengthened HA's authority about hydrocephalus to the general public through a successful public relations and digital media strategy. Stories and infographics about hydrocephalus appeared in 31 national and regional press outlets, garnering over 24 million impressions. In addition, our WALK program was featured on eight television stations and in six local newspapers.

U.S. News & World Report, February 5, 2015, *"Is It Really Dementia? Maybe Not."*

The Washington Post, March 2, 2015, *"Her Mother Seemed to Have Classic Dementia. Or Did She?"*

ABC Television, March 19, 2015, *Grey's Anatomy,* Season 11, Episode 16, *"Don't Dream It's Over"*

NBC-affiliate WNYT-TV, June 29, 2015, *"Living with Hydrocephalus."*

Time Warner Cable, July 28, 2015, Health Matters, *"Adam Page, USA Gold Medalist, and the Greater New York Hydrocephalus WALK"*

Albany Times Union, September 23, 2015, *HEALTHYLIFE, "Hydrocephalus & A Local Woman Has 5 Brain Surgeries."*

The Greenville News, October 10, 2014, *"Drive Owner Sets Sights on Cure for Hydrocephalus."*

THIRD ANNUAL VISION DINNER

VISION DINNER 2015
A TIME FOR AWARENESS. THE HOPE OF A CURE

The Hydrocephalus Association's Third Annual Vision Dinner was held on October 15, 2015, in New York City, at the JW Marriott Essex House. The annual dinner is a six-year campaign launched in October 2013 to raise national awareness about hydrocephalus and, ultimately, find a cure for the condition. The campaign brings together existing and prospective members of the hydrocephalus community – patients and their families, clinicians, researchers, scientists, philanthropists, business leaders and advocates – to share information, spotlight progress and chart a course for the future.

The focus of this year's Vision Dinner was the Hydrocephalus Association Network for Discovery Science (HANDS). HANDS is a dynamic virtual laboratory that connects scientists and clinicians with each other and with state-of-the-art resources and data from top institutions. HANDS is how modern science works best, facilitating collaboration among world class scientists and resources to rapidly tackle new ideas and execute innovative research. The goal for this year's dinner was to raise $500,000 to support the launch of HANDS. We are proud to announce that we exceeded this goal. We are thankful to our Partners in Research and donors who made this possible.

Jerold Chun, MD, PhD, professor at Scripps Research Institute, served as the keynote speaker. He shared the current research being pursued to end hydrocephalus in babies that develop the condition as a result from a brain bleed. Dr. Chun reinforced the importance and limitless possibilities now achievable through HANDS. The evening also featured the meritorious grants awarded to seven HANDS researchers (listed on page 7) who are dedicated to finding a cure and improving the lives of people who suffer from hydrocephalus. Grant awardees had the opportunity to display their research at the Vision Dinner and engage directly with attendees.

Three individuals were honored for their tireless dedication to the elimination of the challenges of hydrocephalus through their affiliation with the Hydrocephalus Association. Kathryn "Kate" Finlayson posthumously received the Inspiration Award. Her mother, Pam Finlayson, accepted the award in her honor and shared her daughter's moving journey and passion for pursuing hydrocephalus research. James "Pat" McAllister, II, PhD, Professor, Department of Neurosurgery, Division of Pediatric Neurosurgery at Washington University and the Saint Louis Children's Hospital, received the Service Award, and Story Landis, PhD, former director of the National Institute of Neurological Disorders and Stroke (NINDS) of the National Institutes of Health (NIH), received the Leadership Award.

The Hydrocephalus Association would like to thank Craig and Vicki Brown for their continued leadership and generosity in hosting this extraordinary evening to raise the profile of hydrocephalus and the important work of the Hydrocephalus Association for our entire community. For more information on how you can support our new HANDS initiative please e-mail hope@hydroassoc.org.

VISION DINNER PARTNERS IN RESEARCH

FOUNDING PARTNER

Team Hydro/Kate Finlayson Fund For Hydrocephalus Research

The Grant and Pam Finlayson family, our Founding Partner in Research, have generously donated substantial funds through Team Hydro in support of four meritorious seed grant proposals that are part of the launch of the HANDS initiative. Team Hydro inspires thousands to get in the water and swim in support of hydrocephalus awareness and research. The Finlayson Family's support is in loving memory of their daughter, Kate, who lost her life to hydrocephalus in 2010.

BENEFACTOR | $25,000 AND ABOVE

Roy and Merilee Bostock
Craig and Vicki Brown
Richard H. Goldman Foundation
Paul H. Gross and Lori Poliski
Jennifer and Jonathan Soros Foundation

PATRON | $15,000 AND ABOVE

Davis and Gilbert, LLC
Merrill Lynch
Morgan Stanley

ADVOCACY IN ACTION

The Hydrocephalus Association Advocacy Steering Committee has continued to monitor and support key legislation that will benefit the hydrocephalus community. Hydrocephalus was once again included on the list of eligible conditions to receive funding under the Congressionally Directed Medical Research Programs (CDMRP) administered by the Department of Defense (DoD). The CDMRP has appropriations of over $247 million which are used to fund the best scientific and medical research aimed at preventing, controlling, and curing disease. We are proud of this continued accomplishment. In addition, two individuals from the hydrocephalus community were chosen to serve as consumer reviewers of research grants, representing the patient and caregiver perspective on the impact of the research on issues such as disease prevention, screening, diagnosis, treatment, and quality of life after treatment.

HA continues to be 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 increases in funding for the NIH, the creation of a National Neurological Disease Surveillance System under the 21st Century Cures Act/Senate Innovation Initiative, telehealth services for our Veterans, and chronic care and reimbursement mechanisms for home based care and expanded telehealth care. In addition, we have launched a grassroots campaign to find co-sponsors for the Advancing Research for Hydrocephalus Act (H.R.2313) introduced by Congressman Chris Smith (R-NJ). This would establish a national hydrocephalus registry that would help us better understand the condition within our population and help to inform decisions around research, which is essential to finding treatment options—and, one day, a cure.

RAISING OUR VOICES ON CAPITOL HILL

On Sept. 17, 2015, the Hydrocephalus Association partnered with more than 300 institutions and advocacy organizations representing researchers, clinicians, patients, and other advocacy groups to participate in the third-annual Rally for Medical Research Hill Day. HA was proud to serve as a Gold-Level sponsor and a member of the Communications Planning Committee for this event.

Members of the Hydrocephalus Action Network (HAN) from Florida, Illinois, Maryland, Virginia, and Washington, D.C, joined hundreds of advocates from across the country on Capitol Hill to meet with more than 200 House and Senate Offices. With Congress debating how to fund the government into fiscal year (FY) 2016 and setting budgetary priorities for the coming year, this was a critical time for advocates to stress the importance of increasing our nation's investment in medical research. This was also an opportunity for our advocates to raise awareness about the challenges of living with hydrocephalus and the importance of research into alternative treatment options and, ultimately, a cure for our patient community.

GRASSROOTS ADVOCATES TURN THE COUNTRY HYDROCEPHALUS BLUE

Hydrocephalus Awareness Month united our grassroots advocates around the country to work with their state and city governments to recognize September as Hydrocephalus Awareness Month (HAM) and to have key landmarks illuminated blue. Thanks to the work of our dedicated HA volunteers, seven new states joined the United States Congress in proclaiming September as Hydrocephalus Awareness Month. They were Connecticut, New York, Virginia, Tennessee, South Carolina, Illinois and Colorado. They joined the states of Indiana, Pennsylvania, West Virginia and Washington, which already held proclamations. In addition, Chicago Mayor Rahm Emanuel and Chattanooga Mayor Andy Berke proclaimed September 9th as Hydrocephalus Awareness Day in their respective cities and the City Government of Grand Island, New York, proclaimed September 19th as Hydrocephalus Awareness Day.

There were also a number of landmarks around the country illuminated a stunning hydrocephalus blue to commemorate HAM. The City of Wichita, Kansas, lit the pillars on their downtown area for the entire month. In St. Louis, Missouri, the James S. McDonnell Planetarium and Science Center shone like a blue beacon in the evenings. In Chattanooga, Tennessee, the Liberty Building turned blue. Most notably, Niagara Falls and the Peace Bridge, the largest major crossing into Canada in the North East, were illuminated blue.

For those not able to travel to see these amazing sites, over 2000 people participated in our Turn the Country Hydrocephalus Blue challenge online. HA challenged everyone across the country to help spread awareness about hydrocephalus and educate the public on key facts about the condition by printing out informational signs, taking photos, and posting them to Facebook, Twitter or Instagram. Our posts were seen over 400,000 times and received close to 38,000 likes. The state with the most posts was Tennessee, followed closely by Minnesota, North Carolina, Arizona, and West Virginia.

LEGACY PROFILE—DEBBY BUFFA

My husband, Bill, and I have three children. Our two oldest daughters have hydrocephalus. Sarah was diagnosed at age four and Stephanie was diagnosed at six months of age. Our son, Brent, does not have this condition. My daughters were diagnosed in 1981 and 1984; Sarah has had 32 shunt surgeries and Stephanie has had three. All three children live in St. Louis. Sarah is 36, Brent is 31 and Stephanie is 35.

I first connected with HA in the early 80's, pre-smart phones and internet, as we searched to find out more information regarding hydrocephalus. I contacted a shunt company, Cordis Corporation, and spoke to Marvin Sussman, PhD. I happened to mention that I was beginning a support group in St. Louis, so he connected me to Emily Fudge who, along with Cynthia Solomon, was organizing a support group in the San Francisco area. This would be my start to a long and deep connection to HA. I joined Emily and Cynthia's group in the early founding years, and in 2005 became a member of the Board of Directors. After ten years of service, I retired from the Board. I traveled to San Francisco for their first conference in l987 and have only missed two since that time. My daughters have become very involved with the Association and Stephanie is co-chair of the annual St. Louis WALK.

We put the Hydrocephalus Association in our family trust before there was a formal Legacy Society. For us, it was simple. We appreciated the care and compassion they gave us during Sarah's many operations and how they shared information to assist the support group I was running in St. Louis. On a larger scale, however, the Association has evolved from not only education and support but active research. Thirty-five years ago, I prayed for a cure for hydrocephalus. Today, the treatment for a child with hydrocephalus is still basically unchanged from treatment in the l950's: a shunt, with all the associated problems of infection and malfunction. A child still has to go into the hospital and have surgery. Complications can change a child's life forever, and by extension, their family's. Third ventriculostomy and other procedures are helping better children's outcomes, however, these procedures are still not a cure. It is for these reasons, among others, that our family put HA in our trust and will continue supporting this tremendous organization. Someday, with the dedication and hard work of all the scientists and physicians and groups like HA, a cure will be found. My mother's heart is still praying hard for this day to come!

My family is devoted to this organization. HA has the respect of the medical community and is truly helping families. With the increase in research on hydrocephalus and the collaboration among medical professionals, we are sure the future will be bright for those living with this condition.

Please, join our Legacy Society today and help this vision come true!

2015 AUDITED FINANCIAL STATEMENT

STATEMENT OF FINANCIAL POSITION
THROUGH DECEMBER 31, 2015

ASSETS

CURRENT ASSETS:	
Cash and cash equivalents	$2,286,295
Investments	223,257
Pledges receivable, current portion	111,583
Grants receivable	200,000
Other receivables	48,758
Prepaid expenses	36,599
Inventory	5,307
Total current assets	**$2,911,799**
INVESTMENTS	$81,118
PROPERTY AND EQUIPMENT, NET	16,372
DEPOSITS	8,544
Total Assets	**$3,017,833**

LIABILITES AND NET ASSETS

CURRENT LIABILITIES:	
Accounts payable and accrued expenses	$50,384
Capital lease payable	1,826
Total Current Liabilities	**$52,210**
LONG TERM LIABILITIES:	
Accrued rent expense	$17,458
Total Liabilities	**$69,668**
NET ASSETS:	
Unrestricted net assets	$1,963,303
Temporarily restricted net assets	893,744
Permanently restricted net assets	91,118
Total Net Assets	**$2,948,165**
Total Net Assets and Liabilities	**$3,017,833**

STATEMENT OF ACTIVITIES
FOR THE YEAR ENDED DECEMBER 31, 2015

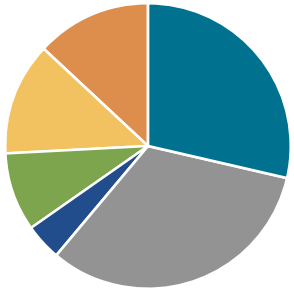
SUPPORT AND REVENUE

Restricted grants and donations	$1,085,009
Unrestricted contributions	908,777
Fundraising (net of expenses of $263,294)	1,303,448
Sale of books, publications and other items	28,621
Contract Revenue	18,812
Interest and dividends	7,534
Net investment gain (loss)	(6,625)
Other income	6,294
Total Support and Revenue	**$3,351,870**

EXPENSES

Research	$1,213,538
Public support and education	726,655
Advocacy	100,466
Conferences	53,192
Total Program Expenses	**$2,093,851**
Walks	259,894
Fund Development	392,127
Administration	533,175
Total Fundraising & Administration	**1,185,196**
Total Expenses	**$3,279,047**
Change in net assets	72,823
Net assets at beginning of period	2,875,342
Net assets at end of period	**$2,948,165**

EXPENSE ALLOCATION



- Research
- Public Support and Education
- Advocacy
- Walks
- Fundraising
- Administration

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