



HYDROCEPHALUS

2010 Annual Report

Moving the Mission Forward

One year after committing to an expanded mission – to eliminate the challenges of hydrocephalus – the Hydrocephalus Association (HA) was eager to sustain its momentum on this larger agenda. By all measures, HA kept the pace and made important strides through its research, advocacy, education and support programs. HA not only kept up the pace, but actually accelerated it through sound implementation on several new strategic directions. In this annual report we highlight our top accomplishments, a few of which are worth previewing here:

- In an effort to increase the number of scientists devoted to hydrocephalus, we continued our funding of the Mentored Young Investigator Program. By the end of the year HA had made seven grants to researchers at major medical research institutions around the country.
- To greatly expand our education and support work, HA turned to technology and fundamentally transformed the way it implements education and support to individuals and families, expanding from a predominantly phone support system to a multi-media and web-based effort. As part of this growth, HA joined the world of social media with a new Facebook and Twitter presence.
- And most importantly, we continued to grow HA's most critical resource: our national network of active and dedicated volunteers who provide the leadership and inspiration for our support groups and WALKs. HA WALKs were held in 25 communities across the nation and support groups were organized and led in 21 communities.

In the pages that follow, we describe in greater detail what these accomplishments mean for our mission and the future of people and families confronting hydrocephalus. We can't acknowledge enough the incredible commitment of thousands of people who give money, time and their wisdom to fuel the hydrocephalus cause. As we look to the future we are inspired by an outpouring of generosity that will fuel our work in the years to come. And together we will make a difference for everyone affected by hydrocephalus!



Paul H. Gross

Chairman, Board of Directors



2010 Annual Report

Round II - Mentored Young Investigator Program

The Mentored Young Investigator (MYI) Research Award Program was initiated by the Hydrocephalus Association in 2009 to support research career development of scientists who demonstrate their intention and ability to continue in hydrocephalus research. Riding the successful launch of this effort, HA sponsored a second round of MYI grants in 2010 with two new awards:

- ***Augurin is a novel choroid plexus-derived peptide hormone that regulates Cerebral Spinal Fluid formation by controlling epithelial cell homeostasis:***

The purpose of this research is to explore the potential of a newly discovered hormone (augurin) in the development of a treatment for hydrocephalus. Sonia Podvin, PhD is the principal investigator under the mentorship of Andrew Baird, PhD at the University of California, San Diego. This project is funded by the Kate Finalyson Research Award.

- ***In children presenting with new diagnoses of hydrocephalus, is ventricular size associated with neuropsychological outcome at six months? A phase II clinical study:***

This prospective, multi-center study is evaluating the relationship between ventricular size and cognition and assessing the predictive value of the neuropsychological tests currently employed for children with hydrocephalus. This project is led by principal investigator Jay Riva-Cambrin MD, MSc with John Kestle, MD, MSc at the University of Utah, serving as the mentor.

Research Initiative Starts Getting Results

Of the five Round 1 awardees in their second year of research, two have submitted applications for continued funding in hydrocephalus to the National Institute of Health (R01 and P01 awards) and both are currently under review. Another HA grantee will be submitting an application for continued funding in mid-2011, and one scientific manuscript on hydrocephalus has already been submitted for publication. Three more manuscripts are in preparation. A presentation from a grantee was awarded the HA Resident's Award at the December 2010 Pediatric Section meeting at the Congress of Neurosurgeons.

Discovering the Mysteries of Cerebral Spinal Fluid

The other exciting research news from 2010 involved the development of a new research program: the Mid-Career Award for Research on Cerebrospinal Fluid Production, Flow and Regulation. Applications will be accepted from experienced investigators with established research programs in basic, translational or clinical research in 2011. Like the MYI program, awardees will be selected through a competitive, peer-reviewed process. Highest priority will be given to innovative research likely to lead to near-term changes in therapeutics and/or clinical interventions.



“One week after my daughter was born she was diagnosed with hydrocephalus—and that was 20 years ago! During those 20 years we have called and shared tears and laughter with the Hydrocephalus Association. When surgeries have taken place we have talked to the Association as much as we have talked to the surgeon’s office, leaning on them for information and support during the hardest of times. We have met other families that understand our hardships and celebrate our joys through our membership and the conferences. This gives us hope, knowledge and comfort. Thank you for all that you have done and you continue to do.”

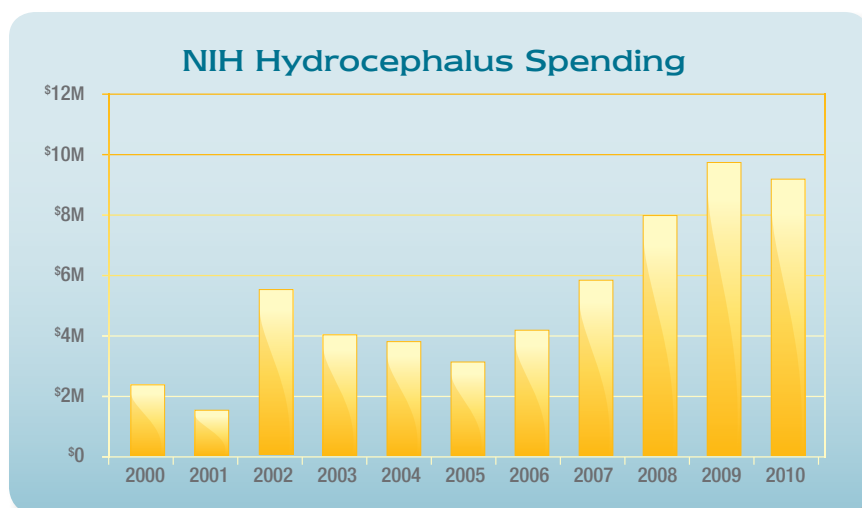
"Thanks so much! All of you are wonderful and you make my life as a mother of a child with hydrocephalus so much easier by having information available for these times in our lives when no one understands what hydrocephalus is. Thanks again for all your hard work, you'll never know how much you have helped our family and our loved ones!"

A True Partnership to Make a Difference

Since 2006, the HA has partnered with the Hydrocephalus Clinical Research Network (HCRN), a network of seven hospitals and academic institutions working together to directly impact the state of hydrocephalus treatment and outcomes. In the 2010 Mentored Young Investigator grant cycle, HA funded one of HCRN's new studies on cognitive outcomes for children with hydrocephalus. This partnership extends HA's support for clinical research in an existing successful research network of investigators, hospitals and their patients. HCRN's success in reducing infection rates by 35% at participating hospitals is a very tangible example of success in improving treatments and outcomes for children who suffer from hydrocephalus.

A Long Term Commitment

Our research mission really started with our efforts in 2004 to get the National Institutes of Health involved in funding more hydrocephalus research. The following graph demonstrates the dramatic effect of HA's efforts that led to the first ever NIH workshop on hydrocephalus in 2005. And while the trajectory is good, the total spending relative to the prevalence of the condition and the burden of the disease is not sufficient by any measure. The Association is committed to maintaining this upward trend.



After successfully launching its Research Initiative, the Association began focussing on the long term mission, and developed a preliminary five year Strategic Research Agenda. This guidance document describes the mission of the HA Research Initiative as stimulating and funding innovative research that improves the quality of life for people living with hydrocephalus and, ultimately, finding a cure.

A New Resource for Individuals and Families

Since its inception in 1986, HA has provided a variety of support and education services to its members. Starting in 2009 and continuing in 2010, HA made a major investment in the capacity of its website to support individuals and families. A major highlight involved the continued development of the site that now features the Hydrocephalus Resource Library. The Library, located at www.hydroassoc.org/hydrocephalus-education-and-support/hydrocephalus-resource-library/, has a searchable online database that includes hundreds of published articles on hydrocephalus that answer many complex questions regarding the condition and contains critical information not found elsewhere. Some examples include: scuba diving with a shunt, flying and increased intracranial pressure, slit ventricle syndrome, pregnancy and hydrocephalus, and many more important issues pertaining to hydrocephalus. Complementing web resources, HA continued to publish over 20 educational booklets and fact sheets, all of which are distributed free of charge on request and through doctors' offices and hospitals.

HA Joins the Social Media Universe

In 2010, HA joined the social media universe and expanded its outreach programs to take advantage of the social-networking websites Facebook and Twitter. By the end of the year HA had **3,587** active users, and this number grows daily. Our support staff are now able to use Facebook and Twitter to efficiently disseminate information about hydrocephalus to the general public and inform them of upcoming events. *Like* us on Facebook and follow us on Twitter.

Support Staff Offer One-to-One Support

The website and social media are only part of the story – our professional and knowledgeable support staff, led by Pip Marks, continues to be available to provide **personalized advice** over the phone and email every day. In fact, over 1,350 individuals used this “high touch” service in 2010.



“Thank you Hydrocephalus Association for all your support you give and hard work that goes into making life better for people like me. I truly cannot express how much it means to know that there are people out there willing to go the extra mile to improve the quality of life for a complete stranger.”

Support Groups Now in 21 States

Complementing the “high touch” work of HA’s staff are the dedicated cadre of volunteer Partners who lead our local Support Groups across the country. In 2010, our partners ran 24 Support Groups in 21 states. Groups met between 4 and 12 times per year and ranged from 10 to 75 members. Go to www.hydroassoc.org for a complete list of Partners.

Scholarship Awards

Once again, for the 16th year, HA awarded educational scholarships to eight students who have hydrocephalus and are pursuing paths of higher education: Hayley Sumner Crumley, Valerie D’Amato, Amber Milliken, Isaac Morales, Alexander Ross Nolan, Michelle Slowey, Nathaniel Watt and Lindsey Winton.



A New Program – Teens Take Charge

In 2010, HA conceived and developed its first advocacy program specifically devoted to teens – *Teens Take Charge (TTC)*. The program has two related goals: to enable teens to take increasing responsibility and ownership of their hydrocephalus, and to empower teens to become effective advocates for the hydrocephalus cause. TTC launched a dedicated website for program participants to network and facilitate fund raising. Teen participants also raised \$17,626 for the program. By the end of the year, TTC was forming its first Teen Advisory Council which will consist of up to ten teens who will provide input and ideas as the program develops.

11th Biennial Conference

HA was happy to host its 11th biennial conference – *It’s all about YOU* – in Cleveland, OH. As with past conferences, the goal was to provide a forum where individuals and families could get tools and make connections to address the medical, educational and social challenges of living with hydrocephalus. Over four full days in Cleveland, conference participants attended over 50 educational sessions, including live video presentations of shunt and ETV surgeries! Featured guest speakers included Marvin Bergsneider, MD, UCLA Adult Hydrocephalus Center; Katrina Gwinn, MD, NIH/NINDS; John Kestle, MD, Primary Children’s Medical Center; Mark Luciano, MD, PhD, FACS, Cleveland Clinic; Joseph Piatt, MD, FAAP, A I Dupont Hospital for Children; Harold Rekate, MD, Barrow Neurological Institute; Marion L. Walker, MD, University of Utah; and Michael Williams, MD, Sandra and Malcolm Berman Brain and Spine Institute. The conference also included plenty of time for individuals with hydrocephalus and their families to meet with medical professionals and participate in interactive peer-to-peer networking sessions.

Raising Awareness & Funds to Fight Hydrocephalus

2010 was a blockbuster year for WALK, breaking all previous records for growth and expansion! The number of WALKs grew from 20 to 25 sites, the number of registered walkers grew by **77%** from 2,702 to 4,791 and WALK revenue grew by an amazing **48%**. On the heels of this success, 2011 promises another record year with 31 WALKS already scheduled. This success is due to the incredible commitment of time and energy by some remarkable people – our 2010 WALK Chairs. A full list of WALKS and our remarkable volunteers can be found at www.hydroassoc.org.

Again in 2010, Team Hydro, led by brothers Peter and Sam Finlayson, ventured into the San Francisco Bay to raise funds for the Hydrocephalus Association. The Team swims from Alcatraz Island to San Francisco's Fisherman's Wharf as part of the city's annual Sharkfest event. Started in 2008 with 4 swimmers raising \$10,000, the event has grown to over 100 swimmers, raising an astounding \$80,400 in 2010! Team Hydro was founded by Peter and Sam Finlayson in honor of their sister Kate. Kate passed away at the age of 26 on November 27, 2010 from a shunt infection.

HA Establishes THE FUDGE SOLOMON LEGACY SOCIETY

Charter Members of the Society include:

- Sally Baldus
- Buffa Family Trust
- Amita and Aseem Chandra Family Trust
- David and Lisa Browdy
- Emily and Russell Fudge
- Barrett O'Connor and Paul Rodgers
- Edith B. Gross, PhD
- Paul Gross & Lori Poliski
- Pip Marks
- June and Raymond Moser
- Cynthia Solomon
- Marion L. Walker, MD

For more information about how to leave a legacy please call 415-732-7040, Ext 10.



In Honor of

Eric Anderson
Nathan Baer
Larry Basirico
Carly Bowles
William & Jeanie Bradley
Hannah Grace Bruce
Daytona Rachelle Burr
Allison Grace Caffey
Julia Cardoso
Jessie Cline
Henry Cozzolino
David and Stephanie Cullen
Gena Curtsinger
Adam Didorosi
Anthony Droham
Penman Family
Ian Chun Farnkopf
Amanda Feld
Phyllis Fineman
Danny and Vicki Goldman
Paul Gross
William Gross
Bethany Hueholt
Sheila and Barry Kliger
Leah Korygoski
Elijah Lawrence
Noah Dilse Layton

Isaac LeVahn
Maralyn Lewis
Grace Maguire
Elyse Mandel
Evan Marks
Flynn Patrick McCracken
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Jameson Miller
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Katie Panasko
Madison Pardi
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Zac Revers
Brandon Roe
Emily Rogers
B. Schnugg
Katie Jane Schuderer
Harrison Silver
Jeffrey Silver
Sophie Slater
Levi Smith
Dara Tannariello
William Vincent
Marshall Williams

In Memory of

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Roger Bawner
Walter Borchardt
Nathan Broaddus
Sonia Burstein
Lucretia Carlomagna
Akhil Kundun Chandra
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\$100,000 and over

Theodore W. Batterman
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\$50,000 - \$99,999

The Brown Family Foundation
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\$25,000 - \$49,999

Medtronic Foundation

\$10,000 - \$24,999

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\$5,000 - \$9,999

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Portland Fire Fighters Association
Ted Regnier
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Sam's Club
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Boyd Smith
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Sara and Quinten Zalesky

"Thank you for all your work to help support people with hydrocephalus and their families. The Hydrocephalus Association website was extremely helpful to me and my family. It helped me prepare to handle the shunt surgery and recovery."

\$500 - \$999

Kerry Adams	Lawrence Dickinson, MD	Milwaukee Kohls	Robert Ryan
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	Tim Kletscher	Riverside Partners	
	Barry Kliger	Larry and Michele Rivkin	
	The Knights of Columbus	María and Isak Rusinek	

2010 Audited Financial Statement

Statement of Financial Position

At December 31, 2010

ASSETS

Current Assets:	
Cash and cash equivalents	\$714,986
Grants and pledges receivable within one year	451,000
Accounts receivable	64
Investment in low duration bond fund	340,936
Investments in equity securities	31,214
Prepaid expenses	13,769
Inventory	11,961
Total Current Assets	\$1,563,930

Permanently restricted investment	
in low duration bond fund	80,718
Pledges receivable in 2012 and 2013	13,000
Property and equipment,	
net of accumulated depreciation	13,227
Deposits – Long term	4,802
Total Assets	\$1,675,677

LIABILITIES

Current Liabilities:	
Accounts payable and accrued expenses	\$64,203
Grants payable	329,171
Lease payable, current	5,480
Total Current Liabilities	398,854

Long term Liabilities:	
Lease payable, non-current	2,102
Total Liabilities	\$400,956

NET ASSETS

Unrestricted net assets	692,515
Temporarily restricted net assets	501,488
Permanently restricted net assets	80,718
Total Net Assets	1,274,721
Total Net Assets and Liabilities	\$1,675,677

Statement of Activities

For the year ended December 31, 2010

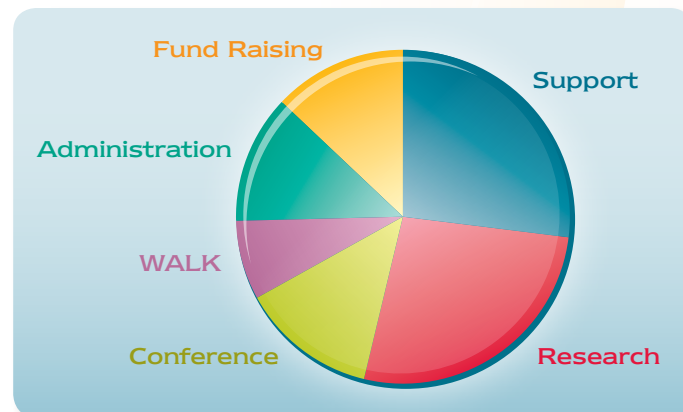
SUPPORT AND REVENUE

Restricted grants and donations	\$877,691
Unrestricted contributions	308,639
Fund raising (\$600,593 revenues	
less \$84,762 expenses)	515,831
Conference fees	54,395
Sale of books, publications and other items	9,295
Interest and dividends	17,679
Net investment gain	3,209
Other income	4,780
Total Support and Revenue	\$1,791,519

EXPENSES

Public support, education and advocacy	\$511,266
Research	507,832
Hydrocephalus conference	249,726
Total Program Expenses	1,268,824
Administration	236,270
Fund raising (Includes WALK)	390,828
Total Expenses	\$1,895,922

Change in net assets	(104,403)
Net assets at beginning of period	1,379,124
Net Assets at End of Period	\$1,274,721





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