

# Hydrocephalus Association



*The Search for a Cure Begins*

ANNUAL REPORT 2009

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## Letter from the Board Chair

We began 2009 with a change to our mission—to eliminate the challenges of hydrocephalus—and pursued its implied direction tirelessly throughout the year. The board of directors and staff completed a five-year strategic plan that calls for the Hydrocephalus Association to drive the hydrocephalus research agenda. That agenda centers on a vision of improved quality of life for those who live with hydrocephalus and on eventually finding preventions and cures. Realizing our vision requires a lot more research—more scientists, more clinicians and more funding.

Our plan called for us to begin funding research in 2009, and with your help we launched our inaugural Research Initiative grants for five young investigators. This half-million-dollar, two-year commitment represents a significant change in the hydrocephalus research landscape. Encouraging careers in and an influx of new talent into hydrocephalus research is a key part of what we must do to drive the research agenda. But ultimately we need to be in Washington, D.C. if we are going to directly influence our government's investment in hydrocephalus research. We plan to hire a new CEO and build our presence in our nation's capital. Direct funding of research and advocacy will be critical success factors in accomplishing our new mission.

As we approach the 25th anniversary of the Hydrocephalus Association, we are amazed by the power of the relationships we have built with our membership. With so many volunteers helping us raise money and awareness, we are energized to fulfill our mission and make the necessary moves to improve the lives of our loved ones with hydrocephalus.



*Paul H. Gross*  
*Chairman, Board of Directors*



# 2009

## The Hydrocephalus Association Makes A Long Term Commitment to Research with Five Inaugural Grants

### RESEARCH INITIATIVE: IMPROVING PATIENT OUTCOMES AND MOVING TO FIND A CURE

In 2009 the Hydrocephalus Association delivered substantial results with the launch of our new Research Initiative. Fueled by the generosity of our donors, the Association raised over \$600,000, with much of the funding coming from major gifts, to support this new effort. After major deliberation over possible research program options, the Association's board of directors, with leadership from its Research Committee, decided on a strategy to address a critical long-term problem that affects the entire research ecosystem: the shortage of dedicated researchers focused on hydrocephalus. In response, the Hydrocephalus Association crafted and launched a Mentored Young Investigator Program. After receiving proposals from scientists across the nation, a Scientific and Medical Review Committee selected five grantees:

#### Quantitative Measurement of Ventricular Volume and Cortical Atrophy to Improve Diagnosis of Normal Pressure Hydrocephalus

Under the leadership of Dana W. Moore, PhD, with mentorship from Norman R. Relkin, MD, PhD at Weill Cornell Medical College of Cornell University, this study will evaluate whether obtaining new information from MRI scans can improve the diagnosis of adult normal pressure hydrocephalus (NPH). Dr. Moore is an accomplished postdoctoral fellow in neuropsychology and a faculty position candidate. She will apply her considerable clinical experience with patients suffering from head trauma and Alzheimer's disease to neuroimaging in hydrocephalus.

#### Lysophosphatidic Acid (LPA) Signaling in Hydrocephalus

In this project, based at Scripps Research Institute, investigator Yun C. Yung, with mentorship from Jerold Chun, MD, PhD will study the role of a small lipid (called LPA) that has recently been identified as a cause of fetal hydrocephalus in mice, exploring whether there is a critical period during brain development in which intracranial bleeding is likely to lead to hydrocephalus. Mr. Yung is a doctoral student in molecular biology and brings a varied research background in cancer and neuroscience to his exploration of a cause of fetal hydrocephalus.

#### Early Versus Late CSF Drainage Treatment in Experimental Neonatal Hydrocephalus

At the University of Utah, Ramin Eskandari, MD (investigator) and Pat McAllister, PhD (mentor) will test their hypothesis that delayed reservoir placement for treatment of neonatal hydrocephalus has consequences that can be measured through MRI imaging, CSF evaluation, neurological assessment and examination of brain tissue. Dr. Eskandari is a fourth-year resident physician in pediatric neurosurgery. He brings basic research experience in both neuroendocrinology and hydrocephalus and a number of publications to this project.

#### The Role of Angiogenesis in Hydrocephalus

At Children's Hospital Boston and Harvard Medical School, Joon W. Shim, PhD, with mentor Joseph R. Madsen, MD, will investigate the vascular biology of hydrocephalus, proposing that hydrocephalus might be mitigated by a pharmacological approach. Dr. Shim is a postdoctoral research fellow in neurosurgery, and brings biomedical engineering expertise to his

study of the tissue response of the brain to hydrocephalus.

#### Effects of VEGF Agonist (rVEGF) and VEGF Antagonist (Bevacizumab) Treatment on Cerebrovascular Density and Permeability, and Learning in a Kaolin Model of Hydrocephalus

Lead Investigator, Dr. Abhishek Deshpande and his mentor, Mark Luciano, MD, PhD at the Cleveland Clinic will employ an established animal model of hydrocephalus to test whether treatment with pharmacological agents can affect the development and progression of chronic adult hydrocephalus. Dr. Deshpande is a physician and doctoral candidate in neurosurgery who seeks to integrate clinical and laboratory expertise in the research setting.

After receiving proposals from scientists across the nation, a Scientific and Medical Review Committee selected five grantees.



*With committed volunteers around the country, HA is providing more support and raising more awareness and financial support than ever before.*

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## **SUPPORTING PEOPLE & FAMILIES**

In 2009 we made a major investment in our capacity to provide support and education to families coping with hydrocephalus. Starting with technology, the Association initiated a restructuring of our website and committed to making our substantial information resources on hydrocephalus (many of which were limited to paper files) available on the site. While the results of this effort won't be available until the end of 2010, the goal is simple: to increase access, and ease of access, to one of the best collections of information on hydrocephalus. The website is already our largest medium for support, having received over 121,000 visits from 88,000 visitors for 2009!

Over the last couple of years we have continued to produce and update our educational publications, including the following:

- About Hydrocephalus—A Book for Families (in English and Spanish)
- About Normal Pressure Hydrocephalus (Adult-Onset)
- Prenatal Hydrocephalus—A Book for Parents
- Hydrocephalus Diagnosed in Young to Middle-Aged Adults
- A Teacher's Guide to Hydrocephalus
- Health-Care Transition Guide for Teens and Young Adults
- Directory of Pediatric Neurosurgeons
- Directory of Neurosurgeons for Adults
- Directory of Neurosurgeons who continue to treat Patients after they Transition from Pediatrics to Adulthood

Together, these resources are part of an ever-growing support system aimed at one of our most important goals: supporting and educating individuals, families and professionals dealing with the complex issues of hydrocephalus. In 2009 we made tremendous progress in this critical arena.

The year 2009 also marked the 15th year we have awarded scholarships to young people who have succeeded with their

education despite the challenges of hydrocephalus. These eight scholarships are generously funded by the:  
Anthony Abbene Scholarships  
Justin Scot Alston Memorial Scholarship  
Gerard Swartz Fudge Memorial Scholarships  
Mario J. Tocco Hydrocephalus Foundation Scholarship  
Morris L. and Rebecca Ziskind Memorial Scholarships

### **These awards support future leaders in the hydrocephalus community.**

Congratulations to our 2009 recipients:

*Erin Rae Breedlove*, Fayetteville, GA  
*Katelyn Dekoski*, Bay City, MI  
*Ryan James Derleth*, Running Springs, CA  
*Lydia Gonzales*, Las Vegas, NV  
*Margaret Hackett*, Chicago, IL  
*Maria K. Nevarez*, Pittsford, NY  
*Justin Mark Salisbury*, Willington, CT  
*Faye Elizabeth Zimmerman*, Slidell, LA

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## **ADVOCACY: CREATING A VOICE FOR HYDROCEPHALUS**

Our advocacy work has several components—grassroots, state and federal legislatures, and the National Institutes for Health (NIH) and other funding agencies. While in 2008 we worked the Hill, in 2009 we further developed our relationship with the NIH and expanded our grassroots advocacy through our WALK program. The work begun in years past was rewarded in June 2009 by the NIH's announcement of the first dedicated hydrocephalus program, focused on improving shunts. We finished the year with a meeting of the 15 members of the trans-NIH working group on hydrocephalus to continue to advance our research agenda.

We recrafted our expansion program, renaming it our Partners Network, to more easily support local groups and expand WALKs as critical steps for building our grassroots advocacy efforts. The Partners Network engages both local advocates and local communities in the larger effort to develop more effective therapies and eventually find a cure. The network is comprised of local support group leaders and WALK chairs, volunteer organizers who lead local fund- and awareness-raising walks. Our signature event, the Hydrocephalus Association WALK program, grew steadily in 2009, with 24 walks across the United States. With the leadership of these volunteers organizing support groups and WALKs, HA is providing more local support, raising more money and educating more people than ever before. In fact, two of our former WALK chairs successfully got Congress to establish September as National Hydrocephalus Awareness month—thank you, Michael and Kim Illions!

### **Hydrocephalus Association 2009 WALKs**

*Alabama, Birmingham:* Kimberly Ketler, Becca Cardin, Rhonda Fort  
*Arizona, Phoenix:* Maggie Varland, Lara Andren, Jane Andren  
*California, Fresno:* Cheryl Merrell, Kelly Fjelstrom  
*California, Oroville:* Jodi Lawrence  
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*Ohio, Cleveland:* Monica Ferrente  
*Pennsylvania, Philadelphia:* Marybeth Godlewski, Erica Stivaletti  
*Texas, San Antonio/Austin:* Sheri Burdine  
*Utah, Salt Lake City:* Vicki Bell, Kelly Varga

To bolster our national effort, we have always been committed to developing and supporting local support groups. In 2009 we increased the number of active groups from 18 (in 16 states) to 23 (in 19 states). Each group is organized and coordinated by dedicated volunteers who provide indispensable leadership to our local support efforts.

### **Hydrocephalus Association Partner Support Groups**

*Albuquerque, NM:* Marnie Wood  
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*Salt Lake City, UT:* Helen Aoki  
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*St. Louis, MO:* Debby Buffa  
*Tracy, CA:* Kim Ruiz-Chavez  
*Tucson, AZ:* Melissa French

The Partners Network is united via a new Partners website, which allows local volunteer leaders to communicate, share information and learn from each other at the click of a mouse.



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# 2009 Audited Financial Statements

## TOTAL

### ASSETS

Current Assets	
Checking Account: Wells Fargo	3,117.40
Checking Account-First Republic Bank	704,195.14
Money Market-First Republic Bank	252,130.03
Charles Schwab	401,837.18
Investment: UBS	21,621.82
Petty Cash	166.90
Accounts Receivable	192,697.22
Grants Receivable	25,000.00
Prepaid Expenses	9,479.49
Commuter Checks	1,259.80
Inventory: Books, Bracelets	15,172.05
<b>Total Current Assets</b>	<b>1,626,677.03</b>

Noncurrent Assets	
Accounts/Pledges Receivable - N/C	60,000.00
Furniture & Equipment	40,356.65
Computer Software	10,585.55
Accumulated Depreciation	(31,791.64)
Deposits	4,876.00
Total Noncurrent Assets	84,026.56
<b>Total Assets</b>	<b>1,710,703.59</b>

### LIABILITIES

Current Liabilities	
Accounts Payable	36,017.86
Grants Payable	275,000.00
Lease Payable	5,055.89
Accrued Expenses: Other	123.32
Accrued Vacation	7,396.39
Total Current Liabilities	323,593.46
Noncurrent Liabilities	
Lease Payable: Long Term	7,986.34
Total Noncurrent Liabilities	7,986.34
<b>Total Liabilities</b>	<b>331,579.80</b>

### NET ASSETS

Unrestricted	956,341.50
Temporarily Restricted	342,564.29
Permanently Restricted	80,218.00
Total Net Assets	1,379,123.79
<b>Total Liabilities &amp; Net Assets</b>	<b>1,710,703.59</b>

## STATEMENT OF ACTIVITIES

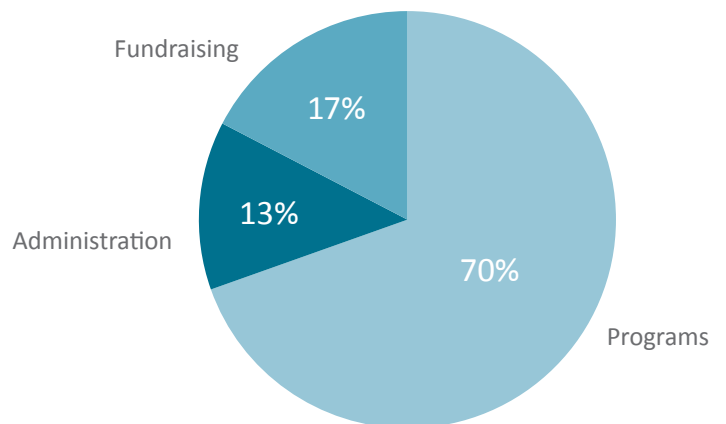
### SUPPORT AND REVENUE

Individual Donations	261,245.37
Foundation/Corporate Giving	36,753.70
Workplace Giving	28,757.87
In-Kind Contributions	50.00
Fundraising Event: Income	488,127.05
Fundraising Event: Expense	(59,581.89)
Sales: Resources	11,590.70
Resources: Postage Paid	8.00
Sales: Other	3,064.50
Conference Fees	500.00
Interest Income	6,298.18
Net Gain (Loss) on Investments	1,654.98
Other Income	2,772.63
Net Assets Released from Restriction	796,579.35
<b>Total Support &amp; Revenue</b>	<b>1,577,820.44</b>

### EXPENSES

Administration	183,371.61
Fund Development	244,006.23
Support, Education & Advocacy	455,289.16
Hydrocephalus Conference	43,153.60
Research	478,677.51
<b>Total Expenses</b>	<b>1,404,498.11</b>

Change in Net Assets	173,322.33
Net Assets: Beginning	781,706.45
Net Assets	781,706.45
Total Net Assets: Beginning	781,706.45
<b>Net Assets: Ending</b>	<b>955,028.78</b>



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