The Search for a Cure Begins

ANNUAL REPORT 2009
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
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:

**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.

**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.

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

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, Orovil**: Jodi Lawrence
- **California, San Francisco**: Sarah Oxford, Pip Marks
- **Colorado, Denver**: Phyllis Rogers
- **Florida, Boca Raton**: Eileen Rodger, Vida Hamilton, Lisa Piazzese
- **Florida, Tampa Bay**: Paula Keyser
- **Illinois, Chicago**: Stacy Buckner, Sherry Reising

With committed volunteers around the country, HA is providing more support and raising more awareness and financial support than ever before.
Massachusetts, Boston: Greg Tocco
Massachusetts, Cambridge: Jennifer Miles
Maryland, Baltimore: Karen Taylor, Terri Smith
Michigan, Detroit: Denise Bechard, Jennifer Bechard
Missouri, St. Louis: Abby Puckett, Maggie O’Shaughnessy, Stephanie Buffa
North Carolina, Graham: April Brantley
New Jersey, Long Branch: June Moser
New Jersey, Washington Township: Lisa Healy
New Mexico, Albuquerque: Mark Medley, Kathy Carillo
New York, Albany: Andrea Barno
New York, Long Island: Mia Padron, Jackie Davidson
Ohio, Cleveland: Monica Ferrante
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
Atlanta, GA: Kymmi Wilson
Austin, TX: Meredith Weiss
Baltimore, MD: Carol Wamboldt
Boston, MA: Stacey Schamber
Bremerton, WA: Rebekah Uhtoff
Cedar Rapids, IA: Rachel Buresh
Chicago, IL: Sherry Reising
Cleveland, OH: Maria Revnyak
Denver, CO: Tammy Knight
Long Island, NY: Mia Padron
MN: Michelle Traxler
MN: Jennifer Buthuis
Morristown, NJ: Missy Shoemaker
Morristown, NJ: Susan Shoemaker
Nashville, TN: Angel Reeves
Novi, MI: Jennifer Bechard
Owasso, OK: Tina Daniels
Philadelphia, PA: Annie Markovits
Phoenix, AZ: Maggie Varland
Pittsburgh, PA: Nicky Snyder
Portland, OR: Therese Chen
Richmond/DC: Annie Mason
Salt Lake City, UT: Nicole Wolthius
Salt Lake City, UT: Helen Aoki
San Antonio, TX: Sheri Burdine
Seattle, WA: Leslie Kempthorne
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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Harold L. Rekate, MD
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Michael A. Williams, MD
Jeffrey H. Wisoff, MD
Emeritus: Michael Edwards, MD
### 2009 Audited Financial Statements

#### TOTAL

**ASSETS**

<table>
<thead>
<tr>
<th>Asset Type</th>
<th>Amount</th>
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<tbody>
<tr>
<td>Current Assets</td>
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<td>Checking Account: Wells Fargo</td>
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<td>Charles Schwab</td>
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<td>Investment: UBS</td>
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<td>Accounts Receivable</td>
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<td>Grants Receivable</td>
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<td>Prepaid Expenses</td>
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<td>Commuter Checks</td>
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<td>Inventory: Books, Bracelets</td>
<td>15,172.05</td>
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<td><strong>Total Current Assets</strong></td>
<td><strong>1,626,677.03</strong></td>
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| 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** |

| **Total Assets**                    | **1,710,703.59** |

#### LIABILITIES

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<td>Grants Payable</td>
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<td>Lease Payable</td>
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<td>Accrued Expenses: Other</td>
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<td>Accrued Vacation</td>
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<td><strong>Total Current Liabilities</strong></td>
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| Noncurrent Liabilities                |              |
| Lease Payable: Long Term              | 7,986.34     |
| **Total Noncurrent Liabilities**      | **7,986.34**  |

| **Total Liabilities**                 | **331,579.80** |

#### NET ASSETS

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<td>Temporarily Restricted</td>
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<td>Permanently Restricted</td>
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| **Total Liabilities & Net Assets**    | **1,710,703.59** |

#### STATEMENT OF ACTIVITIES

**Support and Revenue**

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<tr>
<th>Revenue Type</th>
<th>Amount</th>
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<td>Individual Donations</td>
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<td>Foundation/Corporate Giving</td>
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<td>Workplace Giving</td>
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<td>In-Kind Contributions</td>
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<td>Conference Fees</td>
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<td>Net Gain (Loss) on Investments</td>
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<td>Net Assets Released from Restriction</td>
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<td><strong>Total Support &amp; Revenue</strong></td>
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**Expenses**

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<td>Hydrocephalus Conference</td>
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<td>Research</td>
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**Change in Net Assets**

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<td>Programs</td>
<td>70%</td>
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Individual Donors

$1,000 and up

Angela and Chris Batterman
Sarah Billingshurst and Howard Solomon
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Jeff Brown
Kenneth Brown
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Lawrence Bruno
Gerald Bruskowski
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Junius Campbell, Jr.
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Leo Canion
Romina Canova
Fran Cantrell
Norma Caporale
Connie and Dale Capps
Frederick Capria
Lina Card
Noah Cardin
Joann Cardoso
Rose and Charles Cardoza
Cleona Carleton
Donald Carlisle
Jack Carlomagno-Duggan
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Ellwood and Venna Carlson
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Gus Carpio
Kathryn Carr
Richard Carter
Tom Carter
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Elizabeth Curry
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Joseph D'Adamo
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Jim, Rebecca and Joan Burness
Cindy and Kevin Joslyn
Emma Kaczor
Glenn Karahadian
Colin Kiely
Kristen Klahr
Sharon Kovack
Madeline J. Kyle
Cort Ladden
Krista M. Lamison
John K. Landern
Alex Lawson
Connor LeCompte
Tiki Lipton
Maureen Lorello
Benjamin Lust
Elyse Mandel
Emma Jane Maurer
Kate Maynard
Gordon McComb
Jennifer McLaughlin
Savannah Miller
Cynthia Minakawa
Thomas Mingst
Michael P. Mooney
James Moroz
Jonathan Murgida
Becky Osgood
Charley Otto
Katie Panasko
Benoit Pelletier
Gavin Penkse
Thomas Penman
Sarah Percell
Giovanni Perez
Bo Perry
Pierce Piatt
Dana Pitney
Anna Pofy
Alison Puckett
Victoria Lee Queen
Lauren Ewing Rainwater
Siobhan Reardon
Karl W. Rhodes
Grace Isabella Rosanova
Phillip Rosenthal
Ben Sanchez
Judy and Tom Sanders
Riley Schatz
Bryan Schnugg
Claire Scognamiglio
Christina Sherman
Rosanne Solomon
Elisabeth Sorensen
Houston Stepp
Mr. and Mrs. Drew Stevenson
Mac Tronsdal
Bobby Voss
Tyler Weichert
Julia Wiener
All those with hydrocephalus
All those with NPH
Andrew and Jeanne Woloshyn
Imani Wood
Jackie Zohn
Jessica and Michelle Agricola
Joseph Dewey and Helena Herring
Aaron and Albert Poletski
Dean Laubach

In Memory of

Bernard Alberts
Philip B. Arms
Ellen Billetter
Ruth Bogolub
Fransis J. Browning
Charles Carroccetto
Demetrius Christophides
Betty Conyward
James Copeland
John Cotton
Chuck Daly
Sandy Anthony DeMaggio
Ann C. Domsic
Mary Louise Duffy
Victor Ellis
Elisabeth Falriglia
Gerry Fishkin
Bob Fowler
Gerard Swartz Fudge
Rachel Fulton
Jack W. Gilbert
Sierra Gore
Janet Gorner
Jean Gowanlock
Jerry Grove
Marion Harenburg
Joyce Hazelkorn
Edgar Herring
Jean C. Higgins
Bernadette Kizian Janusiewicz Janus
Jerry Jarnagin
E. Roy John, PhD
Rebecca Grace Jones
Michael Kesselman
Walter Klein
Mr. and Mrs. R.M. Kranz
Makinnua Krebaum
Johnny Dean Lader
Dean Laubock
Cornelius Pieter Lodder
Mary Louise Duffy
Rudolph Masseria
Ronald and Pat McClain
Coach Eli McLaughlin
Christopher Rembert Meister
Tyler Michael
Christian Stephen Molica
Samuel R. Neff, MD

Corporate/Foundation

Aesculap
AGC Technologies
Accularm Security Systems
Advanced Integration
Allstate Giving Campaign
ANI Orthopaedics Group
Aon Foundation
Arapahoe Park Pediatrics
ARISTOI
Arrow Electronics Inc.
Autodesk, Inc.
Bank of Marin
Barnes-Jewish St. Peters Hospital
Barron and Polk P.L.C.
Barron and Polk P.L.C.
Barry V. Goldstein & Associates LLC
Theodore W. Batten Family Foundation
BBVA Compass
Bel Med Inc.
Bessemer Emergency Physicians
Bluff Park United Methodist Church
Boston Pediatric Neurosurgical Foundation
Botz, Deal & Co.
BP Foundation, Inc.
Branch Banking and Trust Company
Brand Aromatics, Inc.
Brantley Auto Sales
Bristol-Myers Squibb Giving Program
Brittingham’s Irish Pub and Restaurant
BSA Troop 225
C&N Heating & Air Conditioning, Inc.
CA Inc.
Cadence Design Systems, Inc
CAL Custom Tile
Cargill Incorporated
Celest M. Losito, Inc.
Centre of Performing Arts
Combined Federal Campaign
Cheers! Michigan
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<th>Address</th>
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<td>870 Market St, Suite 705 San Francisco, CA 94102</td>
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<td>Childers Print and Graphics, Inc.</td>
<td>Toll-free: (888) 598-3789 E-mail: <a href="mailto:Info@HydroAssoc.org">Info@HydroAssoc.org</a> Website: <a href="http://www.hydroassoc.org">www.hydroassoc.org</a></td>
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