

## THE MESSAGE IS CLEAR: HYDROCEPHALUS RESEARCH NOW!

By Bob Jacobsen, President, Board of Directors

For the past 25 years, your Hydrocephalus Association (HA) has provided education, support and advocacy. These are all important goals and we will continue with all of them. But for more than 40 years the only options to manage hydrocephalus have been neurosurgical. The esteemed members of the HA's Medical Advisory Board have concluded that there are more questions about hydrocephalus than there are answers. We need to advance the clinical research aimed at the most effective treatments. The simple fact is that we need to understand more about the basic science of this condition before anyone can consider something such as a cure.

The HA is positioned at the nexus of a movement to strategically drive hydrocephalus research. We are aligned with professional and peer advisors, with Congress and members of government, with other organizations and with key agencies. It is our intent to drive and support the research agenda by directly funding hydrocephalus research. We know, with your help, we can make a difference.

With research as a new goal, the HA's Board of Directors is changing the corporate structure of the organization. The intention of this reorganization is to embody this expanded vision while continuing the strong focus on support, education and advocacy. Operationally, the HA will be organized into two divisions: one that focuses on research and one that focuses on the legacy mission of support, education and advocacy. A Division Director will manage each division. The Board has begun a professionally guided, executive search process to help identify the ideal candidate to fill the new position of Chief Executive of the Association.

Given her incredible impact in advancing the HA's relationship with the National Institutes of Health and the research community, the Board asked our present Executive Director, Dory Kranz, to become the new Division Director for Research.

She is in the process of transitioning from her present position, which is being eliminated, to her new position. Simultaneously, the HA will identify and place a new Division Director for Support, Education and Advocacy. Both Division Directors will report to the Board until the new CEO has been identified and that person is fully on board.

These changes in the HA's corporate structure are a direct result of your past support of this direction for the organization and are endorsed by our Medical Advisory Board. The HA learned a great deal about implementing best practices from our workshop in Bethesda, Maryland earlier this year. We were pleased to gather exceptional input from not only our Medical Advisory Board, but also from industry, parents, funders and peer organizations who have successfully embarked on funding disease research.

The HA is now initiating a Major Gifts program as part of a fundraising campaign that will sustain research efforts as well as our ongoing programs for education, advocacy and support. You will be hearing much more about this soon, and we invite your active participation.

The HA's Board of Directors has also formed a research committee that is experienced in funding of hydrocephalus research to set the initial guiding principles, mission and vision of the HA's new research funding program. Over the next several months, the research committee will gather input from many interested parties. We would especially appreciate hearing from you, and invite you to e-mail Dory ([dory@hydroassoc.org](mailto:dory@hydroassoc.org)) with your thoughts on this important subject.

We are excited about the progress we have made and about the changes to come. We will keep you fully informed about our continuing progress in research and in raising funds via future newsletters. Thank you for your continued support and for all that you do to help! ❖



*'Turning the Wheels of Research'*

## FROM THE EXECUTIVE DIRECTOR

I hope you share my excitement as you read the cover article by our board president, Bob Jacobsen. We have so much to be grateful for in this season of Thanksgiving. A vision held since my earliest days with the Hydrocephalus Association is taking a bold step forward as we work to directly fund research. It will be my privilege to build and lead a new division devoted to this effort and nurture one of my long-held dreams for the hydrocephalus community into reality.

It is humbling and inspiring to witness this growth in mission—a growth made possible by the steady increase in community ownership of and involvement in the HA over the past few years—that has enabled us to take on the task of directly funding research. As I move with anticipation into this next phase of my service to the hydrocephalus community, I look back with pride on what we have accomplished together in the four years since I was entrusted with the leadership mantle of Executive Director.

The organization was poised for a leap of growth, which we have taken in style:

running a local outreach pilot program in seven states that has a waiting list of individuals clamoring to join; hosting networking and fundraising WALK events in more than 25 states; and coordinating national advocacy efforts, which led to a congressional resolution, appropriations report language and a tripling of the National Institutes of Health's annual investment in hydrocephalus research.

The HA is ready for the next step of directly funding research. The community has clearly asked us to take on this effort. I couldn't be more pleased that I get to carry the knowledge I've gained and the individuals I've worked with during my eight years in support and executive leadership roles into this arena that has such heart and meaning for me.

As with most things, this process will take time. I will continue to lead the HA in its current form for the next couple of months as we find a Division Director for the legacy services of Support, Education and Advocacy. I will be available during a thoughtful and thorough transition as I work with a special com-

mittee of the Board on strategic planning for the new Research Division. At the same time, we will begin a search for an overall chief executive officer, which will probably take 12 to 18 months. Let us all be patient with each other as we find our new footing.

Fall is a season of harvest and letting go. As an association, we are harvesting the rewards of our hard work together. We are letting go of one form and I am letting go of a particular role that has been challenging and rewarding in equal measure. Like a maple lets go of its brightly colored leaves, we trust that a new form and new vitality will emerge in the spring. The winter will be a time of reflection and planning.

Your feedback and financial support during this transition are welcome. We would especially like to know of important questions we should consider, names of wise counselors with whom we can consult, strategic issues to address, and successful models from which we can learn. Please contact me directly at 415-732-7040 or [dory@hydroassoc.org](mailto:dory@hydroassoc.org).



## HAVE YOU BEEN DENIED BY SOCIAL SECURITY?

*Reprinted from Orphan Disease Update, Summer/Fall 2008, Vol XXVI, Edition 3 with permission from the National Organization for Rare Disorders (NORD)*

The Social Security Administration (SSA), under Commissioner Michael Astrue, has launched an initiative to identify problems encountered by people with rare diseases when they apply for disability assistance through Social Security. Because these diseases are not on the approved list, the severity of their impact may be underestimated. As a result, patients often are initially turned down but later approved. Many people go through unnecessary delay, frustration and expense in seeking to have an initial decision re-visited.

Commissioner Astrue spoke about this at NORD's annual conference last fall. He also spoke briefly at the 25<sup>th</sup> Anniversary Gala in May. In December, NORD Vice President for Public Policy

Diane Dorman testified at hearings hosted by the SSA and several of our member organizations provided input for her testimony.

Now the SSA has asked for input on questions related to diagnostic criteria for rare diseases, functional impairment and criteria for determining when patients are functionally disabled. These are primarily medical issues and NORD will be distributing a survey and posting it on their Web site for any medical professionals interested in participating who may not receive it through other means.

In the meantime, to assist the SSA in sorting out these issues, we are also interested in stories of individual experiences that help identify problem areas within the current system. If you, a loved one or a patient have such a story to share, please feel free to contact Diane Dorman in NORD's Washington Office at [ddorman@rarediseases.org](mailto:ddorman@rarediseases.org).

The questions for medical professionals working with rare diseases on which SSA is currently seeking input are:

1. Are there any generally accepted functional scores or scales of progression that medical professionals rely upon to determine functional impairment?
2. Are there any generally accepted clinical tests (including genetic or other biomarkers) that can be relied upon to diagnose a disorder or to determine a patient's stage of disease or level of functional impairment?
3. Given the natural history of the disorder generally, is there a certain age (or time since onset) at which the person's functional impairment typically becomes severe?

Anyone wishing to submit responses to any or all of these questions regarding specific diseases or types of diseases may contact Diane Dorman. ❖

## MILLIONS OF U.S. WORKING-AGE ADULTS WITH CHRONIC CONDITIONS GET LITTLE TO NO TREATMENT

By *Karima Roumila,*  
*Outreach Coordinator*

A new national study published in the *Annals of Internal Medicine* and reported by *The New York Times* has concluded that millions of working-age Americans with chronic conditions do not have health insurance and have poorer access to medical care than their insured counterparts. Investigators analyzed a population-based survey from a nationally representative sample of working-age Americans to explore the relationship of common chronic illnesses to health insurance and access to care. They used six years of data (1999-2004) from the National Health and Nutrition Examination Survey (NHANES), which is conducted over a two-year period.

The study estimates that about one-third of working-age adults without insurance in the United States (about 11.4 million individuals) have been diagnosed

with a chronic illness. Many of these individuals forgo medical visits and are less likely to have a standard source of care than individuals with health insurance. Additionally, those without insurance are more likely to use emergency departments for their medical care than individuals with health insurance.

The study found that 22.6 percent of the uninsured with a chronic illness said they had not visited a health professional within the last year. About 7 percent said they typically go to a hospital emergency department for care.

According to the study's authors, the results may underestimate the health problems of persons without insurance and exactly how many people who are uninsured have a chronic illness because the study includes only those who have already received a diagnosis. Individuals who have not had their conditions diagnosed because they are not seeing a doctor or nurse are not included.

The study's principal investigator, Dr. Andrew Wilper, and his colleagues say that their findings bring into question some policymakers' claims that many of the uninsured tend to be young and healthy because their study suggests that many uninsured Americans have health conditions that require ongoing care. The authors suggest that future research should evaluate rates of undiagnosed illness and disease control among persons without insurance. Even more important is the need for future research and advocacy to focus "on ways to expand health insurance coverage."

"This study should serve as a wake-up call for patients and policy makers," said National Health Council President Myrl Weinberg, as reported in the September 2008 **Campaign to Put Patients First** newsletter. "It is critical that we band together as a community and work to ensure that those in greatest need have access to quality, affordable care." ❖

## REPORT FROM HYDROCEPHALUS 2008 CONGRESS

By *Dory Kranz,* *Executive Director*

The second international and interdisciplinary congress, "Hydrocephalus 2008," was held in Hannover, Germany in September. Dr. Petra M. Klinge of the International Neuroscience Institute in Hannover chaired the meeting, which in her words was intended "to challenge established as well as nontraditional concepts in the diagnosis, treatment and outcome assessment of hydrocephalus and focus on new clinical and experimental research issues." This meeting followed in the tradition of the interdisciplinary congress on hydrocephalus hosted by Carsten Wikkelsö of Göteborg University in Göteborg, Sweden in September 2006.

Quality of life was addressed at this congress through a full session that I had the privilege of co-chairing with Dr. Michael A. Williams, medical director of the LifeBridge Health Brain and Spine Institute and member of the Hydrocephalus Association Medical Advisory Board. Some of the exciting research work that is looking beyond

medical outcomes to quality of life include research on pediatric outcomes by Dr. Abhaya Kulkarni and colleagues at the University of Toronto; cognitive outcome research underway by Dr. David Frim and Dr. Maureen Lacy at the University of Chicago; and work by Dr. Nalin Gupta and associates at the University of California San Francisco to understand long-term outcomes for adults treated in childhood.

A new International Society for Hydrocephalus and CSF Disorders (ISHCSF) was inaugurated at the Hydrocephalus 2008 Congress. The ISHCSF has four main goals:

- Promoting international exchanges and encouraging worldwide representation and stimulating research and debate
- Providing and promoting excellence in professional education and research by offering a variety of programs in both the clinical aspects of hydrocephalus and the basic sciences to physicians, young researchers and allied health professionals

- Supporting and advocating an environment that ensures ethical, high-quality care for hydrocephalus both in the developed and the developing world by advancing public education and awareness
- Supporting guidelines, standardized methods, and ethically conducted clinical and basic research in hydrocephalus, CSF disorders and related fields.

Over the three days, 172 presentations were delivered by researchers from 22 countries. It was a delight to see many young investigators in attendance. I expect this congress and the newly formed ISHCSF will prove useful forums for ongoing international collaboration on research related to hydrocephalus in all its forms. Dr. Michael A. Williams of our Medical Advisory Board will chair the next congress and meeting of the ISHCSF, which occurs September 16 through 19, 2009 in Baltimore, Maryland. ❖

## LOVE, PATIENCE, AND PERSEVERANCE ARE PART OF THE BATTLE AGAINST NPH

As told to Tom Smith,  
Outreach and Media Liaison

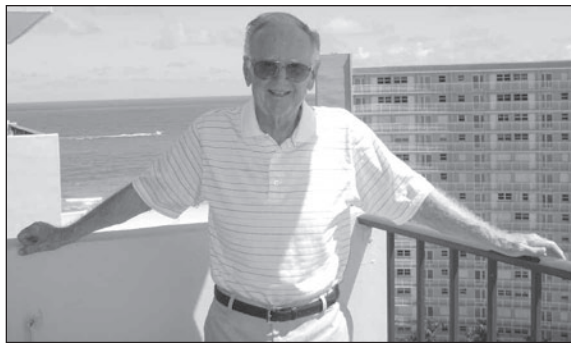
Blessed with a supportive family, Frank Grant will celebrate his 80<sup>th</sup> birthday this October, but it was close for a while there. This is Frank's story, a common one for individuals with normal pressure hydrocephalus (NPH).

Four years ago, Frank first showed signs of the characteristic shuffling gait of NPH. Nothing much was thought of it at first. The typical suggestion was for Frank to pick up his feet. Then, about two years later, the shuffle became much worse and was accompanied by incontinence and dementia—the other common symptoms of NPH.

Frank went to see a neurologist. Based on the MRIs and CT scans that were done, the doctor diagnosed him with neuropathy and spinal stenosis. The doctor told Frank and his family that there wasn't much that could be done.

Several months went by and Frank was getting worse, so his family made an appointment with neurologist Murray Todd, MD to get a second opinion. Dr. Todd reviewed the records and said to come back for a follow-up appointment, but life got hectic and Frank never went back for his follow-up. In September of 2007 Frank had to stop driving. By December, his balance was so affected that he could hardly walk. One night in December 2007 he had to be rushed to the emergency department because of vomiting. An MRI and a CT scan were done, but no diagnosis was made. He was discharged after a few days, unable to walk. Rehabilitation eventually made Frank able to get around using a walker, but after a month he was completely unable to walk and falling down a lot. Frank ended up needing 24 hour care. Family and friends were always there to help during this very tough time.

Every day was getting harder for Frank's wife to take care of him. There was talk about, as a last resort, possibly having to put him in a nursing home. In April of 2008, Frank's family took him back to Dr. Todd. The doctor was com-



pletely shocked to see Frank in a wheelchair unable to get up on his own and not able to walk. The doctor said, "I will get him on his feet or my name isn't Murray Todd."

Dr. Todd says, "Frank's symptoms were not consistent with neuropathy and spinal stenosis but he needed to have new MRIs and CT scans in order to figure out what was really wrong. He couldn't get the tests done because the insurance company refused to grant it because of the first set. It was incredibly frustrating."

In May of this year Frank became violently ill again. Readmitted to the hospital an MRI was run and handed to Dr. Todd. Within two days the verdict was in. Frank had enlarged ventricles, indicative of NPH. Within two weeks he had a consultation with neurosurgeon Dr. Randall Powell to discuss having surgery to have a shunt placed. The surgery was performed on June 9, 2008. The surgery went well, but some drug interactions

lengthened Frank's stay in the hospital. Finally, Frank was released and sent to physical rehabilitation. They had him do some physical therapy, but weren't very aggressive with it, and his family was not seeing any improvement with the surgery. At his postoperative appointment, the surgeon adjusted the drainage rate of the shunt. Within a couple of days Frank experienced some improvement. So, some of his children learned the physical therapy techniques. When Frank was released from the rehabilitation facility he did physical therapy every day, rain or shine, for a month.

Someone close to Frank reflects, "It has taken a lot longer than we thought it would, but the difference is amazing. He has always been very independent and now he is again. He uses his cane when he goes out, but he doesn't need it to get around the apartment."

"I just needed to get the word out there. There are so many misconceptions about hydrocephalus. First off, the shunt isn't a miracle. It took a long time for it to make a difference and a lot of hard work too. But that's something nobody tells you. They make it sound like you'll just walk out of the hospital. But really, it takes work and patience. When I think about how strong and independent he was, the loss of dignity was just terrible. It got so bad we were almost planning his funeral. Now he's got his life back."



### HYDROCEPHALUS AWARENESS MONTH CONTINUES IN LOS ANGELES COUNTY

By Marybeth Godlewski, National Advocacy Director

At 1:00 p.m. on September 2, 2008, Sharon Raghavachary, her husband Saty, and their 4-year-old twins Josh and Becky were all present as the Los Angeles County Board of Supervisors once again declared September as Hydrocephalus Awareness Month throughout the county. Sharon's son Josh was diagnosed with hydrocephalus at 7 months of age. Since then, Sharon and her family, who live in La Crescenta, California, have made great strides in raising awareness within LA County.

To learn more about raising awareness within your community or state, please contact me at 484-270-8423 or [marybeth@hydroassoc.org](mailto:marybeth@hydroassoc.org).



## NEURODEVELOPMENT OF CHILDREN AND TEENS WITH HYDROCEPHALUS

By Jay Wellons, M.D. and  
David Nilsson, Ph.D.

From a developmental perspective, hydrocephalus, as with other forms of neurologic compromise, demonstrates its most prominent disruption to ongoing neurodevelopmental progression of the individual child. As such, many of the developmental consequences of childhood are less obvious, but as the child progresses into adolescence, neurocognitive and neurobehavioral consequences (e.g., emotional disorders, reactive irritability, emotional volatility) become more apparent. Children with neurologic compromise progress adequately with some support through early grade school, but with progression to middle school and the increasing demand for speed and complexity, problems become more apparent in learning. Given the subtlety and complexity of social interaction, children with neurologic compromise begin to struggle to a much greater degree and often do not receive sufficient educational or developmental support to optimize social interaction. It becomes critical to begin neurodevelopmental support early, usually before problems become more apparent. Helping the child “be the best he can be” is the goal of all parents.

Children with a history of hydrocephalus commonly are of normal intellectual ability, but the specific nature of their genetic predisposition and neuropathy leads to a variety of educational problems that need to be addressed individually and as early as possible in developmental progression. Often these children are able to acquire basic skills, but the inherent difficulty is that of conceptually integrating and organizing the information into more complex conceptual units. For example, children with hydrocephalus commonly have reading skills within normal limits, but they do not comprehend easily what they read or are particularly slow in processing the information. As such, children with hydrocephalus tend to require specific educational accommodations to reduce stress and facilitate optimal performance. Often they may require a lot more specific information in explaining circumstances, consequences, and other details.

As for any teenager, the child with hydrocephalus has a strong desire to participate in activities with peers but may struggle to keep up. Most prominent areas are sports, dating, and driving. Sports may present problems given the physical limitations for some patients with shunts and their vulnerability to more severe consequences of concussion. Many sports

require visual-spatial orientation, judgment, and problem-solving, which are routinely difficult for children with any neurologic injury or neurodevelopmental disorder. Given the visual-spatial compromise and decreased speed of processing, driving becomes a particular difficulty for teenagers, given the difficulty finding their way around and the demands for multisensory processing required for driving both within and outside the car. Dating is another problem given the difficulty reading nonverbal social cues, anticipating consequences, and organizing more complex social interactions than children with hydrocephalus have been required to perform earlier in their development.

Each child is unique, and many of the consequences of a child’s ability to perform are highly dependent on his or her hydrocephalus and genetic disposition. A child’s learning environment, the developmental support a child receives, as well as the complexity and severity of their neurologic insult all contribute to developmental outcome. Key factors in the developmental progression are anticipating and recognizing areas of difficulty, intervening early and providing optimal levels of neurodevelopmental and educational support. ❖

### VERMONT NAMES SEPTEMBER 2008 “HYDROCEPHALUS AWARENESS MONTH”

By Marybeth Godlewski,  
National Advocacy Director

Matt Mulligan of Barre, VT, who was diagnosed with hydrocephalus as an infant, was home from the 10<sup>th</sup> National Conference on Hydrocephalus for about four days when he contacted his governor’s office to request support for legislation to create a Hydrocephalus Awareness Month in his state.

The June 2008 conference was Matt’s first, but hopefully not his last. He, like so many others, found the conference extremely educational and inspiring. It was not only a place for him to learn about the condition he lives with, but a place where he was able to meet others living with, treating, researching, and



advocating for the same condition. Matt found one particular session amazing. He felt speaker Stephen Dombrowski, Ph.D., Director of Clinical and Experimental Research in Neurosurgery at the Cleveland Clinic, was the first person to be able to put into words the “who, what, when, where and why” of hydrocephalus for him—an understanding for which we all strive.

This “ah” moment for Matt was a motivating factor for him to become proactive in advocating for awareness of and research for hydrocephalus. With just a phone call and a meeting, Matt achieved his goal. Two months later, a proclamation was signed by Gov. Douglas making September 2008 Hydrocephalus Awareness Month in Vermont. Job well done, Matt!

To learn more about raising awareness within your community or state, please contact me at 484-270-8423 or [marybeth@hydroassoc.org](mailto:marybeth@hydroassoc.org). ❖

## Taking Steps to Improve Life

By Marybeth Godlewski, National Advocacy Director

### DETROIT, MI

On August 17<sup>th</sup>, Denise and Jenn Bechard (mother and daughter) hosted the 2<sup>nd</sup> Annual Detroit 5-mile Hydrocephalus WALK and Family Fun Day in Milford. Thanks to more than 200 participants, the WALK was a huge success, surpassing last year's WALK with a 72% increase in funds raised and surpassing their goal for this year by raising more than \$18,000.

#### Words from event chair Denise Bechard:

*The weather was wonderful and it was a great day of fun, laughter, plenty of food, sharing, educating, and building of a strong support system for the families in Metro Detroit. We had people attend the WALK who lived as far away as England; others came from other states specifically for the WALK. The response was overwhelming, and seeing a school bus full of cheerleaders pull in from Divine Child High School in Dearborn drew a great response from participants. As we gathered everyone together for a group photo, Jenn and I looked at each other in amazement; the support, generosity, and love that surrounded all of us on that sunny day was priceless. Thank you to all of our corporate sponsors who helped us make the WALK possible and to Rich Miller at Miller Media Vision, our official WALK photographer, who went above and beyond to help promote this years WALK.*



### DENVER, CO

On September 7<sup>th</sup>, Phyllis Rogers hosted the 5<sup>th</sup> Annual Denver Hydrocephalus WALK Family Fun Day, held at Redstone Park in Highlands Ranch. Phyllis, a 5-year veteran of hosting Hydrocephalus Association WALKs, was instrumental in aiding our national efforts this year. Her experience, organization skills and calm temperament, help many of the other WALK chairs achieve success. Her motivating force is her 16-year-old daughter Jordan, who has hydrocephalus.

#### Words from event chair Phyllis Rogers:

*More than 200 people joined the 5th Annual Denver WALK this year on a beautiful day in early September. Thank you to everyone who helped make our WALK such a success; we raised \$25,000 this year!*



## Taking Steps to Improve Life

### TAMPA, FL

On September 6<sup>th</sup>, Paula Keyser hosted the 4<sup>th</sup> Annual Tampa Bay Hydrocephalus WALK and Family Fun Day in Largo Central Park. Paula also founded and runs a hydrocephalus support group, which was the first support group to become an affiliate of the HA. Paula's dedication to this cause derives from her son, Jeremy, who was born 7 years ago with hydrocephalus.



#### Words from event chair Paula Keyser:

*Thank you to everyone who came out and attended our 4th Annual Tampa Bay Walk. We had more than 100 participants in the sweltering Florida sun! Special thanks to some community sponsors—East Lake Electric, Shout Out, and Codman—who provided some great music, signage and a balloon arch to celebrate. Also, special thanks to Joe Pavliga from Integra for purchasing and coming to help Al and his team cook out! We raised more than \$13,000, largely due to our fundraising teams. Once again in first place was “Ronnie Bell.” Runner-up was Nicole’s*

*Team, and Burton’s Bunch was in third place. Congratulations to our awesome community and to everyone who participated including three of our dedicated neurosurgeons: Dr. Tuite, Dr. Marlin and Dr. Gaskill. You guys are awesome; thank you for coming out!*



### CLEVELAND, OH

On September 20<sup>th</sup> Monica Ferrante, Hilary Rossen, and Stephen Dombrowski hosted the 6<sup>th</sup> Annual Cleveland Hydrocephalus WALK and Family Fun Day in Mayfield Heights Park. The WALK was attended by more 175



people and raised about \$13,000. Monica Ferrante is presently the acting director of the Northeast Ohio Hydrocephalus Support Group, which was founded by Hilary Rossen, LISW and Stephen Dombrowski, Ph.D., Director of Clinical and Experimental Research in Neurosurgery at the Cleveland Clinic in 2003 and became the HA's second affiliate in 2007. Monica's efforts with this cause are inspired by her 10-year-old son, Vincent, who was born with hydrocephalus.

#### Words from the event chairs:

*It was a beautiful sunny day in Mayfield Heights, Ohio, a suburb of Cleveland. There was a slight chill in the air as we set up around 7:00 a.m., but by 9:00 a.m. it was in the mid-to-high 60s and there was barely a cloud in the sky. Our DJs from Sound Masters were ready to rock. Moondog, the Cleveland Cavaliers mascot, paid us a visit in the morning and was there to lead off our walk. After the walk, the Cleveland Clinic helicopter landed on the ball field and all were allowed to get up close for a look and chat with the pilots. St. Ignatius Circus Company came to do some juggling and Regina High School Clown Ministry attended to face paint. Flower Clown performed a magic show. Tom Tonozzi, a representative for Codman, was on hand to answer questions and show different shunts. Between all the activities, the children played on the playground; there was a raffle with great prizes and lunch was served. It was a very busy day, and so wonderful to see people from near and far come together as one for hydrocephalus.*



## Taking Steps to Improve Life

### SALT LAKE CITY, UT

On September 20<sup>th</sup> Vicki Bell and Kelly Varga hosted the 2<sup>nd</sup> Annual Salt Lake City Hydrocephalus WALK and Family Fun Day, held at Sugar House Park. Vicki's husband, Adam, has hydrocephalus, and Kelly herself has hydrocephalus. Vicki and Kelly did not know each other before they started chairing the WALK event. They both contacted the HA interested in starting a WALK event in Salt Lake City. They are fortunate to have the support of Primary Children's support group, but hope to create public awareness as well.



#### Words from the event chairs:

*A great time was had by the more than 100 people who attended. Although it was very cloudy and rain threatened, the Hydro-Gods were on our side! The rain held off for our entire event! The day started off with Dr. Marion "Jack" Walker, Chief Neurosurgeon of Primary Children's Hospital in Salt Lake City, receiving a declaration from Utah Governor Jon Huntsman declaring the month of September Utah Hydrocephalus Awareness Month!*

*On this day almost \$10,000 was raised to benefit the Hydrocephalus Association. The monies will be used for education, support and advocacy. For the second year in a row "Team Geis" raised the most money. "Shunts 'R' Us," the neurosurgeon team from Primary Children's Hospital also raised a significant amount of money.*

*This year there were a lot of new families in attendance who are affected by hydrocephalus. This was a great reminder of why these walk events are so important. They are a great place for people of all ages affected by this debilitating condition to get together for fun, networking and most of all support; and walk for a great cause!*



### CHICAGO, IL

On September 13<sup>th</sup>, Sherry Reising and Stacy Buckner hosted the 4<sup>th</sup> Annual Chicago 2K Hydrocephalus WALK and Family Fun Day at Lake Arlington Park. Sherry, an adult with hydrocephalus, was in her last trimester of pregnancy and had a toddler in tow at the time of the WALK event! Sherry runs a hydrocephalus support group in Illinois, which recently became an affiliate of the HA. Stacy, who has a son with hydrocephalus, has helped Sherry for the past two years with the WALK event.



#### Words from event chair Stacy Buckner:

*The WALK was really WET! It rained the day before, the day of, and the day after! According to CBS news, Arlington Heights (the suburb where the walk was held) got 10 inches of rain that day, the most ever recorded in one day! Taking the weather into consideration, we had an amazing turnout of almost 100 people. We are estimating that between what was received at the WALK and what was donated online we will either meet or come close to our \$30,000 goal! We were so fortunate to have members from our support group there early to set everything up in the pouring rain. One of the families sponsored a magician, and he was able to perform for everyone (after the actual walk) inside the boat house. . . a perfect way to bring everyone together in a dry area!*

*We received a lot of calls in the morning with people stating their basement was flooding or that streets were closed and they couldn't get to the park, so considering the circumstances the day went really, really well and it was a huge success!!*



## Taking Steps to Improve Life

### LONG ISLAND, NY

On September 21<sup>st</sup>, Doris Kahler, Janine Melomo and Mia Padron, hosted the 3<sup>rd</sup> Annual Long Island Hydrocephalus WALK and Family Fun Day at Belmont Lake State Park. Mia Padron stepped up to the position of WALK co-chair this year and will most likely move into the lead chair position in 2009. Her inspiration comes from her 6-year-old son, Tyler, who has hydrocephalus. Janine and Doris, who founded and chaired the event for the past 3 years, have done so in the memory of Janine's late daughter Giavanna, who passed away March 5, 2004 due to complications related to a shunt malfunction. Janine started the Long Island WALK so others would know, "Giavanna's death was unnecessary in that there were measures that could have been taken to ensure her recovery that were overlooked. The lesson to be learned is to be an advocate for your child, to not take no for an answer, and to listen to your instinct if it is telling you something is wrong, you need to help make it right by insisting on the very best care possible."

Janine and Doris will continue to be a large part of the Long Island WALK event and are happy to see the success of what they started in Giavanna memory continue and grow.

#### Words from event chair Doris Kahler:

*WALK LINY was extremely successful; we had more than 300 attendees and raised almost \$30,000! WBLI, the NY Islanders, Ralph the DJ, and Mary Lewis all donated their time to make our walk extra special. With music playing, good food to eat, and perfect weather we could not have asked for a nicer day. Sparky the NY Islanders mascot danced with everyone and kicked off our 3rd annual WALK. There were crafts for the children and a Chinese auction for everyone. We had about 80 baskets up for auction, which helped raise more than \$3,000 towards our total. Stony Brook University Food Services donated delicious sweets for our bake sale. Several teams came with their own shirts to show their support for our cause. Although this was our third WALK, there were*



*many newcomers who were delighted to see such an active support group here on Long Island. Everyone is already eager for our fourth WALK!*



### EDISON, NJ

On September 7<sup>th</sup>, Kim and Michael Illion's hosted the 2<sup>nd</sup> Annual Edison Hydrocephalus WALK and Family Fun Day at Roosevelt Park. Kim and Michael's inspiration in hosting this event is their 3-year-old son Cole, who was born with hydrocephalus. Kim and Michael also started and run a hydrocephalus support group in the Edison area, and they are very active with advocacy efforts.

#### Words from event chairs Kim and Michael Illions:

*With Hurricane Hanna out of the way, we were greeted by a sun-filled blue sky and more than 250 friends and family. We were honored to be joined by NJ State Assemblyman Jay Webber, former Mayor of Bogota Steve Lonagan, and former U.S. Congressional Candidate Kate Whitman, daughter of our Honorary Chairperson Governor Christie Todd Whitman. Thanks to the generosity of the many registrants and donors we have currently raised over \$42,700 and donations continue to come in.*

### GRAHAM, NC

On September 20<sup>th</sup>, April Brantley hosted the 2<sup>nd</sup> Annual Graham 2K Hydrocephalus WALK and Family Fun Day, at Graham Middle School Athletic Complex. April committed herself to this cause because of her 3-year-old son, Cohen, who has hydrocephalus.

#### Words from event chair April Brantley:

*We had about 160 participants, 40 volunteers, several of our local sponsors present, 6 participants with hydrocephalus and we have raised a little over \$6,000 at this point. Festivities for the day: Inflatable's for kids, snow-cones, cotton candy, popcorn, face painting, door prizes, cake-walk, Wii Raffle, and Troo the Traumaroo from UNC-Chapel Hill Trauma Prevention. Great day!*

### ST. LOUIS, MO

On September 20<sup>th</sup>, Stephanie Buffa hosted the 2<sup>nd</sup> Annual St. Louis Hydrocephalus WALK and Fun Family Day in Tilles Park. Stephanie's mother, Debbie, founded a support group in St. Louis, which is now an affiliate of the HA. Both Stephanie and her sister, Sara, have hydrocephalus. Stephanie works the night shift, causing her to plan most of this event while the rest of Missouri slept.

#### Words from event chair Stephanie Buffa:

*The walk is over; it was great! We had more than 250 people there and raised over \$25,000! So exciting. Everything ran so smoothly and was just perfect. I couldn't have asked for more. Oh, and the rain held out until after the walk! So exciting!*

# News Notes

## OG HATS

**OG**Hats is a volunteer-based, non-profit organization that provides large baby hats for infants born with hydrocephalus. OG Hats was created on April 1, 2008, but the journey began with the birth of Owen Gilliam, who has hydrocephalus. Sara and Brett Gilliam, the founders of OG Hats and Owen's parents, needed a hat for their son to maintain his body temperature but were unable to find one large enough to fit his head. To date, OG Hats have donated more than 400 hats to hospitals and individuals across the United States. For more information, please visit [www.oghats.com](http://www.oghats.com).

## HAVING FUN WHILE RAISING FUNDS BEAD BY BEAD

**C**olette Umar, a 14-year-old from Glen Ridge, New Jersey, who is affected by hydrocephalus, has come up with a creative and enjoyable way to raise funds for the Hydrocephalus Association. She makes beaded jewelry and sells it at her school and donates 50% of the profits to the Association. To view some of her work, please visit [www.groovycoco.com](http://www.groovycoco.com). Thank you Colette for your generosity and thoughtfulness!



## TWINNS SILVER DREAM SUPPORTS HA

**T**winns Silver Dream, a sponsor of the 2<sup>nd</sup> Annual Baltimore, MD Hydrocephalus WALK, offers handcrafted sterling and gemstone jewelry.

During November 2008, when you order from their Web site at <http://store.twinnsilverdream.com>, a portion of the purchase price will be donated to Hydrocephalus Association. Thank you for your support!!

## RECOMMENDED READING

### *Negotiating the Special Education Maze, 4th ed.*

By Winifred Anderson, Stephen Chitwood, Deidre Hayden, and Cherie Takemoto

This book provides an overview of the Individuals with Disabilities Act (IDEA) and its principles, offers real-life examples with various challenges and outcomes, and gives step-by-step advice on what parents of students with disabilities can do to get the support and information they need. It includes different options for resolving disputes. This new edition has expanded sec-

tions about required statewide assessments, methods for solving disagreements between families and schools, and clear descriptions of due process hearings and other legal recourses. Nancy Henderson of EP comments, "The book leaves no stone unturned when it comes to decoding issues that frustrate many parents of students with disabilities. . . Teachers in both special and regular education will also learn a great deal from this guide."

To order, go to [www.EPBookstore.com](http://www.EPBookstore.com)



## Kid's Corner!

By Bonnie Hom, Outreach Assistant

Find the words from the list in the grid. Words may appear horizontally (left to right) or vertically (top to bottom). Some letters are shared among words, so you will see overlap. Challenge yourself and see how many words you can find!

### A Day in the Park - Word Search

B	A	S	E	B	A	L	L	S	K
I	D	U	P	I	C	N	I	C	I
C	O	N	H	I	K	I	N	G	T
Y	G	S	A	N	D	F	S	R	E
C	W	H	F	U	N	L	E	A	P
L	W	I	N	D	Y	O	C	S	A
E	B	N	T	B	I	W	T	S	T
E	B	E	N	C	H	E	S	A	H
B	I	R	D	S	T	R	E	E	S
D	F	L	F	R	I	S	B	E	E
P	A	R	K	D	I	R	T	R	E

- Baseball
- Windy
- Benches
- Sand
- Grass
- Flowers
- Paths
- Frisbee
- Sunshine
- Fun
- Trees
- Park
- Insects
- Bicycle
- Birds
- Picnic
- Dog
- Dirt
- Kite
- Hiking
- Leap

# Hydrocephalus Association 2009 MEMBERSHIP FORM

RENEWAL     NEW

Name: \_\_\_\_\_ Telephone: \_\_\_\_\_

Address: \_\_\_\_\_

Email: \_\_\_\_\_

Name of person with hydrocephalus: \_\_\_\_\_ Birth date: \_\_\_\_\_ Age at diagnosis: \_\_\_\_\_

His/her relationship to you:  self     child     parent     spouse     friend/other relative     N/A (professional member)

Count me in as a member for 2008. Enclosed is my unrestricted donation of:

\$30     \$50     \$100     Other \$ \_\_\_\_\_

**How would you like to receive your quarterly newsletter?**

*Opt to receive your newsletter via email — this will allow the Association to put a portion of the \$30,000 annual printing and postage costs to other programs.*

Please send my newsletter via email to: \_\_\_\_\_

I still prefer to receive a printed copy of the newsletter via the US mail.

Charge my:  VISA     MasterCard     Discover    Amount Charged \$ \_\_\_\_\_

Card No. \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_ Exp. Date \_\_\_\_ / \_\_\_\_ VIN # \_\_\_\_\_

Print Name \_\_\_\_\_

Signature \_\_\_\_\_

Please remove my name from your mailing list.

I cannot afford a donation at this time but I would like to be counted as a member.

**Please check all that apply:**

I am on SSI or Disability.     My medical bills have exhausted my finances.     My income is below \$30,000 per year.

*Please return this form with check, money order or completed credit card information to:*

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Tel. 415-732-7040 ■ Toll Free 888-598-3789 ■ Fax 415-732-7044 ■ Email: info@hydroassoc.org

The Hydrocephalus Association is a national nonprofit organization providing support, education, resources and advocacy for families and professionals. The Newsletter is published quarterly. Dory Kranz is the editor. Articles included in the Newsletter are for the reader's information and do not signify endorsement by the Association. We welcome letters and articles from our readers but reserve the right to edit any material submitted for publication. Information and articles from the Newsletter may be reprinted provided a full citation of source is given.

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### **Hydrocephalus Association**

*serving individuals, families and professionals since 1983*

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## **HYDROCEPHALUS ASSOCIATION RESOURCES AND FACT SHEETS**

**The following resources are available free to our members:**

*About Hydrocephalus—A Book for Families* (in English or 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*

#### **Fact Sheets**

Primary Care Needs of Children with Hydrocephalus

Learning Disabilities in Children with Hydrocephalus

Hospitalization Tips

Headaches and Hydrocephalus

Social Skills Development in Children with Hydrocephalus

Eye Problems Associated with Hydrocephalus

Survival Skills for the Family Unit

Durable Power of Attorney for Health Care Decisions

Endoscopic Third Ventriculostomy

Cerebrospinal Fluid Shunt Systems for Management of Hydrocephalus

Nonverbal Learning Disorder Syndrome

How to Be an Assertive Member of the Treatment Team

Second Opinions

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