

CONGRATULATIONS TO OUR 2008 SCHOLARSHIP RECIPIENTS!

By Bonnie Hom, Outreach Assistant

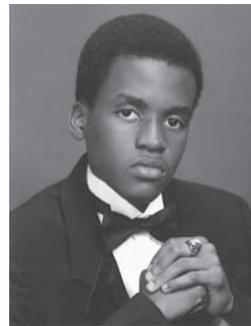
Each year the Hydrocephalus Association awards scholarships to young people with hydrocephalus who are pursuing post-high school education. With the addition of three new scholarships this year, the scholarship committee had the task of awarding a total of 11 scholarships. As you might imagine, it was difficult to choose among the many outstanding applicants. We are pleased to announce that these young adults with hydrocephalus have been selected to receive scholarships this year.

These scholarships were funded by the Gerard Swartz Fudge Memorial Scholarship Fund, the two Morris L. and Rebecca Ziskind Memorial Scholarship Funds, the two Anthony Abbene Scholarship Funds, the Justin Scot Alston Memorial Scholarship Fund, the Mario J. Tocco Hydrocephalus Foundation Scholarship Fund, and the three newly added Laura Beckley Barsotti Memorial Scholarship Funds. We are grateful for their generous endowment so that we can recognize these young adults who have overcome so much and richly deserve a hand. What a great way to invest in the future of our community!

To read their stories, please turn to page 6. A complete list of scholarship finalists appears on page 7.



William "Drew" Davis
Lithia, Florida



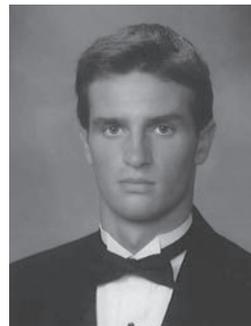
Willis S. Harris
Spring Hill, Florida



Holly



Jeffrey Kosmo
San Diego, California



Ryan
Redwood City, California



Jacob Meyer
Dallas, Texas



Sarah Nichole Plank
Woodbury, Minnesota



Melia Renfer
Sutton, Alaska



Travis Sherrill
Mooresville, North Carolina



Thomas Joseph Sweet
Weiser, Idaho



Lyndsay Werner
Abington, Pennsylvania

FROM THE EXECUTIVE DIRECTOR

The 10th National Conference on Hydrocephalus that took place in June in Park City, Utah was a great success. The theme, “It’s About Life,” proved as inspirational as we had hoped. It was an uplifting experience for those of us who lead and serve the HA to personally connect with so many unique and precious members of our community. At the beginning of the conference Bob Jacobsen shared with us a poem (*shown at right*) that, by all accounts, came true.

We share excerpts from participant feedback, heartwarming photos and gratitude to those who made it all happen in the article on page 8. For more information about the conference, including podcasts of general sessions, click on the 2008 Conference Update link on our website home page, www.hydroassoc.org.

The Distance

The distance between us
is holy ground
to be traversed
feet bare
hands raised
in joyous dance
so that once it is
crossed
the tracks of our pilgrimage
shine in the darkness
& light our coming together
in a bright & steady light.

—Rafael Jesus Gonzales

We list with gratitude our corporate and foundation donors, whose support of our conference, our WALK events, and

our programs allows us to accomplish the exciting successes we have experienced as a community. Additionally, because we inadvertently left the \$250 to \$500 donors out of the list of individual donors in the last newsletter, we name them with gratitude in this issue and hope you will forgive our oversight.

May your summer be full of rest, relaxation and rejuvenation. Check out our summer reading list on page 16 if you have some time to enjoy a good book or two.

The poem, “The Distance” has been reprinted with permission from the author. It originally appeared in RUNES—A Review of Poetry: Connection; CB Follett & Susan Terris, Eds.; Arctos Press, Sausalito, California, Winter 2007; author’s copyrights.

ADVOCATING FOR YOUR CHILD CAN MAKE 2008 GREAT

By Marcia Kelly

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As a parent, you are the best advocate for your child with disabilities. By gaining knowledge about the disability and disability rights laws, you can help ensure that your child receives the services and education to which he or she is entitled. As you look forward to a new year filled with possibilities, you may want to consider these three ways to be an effective advocate for your child.

1. Understand your child’s disability and think about its implications.

“Knowledge is power,” says Virginia Richardson, PACER Parent Training Manager. “In order to advocate effectively for your child, it’s important to know all you can about your child’s disability and how it may affect all areas of his or her life—from education to health care to social relationships.”

- Talk to other parents whose children have disabilities similar to those of your child to gain practical information and resources.

- Learn as much as you can from professionals who work with your child and from the Web, library, and other sources.
- Find information and support at PACER Center and the disability organization appropriate for your child.
- Decide what information is useful to you based on your values, priorities, and cultural traditions.

2. Have high expectations within the context of your child’s challenges and abilities, and involve your child in his or her own success.

“Remember that your child is a child first,” Richardson says. “Acknowledge the difficulty the disability may cause in your child’s life, but always be aware that we all succeed in life based on our strengths. Children need opportunities to explore and develop skills and interests, hobbies and natural talents.”

- Affirm your child’s strengths, such as a kind heart or good memory.
- Help your child understand how he or she learns—whether by using his or her eyes, ears, hands, or some other way.
- Explore how assistive technology might help your child learn and reach goals.

- Challenge your child—and support his or her efforts at trying new things.

3. Learn about the state and federal laws that address the rights of people with disabilities.

“Three federal laws protect the education and civil rights of people with disabilities,” Richardson says. “By understanding these laws, parents can be advocates for their children’s rights.”

- The Individuals with Disabilities Education Act (IDEA) ensures a free appropriate public education (FAPE) for all children with disabilities.
- The Americans with Disabilities Act (ADA) prohibits discrimination on the basis of disability in the workplace, postsecondary education, public services, and community settings.
- Section 504 of the Rehabilitation Act of 1973 prohibits agencies or organizations that receive federal funds from discriminating against qualified individuals solely on the basis of disability.

No one understands your child better than you, and no one else has the vision for his or her future that you do. If you would like more information on the areas mentioned, visit www.PACER.org or call PACER and ask to speak with a parent advocate. ■

THE ROLE OF NEUROPSYCHOLOGY IN ASSESSING AND MANAGING LEARNING CHALLENGES

By David E. Nilsson, Ph.D.

At our national conference in Park City, Utah in June, Dr. Nilsson provided an overview of the specific areas of interest for neuropsychological testing. Below is the handout he prepared for his wonderful presentation.

In our culture, often we refer to IQ, which is probably the least-sensitive measure of neurologic injury or the needs of children with neurodevelopmental disorders. Neuropsychological testing works to understand the broad spectrum of intellectual and cognitive skills toward the end of optimizing educational support and other developmental intervention.

Although there are many characteristics in common for children with a diagnosis of hydrocephalus, the learning pattern or profile is unique for each child. A very common descriptive diagnosis for this group of children and adolescents is that of nonverbal learning disorder (NLD or NVLD). On the surface, NLD does not appear to be that much of a problem. The child may struggle with visual-spatial/perceptual-motor tasks, but language commonly appears intact. However, a major problem is that of conceptually integrating and organizing information in order to learn, function socially, and participate in a variety of activities of daily routine (e.g., sports, driving, dating). Reading of nonverbal social cues heavily involves visual-spatial/perceptual integration and the general organization of information to make sense of the isolated detail available. These problems, which may be apparent early, become more disruptive as development progresses.

I have often been asked how early children should be assessed and when intervention should begin. It is not so critical that extensive neuropsychological testing be administered to infants and toddlers. In anticipation of the potential neurodevelopmental consequence of hydrocephalus, parents should provide a particularly rich developmental environment early, providing high levels of stimulation and support to a greater degree than we would for a child without such a history. A problem with testing early is

that there are relatively few skills that are fully developed and there is a great deal of change through those first years of life. In managed health care, it is particularly critical to judiciously use neuropsychological testing because there are commonly limits to its availability.

The primary function of neuropsychological testing should be to identify specific deficits and to communicate the logic of the difficulties for that individual child to not just the parents but to teachers and others interacting with the child. Neuropsychological testing is also critical in the process of monitoring ongoing neurodevelopment. It is not uncommon for children to regress (i.e., not be able to keep up developmentally). As such, their scores drop, suggesting a pattern of “loss” of function; in reality, they are not keeping up with the demands for speed and complexity required of the test items. Neuropsychological testing is of little value, unless it is specifically applied to the child’s development, providing feedback to therapists, educators, day care providers, and others who interact with the child.

Like many forms of brain injury, parents of a child with hydrocephalus often ask, “What’s the use in providing developmental support? They have brain damage and we cannot fix that.” Although that is true, by providing the child optimal developmental support, parents are better able to help keep the child developmentally on track. Children with hydrocephalus require more stimulation to acquire basic skills that most children acquire automatically. In addition to acquiring those skills, early intervention provides adaptive skills and strategies that children will require as they progress educationally and socially. It becomes particularly critical for this group of children that they learn to be able to understand and recognize their areas of difficulty and participate in the process of identifying, implementing, and evaluating adaptive and compensatory strategies. It is particularly critical for them to ask questions and ask for specific direction and support in completing tasks or learning in a specific environment. ❖

TURNING UP THE DIALS ON RESEARCH

By Dory Kranz, Executive Director

Research is essential to creating a better reality for people living with hydrocephalus. The Association has been taking a progressively more active role in strategically driving research through national advocacy over the last five years. Since June of 2007, the Board of Directors, Medical Advisory Board and management have explored the potential for the Association to take a more direct role in strategically driving and funding research. We have taken the following steps to ensure organizational readiness and inform wise decisions as we move forward on this exciting new strategic initiative.

- Build support at all levels of voluntary leadership through meetings of the Board of Directors and Medical Advisory Board.
- Conduct a professional development assessment which demonstrated organizational capacity and a desire among members for HA to take on raising money to directly fund research.
- Host a multi-stakeholder roundtable on “Accelerating Hydrocephalus Research” with representatives from: researchers, clinicians, parents, advocates, venture philanthropists, private foundations, government agencies, and peer advisors from patient advocacy groups who already directly fund research in various ways.

From these advisory perspectives we hear a resounding recommendation to move into directly funding research – as a way to both strengthen the support, education and advocacy services to which we remain deeply committed and turn up the dials on research toward better treatment and a cure. With clear advice about wise places to begin this effort for maximum impact, the Association management is working on a strategic plan to present to the Board of Directors.

If you would like to offer insight to—or financial and moral support for—this exciting new initiative, please contact me. I look forward to hearing from you. ❖

FOCUS ON HYDROCEPHALUS, PRESENTATION BY DR. JAMES DRAKE

By Mary J. Dufton

This article is reprinted with permission from the Spina Bifida & Hydrocephalus Association of Ontario's (SB&H) Current Newsletter, Winter 2008

Dr. James Drake is Associate Professor at the University of Toronto, Hospital for Sick Children. He is a member of the Hydrocephalus Medical Advisory Board (MAB).



Diagnosis and treatment of hydrocephalus have made great strides over the last 20 years, and while the news is not all good, Dr. James Drake remains optimistic.

Dr. Drake is a renowned pediatric neurosurgeon who earned a reputation in hydrocephalus research. He opened the Hydrocephalus Research Laboratory at Toronto's Hospital for Sick Children in 1988. He is a professor of surgery at the University of Toronto, a senior associate scientist at the Hospital for Sick Children Research Institute, and Chief of the Division of Neurosurgery at the Hospital for Sick Children. He is SB&H's Medical Advisor and a staunch supporter of the association and of individuals with spina bifida and hydrocephalus.

At the recent SB&H annual meeting, Dr. Drake provided an update on hydrocephalus research, including prevalence rates, causes, treatment, new shunt technologies, and secondary conditions.

According to Dr. Drake, hydrocephalus is sometimes confused with other medical conditions.

"We see two or three patients a week at our clinic who are sent to us with the diagnosis of hydrocephalus and don't have the condition. It generates a lot of concern in the families and they come to the clinic expecting a shunt."

He explains that there is a condition called external hydrocephalus where babies have a little extra fluid on the brain. It is identified through an MRI or CT scan. One of the first doctors to identify this condition was a colleague, Dr. Robin Humphreys.

Initially, these babies were shunted to deal with excess fluid in the head, but they don't have hydrocephalus and they can expect to live a normal life, he explains. "Just because you have a little extra fluid doesn't mean you have hydrocephalus."

At the other end of the spectrum, seniors

also experience a condition called Normal Pressure Hydrocephalus (NPH).

"As we age our brains shrink a bit and we have increased fluid in our heads. It is getting a lot of attention right now because the North American population is aging and we are getting more people with potentially this condition. This condition affects our memory and concentration, similar to Alzheimer's disease. It can be hard to tell which is which. Is it hydrocephalus or an age-related condition?"

Although the number of surgeries for children with hydrocephalus has reduced by slightly more than half, the prevalence of the condition has changed and the population examined is not the same as it was two decades ago.

"When I started at Sick Kids, they were doing almost 400 operations a year for children with hydrocephalus," Dr. Drake says. "Now we are down to just over 200. So things have changed dramatically and we regard that as a good thing. The incidence of the condition itself however has changed and that has made us recognize that when we talk about information from 20 years ago we have to be careful because we are looking at a different population."

Dr. Drake remarked on a study conducted by Dr. Doug Cochran, a neurosurgeon in Vancouver, which concluded that there has been a 60% decline in the incidence of hydrocephalus across Canada between the 1990s and 2000.

"In our hospital, we have seen the same thing," he adds. "In the 1980s, 77% of patients with spina bifida needed shunts, which, once again, we regard as a good thing."

According to Dr. Drake, "The reasons for the decline in the rate of hydrocephalus are uncertain; however, it is believed that folate supplements and the addition of it in certain foods are a contributing factor. There is also better prenatal screening in terms of blood work and diagnostics. Ultrasound testing has become a feature for virtually every pregnancy in Ontario. It is also very easy to access pregnancy termination if the parents wish that."

MRIs are now being used in prenatal treatment and diagnosis which makes it possible to examine babies in the uterus and determine potential difficulties.

He adds, "Initially we were very reluctant to do MRIs on pregnant women, but now we believe it is very safe. Moreover, new technology has improved their capabilities and imaging quality."

While there have been technological changes to shunts over the years, Dr. Drake is skeptical about the impact.

"Two brand new valves were tested against an old one and there wasn't much difference in how the patients fared. Forty percent of the patients returned in the operating room within a year and not affected by the valve. The infection rate was eight percent. A new design by Codman, a shunt manufacturer, has a programmable valve, but this did not make much of a difference to the patients."

International studies have been undertaken on the use of a programmable shunt valve versus a non-programmable shunt valves and their effects on normal pressure hydrocephalus. A randomized study was conducted in Holland, which was called the Dutch Normal Pressure Hydrocephalus Study. The authors concluded that if a low pressure shunt is used the results might be better. The Journal of Neurosurgery recommended a programmable valve but realized they did not have enough evidence to make that statement.

"If you were to ask me what the best valve is, I'd have to be honest and say I don't know. We are looking very hard at this and we have been encouraged by new things, but we have to be very careful that we have tested these shunts very carefully and follow these patients for a long time."

FOCUS ON HYDROCEPHALUS, PRESENTATION BY DR. JAMES DRAKE (continued)

Shunt infections continue to occur in patients and are problematic.

“If you have one shunt infection the chances of developing another one immediately afterward are very high at about 25 percent.”

There have been innovations in shunt design and work continues, he notes.

“Codman has a new shunt design that has antibiotics buried in the hardware. These antibiotics are released when the hardware is implanted. There has been mixed information about this. Two trials were conducted that supported the antibiotics and one that does not.

“More investigation is needed. One thing we have learned in the last 20 years is that it is way more complicated than we think. We are also looking at whether the patients are returning to the operating room or not and how the patients are doing.”

A hydrocephalus outcome questionnaire has been developed and is being used around the world. It’s a 51-item questionnaire to determine the individual’s overall health and explores a variety of areas of their life such as their peer relationships and how they function daily. Whether or not the patient has seizures has a significant impact on how the patient is functioning—even more so than shunt infections. Another significant factor is proximity to a hospital.

Although as a pediatric neurosurgeon, Dr. Drake is not involved in adult care, he knows that there is evidence that patients with shunts often have headaches and it is very difficult to determine the cause. He adds, “Depression is also very common in shunted patients and more attention is needed to determine the exact cause.”

Dr Drake has done extensive work in the development of the third ventriculostomy surgery, which is groundbreaking. The procedure involves placing a scope inside the brain. Instead of inserting a shunt, with the use of forceps, a two-millimeter in diameter opening is made. A small balloon is inserted to enlarge the opening to allow the fluid to flow freely.

“It’s a very slick operation that is shorter than a shunt operation and it has more

risk. It requires a professional with a lot of skill. We have been doing this operation for 20 years and are still learning about it. It can be done in young children; the youngest we have done was a 10-month old child and we have followed them for 18 years. It can be very durable.”

Studies on the success rates of the third ventriculostomy procedure have found that age of the patient is the main determinant in the outcome.

“Patients who are operated at a very young age actually did the worst in terms of returning to the operating room. The younger the child, the less successful the operation will be. Interestingly, younger patients with shunts also don’t do as well.”

Priorities for research in hydrocephalus include methods of diagnosis, outcomes, complications, quality of life for patients, neurocognitive outcome, better models and novel interdisciplinary approaches.

In order to effectively address hydrocephalus, a collaborative approach is best.

“Hydrocephalus is a very complex problem and individuals working on their own are not likely to have much of an impact. We are still waiting for the ‘Einsteins of shunts’ to show up but we think that by working together we will do much better.

“Along those lines, we have established a Hydrocephalus Clinic Research Network (HCRN), located in Salt Lake City, Utah. It was funded by an American donor who has a child with hydrocephalus. We have started with three centers which are very interested in hydrocephalus in Salt Lake City, here in Toronto and in Birmingham, Alabama. We are starting with four projects: Anonymous Registration of Patients, Shunt Infection Protocol, Treatment of Intraventricular Hemorrhage and Ultrasound-Guided Shunt Placements.”

Although Dr. Drake remarked that not all the news he gave us was good, he emphasized that if we are going to move forward, we have to look very hard at what we are doing.

“We don’t want to introduce treatments that aren’t effective. I think we are on the threshold and are about to make some major discoveries. I think it will

have to come from networks and collaborations. There is growing interest in hydrocephalus. ❖

QUESTIONS FROM THE AUDIENCE

Question: *Are there any studies on those of us who were shunted, say in the mid-60s? Is my shunt a time bomb in my head? Are there things that can hurt me as I age?*

Dr. Drake: I think we have learned a couple of things. The shunt technology and materials haven’t really changed in about fifty years. The material does wear out in some patients, but it seems to be more resilient in adults than children. There are patients who, for whatever reason, their shunt stops working and we may think they don’t need it anymore. They can develop problems later, so I still think patients need to be regularly followed with medical care. There are no common problems that we see, so I don’t think you need to worry about any time bombs.

Question: *Should follow up be with your neurosurgeon?*

Dr. Drake: There are pediatric hospitals and adult hospitals, just as there are pediatric surgeons and adult surgeons. I can’t speak on their behalf. All pediatric neurosurgeons are interested in hydrocephalus because that is what we see. Adult neurosurgeons are different. There are, however, at virtually every center, neurosurgeons who are interested, so I think it’s a question of trying to find that doctor. Most of the neurosurgeons can deal with a shunt problem, that’s very straight forward.

Question: *My daughter had a shunt put in at birth and it was just revised this June after 12 years of no problems. Does she have a better chance that she will continue on with no problems considering the life of the first shunt?*

Dr. Drake: Unfortunately, whenever you operate on a shunt, you reset the clock to zero; however, it is very good that she is older as younger patients do not do as well.

2008 SCHOLARSHIP RECIPIENTS (continued from page 1)

William “Drew” Davis is the recipient of the **Justin Scot Alston Memorial Scholarship**. He will attend Hillsborough Community College in the Fall semester and then transfer to a four-year university. His interests vary from television broadcasting to public relations to radiology. Despite being born with Goldenhar Syndrome and hydrocephalus and undergoing 46 surgeries, Drew is outgoing, persistent and an advocate in his community. He was a delegate for the Florida Youth Leadership Forum and presented at the Florida Federation Division on Career Development and Transition Conference. He is also a member of the American Red Cross and Fellowship of Christian Athletes. He says, “By far, the most important and enjoyable activity in my life is spending time with my family.”



Holly (who prefers not to have her full name or story published) is one of three recipients of the **Laura Beckley Barsotti Memorial Scholarship**.



Willis Harris is one of two recipients of the **Gerard Swartz Fudge Memorial Scholarship**. His hobbies include reading, writing poetry, conversing about politics, and volunteering. He says, “When I was younger I was sad a lot because I was never able to do what the other kids my age were doing, but as I got older I realized that it is OK that I can’t play sports or that I never spent a full eight months in school because [it has helped me] develop a passion for learning. Hydrocephalus taught me to learn all that I can because after 10 brain surgeries and almost dying twice, I learned to cherish knowledge. With knowledge you can always gain more knowledge, and that is what I have been doing for almost 20 years now.” After receiving his degree at Florida Gulf Coast University, Willis plans to pursue a master’s degree to further his education.



Jeffrey Michael Kosmo is one of two recipients of the **Anthony Abbene Scholarship**. His area of interest is business. He has served on his high school’s student body for four years which included the position of vice president in his senior year. Jeffrey was diagnosed with a brainstem tumor at the age of four and then with hydrocephalus later on in elementary school, but his physical handicaps have not prevented him from participating in the sport he loves—baseball. He was the statistician and manager for the Junior Varsity and Varsity baseball teams. He says, “Sitting in the dugout, game after game, I became part of something much bigger than myself: a team.” His life experiences have taught him to be a more compassionate, spiritual and determined person.



Jacob Louis Meyer is one of three recipients of the **Laura Beckley Barsotti Memorial Scholarship**. Jacob will pursue an MBA degree in accounting and will major in accounting and business management and minor in Spanish at Drake University. He sings bass for two varsity choirs and is an avid bowler since the age of four. He is also involved in the environmental club called Roots and Shoots, and is a member of the National Honor Society. Jacob has a learning disability, but that did not prevent him from taking twelve advanced placement and pre-advanced placement classes. Although he learns a great deal from his classes, he uses himself as a teaching tool for people who are unaware of hydrocephalus. He wants to help others with hydrocephalus by advocating for further funding of hydrocephalus research.



Sarah Nichole Plank is one of three recipients of the **Laura Beckley Barsotti Memorial Scholarship**. Sarah, who plans to become a history teacher, has been accepted into the teaching program at the University of Wisconsin at River Falls. Despite the complications of having hydrocephalus and dystonia, Sarah was on the soccer team and the ski team.

When she is not in school or participating in sports, she volunteers for Wishes and More and Big Brothers and Big Sisters. She has received numerous awards for academic excellence and community service which has highlighted her determination in reaching her goal “to be a successful, independent and compassionate member of our society.”



Melia Renfer is one of two recipients of the **Morris and Rebecca Ziskind Memorial Scholarship**. She is currently studying pre-nursing at the University of Alaska to be a flight nurse and practice emergency medicine. She is also considering earning a Masters in Physical Therapy to achieve her goal of practicing hippotherapy, a treatment strategy that uses the movement of a horse to achieve therapeutic benefits. During the summer, she works as a wrangler and coordinates and teaches group riding lessons to teens. Her struggles with hydrocephalus, such as having issues with balance, have helped her become a better teacher because she had to re-learn the riding skills. She says, “The horses have taught me patience and how to persevere, and those are the things I teach my students.”



Ryan (who prefers not to have his last name published) is one of two recipients of the **Morris L. and Rebecca Ziskind Memorial Scholarship**. Ryan is currently in his third year at Cal Poly St. Luis Obispo pursuing a degree in mechanical engineering. He was diagnosed with a brain tumor and hydrocephalus at three years of age, which led to some difficulty with his memory and learning disabilities. These conditions have not deterred him from pursuing higher education. Ryan devotes much effort and time toward academics and says, “I value my education and feel it is crucial to my success in life.” Outside of school, Ryan has volunteered at Special Olympic events, tutored, and helped build houses in Mexico for families in need. His life experiences have taught him integrity, compassion and leadership.

2008 SCHOLARSHIP RECIPIENTS (continued)

Travis Sherrill is the recipient of the **Mario J. Tocco Hydrocephalus Foundation Scholarship**. Travis will study broadcasting or journalism at Gardner-Webb University. He loves baseball and NASCAR and has been the public address announcer for two baseball teams since 2003 and co-hosted a weekly webcast program. Travis was diagnosed with prenatal hydrocephalus and says, "I know there are other complications that can arise from hydrocephalus, but I am fortunate to have only seizures and blindness to adapt to." In addition to sports, Travis is very active in his church youth group and will volunteer as a camp leader this summer for the Young Life Camp. He looks forward to the opportunity to provide service to other teens and give back to the community.



Thomas Joseph Sweet is one of two recipients of the **Gerard Swartz Fudge Memorial Scholarship**. Thomas will pursue a bachelor's degree in education and plans to be an entrepreneur and have his own business. He describes himself as sociable and active in his community. He volunteers at an after-school program to help elementary school students with their homework, participates in a walking program to promote exercise, and is involved in the Ho Ho Express to help underprivileged children during the holiday season. Although academia is challenging for him, he does not let his limitations or disabilities stop him from "living and being happy. I have a supportive family... good friends and teachers that have been willing to take the extra time to help me. I am lucky!"



Lyndsay Werner is one of two recipients of the **Anthony Abbene Scholarship**. She is currently a student at Alvernia College, pursuing a bachelor's degree in education and she plans to get a master's degree in education. Born with hydrocephalus, she states, "Medical technology has made it possible for me to live a fairly normal life, with the inconvenience of occasional brain surgery. I lost count of my shunt revisions somewhere after twenty of them." Although she has spent a lot of time in hospitals, she has worked hard to complete a challenging high school curriculum and care for her five younger brothers. Lyndsay wants to help others with hydrocephalus by providing them comfort and support, just like those who have visited her and made her smile when she was in the hospital.



CONGRATULATIONS TO THE 2008 SCHOLARSHIP FINALISTS!

Victoria Ackman, Nebraska

Alyssa Adams, California

Jessica Agricola, California

Harrison Allen, Georgia

Roberta Bader, Pennsylvania

William Bakos, Ohio

Aaron Behnke, Missouri

Anna Blake, Maryland

Jesse Bolinger, Iowa

Andrew Brehmer, Wisconsin

Katelyne Brown, South Carolina

Patricia Bugh, Colorado

Chelsea Caniglia, Texas

Gregory Cooper, Michigan

Andrew Cousins, Pennsylvania

Catharine Cox, Virginia

Miles Cramer, Maryland

Katelyn Dekoski, Michigan

Hunter Dellinger, North Carolina

Emily Dempsey, Delaware

Matthew Duggan, Massachusetts

Jessica Duncan, California

Matthew Dutro, Ohio

Amanda Feld, Pennsylvania

Chentell Graham, Idaho

Sarah Hochberg, New York

Benjamin Jaehning, Colorado

Kevin Joslyn, Massachusetts

Shehani Karunanayake, Gampaha,
Sri Lanka

Josephine Kelley, Georgia

Shaylyn Kelly, Massachusetts

Rebecca Kemen, Indiana

Greg Kirby, Oregon

Stephanie Kluttz, North Carolina

Michelle Koehler, New Jersey

Laura Landers, Arkansas

Alison Laven, Minnesota

Joshua Levy, New York

Jenna Lodge, Virginia

Christopher Loveless, Illinois

Grace Majors, Illinois

Daniella Matthews-Trigg New
Mexico

Sara McCumba Texas

Mallory McGinnis, Arkansas

Nichole McKeever, Ontario, Canada

Brandon Miller, Illinois

Sarah Morgan, Michigan

Nora Morrison, Texas

Virginia Muhuthia, Ngong Hills,
Kenya

Maria Nevarez, New York

Brendan Neville, Michigan

Juliette Ohan, California

Jack O'Shaughnessy, California

Christine Pappalardo, Illinois

Prisca Patrick, Mississippi

Lara Pontiff, South Carolina

Cameron Poole, Massachusetts

Benjamin Rankin, Kentucky

Michael Riccio, Florida

Sari Rosenfield, Michigan

Jennifer Sandwell, Oklahoma

Naunie Stedman, Colorado

Quintessica Telsee, Louisiana

Antonette Travline, Wisconsin

Bryn Van Horn, Colorado

Patrick Waller, Virginia

Hannah Walton, Michigan

Crystal Williams, Alabama

It's About Life

2008 CONFERENCE IN PARK CITY, UTAH

Our 10th National Conference on Hydrocephalus wowed 'em in the beautiful mountains of Park City, Utah. We had presentations, scenery, talent, Boozle bear stuffing, dancing, dining, laughing and smiling. We met new friends and said hello to old friends. Special thanks to our Conference Medical Directors, Dr. Marion (Jack) Walker and Dr. John Kestle, for their hospitality and the quality of clinical and scientific expertise they brought to the conference; our Board of Directors;

our Medical Advisory Board; and our incredible sponsors and volunteers. We also give very special thanks to Sherman Alexie, Dr. Douglas Brockmeyer and Dr. Edward Clark, our keynote speakers. However, the biggest thanks go out to you, the members of our community, who make it all happen. Here are some of the comments we have received letting us know what the conference meant to you. ❖

"...congratulations on an amazingly successful conference launched with Dory's wonderful update on HA activities. I am thrilled to be a part of the new directions and feel very confident that we can all figure out the best path into the future."

"...Kudos to all; it was another outstanding conference from start to finish. ...the affirmation from our community shows how important these conferences are."

"...It was a wonderful and informative Conference this past weekend in Park City, Utah. I had the pleasure of meeting so many people living with Hydrocephalus and I feel even more inspired and compelled to become further involved."



Meet our WALK chairpersons.

"...Please accept my deep appreciation on behalf of your staff and board for organizing an uplifting conference for me and the other hydros and their families who came to Park City."

"...I cannot thank you enough for starting the conference off with the small breakout groups for Mothers and Fathers...From the time the boys met they wanted to spend as much time as

they could together. Please pass along my thanks and appreciation to ALL involved in making this happen."

"It was ...truly inspirational."

"Thanks again for another terrific conference. This was our fourth, and we continue to get more and new things out of each one. My son is now 13 and our whole family continues to grow, learn, and meet and help others thanks to the Association."

"Our family just returned home from the conference and we wanted to say that we really enjoyed ourselves. The sessions were very informative and helpful, and we made many personal connections with other families, which was very valuable. We left on Sunday feeling encouraged and inspired. The kids also had a blast at the day camp. This was our first conference and it will definitely not be the last."

"Thanks for a very valuable conference. We always appreciate the effort and energy that goes into creating these successful events. ...The kids camp was terrific. Our children thoroughly enjoyed and it gave us the opportunity to get the most out of the sessions."



Conference sessions were informative and well attended.

"...What an absolutely wonderful time my husband and I had at the conference! We appreciate the support that the Hydrocephalus Association has provided us along the way...and the avenue in which we parents and advocates are able to network to find others out there that share in our experiences, both the good and bad. I think it has brought about relationships that will remain for a lifetime! It couldn't get any better than that, and for that, I am one parent that is eternally grateful!!!!"



Welcome to Boozlepaloosa 2008!
The Boozle-making session was a hit with the young crowd.

Some of us know that Boozle-making is a serious business.

It's About Life

DISTINGUISHED ACHIEVEMENT AWARDS

Hydrocephalus Association Distinguished Achievement Awards were given at the 10th National Conference on Hydrocephalus to Cynthia Solomon and Dr. Michael Edwards in recognition of their work on behalf of the community of people with hydrocephalus. The award, shown here, features a painting entitled "My Shunt." The artist, Tim Kean, at the age of 24, painted the piece during the summer of 2005 while he endured an eight-week stay in the hospital due to complications of hydrocephalus.

CYNTHIA SOLOMON

In the early 1980s, Cynthia Solomon, a mom confronted with her son's diagnosis of hydrocephalus, recognized the need for an organization to support and foster the needs of individuals and their families and friends who are impacted by this condition. At that time, there was a lack of information available to individuals and their families impacted by hydrocephalus. The industry had not yet recognized patients and families as the "customer" for shunt products; they were focusing primarily on clinicians. By applying her knowledge in the health care field and her incredible organizational skills, Cynthia was instrumental in setting up the infrastructure and providing direction for the Hydrocephalus Association. Over the years, she has been active on the Board and contributed to the organization in many other ways. She has developed a Personal Health Record (PHR) specifically designed for patients with hydrocephalus and she is a leader in the development and regulation



of electronic medical records nationally. Cynthia continues to be an enthusiastic supporter and friend of the Association.

MICHAEL EDWARDS, M.D.

Dr. Michael Edwards was the neurosurgeon caring for a number of the individuals with hydrocephalus whose parents founded the Hydrocephalus Association. In addition to providing the direct care and support for his patients and counsel to their families, he recognized the need for an organization to provide education, support and advocacy for individuals with hydrocephalus as well as their families and health professionals treating this condition. Before a formal Medical Advisory Board (MAB) was formed, he served in this capacity, answering questions, speaking at meetings, assisting with the development of the first patient manual developed by the Association. Over the years, Dr. Edwards has continued to serve on the MAB in active and emeritus capacities, and he is always available to his patients and to the Association when help is needed.

Cynthia and Michael's vision and enthusiasm continue to inspire those actively involved in the hydrocephalus community. ❖

2008 CONFERENCE IN PARK CITY, UTAH (continued)

"...All of the sessions were top notch, and there was a lot of information shared!"

"...thank you all for a very, very special conference...for taking the time to make the conference a place where I felt that he matters. Your efforts were felt and I believe that the association is moving in a direction that will really, serve our community, our tribe, our family."

*Frolicking...
it can happen to anyone.*



Tee Shirts, Hats and Picnic Blankets Available

We have a limited number of 2008 Conference tee shirts in stock along with Hydrocephalus Association hats and picnic blankets that fold up into a convenient carrying case.

To order call 888-598-3789.



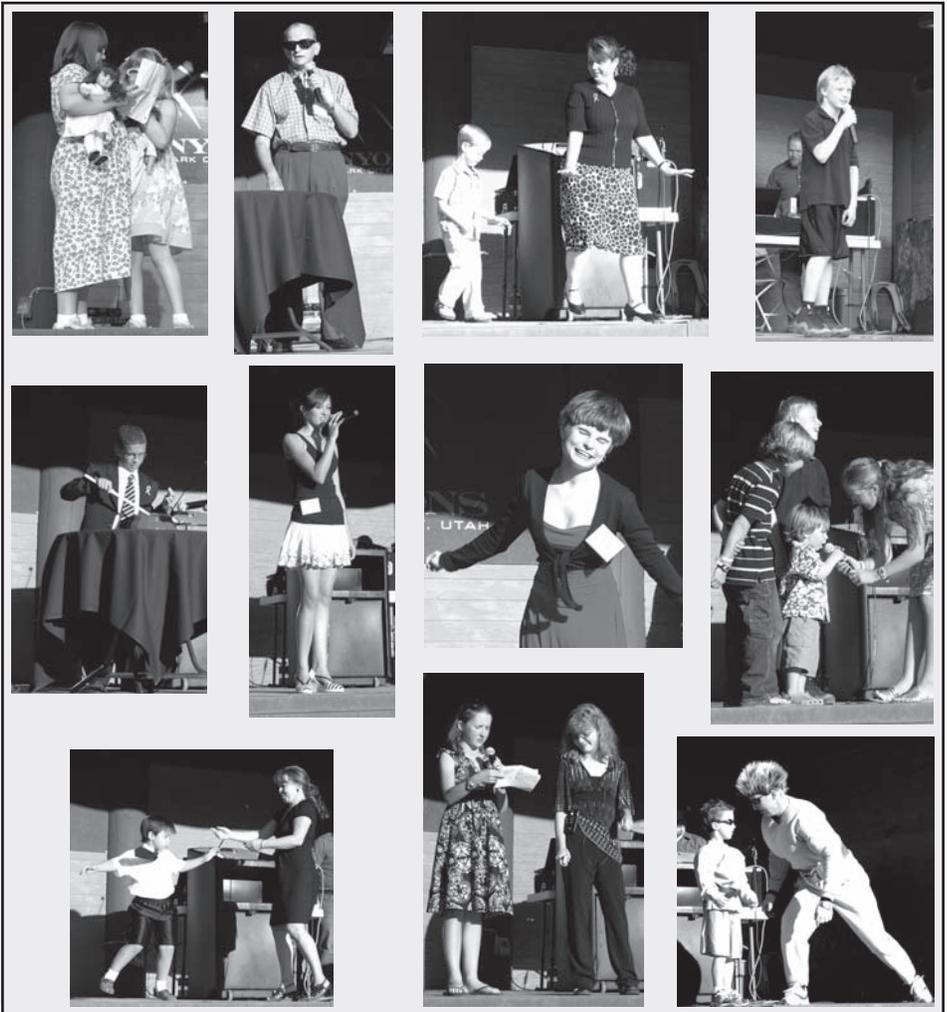
It's About Life

TALENT SHOW = TALENT SHARE

At the 10th National Conference on Hydrocephalus we had a chance to see some of the many talents we share. At our first community "Talent Share" in a beautiful outdoor theater, we had dancing and singing and drumming and poetry and a couple of small plays. Special thanks to all of our participants for helping to make this such a rich experience.

2008 TALENT SHOW PARTICIPANTS

- Paula and Jeremy Keyser
- Madison, Mitchell and Matthew Pardi
- Chris and Joseph Batterman
- Milt Newman
- Maria and Leah Tatman
- Drew Duncan
- Hilda and Lucas Lawrence
- Maria Tatman
- Samantha Dunn
- Angela Batterman
- Lisette Tischner and Sarah Norh
- Kate Bradley
- The Teanarello Kids
- Elijah Lawrence



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Aesculap, Inc.



The Hydrocephalus Foundation, Inc.
"Reach Out, Reach Up"



Kid's Corner!

By Bonnie Hom, Outreach Assistant
Special thanks to Jacqueline Lui

Walk in Park City, Utah

There are seven differences between these two pictures. Can you find them all?



Hydrocephalus
I have an ugly thing, called hydrocephalus. You have hydrocephalus when you are a prementure baby and you have a shunt. Shunts are things that can help you stay alive. There's a bord of dreictors that have a meeting and I goiny to Salt Lake city for the next meeting. I have a stuffed

and I put the shunt in.
→ We always go on a 5 mile hike each year. My family and I meet with the the group once a year. After the hike we eat. Next we chat. And then it's time to go home.

Hydrosefelus

By Tess, 10 years old

The second picture is missing:
cloud, stripes on shirt,
walking stick,
pocket on shorts,
flowers, tree trunk,
sun (replaced by moon)

ANSWER:

RESEARCH ADVOCACY UPDATE—ON THE HILL IN MAY

By *MaryBeth Godlweski, Advocacy Director*

We are pleased that our advocacy efforts are starting to pay real dividends. The National Institutes of Health (NIH) nearly tripled funding for research related to hydrocephalus (from \$650,000 to \$1.73 million) in the first budget cycle after our congressional resolution and appropriations report language were passed. This funding is a great show of support during a year in which the overall NIH budget did not increase. Although the numbers are still unacceptably low compared to what is needed for ongoing research, we are actively building on this triumph.

We are focusing our efforts on several important fronts:

- 1) Continue working to secure strong hydrocephalus report language in the relevant House and Senate appropriations bills.
- 2) Increase awareness and support of hydrocephalus issues in Congress to insure hydrocephalus-related language is included in all appropriate bills.
- 3) Reach out to other federal health agencies to enlist their help in working on hydrocephalus.
- 4) Develop new allies and supporters to maximize our chances of success.

In May, HA Executive Director Dory Kranz and I continued to take action on all fronts through a series of Congressional and agency meetings arranged with the help of Government Relations Consultant Deborah Outlaw. Each meeting afforded us the opportunity to make progress on HA's advocacy agenda while creating opportunities for future involvement.

Here are some highlights of our meetings:

- Rep. Jean Schmidt (R-OH), the first woman to represent Southern Ohio in Congress, expressed exemplary personal interest and commitment to hydrocephalus as well as a keen understanding and willingness to help with key issues facing our community. Although her committee assignments in Congress do not have direct health

care jurisdiction, Rep. Schmidt will be a key ally. We were introduced to Rep. Schmidt through Jenny Ahl, a member of the HA's Northeast Ohio Affiliate, who came forward after I spoke at a support group meeting about our advocacy and awareness efforts.

- We met with John Myers, the senior health legislative assistant for Sen. Arlen Specter (R-PA), to thank him for the Senator's past support and to promote continued interest in HA issues. Congressional staff is inundated daily with hundreds of requests, so it is important we continue to stay in close touch with staffers in all offices.
- We visited the office of Sen. Dianne Feinstein (D-CA) to introduce HA and emphasize our California presence. We provided an overview of the history of HA and the basic issues surrounding hydrocephalus to Legislative Assistant Kristin Wikelius, who was interested and receptive.
- We met with Sen. Hillary Clinton's (D-NY) legislative assistant, Ann Gavaghan, to express our gratitude for the Senator's support in introducing Senate Resolution [S. Con. Res. 63] earlier this year and to encourage the Senator's continued support.
- Through Senior Legislative Assistant Travis Robey we thanked Rep. Mike Thompson (R-CA) for his leadership with House Resolution [H Con. Res. 74], which passed in 2007.
- Sen. Patty Murray (D-WA) is particularly interested in veterans' health care issues and has sponsored various legislation promoting specific health care needs for this population. We met with Legislative Aide Patrick Loney to educate about HA and enlist support for hydrocephalus-related language as these bills move forward.
- Rep. Tim Murphy (R-PA), the only child psychologist in Congress, has a special appreciation of issues affecting children, and he serves on the House committee charged with direct oversight of substantive health legislation. In meeting with Legislative Director

Brendan Belair, we introduced HA and expressed the strong grassroots interest in Pennsylvania, which served as a foundation for building a positive relationship for future efforts.

- While meeting with Denise Daugherty of the Agency for Healthcare Research and Quality (AHRQ) we were able to draw some possible links to HA research with AHRQ's overall mission and research agenda. We learned of an upcoming federally spearheaded pediatric medical device meeting in July that one of the HA's Medical Advisory Board members will attend.
- A meeting at the Institute of Medicine (IOM) included representatives from four IOM divisions with interests in public health, children's issues, and military/veterans research and afforded HA the opportunity to address a number of our key issues from a wide-ranging perspective with members of this prestigious scientific community.
- HA participated in an all-day meeting with senior staff from the National Institute of Neurological Disorders and Stroke (NINDS) and other members of the advocacy community to discuss ways in which important research needs can be met, particularly in a time of increasingly tight NIH budgets. We appreciated the opportunity to provide feedback on hydrocephalus research needs with senior NINDS staff while building on our positive relationship for future interaction.

We continue to enhance our advocacy outreach to Congress and federal agencies on behalf of all those whose lives are touched by hydrocephalus. The May series of meetings helped move us forward, serving as useful adjuncts to our ongoing efforts to increase interest and support for hydrocephalus research at NINDS and other federal agencies. We expect this momentum to continue in the months ahead as we gear up for a new Congress that we hope will be keenly interested in addressing major health issues. ❖

BLOOMSBURG, PA KICKS OFF WALK SEASON

When Emylee Waterman was 2 months old, she was diagnosed with hydrocephalus. Now she is 17 years old, and on Saturday, June 7th, Emylee and her friend, Rachel Shaffer, kicked off the 2008 WALK season in Bloomsburg, PA. The two teenagers took command, planning and executing the entire event, which included a picnic, special auction, games and face painting.



Emylee and Rachel

Walking for awareness

www.hydroassoc.org/help/walk
for information about
WALK events in your area.

"I am so in awe over these two girls," says Marybeth Godlewski, National Advocacy Director. "They've been planning this since November. Emylee is a junior in high school and she completed her finals the week she was putting on an event. Most of the time when you're planning an event you're a nervous wreck, but I was talking to the girls a couple of days before and they actually giggled. If you're giggling four days before an event...you're special."



WALK Season is Here! We'll Help You Get the Word Out

Having kicked off our WALK Season in Bloomsburg, PA it is time to consider how best to get the word out about the upcoming WALK events. The most critical element in getting media exposure for a WALK event, or any event, is time.

Starting at least a month ahead of time provides the best opportunity for media success. I am eager to help craft and pitch stories. Looking toward September, we have as many as five events in a single weekend, so please contact me in early August if your event is in September. Let's work together to achieve maximum media exposure for these events!

To discuss an upcoming event, contact me at 415-732-7043 or Tom@hydroassoc.org.

STANFORD SWIMMERS RAISE FUNDS AND AWARENESS TO HONOR SISTER

By Tom Smith, Outreach and Media Liason

On June 28, almost 970 hearty souls braved the icy currents of San Francisco Bay in an annual "Escape from Alcatraz" swim known as Sharkfest. The swim is 1.5 miles long and goes from the notorious prison to San Francisco's Aquatic Park. Pete Finlayson, his brother Sam, and friends from Stanford participated in honor of Kate Finlayson, Pete and Sam's sister. Says Pete, a member of Stanford's Varsity Water Polo team, "Kate is one of the kindest, most inspiring people I've ever met."

Diagnosed with hydrocephalus shortly after birth, Kate Finlayson, now 23, was a competitive swimmer until medical complications over the past few years forced her to undergo more than 60 surgeries. Because of these complications, Kate finished high school bedridden and has recently been forced to drop out of college. A particularly rough recent hos-

pitalization inspired her brothers to help however they could.

By participating in Sharkfest with their teammates they have raised thousands of dollars for the Hydrocephalus Association while increasing awareness. At the end of the race, huddled in bright red robes, tee shirts blazoned with "Team Hydro" and grins a mile wide, they could hear the loudspeaker calling out their names.

Sharkfest divides contestants into several categories: age (broken down into five-year increments) and wetsuit or non-wetsuit competitors. Most swimmers opt to wear a wetsuit because the Bay is notoriously cold; however some swimmers decide to add an extra challenge by not wearing one.

Team Hydro did themselves and all of us at the Hydrocephalus Association proud by not only participating in the event, but by placing in all categories. Three members placed first in their age-group, with one member coming in

second. They also had the second place finisher in wetsuit and non-wetsuit categories as well as sixth and tenth place finishers in the non-wetsuit category.

We at the Hydrocephalus Association would like to thank and honor these athletes. Pete Finlayson, Sam Finlayson, Steven Wright, Ryan Kent, Ryan McCarthy and Andrew Rogers are brothers and friends joined together for the sake of Kate Finlayson and everyone living with hydrocephalus. ❖



Team Hydro: (left to right) Steven Wright, Peter Finlayson, Sam Finlayson, Ryan McCarthy

Donors

We inadvertently left the \$250 to \$500 donors out of the list of individual donors in the last newsletter, we name them with gratitude in this issue and hope you will forgive our oversight

SUSTAINER: \$250-\$499

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Participate in Research into the Quality of Life of Individuals with NPH

The Spina Bifida and Hydrocephalus Association of Ontario (SB&H) is looking for quality-of-life information from individuals with normal pressure hydrocephalus (NPH). SB&H is proud to be supporting the research of Dr. Safraz Mohammed from St. Michael's Hospital Division of Neurosurgery. He is working under the supervision of noted neurosurgeon and adult hydrocephalus expert Dr. Michael Cusimano. Dr. Mohammed and his research team are developing a comprehensive questionnaire to assess the quality of life of people with NPH. He is asking people with NPH to complete a preliminary survey to determine the best questions to include in the final questionnaire for the study. We encourage you to complete the survey. The more who participate, the more reliable the questionnaire will be.

By completing this survey, you will help doctors understand the impact of hydrocephalus on a person's life. Doctors can use this information to tailor treatment to meet the specific needs of each person. No identifying information will be collected, and your responses will be anonymous.

To complete the survey online, go to:

<http://www.sbhao.on.ca/research.asp>

To receive a questionnaire on paper along with a postage paid return envelope so you can return it at no cost to you, please contact SB&H at:

P.O. Box 103, Suite 1006
555 Richmond Street West
Toronto, Ontario M5V 3B1
or 1-800-387-1575

Corporate and Foundation Supporters 2007

Corporate and foundation grants, accounting for about a third of our revenue in 2007, allow us to expand programs and improve our efficiency and effectiveness. Grants directed to sponsor WALK events insure that all of the money raised by participants can be used for mission-related programs. Thank you all for your generous support.

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NEW JERSEY SET TO ANNOUNCE SEPTEMBER 2008 AS HYDROCEPHALUS AWARENESS MONTH

On June 6th, 2008 Congresspersons in the State of New Jersey voted to let Senate Resolution No. 49 and Assembly Resolution No. 124 out of committee and onto the floors of the Senate and State Assembly for votes. The resolutions call for naming September 2008 as "Hydrocephalus Awareness Month" for New Jersey. The resolutions have passed unanimously in both houses of legislature and are awaiting the governors signature, which is expected soon. The Garden State joins California, Pennsylvania, and a growing list of states bringing awareness to hydrocephalus across the country.

As we all know, one of the greatest challenges facing the hydrocephalus community and the state of health care in general is the question of awareness and lack of national, or even statewide, standards for diagnosis and treatment

The Association salutes Sens. Joe Kyrillos (R), Senator Joe Vitale (D) and cosponsors Sen. Leonard Lance (R) and Assemblyman Jay Webber (R) for introducing this resolution and thus drawing statewide attention to hydrocephalus. Special thanks also to Michael Illions, Hydrocephalus Association advocate for the state of New Jersey for his work in making this happen. ❖

Late Breaking News

As of July 22, the NJ State Assembly has adopted AR124 naming September as Hydrocephalus Awareness Month.

SUMMER READING

Looking to add to your summer reading list? We are happy to help with some suggestions! We have tried to include some reading for everyone, though most of these recommended books are for parents, teachers and professionals working with children with hydrocephalus. The quoted reviews in certain titles are from leading professionals and specialists in their fields.

Learning Disabilities and Challenging Behaviors: A Guide to Intervention and Classroom Management, 2nd Edition

By Nancy Mather, Ph.D. and Sam Goldstein, Ph.D.

“One of the best books about learning disabilities. . .that I have seen in a long time. Its greatest strength is in its practical suggestions. . .These authors have done a splendid job of providing a readable text for both the beginner and the advanced student in the field of learning and behavioral difficulties.”

Road to Reading: A Program for Preventing and Remediating Reading Difficulties

By Benita A. Blachman, Ph.D. and Darlene M. Tangel, Ph.D.

“Here are the follow-up lessons that we’ve all been waiting for. . .*Road to Reading* can be used in conjunction with any reading series to ensure that primary grade students build the fluency in word identification essential to comprehension.”

The Special Needs Planning Guide: How to Prepare for Every Stage of Your Child’s Life

By John W. Nadworny and Cynthia R. Haddad

“Excellent. . .simply written and understandable, yet concise enough to serve as a road map that will assist families of persons with special needs to navigate the highway of life from childhood to adulthood.”

“Will become a classic for families who have special needs children. . .There is no other resource book like it for parents.”

Powerful Writing Strategies for All Students

By Karen R. Harris, Ed.D., Steve Graham, Ed.D., Linda H. Mason, Ph.D., and Barbara Friedlander, M.A., NBCT

This book has highly effective, field-tested lesson plans for the students in every elementary and middle school classroom who struggle with writing. The practical how-to follow-up to Graham and Harris’s popular *Writing Better*, this book is just what K–8 educators need to advance all students’ writing skills, whether they have learning disabilities or just need extra help.

Young Children with Disabilities in Natural Environments: Methods and Procedures

By Mary Jo Noonan, Ph.D. and Linda McCormick, Ph.D.

“An interesting book. . .[with] excellent ideas that teachers and parents can use to support young children with disabilities.”

Why Is Math So Hard for Some Children? The Nature and Origins of Mathematical Learning Difficulties and Disabilities

Edited by Daniel B. Berch, Ph.D. and Michèle M.M. Mazzocco, Ph.D.

“The best analysis and presentation of the science of learning disabilities and difficulties in mathematics development to date. This is a profoundly important book.”

Everybody’s Different: Understanding and Changing Our Reactions to Disabilities

By Nancy B. Miller, Ph.D., M.S.W., and Catherine C. Sammons, Ph.D., M.S.W.

“This is a great book. It provides us with a way to understand our feelings and move beyond fear and discomfort toward a greater tolerance and appreciation for all peoples. It’s a must-read for anyone working or living with persons with disabilities. In fact, it’s a must-read for everyone who cares about creating a more loving world.”

Love you to Pieces: Creative Writers on Raising a Child with Special Needs

Edited by Suzanne Kamata; includes an excerpt from Marcy Sheiner’s book, *Perfectly Normal: A Mother’s Memoir (Marcy’s son Daryl was born with hydrocephalus.)*

It’s a terrific collection, with writing by Jayne Anne Phillips, Michael Bérubé, and a host of others. Kamata says in her introduction, “I’m the kind of person who looks to literature to make sense of life, so when I learned my daughter was deaf and had cerebral palsy, I sobbed for a while and then logged onto Amazon.com.” Finding little in the literary genre about children with disabilities other than the “inspirational” model, she got to work.

Note that, in her intro, Kamata made the mistake of saying that hydrocephalus wasn’t successfully treated with a shunt un-



til the 1970s. Daryl was born in 1965; the shunt had been in use since the 1950s.

Parenting Children with Health Issues: Essential Tools & Tactics for Being a Great Parent When Every Moment Matters

By Foster W. Cline, M.D. and Lisa C. Greene

Introducing a first-of-its-kind program created to teach parents, caregivers, medical providers and mental health professionals essential tools, tips and tactics for raising kids with chronic illness, medical conditions and special health care needs. Whether a child struggles with weight problems, diabetes, cancer or any other health issue, you will learn the skills you need to help children comply requirements, cope well with health challenges, and live hope-filled lives. Get practical and compassionate answers to your toughest questions as you discover effective ways to communicate about health issues with children of all ages.

“This book beautifully speaks to the special issues of parenting children with chronic medical conditions.”

To order this book, go to www.ParentingChildrenWithHealthIssues.com.

Changed by a Child: Companion Notes for Parents of a Child with a Disability

By Barbara Gill

“While this book is written for parents, it should be mandatory reading for medical students, pediatricians, as well as students and practitioners in the health professions. This is a book to treasure and to read and reread many times. Barbara Gill is to be thanked for putting into words what most of us may feel but often find it difficult to describe.”

Bridging the Gap: Raising a Child with Nonverbal Learning Disorder

By Rondalyn Varney Whitney

Your child may be one of the millions who suffer from Nonverbal Learning Disorder, a neurological deficit that prevents children from understanding nonverbal cues such as tone of voice and facial expression—

SUMMER READING (continued)

subtle signals that play a crucial role in communication. Though they are exceptionally bright and extremely articulate, these children often have difficulty in social situations and can become depressed, withdrawn, or anxious. In *Bridging the Gap*, Rondalyn Varney Whitney, a pediatric occupational therapist, provides strategies that will help you put your child on the path to a happy, healthy, fulfilling life.

The Memory Bible: An Innovative Strategy for Keeping Your Brain Young

Gary Small, M.D.

We all forget things sometimes—our keys, a phone number, the reason we went to the market—and our forgetfulness only increases with age. According to Dr. Gary Small, Director of the UCLA Center on Aging, we can easily eliminate much of this problem with his innovative memory exercises and brain fitness program.

“I highly recommend this book to all who wish to keep their brains fit and their memories at peak performance as they age.”

Sibshops: Workshops for Siblings of Children with Special Needs, Revised Edition

By Don Meyer, M.Ed., and Patricia Vadasy, Ph.D.

“A real winner. It is clear, concise, and full of great information. A must read for those interested in serving and supporting siblings of people with special needs of all ages.”

“The authors have not left out anything that would be useful in starting one of these highly effective play and discussion groups. Written in a lively, informal, easy-to-understand way, this book is excellent.”

My Brain Won't Float Away/Mi Cerebro no va a Salir Flotando

By Annette Perez

In her first children's book, Puerto Rican author Annette Perez tells her true story of growing up with hydrocephalus. Pérez narrates her tale told through the eyes of Annie, an eight-year-old girl, who is the target of ridicule inflicted by the children at her school. Despite being ostracized at school for being different, Annie overcomes her fear of not being accepted by her peers through the realization that her condition is her strength rather than her weakness as others might see it. Annie's optimism at the conclusion of the story leaves readers inspired and hopeful.

There are few children's books on special needs, and virtually none about hydrocephalus. When asked about what she wishes to achieve, Ms. Perez writes, “With this book, I hope to raise some awareness in people, both adults and children. I want people to understand that we, as disabled people, have feelings too. Furthermore, I want to give some hope and awareness to those individuals who are living and dealing with a similar situation.”

To order this book, go to:
www.editorialcampana.com

Having Hydrocephalus: A Book for Children and Families

By Ellen and Brian Kaczor

This book is a simple story to help explain complex medical language to a child about having hydrocephalus and a shunt. The book also includes important contact information for additional resources and support.

Elvin The Elephant Who Forgets

By Heather Snyder, Ph.D.;
illustrated by Susan Beebe

A delightful children's book about a little elephant named Elvin, who has a tree branch fall on his head! He can't count his figs, gets mixed up at school, and doesn't get along with his friends and classmates. This is a great book for understanding brain injury and its effects at school.

To order this book, go to:
www.lapublishing.com

A Hit on the Head and Where It Led

By Jennifer Cooper-Trent
Illustrated by Anthony Mitchell

This children's book has wonderful color illustrations that tell the story of a young boy who is hit by a car while riding his bike. He has an ambulance ride to the emergency department and has many tests in the hospital, including a CAT scan and neurosurgery. After he goes home, he returns to school and is puzzled by the reactions of his friends and discouraged by difficulties with school work. This book is for children's hospitals, pediatric rehabilitations programs, schools and home care agencies. Families, nurses, child life specialists and teachers will find it useful to help children understand what it means to have a brain injury and to educate their siblings, peers and classmates.

To order this book, go to:
www.lapublishing.com

The Get Well Soon... Balloon! When A Parent has a Brain Injury

By Vicki Sue Parker
Illustrated by Susan Beebe

This story captures the upheaval in a child's world when a parent has a brain injury. It helps family members explain the effects of a brain injury to children. Most of all, it helps children understand their feelings as they try to make sense of their altered world. This book is a helpful tool for young children as they grieve and struggle to reform their relationship with a parent.

To order this book, go to:
www.lapublishing.com

The Sibling SLAM Book: What it's REALLY Like to Have a Brother or Sister with Special Needs

Edited by Don Meyer

Give teenagers a chance to say what's on their minds and you might be surprised by what you hear. Don Meyer invited a group of 80 teenagers to come together from all over the United States and abroad. They talked openly about what it's like to have a brother or sister with special needs. Their unedited words are found in this brutally honest look at the lives, experiences, and opinions of siblings who have brothers or sisters with special needs.

To order this book, go to:
www.lapublishing.com

Miracle in Lane 2 (DVD)

Distributed by Buena Vista Home Entertainment

Actor Frankie Muniz (*Malcolm in the Middle*) stars as Justin Yoder, a 12 year old living with spina bifida and hydrocephalus. Justin refuses to let his physical challenges interfere with his desire to win a trophy. Justin discovers that it's perseverance that makes a winner as he prepares for a national soapbox race. The movie also addresses family issues that can arise when one child has a disability. It's a fun, fresh, story that combines courage, challenges and thrills. (Base on a true story.)

Available from:
www.amazon.com or
www.disneydvd.com



News Notes

BOOZLE'S BIG PREMIER A HIT!

Many people got their first look at Boozle Bear at this year's conference in Park City, Utah. Boozle made a great first impression, but it was a long road getting this bear to the conference. A patent needed to be filed; then child safety tests needed to be performed; then more tests were needed for Pennsylvania, Ohio and Massachusetts; then we needed to change Boozle's labels; then we had supply issues; then we had to figure out the cost feasibility if we needed to mail

boxes of fabric to be cut, or embroidered, or stuffed, or sewn. We had many stops and starts. Individuals who originally contacted the Association to help may not have received the response they expected, and we sincerely apologize. However, most of these difficulties are now behind us—we hope—and we want to have 25 bears at each of the 30 walks planned this fall. That means 750 bears by October, so we will need lots of help! We are looking for people to trace and

cut out the 3 pieces and/or embroider on the faces. Machine sewing is not required, but we can always use more help if you are able. (As for stuffing the bears, we are still working on that part!)

If you would like to help us meet our Boozle Bear goal, e-mail Sarah Zadoroznyj at sarah@boozlebear.com. You can also check www.boozlebear.com for updates and information on our progress. ❖

RADIO HOST SEEKS GUESTS

Richard Cohen, author of *Strong at the Broken Places* (of which a review was reprinted from *The New York Times* in our Spring newsletter), is hosting a weekly one-hour radio broadcast of the same name on WABC in New York City. Mr. Cohen is an award-winning journalist who has lived for many years with colon cancer and multiple sclerosis. He worked with the National Health Council to identify individuals with chronic diseases and disabilities profiled in his book.

Now he is asking for help once again—this time to identify people within patient advocacy organizations to appear on his radio program. As Mr. Cohen describes it, "This is a program about coping with disabilities and chronic illnesses. No show like this has been done. We all have a stake in telling our stories. The content focuses on coping scenarios and

stories that apply to many, if not most, chronic illnesses. I want to deal with subjects such as anger, self-esteem challenges, kids, relationships, financial problems, denial, the idea of damaged people, dealing with docs, and so on. We have much in common about the personal, human challenges."

If you are willing to talk publicly about the challenges you face, please contact Mr. Cohen directly, with a copy to Myrl Weinberg:

richardcohen77@aol.com

Weinberg@nhcouncil.org

This is an opportunity to gain increased visibility for the National Health Council and the Hydrocephalus Association in pursuit of our shared mission to provide a united voice for people with chronic diseases and disabilities. ❖

NIGERIAN CONFERENCE

We recognize that hydrocephalus is a worldwide phenomenon and commend any effort to raise awareness around the globe. Unable to attend the 10th National Conference on Hydrocephalus in Park City, Utah, Afolabi Fajemilo, president of Festus Fajemilo Foundation in Nigeria, organized his own seminar on hydrocephalus and spina bifida. On the 19th of June, in solidarity with the opening of our conference, the seminars took place at the Lagos State University Teaching Hospital. The main effort was to sensitize the public and raise awareness in a place where health issues have profound spiritual and social stigmas. ❖



WHAT PEOPLE ARE SAYING ABOUT WWW.PACERKIDSGAINSTBULLYING.ORG

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"I think this is a good Web site for kids because some of my friends have been bullied and I am going to tell them to go on this Web site. This is a very, very, very good Web site. . . I hope you keep this Web site."

New York, Girl, age 9

"Bullying is not cool. You should always be respected no matter how short or if you have big ears, and as long as you're yourself, no one can tease you. You control your life, not bullies, and we are all the same anyway. We have ears and noses and mouths; some have glasses, but who cares. . . who cares?"

Maryland, Boy, age 12

"I want to thank you for creating the PACER Kids Against Bullying Web site. This is the most comprehensive, outstanding, creative collaboration of resources (bullying or otherwise!) I have ever found on the Internet or via movies. I love the interactive nature of the site. The movies are excellent. The graphics are fabulous. I appreciate the work that your organization is doing to help keep kids safe."

School Counselor, Texas

Hydrocephalus Association 2008 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 \$ _____

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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:

Hydrocephalus Association ■ 870 Market Street ■ Suite 705 ■ San Francisco, CA 94102
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

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Website: www.hydroassoc.org · Email: info@HydroAssoc.org

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

College & Hydrocephalus

Understanding Your Child's Education Needs/IEP Resource Packets



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