

HYDROCEPHALUS

▪ **A S S O C I A T I O N** ▪
SUPPORT EDUCATION ADVOCACY

SUMMER 2007

VOL. 25, NO. 3

Congratulations to Our 2007 Scholarship Recipients!

We are delighted to award eight scholarships to these outstanding young adults with hydrocephalus. The scholarships were funded by the Gerard Swartz Fudge Memorial Scholarship Fund, the Morris L. and Rebecca Ziskind Memorial Scholarship Fund, the Anthony Abbene Scholarship Fund, the Justin Scot Alston Memorial Scholarship Fund and the newly created

Mario J. Tocco Hydrocephalus Foundation Scholarship Fund. Our congratulations to the recipients and to all the impressive people who applied for this year's scholarships. To read about them, please turn to page 16. For a list of the finalists, go to page 19.



Keith True
St. Charles, Illinois



Haylea Lynn Blank
Thomasville, North Carolina



Brent Michael Meyers
China Township, Michigan



Amanda Shank
Ithaca, New York



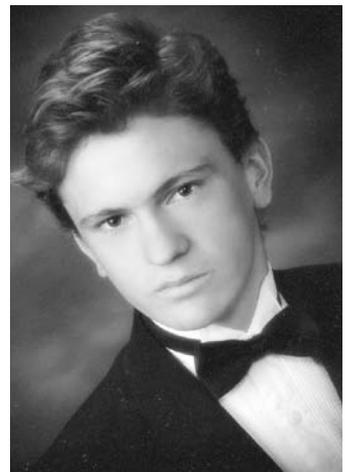
Nicholas Allan Orrison
Raleigh, North Carolina



Natalie Geis
Kaysville, Utah



Daniel Hohman
Spotswood, New Jersey



Marcus Booth
Flower Mound, Texas

From the Board President

By Bob Jacobsen

In February I had the pleasure of attending the National Health Council's 20th Voluntary Health Leadership Conference. The groups in attendance included the American Cancer Society, the American Heart Association, the Spina Bifida Association, the American Diabetes Association and, for the first time, our own Hydrocephalus Association. It was a powerful experience to join our voice with those of other nonprofit advocacy groups and to look at our common issues, such as our national healthcare crisis, the need for innovative research funding models and best practices in board growth and development.

The National Health Council requires that its members meet 41 standards of excellence in areas such as governance, personnel policies, programs, fundraising, finance, accounting and reporting, and evaluation. It's a real testament to the quality of the Association that we were accepted into membership, and I salute those who worked diligently to make it possible. I came away from the meeting convinced that HA can learn and do far more with this group than we could by ourselves.

The Board of Directors continues to focus and make progress on the Association's strategic priorities, including core services, expansion, fund development and advocacy. Our goal remains to make sure that *everyone* dealing with hy-

drocephalus receives support, education and ongoing quality care. That's an enormous challenge, and I want to personally thank all of our members, staff and my fellow Board members for their continuing contributions to this cause. In this issue of the newsletter, you'll be reading about efforts toward a hydrocephalus documentary and progress toward transition of care. With your help, we are succeeding.

Finally, speaking of contributions, I want to congratulate Board members Ray Moser and Jim Kranz, who just successfully and safely completed the 2007 Cannonball One Lap of America race, with the Hydrocephalus Association as their charity. Thank you for your dedication, focus and leadership! ■

Conference Reminder



Photo by Alan Miller

The Canyons Resort in Park City, Utah, is ready to take your reservations for our 2008 conference. Call 888-226-9667 and ask for the Hydrocephalus Association Conference rate for June 19–22, 2008.

The Canyons consists of two properties across a courtyard from each other in the beautiful Wasatch Mountains outside of Salt Lake City. The Grand Summit Hotel starts at \$139 for a single or double room; the Sundial Lodge is more family-oriented, with kitchenettes, shared washer/dryers and rooms starting at \$109.

A **storytelling performance** by the incomparable Sherman Alexie

A gondola ride to a **dessert reception** at mid-mountain

A **family-friendly resort** with a pool

Our first-ever **Kids' Camp** for children ages 3 to 12

Book your 2008 conference accommodations now!

The Canyons Little Adventures Children's Center will have a Kids' Camp for our conference participants; the camp runs from Friday through Sunday, is available at a 5 percent discount and can accommodate up to 50 children ages 3 to 12. Pre-registration is required two months prior to arrival. The 2008 cost is not yet finalized, but 2007 pricing is \$62 per day, including two snacks and lunch. The earlier you book, the easier it will be for us to plan an appropriate curriculum for these lucky kids! If your child has special needs and you would like our

help working with the Children's Center to manage this appropriately, please let us know.

To get a feel for the activities possible at Kids' Camp, or for more information about either property, check out The Canyons website at www.thecanyons.com.

Park City is a fun mountain town with shops and restaurants, and Utah has lots of beautiful national parks. Come early or plan to stay afterward and enjoy the bounty.

The 10th National Conference on Hydrocephalus: "It's About Life!" Be there!

Hydrocephalus Is Going to Hollywood

By Lori Poliski



Photo by Rob Casey

The Association is thrilled to announce our collaboration with noted filmmaker, poet and author Sherman Alexie. Those of you who were lucky enough to hear Alexie speak at the HA national conference in Chicago in 2002 or in San Francisco in 2004 will remember his engaging style of storytelling, full of wit, pathos and humor. Imagine a weaving of stories, including Sherman's own, about living with hydrocephalus, treating hydrocephalus and furthering hydrocephalus research that creates a national buzz, makes hydrocephalus a household word, galvanizes congressional action, and drives more research funding. A new documentary film that achieves this is our goal.

Alexie, a Spokane/Coeur d'Alene Indian who was born with hydrocephalus, is donating his time, energy and passion to this production, for which we are very grateful. The creative production team of screenwriter Alexie and producer Larry Estes has a proven track record—the team won the two top popularly voted awards at the Sundance Film Festival in 1998 for *Smoke Signals*, and returned to Sundance in 2002 with co-producer Christy Cox with the world premiere of Alexie's directorial debut, *The Business of Fancydancing*. We are so fortunate to be working with this team! To read more about Sherman Alexie, Larry Estes and Christy Cox go to www.fallsapart.com.

We are aiming for the feature-length movie to be completed by mid-September, in time to be submitted for the 2008 Sundance Film Festival and other high-profile film festivals. Production began this past February in Africa and Detroit and will continue through the summer. The story weaves together the lives of both children and adults with hydrocephalus and centers around the suffering and frustration inherent in living with this lifelong neurological condition and the hope offered by brilliant, wise, dedicated researchers who could benefit from much-needed but scarce support.

Dory Kranz, the executive director of HA, is co-producing the film along with me. "We are excited about this documentary's potential to raise awareness about hydrocephalus on an international level using artistry, humor and poignancy," says Kranz. "Not only do we wish to be recognized at film festivals around the world, but we have high hopes for distribution in theaters and on major television outlets like HBO and PBS," she adds.

We are continuing the process of raising money to finance the documentary as we go, and we greatly need your help to complete this project, distribute and market it. It's our understanding that it will cost at least \$125,000 to make the film. If you are inspired by this idea, we would be grateful for your contribution, however great or small. Every dollar raised will help us bring this vision to fruition. Also, if anyone has film industry connections that could help to increase the documentary's visibility, please email me at lpoliski@hydroresearch.org. Stayed tuned for updates!

Lori Poliski is an HA member, president of the Seattle Children's Hospital Hydrocephalus Research Guild and a parent of a child with post-IVH hydrocephalus. ■

Hydrocephalus Advocacy Inspires Citizenship

Shortly after meeting with members of Congress as part of the Hydrocephalus Association's Advocacy Day in 2006, Paula Keyser realized it was time to apply for naturalization so that she could become an American citizen and vote on issues of importance. As she says, "It is such a humbling experience to accompany your family to our nation's capitol and realize that most of the representatives there have never even heard the word hydrocephalus—and unless you're

a constituent, your word doesn't hold much weight. We have so much work to do to get the word out about this condition and find a cure. Every voice counts, and I want mine to be one of them!"

Paula's citizenship application process began in June 2006, and on April 26, 2007, Paula was officially sworn in and given her certificate of naturalization at a ceremony at the Tampa Convention Center. "The first thing I'm going to do is register to vote, so that I can talk to these

legislators as a constituent and educate them on hydrocephalus and the issues that surround children and healthcare today," she says.

With her husband, Mark, Paula leads the HA Tampa Bay affiliate organization, which is part of the affiliate pilot program we launched this spring. Congratulations on two big firsts, Paula, and welcome to citizenship. We are very proud of you! ■

Raising the Profile of Transition of Care

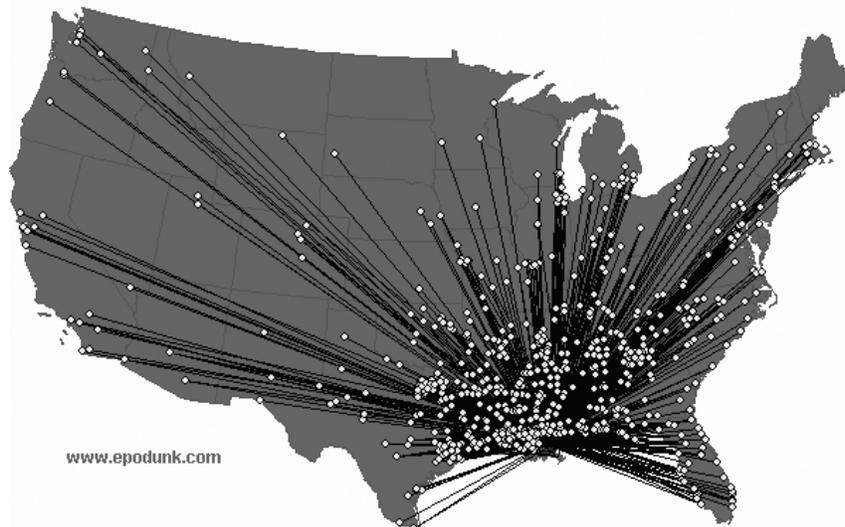
By Pip Marks and Dory Kranz

Thanks in large part to Dr. Harold Rekate and Dr. Joseph Piatt, two Hydrocephalus Association Medical Advisory Board (HA MAB) members, awareness about the transition from pediatric to adult-centered care is being raised within important professional medical societies. It is with gratitude, delight and hope that we share with you recent attention by the American Association of Neurological Surgeons (AANS), the Pediatric Section of the AANS and Congress of Neurological Surgeons, and the American Academy of Pediatrics (AAP) as they take up the cause of addressing transition concerns with us. These organizations are large and don't tend to move quickly; it may be a while for these efforts to bear fruit. We can, however, celebrate their efforts.

Transition to adult care settings is a critical challenge to members of the Hydrocephalus Association, many of whom have already or will soon be forced to transition out of their pediatric care setting and find adult-centered care. The issue of transition of care is not specific to hydrocephalus, but is shared by many conditions and diseases that are medically or surgically treated in childhood, including spina bifida, cerebral palsy, syringomyelia and congenital heart malformations. The medical community performs lifesaving interventions in childhood that allow people to grow into adulthood; however, they have chronic pre-existing conditions that make them virtually uninsurable and a mystery to

those who were trained in adult medicine during a time when there were not yet adults with these conditions. It is a frontier that is in great need of wise leadership and positive change.

The AAP's 2002 "Consensus Statement on Health Care Transition for Young Adults with Special Care Needs" inspired and informed HA's *Health-Care Transition Guide for Teens and Young*



Dr. Hal Rekate used this map of the diaspora (a scattering of people from their ancestral home) created by Hurricane Katrina in his Matson Lecture at the AANS to suggest how children are scattered from their pediatric neurosurgery "home" when they become adults."

Adults, which was published in 2003. In our Transition Guide, we focus on helping families and teens—beginning years before aging out of pediatric care—to work with potential providers of adult healthcare and put transition plans in place. But even with the best plans, adequate care is often not available or accessible within our current healthcare system for adults with complex, chronic medical conditions from childhood.

In 2004, pediatric neurosurgeon Dr. Andrew Parent wrote an article for *Pediatric Short Cuts*, a publication of the Pediatric Section, titled "What Happens When Our Patients Grow Up? Taking on

the Tough Topic of Transitional Care." In this article (reprinted in the HA Spring 2005 newsletter), Dr. Parent boldly states that all neurosurgeons must address the issue and acknowledge the impediments to appropriate transitional care for their patients before they can resolve the problem—which they must do for the good of their patients and the larger medical community.

In 2005, at a meeting of the HA MAB, Debby Buffa—member of the HA Board of Directors and mother of two daughters with hydrocephalus who are in the transition process—presented a heartfelt letter regarding the issues of transitional care for young adults with hydrocephalus. A lengthy dialogue ensued among the HA MAB members, and the topic was embraced as one of importance for our Association to continue to address—

and for our HA MAB members to raise in other venues.

In January of 2006, Dr. Piatt proposed to the AAP Annual Leadership Forum (ALF) that transition to adult care settings for children with chronic medical and surgical conditions be made a top priority. The ALF is the AAP's political, operational and strategic planning meeting, where resolutions are adopted and prioritized for recommendation to the board of directors. Dr. Piatt was an eloquent advocate: "Only the AAP can address systematic issues such as the benefit policies of CMS and other payors, the regulations of social service organiza-

tions, the structures of physician practices, and the training of medical and surgical subspecialists. If the AAP does not take ownership of this issue, no one else will." The resolution passed with only supportive testimony from the floor, and ultimately it squeaked into the top 10 priorities.

These resolutions are not binding on the AAP board, which still needs to decide where to put its resources and how quickly to act. With Dr. Piatt's guidance, the Association worked with the National Health Council, the National Organization for Rare Disorders, the Spina Bifida Association and other condition-specific advocacy groups with whom we share a stake in this issue to send an orchestrated message of support to the AAP. Many letters were sent to Dr. Jay Berkelhamer, President of the AAP board, encouraging action on this priority. The Hydrocephalus Association will have an exhibit booth at the 2007 AAP annual meeting in San Francisco to show our support and keep this issue of transition in the limelight.

Dr. Piatt warns, "Even if the board does convene a task force, and even if the task force's recommendations are adopted, this process will yield benefits for our patients only over a very long timeline. Problems particular to neurosurgery, such as how to provide services for 30-year-olds with hydrocephalus, are not likely to receive focused attention. So this initiative complements but does not compete with efforts within our own subspecialty, as keynoted recently by Hal ReKate at the December meeting, to solve our own continuity-of-care problems."

As Dr. Piatt mentions, another HA MAB member, Dr. Harold ReKate, has been working diligently within the Pediatric Section of the AANS/CNS. In December 2006, Dr. ReKate convened an affinity group at the Pediatric Section meeting that drew at least 100 people. The attendees explicitly recognized the issue's importance, and shared examples of problems and solutions. Those assembled realized that we don't yet have the

answer, and that any one solution is not likely to work in all medical institutions or states; a group is forming under Dr. ReKate's leadership for further exploration.

Keeping this issue at the forefront, Dr. ReKate chose it as his topic for the prestigious Matson Lecture at the April 2007 annual meeting of the full AANS: "A Contemporary Diaspora—The Role of the Neurosurgeon in the Transition of Care for Pediatric Neurosurgical Patients." Showing a picture of the far-flung migration pattern of those displaced by Hurricane Katrina, he compared diaspora—the migration and scattering of peoples from their ancestral homes—to young adults with hydrocephalus having to leave their pediatric hospital homes. Dr. ReKate talked about the concern of "too many pitchers and not enough catchers," referring to the number of pediatric neurosurgeons passing on "their kids" to too few adult neurosurgeons who are willing and qualified to take care of them. He proposed redefining the Pediatric Section as a Joint Section on Pediatric and Congenital Care, which would address surgically relevant congenital disorders and support those who commit to their care throughout life. In addition, he proposed building bridges with med-peds practitioners who have had two years of pediatric specialty training

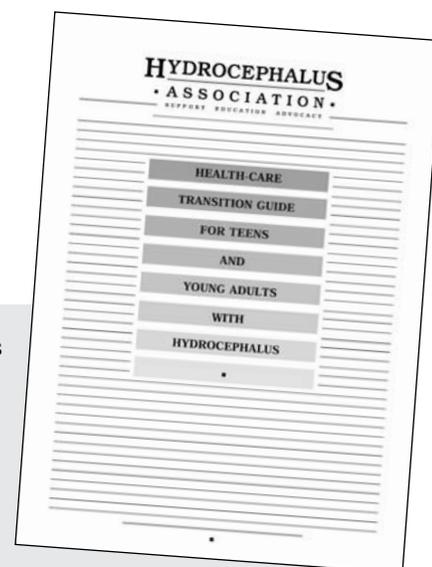
and two years of internal medicine and are board eligible in both.

Med-peds practices that aim to provide continuity of care for children who have been treated since infancy are being developed across the country, including in Phoenix, under the leadership of Dr. ReKate; in Cleveland, under the leadership of Dr. Mark Luciano; in Jacksonville, under the leadership of Dr. Hector James; and in Salt Lake City, under the leadership of Dr. Marion L. (Jack) Walker and Dr. John Kestle.

As a recent member of the National Health Council and longtime member of the National Organization for Rare Disorders, it is rewarding for HA to be working together with organizations advocating for our brother and sister conditions, as well as with members of our Medical Advisory Board, to create systemic healthcare change that will benefit us all. ■

Our **Health-Care Transition Guide** is for teens, young adults and their families. It is an important tool to help them in understanding and implementing the transition to adult-centered medical care. The booklet is free to members. PDF copies are available via email. Please email or call us for a copy at info@hydroassoc.org or 888-598-3789.

Dr. ReKate writes in the Guide: "The follow-up of patients with hydrocephalus is the responsibility of the neurosurgeon.... What is important is that whoever performs the evaluation should be thoroughly schooled in the evaluation of shunt-dependent patients, be willing to let the patient and the patient's family speak about potential problems, understand the need for a rapid response and be able to converse with the treating neurosurgeon immediately and frequently about problems that have been identified."



NIH Grant Awarded to Dr. Bergsneider for Hydrocephalus Research

By Debra Howell

We are excited to report that Dr. Marvin Bergsneider, Director of the UCLA Adult Hydrocephalus Center and a member of our Medical Advisory Board, has been awarded a \$1 million grant from the National Institutes of Health (NIH). His study has two main purposes: to better understand the significance of CSF flow as it undergoes pulsation in hydrocephalus, and assess whether endoscopic third ventriculotomy (ETV) is an effective treatment for hydrocephalus.

A main thrust of the study is to collect physiological data to help in understanding the significance of pulsatile CSF flow in relation to normal intracranial dynamics and intracranial dynamics in the context of hydrocephalus. In doing this, researchers will look at whether there is evidence to support the hypothesis that cerebral blood flow is dependent upon the pulsatile movement of CSF, which occurs in response to the likewise pulsatile nature of blood flow in the arteries. One of the questions to be answered is: If there is an obstruction to CSF movement, which is the hallmark of hydro-

cephalus, does this affect blood flow to the brain? There has been increasing interest in pulsatile CSF flow, including Dr. Michael Egnor's tuned oscillator theory, which suggests that the rhythm of intracranial pressure (ICP) waves is "tuned" to the rhythm of the heartbeat, so that CSF leaves the cranium and flows into the spinal area as arterial blood flows into the cranium with every heartbeat, and returns when the blood leaves the cranium with every pulse.

Measurements to be used include continuously recorded waveforms of ICP, middle cerebral artery velocity (using transcranial Doppler) and peripheral blood pressure. In addition, patients will undergo MRI studies to determine waveforms of CSF flow at various locations, arterial blood flow in the carotid and vertebral arteries, and outflow in the veins. An electrocardiogram will be recorded and used as the timing reference point to determine the exact timing of CSF, blood and tissue movement within the cranium. These measurements will be obtained before and after surgery for hydrocephalus patients, and in healthy adult subjects to obtain control-group data. Researchers will use this informa-

tion to model CSF movement in relation to pulsatile blood flow.

The second specific aim is to assess the efficacy of ETV in the treatment of hydrocephalus, primarily in communicating hydrocephalus. The study will be a prospective clinical study comparing a VP shunt to ETV. In addition to looking at success and complication rates, researchers will use the information gathered about CSF and blood flow movement, as described above, to determine predictive physiological variables for treatment success. Dr. Bergsneider and his research team hope that at the end of the study, they will be able to tell any given patient whether he or she will respond to ETV.

Study participants will be adult patients with hydrocephalus, including normal pressure hydrocephalus (NPH) patients. Participants can come from anywhere in the United States.

We congratulate Dr. Bergsneider for his NIH grant, and thank him for his extensive knowledge and steadfast dedication to hydrocephalus research and treatment. ■

Resources and Reading for Older Adults and Caregivers

Compiled by Debra Howell

If you are an older adult or care for someone who is, keep reading for some useful and interesting health-related resources.

NIHSeniorHealth.gov

NIHSeniorHealth.gov has been designed with seniors in mind. The site is based on the latest research on cognition and aging, featuring short, easy-to-read segments that are accessible in a variety of forms, including large-print and audio. It also links to MedlinePlus, which has

more detailed consumer health information. For more information, visit www.nihseniorhealth.gov.

Consumer's Tool Kit for Health Care Advance Planning

Good advance planning for healthcare decisions is, in reality, a continuing conversation—about values, priorities, the meaning of one's life and quality of life. To help you in this process, the Consumer's Tool Kit for Health Care Advance Planning contains a variety of self-help worksheets, suggestions and resources. The tool kit does not create a formal ad-

vance directive for you. Instead, it helps you do the much harder job of discovering, clarifying and communicating what is important to you in the face of serious illness. To access the tool kit, visit www.abanet.org/aging.

Medicare Interactive and Medicare Rights Center

The Medicare Interactive (MI) website is designed to help older adults and caregivers escape the healthcare maze and get needed care. The site is comprehensive and easy to navigate. Sections include MI Counselor, which answers questions

about healthcare benefits and options, and how to access health benefits; MI Community, where people share their stories and learn from others; MI Local Services, where users can find community services in their area; and MI University, which covers the ins and outs of Medicare via interactive multimedia lessons.

MI was designed by the Medicare Rights Center (MRC), the largest independent source of healthcare information and assistance in the United States for people with Medicare. Since its founding in 1989, MRC has been helping older and disabled Americans, their caregivers and the professionals who serve them understand their healthcare rights and benefits so that they get the healthcare to which they are entitled.

MRC works on three fronts: providing direct services to individuals who need answers to Medicare questions or help securing coverage and getting the healthcare they need; educating consumers, including caregivers and the professional counselors, about healthcare benefits and rights; and advocating for policy changes that will benefit all people with Medicare.

Visit Medicare Interactive at www.medicareinteractive.org and Medicare Rights Center at www.medicarerights.org.

New Long-Term Care Planning Website

The National Clearinghouse for Long-Term Care Information has a new website that provides comprehensive information about long-term care planning, services and financing options, along with tools to help people begin the planning process.

The site is a project of the Health and Human Services Administration on Aging, Centers for Medicare and Medicaid Services and the Assistant Secretary for Planning and Evaluation; it's designed to increase public awareness about the risks and costs of long-term care and the potential need for services, and to provide objective information to help people plan for the future.

The website also supports the Own Your Future education campaign, a joint federal and state initiative designed to increase consumer awareness about planning for long-term care.

For more information, visit www.longtermcare.gov.

Training Videos for Family Caregivers

Healing Arts Communication, a company that produces informational and training videos and DVDs on caregiving and other long-term care topics, has added new programs to its collection. The series focuses on topics such as measuring vital signs, managing medications, helping someone use a wheelchair, personal care and caregiver wellness. For more information, visit www.homecarecompanion.com/videos.html.

The American Bar Association Legal Guide for Americans Over 50

An updated legal guide for baby boomers and their parents, endorsed by the American Bar Association Commission on Law and Aging, is now available. The book contains new chapters on elder abuse, financial planning for incapacity, advance planning for healthcare decisions, and marriage and divorce. It also contains information on Social Security, Medicare, Medicaid and other government programs. The guide can be ordered from the ABA at www.abanet.org/aging or from Amazon.com.

Heart Wide Open—Self-Care for Caregivers

By Sandi Kimmel and Patrick Murphy

This booklet helps caregivers of people with any illness to manage the feelings associated with being a caregiver. It includes chapters on eating chocolate and playing—important things to remember to do when caring for someone else! To order, contact Sterling Heart Publishing at 619-838-1170 or order online at www.sterlingheart.com.

Self-Care and Support for Family Caregivers

The National Cancer Institute has created three publications for caregivers, focusing on family caregivers' needs for infor-

mation and support. While the booklets are written for families and friends of cancer patients, the information is applicable to anyone caring for someone over the long term. For more information, visit www.cancer.gov/cancertopics/When-Someone-You-Love-Is-Treated. ■

Hydrocephalus Database Registry Update

The data that we have collected through the Association's Hydrocephalus Database Registry continues to yield results. A team of researchers and clinicians at the University of California at San Francisco used the data to write "Long-Term Outcomes in Patients with Treated Childhood Hydrocephalus," which was published in the May 2007 issue of the peer-reviewed *Journal of Neurosurgery: Pediatrics*. Congratulations and many thanks to the team at UCSF: Nalin Gupta, MD, PhD; Jeanna Park, BA; Margaret Wrensch, PhD; and Yvonne Wu, MD, MPH. Our continuing gratitude also to Association co-founder and past board member Cynthia Solomon for her vision and hard work in designing and creating the database registry.

One key finding of the paper was no surprise: Shunt complications are common; 54 percent of patients had four or more shunt revisions and 9 percent had three or more shunt infections. A free downloadable copy of the article can be found on the *Journal of Neurosurgery: Pediatrics* website: www.thejns-net.org/peds/issues/v106n5/pdf/p1060334.pdf.

If you haven't entered your information into the database, log on and be counted! Fill out our survey electronically on the secure, HIPAA-compliant site www.hydrocephalusdatabase.org, or request a paper copy from the HA office. This data is critically helpful, because documentation of unsatisfactory long-term outcomes and complications in current diagnosis and treatment is important to making our case for more federal support of hydrocephalus research. Make your voice heard in our collective call for change.

Advocacy Update

National Advocacy

Help strengthen our case for appropriations report language and lay the groundwork for future advocacy efforts by getting to know your legislators and educating them about hydrocephalus through your personal story. One of the best times to meet with legislators is during “district work periods,” when they are at their home office. The summer district work period is August 6–31, 2007.

Contact our national advocacy director, MaryBeth Godlewski, for assistance making an appointment; talking points, brochures and other materials to take with you; and information about important committee assignments. You can reach her at marybeth@hydroassoc.org or 215-651-1917.

We have champions in the House and Senate proposing hydrocephalus report language in the FY 2008 appropriations bills (read more about this in MaryBeth’s profile on page 10). At least 35 people have responded to our email advocacy alert and sent personal written testimony in support of this budget language to the chair and ranking member of the U.S. House and Senate Appropriations Committees this spring. Won’t you do your part over the summer?

Don’t put your legislators on a pedestal—get to know them as people and ask for their help.

State-Level Advocacy

Inspired and informed by MaryBeth Godlewski and Kelly Rambo’s success in having November declared Hydrocephalus Awareness Month in Pennsylvania last year, Shannon Christian tells her story of legislative success in Colorado:

One of the most difficult aspects of having a child with hydrocephalus is feeling helpless and powerless. At the same time, I want to make a significant difference in the life of my 2-year-old son, Reece. I recently found an easy yet very powerful way of helping Reece and all of the individuals in Colorado who

have hydrocephalus. I contacted my state senator and asked that she sponsor a resolution declaring September Hydrocephalus Awareness Month.

However, before I ever started down this path, I needed to be convinced that it was worth my time. For one, I didn’t know who represented me in the state senate, so I didn’t know whom to contact. Furthermore, I have no background in politics or the legislative process. I’m ashamed to admit it, but I usually don’t even vote for local candidates; it takes



Shannon and Reece Christian with Colorado State Senator Spence

too much time to sort through all the candidates and what they stand for. After being reassured and encouraged by MaryBeth Godlewski, I tracked down an email address for my state senator. I emailed Senator Nancy Spence about Reece, his condition and my desire to have her sponsor a resolution. I decided I could always throw in the towel if it became too difficult.

I sent my email to Senator Spence on a Wednesday afternoon; that evening I had a response from her asking if I could bring Reece to her office the following week. By the end of our meeting, Senator Spence was more educated about hydrocephalus, and she had made a commitment to sponsoring a resolution. She followed up by faxing me working drafts of the resolution, asking whom I wanted to send copies of the resolution to and inviting me to be her guest when the resolution was introduced. When the

resolution was introduced in the state legislature six weeks later, my senator and representative acknowledged me and Reece and publicly asked that the resolution be read aloud. I received a standing ovation and was thanked by many legislators for taking the time to travel to the state capital.

I was awestruck by how simple it was to achieve something so significant, and how willing my state senator was to help me. She didn’t expect me to be a legislator; she merely wanted to know about hydrocephalus and about my child. I simply had to talk about Reece and about his condition, two areas in which I am an expert like no one else. Senator Spence was happy to involve me, and I wanted to be involved—but I also know that had I chosen not to go to the state capital, I could have easily communicated the necessary information about Reece and his condition over the phone or via email. The Hydrocephalus Association was fully supportive and available to me when I had questions, and it was easy to get the information I needed to make the resolution a reality.

The most gratifying aspect of having September declared Hydrocephalus Awareness Month in Colorado is that it honors Reece and all the other Coloradans who have hydrocephalus. My hope is that eventually every state will have a Hydrocephalus Awareness Month to recognize those who have the condition and are so deserving of greater understanding. In my mind, this simple yet powerful act of having a statewide resolution is not only empowering, but is a stepping stone in the greater goal of securing more funding, better treatment and, my hope of all hope, a cure for hydrocephalus.

Similar efforts are under way in other states. Will your state be next? MaryBeth says, “Don’t stop with a resolution or an awareness month; invite a legislator, mayor or governor to chair or speak at a TEAM event in your state.” ■

Telling the Teacher: What I Want My Child's Classroom Teacher to Know

Adapted by Pip Marks from an article by Patricia Bill that appeared in Pacesetter, fall 2006. Used with permission from Pacer Center.

Most children with disabilities are included in the regular classroom for part of their day, yet many general classroom teachers say that sometimes they feel unprepared and uncertain about how to work with students who have special needs. Many add that they would welcome help.

"We parents understand that teachers are incredibly busy with large numbers of students, lack of resources and other challenges," says Beth Davis, a mother of two teenagers with disabilities. "I've always encouraged both of my children's teachers—yes, even all the ones in high school—to contact me if I can help them understand anything at all about either one of my children."

Like Davis, many parents of children with disabilities are willing to help teachers and others at school to work with their child. However, some families don't offer help or suggestions, either because they believe that the teacher must know best or they don't want to appear critical of the teacher.

In the spirit of parent-school partnerships, you may wish to share the following ideas at your child's school.

My child is a person

- Greeting my child by name when he comes to class can make a huge difference in his day. Developing a relationship with him establishes his existence. You set the stage for how others at school treat him.
- Like any child, mine is unique. She has passions, dislikes, things she is good at, things she is not. Your efforts to learn about her interests and strengths validate her.

- My son's identity is more than a diagnosis or a label on an IEP. The disability is only part of who he is. Please look beyond it to see more of him.
- Understanding the disability may affect how you perceive my daughter. I am happy to give you information or help you find it.
- Please be discreet. What you say about my son—good or bad, in the teacher's lounge or elsewhere—affects his reputation, as well as your own.

We can talk

- I gladly will share ideas and thoughts as well as concerns about my child. If you contact me, I can probably offer insight into her behavior and share strategies that work at home.
- My son may look like a typical 12-year-old, but his disability is real. Our family worked with professionals through a long and sometimes painful process to reach a diagnosis for him. If you acknowledge that my son has a disability, we can communicate openly about how to address it.
- The only way my daughter can succeed at school is through our partnership. I know that you are a professional, but I am an expert when it comes to my child, and I will be part of her life forever.

My child can learn

- You can relax. I don't expect miracles, but I hope you will have high expectations for my son. I assume he can do a certain task until he proves otherwise. If we work together, our expectations for him likely will be realistic.
- Arranging groups and teams to include everyone will help my daughter feel that she belongs to the class and the school community. She learns from her peers.

- My child's experiences in your classroom are the foundation of his future success at school or in employment. Encouragement is crucial for him to keep trying.
- My daughter may not be able to express herself in customary ways, but she benefits from being in your class. She gains knowledge, even if she is slow at a task, scores low on tests or does not respond at all. Her IEP, which you have received, tells what accommodations she needs in order to progress.
- My child probably can develop his abilities—if we encourage him. It may be easy to coddle him, but together we need to help him fly on his own.
- Try using code words or discreet signals to guide my daughter. Calling out her name in class for what her disability will not allow her to do ("Mary, sit down," "Mary, be quiet" or "Mary, hurry up") brings negative attention and affects her self-esteem.

My child has gifts

- Children with all types of disabilities can offer much to others. If you look for it, my child can contribute something valuable to the classroom that no one else can.
- Above all, I hope you can find something to genuinely like about my child. I know you will.

NOTE: The Teacher's Guide, published by the Hydrocephalus Association, is an excellent resource and reference tool for your child's teachers. In the spring issue of the newsletter, Pip Marks and Deborah Phillips presented tips on how to use the Guide. A copy of the Guide is available free to our members. Additional copies cost \$3. To request a copy, call the office (415-732-7040) or send an email to info@hydroassoc.org. ■

We Welcome MaryBeth Godlewski to the Association Staff

MaryBeth Godlewski, our new national advocacy director, has an agenda: to find a cure for hydrocephalus before her daughter, Emma, has another shunt malfunction. Emma, now 10, has undergone 35 brain and skull surgeries, 28 of which were shunt revisions. As an HA member, an advocate and now as director of our advocacy efforts, MaryBeth holds a strong commitment in faith that a cure will be found. Lucky for us, she is putting her creativity, passion and drive behind that faith.

A woman with a strong service ethic, MaryBeth co-chaired our first Pennsylvania TEAM walk-run in November 2005. The event was in honor of a well-loved local neurosurgeon, Dr. Samuel Neff, who had died suddenly. Through her organizing experience, MaryBeth met other families affected by hydrocephalus and saw the great need for awareness, resources and improved medical outcomes. Clearly, Emma's story was not the only heart-wrenching one. Moved to become more involved, MaryBeth attended the Association's Ninth National Conference in Baltimore in 2006, with her family in tow. Her sense of the urgency and magnitude of the need for change was expanded yet again. A born fixer, MaryBeth found her mind racing with ideas of ways to create this change.

Advocacy Day 2006 was like an Independence Day for MaryBeth, freeing her from feeling intimidated by state and national legislators, who had previously occupied a pedestal in her mind, and pointing her on a path of action. If you have ever met or spoken with MaryBeth, you might find it hard to believe that she was ever intimidated by anyone. But, in her words, "Advocacy Day completely empowered me. I realized that legislators weren't above me, and that I have a right to approach any legislator and ask

them to create change for Emma and for all people with hydrocephalus. And now I do."

We'd like to share with you a story that illustrates MaryBeth's willingness and ability not only to ask, but to move legislators to action.

Michael Smerconish is a radio talk show host and political commentator who has a personal relationship with Senator Arlen Specter (R-PA). His children attend the same school as MaryBeth's,



MaryBeth, her daughter Emma and U.S. Senator Arlen Specter

giving them a common interest. From listening to his show, MaryBeth learned that Smerconish likes tomato pie (a Philadelphia treat much like pizza without cheese). One day while his show was on the air, she brought a tomato pie to the radio station as a gift. Smerconish came out of his studio every 20 minutes, during commercial breaks, for another piece of tomato pie. At the end of his show, after the last piece of the pie was eaten, he agreed to talk with Senator Specter about hydrocephalus.

At MaryBeth's invitation, Smerconish's wife, Lavinia, served as honorary chair of the Second Annual TEAM

PA Hydrocephalus Walk-Run, which included a pre-event cocktail party. MaryBeth had faith that if his wife was present, Michael would attend. At the party, MaryBeth introduced HA's executive director and an HA Board member to Michael and his producer, and the weight and scope of her cause were strengthened in their minds.

Several weeks later, MaryBeth received a 5 a.m. email that Senator Specter would be in Michael's studio that morning, giving her the opportunity to make her pitch in person; during a commercial break, she told Specter about HA's goals for increased federal support of hydrocephalus research. Unable to say no to such a charming young lady, he agreed to help with our next step: appropriations.

As a result of MaryBeth's connections, commitment and passion, report language has been introduced into the 2008 House and Senate appropriations bills. When Senator Specter called a press conference on flat funding for biomedical research shortly after introducing our report language this spring, MaryBeth and Emma went to Washington, D.C., to renew their personal connection with Specter and keep the cause of hydrocephalus alive in his mind and heart.

This story of one person's connections and infectious enthusiasm recalls the words of Margaret Mead: "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has."

If you are inspired by MaryBeth's story and want to join our band of thoughtful, committed citizens actively advocating for change in the world of hydrocephalus, please contact her at marybeth@hydroassoc.org or 215-651-1917. ■

My Run for Political Office

By Laura Mick

Last summer, the Manchester City Democrats asked me to run for state representative for Ward Six in Manchester, New Hampshire. I gave it a lot of thought during the next week. I had spent the previous years volunteering for various local and national campaigns all across the state. My healthcare story as a young woman with a serious health condition on high-deductible insurance had been private, but not telling it had become painful—so I had chosen to share it earlier that year, through the website of Americans for Health Care, an organization devoted to advocating for affordable, accessible healthcare. All week, I thought about these exciting considerations, along with fears of holding down a full-time job and making frequent trips to Concord to serve my constituents—if I even won. Ultimately, I accepted the Manchester City Democrats' nomination. In the early morning on June 9, along with a group of other Democratic and Republican hopefuls, I registered my name at city hall as it would appear on the ballot. Coincidentally, this took place only one week after I returned home from the Hydrocephalus Association conference!

My involvement with Americans for Health Care began with a simple postcard I got from their state group, New Hampshire for Health Care, as New Hampshire's presidential primary was picking up speed. The postcard gave information on ways to help, and I started to work with the organization. I have met dozens of incredible, like-minded people by getting involved. I feel that it was only natural to show my gratitude with volunteer hours and support by spreading the word about the campaign to reform our healthcare system. I don't want anyone to ever feel as alone as I did when the all the major insurance companies deemed me unfit for individual insurance. Everyone needs a productive way to vent emotion,

and I found mine. My activism included going to numerous events wearing a purple New Hampshire for Health Care T-shirt—the trademark of Health Care Voters across the United States. Health Care Voters are people who pledge their commitment to fighting for improved healthcare. New Hampshire for Health Care sent all Health Care Voters in Ward Six a copy of my healthcare story. They gave me permission to go door-to-door with hundreds of copies for the rest of my constituents as well. What a feeling of exhilaration that was!

I lost by only 36 votes in November, behind incredibly supportive incumbents (yes, on both sides of the aisle!). Our numbers were all within the thousands somewhere. The experience was amazing, and it brought me closer to my definition of what womanhood means. It's never about what the person next to you has accomplished, or what scale is being used for "the norm." It's about what I myself was able to accomplish. That's an excellent lesson for life after the election, as well. I knew I took all the steps necessary to win as a relatively unknown candidate, and I left Election Day up to the voters. I hope that all the future politicians reading this can experience just once what door-to-door canvassing feels like. All the dead-end conversations I once had with hospitals and insurance companies no longer mattered. Two days before Election Day, I even got nicely scolded by one of my constituent's mothers for canvassing in the dark. I graciously accepted her flashlight and was on my way.

The benefits of an individual with hydrocephalus becoming politically involved are endless. Volunteering with people from all walks of life, whether locally or nationally, is a life-changing experience. It's a time to exchange unique stories—in our case, about hydrocephalus, a chronic and multifaceted medical condition. Campaign staffers are grateful for the help they receive; after all, an or-

dinary citizen is getting their candidate's message out. Two ways that beginners can start making a difference within the hydrocephalus community are familiarizing themselves with their senators' and assembly members' views on healthcare issues, and—equally important—writing letters to the editors of newspapers across the United States to shed light on what it's like to know hydrocephalus personally. In particular, we can write to our representatives requesting that they support our hydrocephalus report language in the 2008 appropriations bill.

Laura's story can be found at www.americansforhealthcare.org/health-care-story-of-the-week/2006/6/14/laura-mick-manchester-new-hampshire.html. ■

New ICD-9 Code for NPH

Thanks to the efforts of Hydrocephalus Association Medical Advisory Board member Michael A. Williams, MD, of Johns Hopkins Hospital in Baltimore, normal pressure hydrocephalus (NPH) now has its own code in the International Classification of Diseases (ICD-9). The Centers for Medicare and Medicaid Services, which oversees the ICD, has announced that a new code for Idiopathic NPH, 331.5, will be available for use on October 1, 2007. This new code will make the separation of data about NPH from that about other forms of hydrocephalus easier and more reliable.

We owe Dr. Williams a debt of gratitude for figuring out how to make this happen, wading through the formal process and giving personal testimony. We also thank our other Medical Advisory Board members, and the allies who supported this effort with letters and faxes. Way to go, team! ■

What Is One Lap of America and How Does It Relate to Hydrocephalus?

By Jim Kranz

Late last year, a fellow HA Board member, Ray Moser, asked me to join him in the One Lap of America road rally to raise money and awareness for hydrocephalus. What is One Lap of America, you ask? On the surface, it's eight days of car racing at various tracks around the country, with seven nights of highway driving between the events, covering 4,600 miles. It's a test of endurance and reliability of both the vehicle and the team. It's the mother of all road trips. It's an opportunity for you and your best friend to learn to hate each other. It's brutal, yet gratifying. It's a great way to stress out a perfectly good car. It's been described in many ways, but in the end, if you've never run One Lap of America, you'll never really know what it's about.

What happens if we take this description and change it just a little bit? What is hydrocephalus, you ask? Well, on the surface, it's a life-long challenge, filled with the unknown. It's a test of endurance and reliability of the person with hydrocephalus, his or her family and the medical team. It's the mother of all road trips. It's an opportunity for you and your doctor to learn to get to know each other and at times hate each other. It's brutal, yet gratifying. It's a great way to stress out a perfectly good brain. It's been described in many ways, but in the end, if you don't have hydrocephalus, you'll never really know what it's about.

During my eight-day adventure, I had the opportunity to explain to numerous fellow racers, gas station attendants, spectators, restaurant employees and curious individuals what hydrocephalus is and what we were doing. Many had never heard of it. However, a couple of

people said, "Oh, yeah, I know someone with hydrocephalus." I was heartened by the generosity and interest of these individuals.

I also had the opportunity to see our community in action. We were offered free places to stay, even though we would



Top: One Lap race car drivers Paul Heilman, Jim Kranz and Ray Moser with their inspiration, Jessica; bottom: racing fan Christopher Talbot takes a turn at the wheel.

be arriving in the middle of the night; however, we chose to seek food instead of shelter. Our first support team arrived at the track in Tooele, Utah. They gave us sandwiches and homemade cookies. Let me tell you, the cookies lasted less than 100 miles! Our supporters also provid-

ed messenger service, and when one of our competitors needed parts for their car from an hour away, Lynn and Mickey loaned them their car. Colleen drove me back to my hotel so I could retrieve my forgotten watch and book. Christopher, an 8-year-old who has hydrocephalus,

was excited to drive our race car and have his picture taken in the winners circle.

In Pueblo, Colorado, we were joined by Brad, a young adult with hydrocephalus, on his birthday. When Brad found us and asked what he could do to help, we quickly placed an order for supplies and lunch. Before Brad could head out, we were joined by Adriana, a young lady with hydrocephalus, and her family; they arrived with glitter signs and lunch, complete with picnic table and tablecloth. Brad switched to dinner duty and ran out in the afternoon to bring us salads and fruit. After eating road food for days, this was one of our finest meals. The gang cheered us on and, as competitors left the track, they held their glittery "Honk for Hydrocephalus Awareness" sign high up overhead. And the horns were blaring!

We were also given many phone numbers and offers of support and help along our route. Fortunately our trip went smoothly, and we didn't need to call any of our wonderful community members in the middle of the night asking for help. It sure was comforting to know that people were there for us almost everywhere we went.

I also had the very special privilege of bringing along four prototype teddy bears with shunts. The Association is de-

veloping the bears as a teaching tool for doctors and nurses, and as a way for children with hydrocephalus to talk about it with family and friends. The bears have actual shunts and can be used to demonstrate how a doctor inserts the shunt and drainage tubing under the skin from the brain to the belly area. I gave away all four bears on the trip, three to children with hydrocephalus and one to a child without hydrocephalus. I'm happy to report that I've heard from all four families, and the results have been amazing. All of the children have shown family members and friends the bear and explained how the shunt is installed. In some cases, the children had never spoken to anyone about their hydrocephalus before.

Not even a week after the event, I received a touching letter from Christo-

pher's mom that said, in part, "Christopher is so smart; he sees all his differences and he felt very lonely. He knew he was different because of his medical issues. Now, with Hydro Bear, he is not alone anymore, because this little scruffy bear is just like him."

Overall, we placed 72nd out of 100 teams, and had a great time. Our goal was to raise awareness and \$100,000. We've already exceeded our awareness goals, and expect future coverage in *Car & Driver* magazine and on Country Music Television. We fell shy of our financial goals, but we're very pleased with the \$30,000 we raised and hope you will still consider contributing. I would like to thank our official car sponsors for their support: Moser IP Law Group, Pappa John's Pizza, Global Locate, Walsh Ben-

efits; Teradici Corporation, The Winery at Holy Cross Abbey; Edmonds PC Intellectual Property Attorneys; Codman, a Johnson & Johnson Company; and Medtronic Neurologic Technology. ■



Kid's Corner!

By Bonnie Hom

Please find the 20 words listed in the grid. All the words can be found reading across (left to right) or down (top to bottom). Some letters will be shared among words so you will see overlap. There are also words in the grid that are not listed. You may want to challenge yourself and see how many words you can find. Enjoy! (The answers are on page 21.)

P.S. If you have any comments or suggestions about this Kids Corner or past ones, please email bonnie@hydroassoc.org.

Word Search

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

Catheter
Disability
Research
Diagnosis
Pressure
Insurance
Infection
Support
Ventricles
Programmable
Hydrocephalus
Obstruction
Education
Brain
Complication
Shunt
Ultrasound
Advocacy
Treatment
Link

TEAM Hydrocephalus 2007 Walkathons: Getting Bigger, Growing Stronger



TEAM Hydrocephalus 2007

The list is amazing! Our TEAM Hydrocephalus Walkathons are getting bigger and growing stronger. These events provide great opportunities to promote hydrocephalus awareness, bring together a local hydrocephalus community for support and raise funds to help all those affected by hydrocephalus.

For additional and up-to-date information on these TEAM events and more, be sure to check out our website at www.hydroassoc.org/TEAM.htm. You'll be able to register for events, donate to events and learn how to start your own event.

TEAMS are hosted by wonderful volunteers who generously put their time, commitment and determination into running these outstanding events. We truly thank them for all of their hard work. Please come and show your support if an event is planned in your geographic area. And go TEAM!

Current TEAM Hydrocephalus 2007 Walkathons:

Albuquerque, NM

October 20, 2007

Village of Los Ranchos Park

Contact: Kathy, (505) 446-3575,

kdlc@netzero.net; or

Marnie, (505) 897-1889

planedreamin@hotmail.com

Atlanta, GA

September 23, 2007

Alpharetta Recreation & Parks

Contact: Keith and Kerry

teamatlantaga@yahoo.com

Austin/SanAntonio, TX

October 6, 2007

Landa Park in New Braunfels

Contact: Sheri

texashydrowalk@wmconnect.com

Chicago, IL

To Be Announced

Contact: Sherry, (708) 574-5790,

walkchicago@sbcglobal.net

Cleveland, OH

August 5, 2007

Cleveland Metroparks Zoo

Contact: Hilary, (440) 684-9454,

hkr0927@aol.com

Denver, CO

September 9, 2007

Northridge Park in Highland Ranch

Contact: Phyllis, (303) 346-9566,

hydropr2@comcast.net

Detroit, MI

September 12, 2007

Kensington Metropark in Milford

Contact: Denise, (732) 812-2314,

suzychapstick128@aol.com

Edison, NJ

September 9, 2007

Roosevelt Park

Contact: Kim, (732) 634-1283,

kai0424@aol.com

Greensboro/Durham, NC

September 22, 2007

Graham Middle School, Goley St. Field

Contact: April, (336) 213-2183,

abrantley25@triad.rr.com

Houston, TX

To Be Announced

Contact: Mary,

houstonhydro@yahoo.com

International Falls, MN

To Be Announced

Contact: Sherry, (218) 283-3721,

nocurse72@hotmail.com

Long Island, NY

To Be Announced

Contact: Janine and Doris

teamhydrocephaluslyny@yahoo.com

Louisville, KY

October 6, 2007

Otter Creek Park in Brandenburg

Contact: Elizabeth, (502) 548-3817,

Philadelphia, PA

November 4, 2007

Norristown Farm Park

Contact: Kelly, (610) 764-7720,

Keli693@aol.com; or

Erica, (215) 704-3198,

divacantor5@yahoo.com

Providence, RI

To Be Announced

Contact: Joann, (401) 405-0343,

momoftriplets@cox.net

Sacramento Valley, CA

September 22, 2007

Feather River Recreation & Park District in Oroville

Contact: Jodi, (530) 534-8043

Salt Lake City, UT

September 22, 2007

Sugar House Park

Contact: Vicki and Kelly,

(801) 446-7562,

teamhydro.sl@gmail.com

San Francisco, CA

September 23, 2007

Crissy Field/The Marina

Contact: Pip, (415) 732-7040,

pip@hydroassoc.org

St. Louis, MO

September 30, 2007

Creve Coeur Park

Contact: Abby, (636) 922-2164,

puckett4@sbcglobal.net

Tampa Bay, FL

September 2, 2007

Largo Central Park

Contact: Paula, (727) 415-7339,

hydrosupport@gmail.com

Washington, DC

September 16, 2007

Burke Lake Park

Contact: Mimi, (703) 406-8021,

mkr3@cox.net

Remember to visit www.hydroassoc.org/TEAM.htm for registration, donations and more information about these events.

Fundraising Thanks: Golf Outing, Diamond Sale, Marathon Runner

The Graham family of Chico, California, are becoming expert fundraisers. In conjunction with Result's Radio, they organized a golf tournament that was held on April 16. It was a fun-filled day that included a round of golf, lunch, drinks, dinner, a raffle and a silent auction. Over \$4,500 was raised for the Association from the raffle and silent auction! Many family and friends of the Graham family came out to help, along with Association members Mary Jane and Jamie Kelly. Thank you to everyone who was involved in making this event an amazing success!

Member Nathalie Basick Guarch of the Miami, Florida, area is selling a five-inch crystal diamond from her family

store, Unusual by Giselle, located in Key Biscayne. She calls this her Hydrocephalus Awareness Project. The diamond reminds Nathalie of her little gem, who has hydrocephalus. One hundred percent of the profits will be donated to the Association. Thank you, Nathalie!

Member Mariska Snijder from the United Kingdom ran a half-marathon on March 25, 2007. The half-marathon is run every year by as many as 10,000 people. This year marked the fourth time she has run it. Mariska was born with hydrocephalus and decided that this year it would be nice to run for a charity that means something personal to her. This is our first event overseas; thank you, Mariska! ■

Birthday Boys



For the sixth consecutive year, Jack Johnson held a fundraising birthday party and asked guests for donations to be made to the Association in lieu of gifts. Jack raised \$300 on behalf of his younger sister, Grace, who has hydrocephalus. His mom, Robyn, says, "My husband and I are so proud of our son. What has been equally exciting is to see others be inspired to do something similar to benefit a worthy cause." Happy 11th birthday, Jack! ■



Rob Montgomery celebrated his third birthday with family and friends at a benefit held in his honor. Rob was diagnosed with hydrocephalus at 11 months and is doing great! The benefit included an evening of dinner, kids' games, musical entertainment and a silent auction. Rose and David, Rob's parents, donated \$1,000 from the proceeds to the Association "to help more than just our son." Thank you Rob, Rose and David. Happy third birthday, Rob! ■



Thank You to Our Corporate and Foundation Supporters

One-third of our annual revenue comes from corporate and foundation program grants, and TEAM sponsorships. This essential support allows us to enhance and expand programs and services to benefit our community of people affected by hydrocephalus. Thank you for your generous financial support in 2006!

Platinum Sponsors: \$25,000+

Codman, a Johnson & Johnson Company
Medtronic Foundation
Medtronic Neurologic Technologies

Gold Sponsors: \$5,000–\$24,999

Aesculap
Ahn Family Foundation
BrainChild Foundation
George H. Sandy Foundation
Integra Foundation
Integra Life Sciences
One Small Voice Foundation
Phoenix Vygon Neuro
Rudi Schulte Research Institute
Sophysa

Silver Sponsors: \$1,000–\$4,999

Autodesk, Inc.
Chief Industries, Inc.
Craig & Vicki Brown Family Foundation

Dome Construction Corporation
GFDS Engineers
ISPE—San Francisco Chapter
Nibbi Brothers Construction
Ryan Associates

Bronze Sponsors: Up to \$999

1st Bank of Littleton
A+ Children's Therapy
A1A Family Eye Care, Inc.
Alan B. Almand, PA
Arapahoe Park Pediatric
Ashenfelter & Forster
Atlantis Custom Pools, Inc.
Clift & Co. Pools & Spas, Inc.
The Colleran Firm
Colorado Rockies Baseball Club
Cowboy Auto Repair
D & J Transport Solutions, Inc.
Downeast Pension Services, Inc.
Droste Consulting, Inc.
Edward Svendson Excavating
F & R Tafoya Painting
First American Title Insurance Co.
Fiserv Lending Solutions
Fisheye Video Productions, Inc.
Galileo Pools
Guthrie Builders
Hair Jazz
Hartco Sales, Inc.
HPE Group

HSM Electronic Protection Services
Hydrocephalus Support Group
Jackson RV
The Krizner Group
Lerner Corporation
Long Island Precast, Inc.
Method 360, Inc.
Metro Pain Center, Inc.
National Refund & Marketing Services, Inc.
Omni Hair Design
Power Communications
Purple Sage Antique Guns
Rambo Ventures, LLC
Red Robin Gourmet Burgers
Schley Look & Guthrie LLP
The Sign Station
Small Wonders Imaging, LLC
St. Lawrence & Atlantic Railroad Co.
Sync, Inc./Subway
Taykar Mechanical, Inc.
Toyota Motor Engineering & Manufacturing North America, Inc.
Trendsetters Hair & Skin Care, Inc.
U.S. Central Agency Services Corp.
W. West Equipment and Furnishings
Wapner, Newman, Wigrizer & Brecher
Wolfdale's
Yerkes Associates, Inc.

Meet Our 2007 Scholarship Recipients!

Keith True is the recipient of the Mario J. Tocco Hydrocephalus Foundation Scholarship. He plans to major in biology at either St. Louis University in St. Louis, Missouri, or the University of Illinois in Champaign, Illinois. A recent graduate of St. Charles North High School in St. Charles, Illinois, Keith has been on the honor roll every semester while maintaining a 5.0 grade-point average, and

was inducted into the National Honor Society. He enjoys playing volleyball and is on the varsity volleyball team at his high school. At 16, he was diagnosed with hydrocephalus and a brain tumor. He intends to pursue a career in medicine in hopes of becoming a pediatric neurologist. Keith says, "I see it as my way of giving back to the medical community that has given me a second chance at life."

Nicholas Allan Orrison is the recipient of the Justin Scot Alston Memorial Scholarship. He has been accepted into his top choice school, Western Carolina University in Cullowhee, North Carolina, and plans to major in communication studies with an emphasis on broadcast journalism. He hopes to one day become a radio morning-show host. Nicholas has been very active in sports, including

golf, indoor track, cross country, Ultimate Frisbee, swimming, indoor soccer and baseball. In addition to his sports involvement, he volunteers for the Special Olympics and the Red Cross. Nicholas wants to set an example for children with hydrocephalus: "I want to help younger kids realize that although there are limitations, there is a tremendous amount of things they can do!"

Haylea Lynn Blank is the one of two recipients of the Morris L. and Rebecca Ziskind Memorial Scholarship. She enjoys reading medical or mystery books and watching television programs such as *Grey's Anatomy* and *ER*. She has volunteered at High Point Regional Health Systems in High Point, North Carolina, since the eighth grade and is a member of the National Beta Club. On the weekends, Haylea works as a waitress. Inspired by a radiology technician at the High Point Regional Health Systems whom she had much contact with as a patient with hydrocephalus, Haylea aspires to be a certified radiology technician. Born three months premature, she explains, "The impact [of hydrocephalus] on my life is big but in the same sense little because I am fortunate to be here—I am glad every day for the life I have."

Natalie Geis is one of two recipients of the Morris L. and Rebecca Ziskind Memorial Scholarship. She currently attends the University of Utah and has a strong interest in medicine and nursing. Natalie has played basketball since she was seven years old and was a starter on her high school varsity basketball team. After a shunt complication two years ago, Natalie has worked relentlessly to remember basketball plays and adapt to the quickness of the game. She says that having hydrocephalus is "a reminder that I am different and my differences are not a handicap." When she is not attending classes, she works part-time as a phlebotomist. She now coaches basketball and mentors kids.

Brent Michael Meyers is one of two recipients of the Gerard Swartz Fudge Memorial Scholarship. He will attend Grand Valley State University in the fall to study physical therapy. He acquired hydrocephalus two weeks prior to starting his freshman year in high school. Prior to surgery, Brent played football, basketball and baseball. Post-surgery, he continues to play basketball and baseball and refuses to allow hydrocephalus to keep him from participating in his favorite hobbies. Although he does not play football, he became manager of the team and was voted captain this year. In addition to sports, he enjoys listening to music, attending dances, and riding snowmobiles and dirt bikes. Brent has high regard for his family and friends who have "been encouraging every step of the way." The support he has received from loved ones and health professionals has led Brent to be "a more caring and thoughtful person."

Daniel Hohman is one of two recipients of the Gerard Swartz Fudge Memorial Scholarship. He enjoys spending time with family and friends, playing baseball, watching movies and riding his bike. He has been actively involved in extracurricular activities and volunteer work, including the National Honor Society, Student Council, Math League and Children's Hospital of Philadelphia's Youth Advisory Committee. He plans to enter college in the fall to pursue a degree in social work. Daniel has a brain tumor and hydrocephalus with two VP shunts, but that does not keep him from leading an active life. His experiences as a patient and his desire to help children have heightened his interest in social work. Daniel says, "I want to be able to help parents understand that their children can lead a normal life with hydrocephalus. I can explain to others all the activities that I enjoy despite having hydrocephalus."

Amanda Shank is one of two recipients of the Anthony Abbene Scholarship. She is preparing to enter her second year at Tompkins Cortland Community College in Dryden, New York. She plans to earn a two-year liberal arts degree and then transfer to a four-year college to pursue a second degree. She currently attends school full-time and works full-time at a food market. Amanda believes that hydrocephalus has had a small impact on her life since birth, but that changed drastically in December 2004 when her twin sister, who also had hydrocephalus, passed away. Amanda's high school math teacher, Helen Gibson, says, "I admire Amanda for her courage, perseverance, integrity and work ethic." Amanda lives in an apartment on her own, and says, "I enjoy being independent and being able to do things for myself."

Marcus Booth is one of two recipients of the Anthony Abbene Scholarship. He has been accepted into the honors program at Tulane University, where he will major in biology with the intention of entering medical school upon graduation. Marcus says medical school is an opportunity "where I can learn new ways to change someone's life the way my surgeons changed mine." Marcus is the president of the Math Club and a dedicated team member representing his high school at the University of Interscholastic League competitions. Every summer, he volunteers at the Parkland Memorial Hospital in the orthopedics department. In his free time, he plays jazz piano and classical guitar. Marcus is working toward his goal of becoming a surgeon and says, "My goals are fairly lofty, so I work hard to not lose sight of any of them."

NOTE: See page 19 for a complete listing of our scholarship finalists. ■

Strategies for Working with Discharge Planners

What do you do when your loved one goes to the hospital? If you are caring for someone with dementia, you probably worry about the hospital's understanding of the illness and the ways your loved one needs to be cared for. If there is an acute episode—for example, a stroke, a broken hip or pneumonia—you worry about your loved one getting better, and what his or her needs will be when he or she leaves the hospital.

Often, caregivers spend many hours at the hospital, overseeing care and offering support. By the time your loved one is discharged, you might be more tired than ever—and you might be scared that you won't know how to provide care now.

So, what happens when the hospital stay is over? We've all heard about the late-Friday-afternoon discharge from the hospital. You have been there every day, talking to the nurses about your loved one's condition and needs. Suddenly, you are told that he or she is going home this afternoon. There has been no discussion about home care needs and what you need to know.

Perhaps you've met with a discharge planner, who has told you a little bit or arranged for your loved one to go to a rehabilitation facility for physical therapy. Or you have been told to look at nursing homes and let the discharge planner know what you've decided. You may have been told that your loved one needs 24-hour care, but no one has told you how to find that care or what it will cost. You may not even know how to get your loved one home from the hospital—who will pay for an ambulance if it's needed, how will he or she get up the stairs in the house, where will he or she sleep if the bedrooms or bathrooms are upstairs?

Several governmental agencies and research projects have examined the discharge planning process, the fragmentation of services and what caregivers

need to know to succeed in navigating the care system. All agree that changes are needed to make discharge planning more successful.

It has been well documented that patients are being discharged from the hospital “quicker and sicker” than in the past. This also means that patients have more complex care needs and may be dealing with multiple illnesses and disabilities. Nurse discharge planners may tell you about medical situations, and social work discharge planners will tell you about community organizations, but in too many cases, no one is overseeing the information and the referrals you are given or how to access and coordinate the help you need.

If your loved one is discharged to a rehabilitation facility, the discharge planner at the hospital will assume that someone at the facility will answer your questions. Unfortunately, the staff at the facility may not be trained to respond with the information you need. There is no care coordination across the discharge process, from hospital to facility to home care. You may be left stressed, confused and feeling helpless.

What can you do under these circumstances? First, it is important to be an advocate not only for the patient but also for yourself. Be aware that there is an appeals process available if you feel your loved one is being discharged too soon. (See “For more information” at the end of this article.) Write down your questions and make sure you get answers before taking your loved one home.

The first set of questions is about the illness:

- What is it and what should you expect in terms of recovery?
- What should you watch out for?
- Will you get home care and will a nurse or therapist come to your home to see that the patient is doing OK?
- How do you get help—advice about

care, information about danger signs, a phone number for someone to talk to, follow-up medical appointments?

- Have you been given information either verbally or in writing that you understand and can refer to?

The second set of questions is about treatment and care:

- What medicine should be taken and when?
- What side effects should you be looking for?
- How do you help your loved one transfer from a bed or chair to standing; what do you do if he or she falls (particularly when you are holding him/her)?
- What medical equipment does your loved one need—e.g., a hospital bed, commode or walker—and how do you use them?
- Will someone come to your home and do an assessment to see if you need home modifications to care for your loved one in his or her new condition?

Third, where to find help in your community:

- What agencies are available to help you with, say, transportation or meals?
- What is adult day care and how do you find out about it?
- What public benefits are you eligible for, such as In-Home Supportive Services?
- Where do you start to look for such care? (Make sure you are given specific referrals and not just a resource guide, which can be overwhelming.)
- Whom can you call to help with these referrals or if you have trouble connecting with an agency?

And, finally, you need to have the discharge planner address your needs as a caregiver.

This means that they should assess your ability to do the required tasks:

- Have they trained you in transfer skills?
- Do you know how to turn someone in bed so he or she doesn't get a bedsore?
- Do you know how to help someone swallow a pill or give an injection?
- Does your loved one require help at night and, if so, how will you get enough sleep?
- What things are scary or uncomfortable for you to do, e.g., changing a diaper?
- What medical conditions and limitations do you have that make providing this care difficult?

We know that if your health is compromised in caring for someone, he or she will return to the hospital or need nursing home placement sooner. It is important for you to say, "I cannot do that," rather than to hurt yourself or your loved one trying to do something.

We often get calls from caregivers saying that they don't know where to start to get help, or are confused by what the discharge planner has told them. Feel free to call your Caregiver Resource Center if

you need guidance when your loved one is in the hospital and when the discharge plan is being made. And most important: Don't be afraid to be assertive in getting your concerns addressed before your loved one comes home.

For more information

Center for Medicare Advocacy's
Tip Sheet for Beneficiaries: Hospital
Discharge Planning
www.medicareadvocacy.org/CovAndApps_DisTips.Hosp.Bene.pdf

Medicare
(800) MEDICARE
www.medicare.gov

Medicare Rights Center
Medicare Home Health
eligibility information
www.medicarerights.org/maincontenthomehealtheligibility.html

A Family Caregiver's Guide to Hospital Discharge Planning, published by the National Alliance for Caregiving and the United Hospital Fund of New York
www.caregiving.org/pubs/brochures/familydischargeplanning.pdf

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If your needs are not being met, "Planning to Leave the hospital," a publication of Planning for Elders, suggests the following:

If you have Medicare (with or without Medicaid or other coverage):

- Insist on a written notice.
- Find the Medicare Quality Improvement Organization for your state at the MedQIC website: www.medqic.org.
- Find the State Health Insurance Assistance Program for your state at the SHIP website: www.healthassistancepartnership.org.
- Be aware that you may have the right to an expedited appeal.

If you have Medicaid but no Medicare contact the Legal Aid Society in your area. If you have private insurance but not Medicare, call your insurance company or HMO to find out about its rules and the appeal process. ■

Congratulations to the 2007 Scholarship Finalists

Tricia Ambrosini, IL	Blake Coers, IL	Jacob Hirsch, CA	Christopher	Kristen Stafford, IN
Eleanore Arnold, CA	Sherea Combs, NV	Truc Ho, AZ	McQuilkin, CA	Krystal Swartz, TN
Roberta Bader, PA	Catharine Cox, VA	Ashley Isaac, OH	Nicole Mellett, PA	Trevor Terpstra, MI
William Bakos, OH	Courtney Daly, IL	Christina King, FL	RKvia Shavon	Meredith Vitrano, MD
Carlyn Barrow, NH	Emily Dibbell, NY	Michelle Koehler, NJ	Mendez, NJ	Melissa Wiltsey, NJ
Evan Bean, FL	Cayla Doyno, OH	Ryan Lake, TX	Megan Nannarone, MI	Catherine Anne
Steven Bertz, CT	Dylan Fitzpatrick, FL	Amanda LeClair, KS	Cathy Ostefeld, NJ	Windyk, MN
Lindsay Bimmler, MA	Abraham Flanigan, IA	Alissa Lehmann, AZ	Christine Pappalardo, IL	Nathaniel Wong Loi
Jessica Borjon, IL	Catrina George, TX	Adam Lickliter, IN	Danielle Player, NJ	Sing, NY
Alison Boulanger, MA	Kirsty Grant, FL	Michael Liptrap, WA	Chad Rapoza, CA	Chelsea Wright, AZ
Veronica Brockett, NY	Olivia Greene, FL	Cody Mace, WA	Melia Renfer, AK	Jamie Wright, TX
Christine Burke, CA	Meaghan Handzlik, NY	Christopher Martin, MI	Elizabeth Roudette, TX	Madeline Ziser, CA
Robert Carlson, CO	Robyn Harold, CA	Laura McDonnell, CA	Jonathan Smelcer, TN	

Regional Support Groups are Expanding!

By Pip Marks and Debra Howell

Paula Keyser, who is the leader of the Hydrocephalus Association's affiliate in Tampa Bay, Florida, reports a very successful hydrocephalus picnic this past April; with a speaker presenting on Medicaid waivers. Paula hosts support group meetings bimonthly and invites everyone in the area to attend. Her June meeting will feature a neuropsychologist presenting on neuropsychological evaluations and hydrocephalus. Paula continues to do great work in raising public awareness of hydrocephalus at the local level through newspaper articles and television interviews. September 2 is the date for the Tampa Bay TEAM Hydrocephalus event. To contact Paula, TampaBayFL@hydroassoc.org.

Hilary Rossen and Stephen Dombrowski, our affiliates in Cleveland, Ohio, hold monthly meetings with a variety of presenters and topics. April's meeting discussed hydrocephalus research. They will hold their fifth Annual Hydrocephalus Run, Walk and Family Day on August 5, 2007, and would love the support of local Association members. To contact Hilary about support group meetings dates and the August 5 event, NEOhioHydroassoc.org.

Our vision for more local hydrocephalus support groups is coming about. In addition to our two pilot regional affiliates mentioned above, there are three newly formed hydrocephalus groups in Arizona, New Jersey and Illinois.

- Maggie Varland, a neuroscience program coordinator at Barrow Neurological Institute in Phoenix, Arizona and a member of the Regional Expansion Advisory Committee, has joined forces with Milton and Phyllis Newman, members of the Hydrocephalus Association, to form a NPH Support Group at Barrow. Meetings are held

about three times per year and feature a speaker and time for people with NPH and their families to share and support each other. Milton and Phyllis facilitate the meetings; and Maggie provides logistical support and recruits physicians and other medical professionals as speakers. Past speakers have included Dr. Harold ReKate, chief of pediatric neuroscience, and Dr. Jiong Shi, medical director of the NPH program, both from Barrow Neurological Institute.

Milton's advice for people thinking of starting a support group: "All you need is a strong sense of wanting to help others in the same situation. Then get in touch with people who can help you, to give you ideas and [a way to contact people] in a like situation. If you feel very strongly, as we did, then you will be able to overcome whatever problems arise. We found very few problems, quite possibly because we had very able help from Maggie and the Association." If you would like more information on the Barrow Neurological Institute NPH support group, email Milton at miltnew@cox.net.

- Hydrocephalus Association member Kim Illions from Edison, New Jersey, and Deborah Rabick from Chicago, Illinois, have both started local hydrocephalus support groups and are also interested in becoming our affiliates in the future. We support the growing of these groups by sending out emails to all members in their areas regarding meeting dates and events, and by supplying educational booklets.

If you meet people from any of these areas, be sure to let them know that local support is available. And if you would like to know more about our Regional Support Affiliate Pilot Program, contact pip@hydroassoc.org. ■

2003 HA Scholarship Recipient Caitlin Maynard Interns with Nancy Pelosi

Caitlin is a past recipient of a Hydrocephalus Association scholarship and has been very involved with the Association and attended conferences. Her family organizes a Thanksgiving Run in Massachusetts every year to raise funds for the Association.



Caitlin writes, "This past semester I had the privilege of interning in the office of the Speaker of the House of Representatives, Nancy Pelosi. I worked in her personal office in Washington, D.C. My work involved receiving the mail, sorting and entering it in the database, mailing letters to her constituents, and working with the appropriations information for San Francisco. I am a social work major and have learned in the past three years of schooling that social programs are changed through government, so I took this internship to learn social work policy and lobbying where it happens, in the government. I learned so much from this internship and met many wonderful people. My special thanks to Speaker Pelosi and her chief of staff, John Lawrence." ■

Board Member Profile: Mark Geiger



A word of advice: When Emily Fudge, founding member of HA and a giant of a human being amazingly wedged into a petite frame, suggests that it would be a “good idea” for you to join the Board of Directors of the Hydrocephalus Association, it’s in your best interest to do so. I joined in 2001, about five minutes after

her comment. I acquired hydrocephalus in 1982 at the age of 14; when I graduated from college in 1991, my mother persuaded me to interview for a job with a shunt company, which has led me on a 16-year journey in hydrocephalus shunt sales and marketing. What an adventure! Make no mistake about it: There are some very committed people in this business who would give their left arm to drive a spike into the heart of hydrocephalus. You’ve no doubt seen or met some of them, I’m sure.

I have a lovely wife and two beautiful daughters, ages six and two. Being a parent has given me the deepest respect for parents of children with hydrocephalus. I’ve worked six HA national conferences and have sat on the Scholarship Committee for five years. When approaching these tasks, I often postulate that there’s

no way each time can top the last time—but they consistently do. Why? It’s because of the amazing people in the HA community and on the staff.

An account I wrote about a nine-year-old girl with hydrocephalus who attended my company’s holiday program has been accepted for publication in the 2007 *Chicken Soup for the Soul Christmas Treasury*. I wrote it because this girl’s difficult experience—turned—triumphant success embodied the uncanny heart, wisdom and spirit of you, the people who make this organization so wonderful. As I wrote in my article, “this tiny source of brilliant light knocked us all off our chairs with a gesture so uncommon.” I’m donating the money from the article to the Hydrocephalus Association to help administer the scholarship fund. Who’s with me? ■

Medical Advisory Board Member Dr. Bruce Kaufman Soars

On June 20, 2006, pediatric neurosurgeon and pilot Bruce Kaufman, MD, accompanied by master certified flight instructor and Midwest Airlines pilot Matthew McDaniel, completed a record-setting flight they have nicknamed Romp Around Wisconsin. The National Aeronautics Association certified this flight as a record—the fastest time to land at all public airports in Wisconsin: 16 hours and 42 minutes—and has recently chosen it as one of the five most memorable records for 2006!

The goal was to land at every airport in Wisconsin in just one day. That’s a total of 104 airports and more than 2,000 miles. The aircraft, owned by Dr. Kaufman, is

a single-engine Cirrus SR-22 christened Blue Kids One in honor of the hospital’s “blue kids” logo.

The flight was a fundraiser for the pediatric neurosurgery program at Children’s Hospital of Wisconsin. All expenses associated with the flight were donated by the two pilots.

“Matt and I decided to tap into our love of flying, and combine it with our devotion to children, to create a different kind of fundraiser,” says Dr. Kaufman. “Not only does this set a national record, but I am hoping this adventure serves a greater purpose of raising awareness and funds for Children’s Hospital.” ■

Kid's Corner Answers



Catheter	Insurance	Hydrocephalus	Shunt
Disability	Infection	Obstruction	Ultrasound
Research	Support	Education	Advocacy
Diagnosis	Ventricles	Brain	Treatment
Pressure	Programmable	Complication	LINK

IBM selects Hydrocephalus Association as Approved Charity

We were recently informed by HA member, Clifford Musante who works for IBM and initiated the application process, that the Hydrocephalus Association has been added to the IBM Employee/Retiree Approved Charity List. This means that we will be listed for selection by IBM employees and retirees nationwide who may wish to make a pledge to contribute through the IBM Employee/Retiree Charitable Contribution Campaigns. Our charity code is ON517. IBM does not promote any of the not-for-profit organizations on their list, so if you work for IBM or know people who do, be sure to specify our code, ON517, when making a pledge during their annual charitable campaign.

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

Edited by Daniel B. Berch, PhD, and Michele M. Mazzocco, PhD (Brookes Publishing Company)

More than 35 internationally known contributors share their expertise in this comprehensive and multidisciplinary resource that gives educational professionals in-depth and practical insight into mathematical learning difficulties and disabilities. Topics discussed include risk factors for developing difficulties with math, neuropsychological factors in mathematical learning disabilities, information-processing deficits, the role of genetics and effective instructional interventions. Order it through www.brookespublishing.com/store/boks/berch-68646/index.htm.

Raymond's Room

By Dale DiLeo

In a controversial new book, *Raymond's Room: Ending the Segregation of People with Disabilities*, author Dale DiLeo makes the case that today, as in the past, people with disabilities are segregated in institutions and programs away from the rest of society. Through memoirs of experiences and practical advice, *Raymond's Room* outlines how this segregation has stifled the potential of millions of people to live quality lives.

Many disability services are now and historically have been delivered in separate, specialized settings. DiLeo maintains that these places were and are segregated and damaging. He calls the current system "the disability industrial complex," a reference to President Eisenhower's warning phrase, "the military industrial complex," more than 40 years ago. DiLeo also proposes a plan for changing the current system.

Raymond's Room can be ordered at www.raymondsroom.com or (800) 280-7010.

New Dandy Walker Support Group

The Dandy Walker Alliance (www.dandywalker.org) is an all-inclusive organization comprising individuals directly and indirectly affected by Dandy Walker who share a collective interest in supporting educational and informational activities and nonpartisan research to increase public awareness of this congenital condition.

An excellent source of information on Dandy Walker syndrome is *The Official Parent's Sourcebook on Dandy-Walker Syndrome*, edited by James N. Parker, MD, and Phillip M. Parker, PhD (Icon Health Publications). Order it from your local bookstore or online retailer.

My Body of Knowledge: Stories of Illness, Disability, Healing, and Life

Edited by Karen Myers and Felicia Ferlin (PageFree Publishing)

The editors' keen awareness and sensitivity to their subject comes from their own experiences as people living with disabilities. Karen Myers was diagnosed with FSH muscular dystrophy at age 13; Felicia Ferlin's repetitive strain injury led to thoracic outlet syndrome. Both editors now live and write in San Francisco. *My Body of Knowledge*—honest, raw, humorous and poignant—contains the work of 34 new and established authors. What is it like to live with a chronic illness or disability? How does it feel from the inside? These are some of the questions explored by an eclectic array of writers through essays, poetry and fiction that access the wealth of insight that people with disabilities have, simply from living in their bodies. The collection is available through your local bookstore or online retailer.

New Website: Call for Photos

Our new website design will be full of photos of and by people with hydrocephalus. We invite you to share your photos with us either via an Internet upload or by sending them to the Association office.

To upload your photos via the internet, go to <http://hydroassoc.12hna.com/flickr>. First, you must click on the box to accept the release. Then, find the photos you want in your browser and upload them. Each photo must be under 9MB. You can upload five photos at a time. After you upload photos, you can go to flickr.com and search for the keywords "Hydrocephalus Association," and the uploaded pictures will appear.

HYDROCEPHALUS ASSOCIATION 2007 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 2007. Enclosed is my unrestricted donation of:

\$30 \$50 \$100 \$250 \$500 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 U.S. 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:

Hydrocephalus Association • 870 Market St. #705 • San Francisco, CA 94102

Tel. (415) 732-7040 • Toll-Free (888) 598-3789 • Fax (415) 732-7044 • Email info@hydroassoc.org

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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 Healthcare 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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