

HYDROCEPHALUS

▪ ASSOCIATION ▪

SUPPORT EDUCATION ADVOCACY

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10th National Conference—Park, City Utah: It's About Life

By Dory Kranz

THE GOAL of the Hydrocephalus Association's biennial national conference is to provide tools and connections to address the medical, educational and social challenges of living with hydrocephalus—and to enjoy getting together with each other! This will be my fifth conference, and I look forward to seeing many of the wonderful friends I have made through these community gatherings.

Highlights of the conference, scheduled for **June 19–22, 2008, in Park City, Utah**, include a keynote performance by poet/author/filmmaker Sherman Alexie, the first-ever Robert Pudenz Lectureship sponsored by the Rudi Schulte Research Foundation, a hands-on brain anatomy and physiology lab, our ever-popular interconnection sessions where you can meet other people in similar situations and the cornerstone educational sessions by our top-notch team of medical professionals and researchers.

We are grateful to our **conference sponsors** who generously underwrite a significant portion of the conference, which allows us to keep the registration fees well below our cost to produce the conference. Many of these sponsors also design and manufacture shunts and they will have models there for you to see and feel. We thank the following sponsors who have already pledged their support:

Codman, a Johnson & Johnson Company
Medtronic Neurologic Technologies
Medtronic Foundation
LifeBridge Health Brain & Spine Institute
Integra
Aesculap
Sophysa

One of the key ingredients of a great

conference is the participants, and we invite all of you, young and not-so-young, to join us in creating our best community gathering ever. After our last conference in Baltimore in 2006, that year's medical chair, Dr. Mike Williams of LifeBridge Health Brain & Spine Institute, said, "It's not about shunts, it's about life." Co-medical chairs for the 2008 conference, Drs. John Kestle and Marion "Jack" Walker of Primary Children's Medical Center in Salt Lake City, couldn't agree more, so the focus for 2008 is "It's About Life!"

Conference Registration

Registration forms and a full conference schedule will be available soon to download from our website. We will also be happy to mail you a copy upon request.

Accommodations

We are excited about the family-friendly Canyons Resort properties in Park City, which will host our conference in the beautiful mountains outside of Salt Lake City. For more information, see their website (www.thecanyons.com). For reservations, call the Canyons Resort (888-226-9667) and let them know you are with the Hydrocephalus Association group.

Transportation

From Salt Lake City Airport to The Canyons Resort in Park City takes 45 minutes to an hour (36 miles on a six-lane highway). We have contracted with All Resort Group to provide shared-ride van service

from Salt Lake City Airport to The Canyons at a discounted rate. The shared shuttle is \$28 per person and leaves every 20 to 30 minutes. All Resort also has rental cars that can be rented right in Park City. Their phone number is 800-457-9457, and their website is www.allresort.com. The Hydrocephalus Association is group #5350—use this number to get the discounted shuttle rate.

It is possible to fly into Salt Lake City from most major cities in the US and arrive by 1:30 pm, which should allow you to easily get to The Canyons for the starting session at 4 pm.

Financial Aid

A limited amount of financial aid is available to members of the Hydrocephalus Association to cover conference registration fees. Financial aid is awarded based on need. Please call our office to request a financial aid application form.

Kids' Camp

The Canyons will accommodate up to 50 children a day in their summer camp Friday through Sunday. The cost is \$65 per day per child. Through a grant from eBay, a limited number of scholarships are available. Please make your reservations directly with the Association by emailing us at info@hydroassoc.org or calling 415-732-7040. Let us know if there are any special needs that require accommodation.

Conference Schedule

Sessions begin at 4 pm on Thursday, June 19, and conclude at noon on Sunday, June 22. Much of the richness of the conference lies in connections and conversations outside of scheduled sessions. We hope you'll join us for the whole time. ■

If you have any difficulty making reservations directly with The Canyons, please call us right away so we can intervene.

From the Executive Director

By *Dory Kranz*

AS WE ARE WELL AWARE, shunt and AETV treatments for hydrocephalus come with many complications, and are not cures. Until dramatically improved treatment options and, ultimately, a cure are found, people affected by hydrocephalus will rarely lead lives free of repeated medical intervention and worry. For the first time in 50 years, we are seeing multidisciplinary groups of highly qualified researchers coming together around the premise that shunts have not solved the problem and rethinking the whole condition from the beginning with two goals in mind: (1) significantly advance multicenter clinical research aimed at novel and effective approaches to treatment, and (2) establish a high priority on funding for basic science aimed directly at promoting recovery and discovering a cure for hydrocephalus. The community of hydrocephalus researchers is poised to make great strides, the National Institutes of Health (NIH) and Congress are on our side, and we want to do all we can to make this “hydrocephalus research renaissance” a reality.

Therefore we ask ourselves, what is the highest leverage role that the Hydrocephalus Association can play in hydrocephalus research? By engaging with this question, we join esteemed organizations and agencies that are leading the way:

- **the BrainChild Foundation of Arizona**, which is pioneering a collaborative research approach that combines new experimental information from basic scientists and clinical applications to understand causes and improved treatment of hydrocephalus;
- **the Hydrocephalus Clinical Research Network (HCRN)**, which is a multicenter network focused on clinical trials in pediatric hydrocephalus;
- **the NIH**, which, through its 2005 workshop to set a national research

agenda for hydrocephalus, helped to spawn the HCRN; and

- **STARS of Michigan**, which funds early research projects focused primarily on shunt and other treatment technologies.

During my three years as executive director, I have seen the great strides these organizations are making in hydrocephalus research and invite you to read more about them in the research review article on page 13. I am pleased to be in a position to catalyze and facilitate this critical dialogue with the HA Board of Directors, Medical Advisory Board, staff and members as we progressively rethink and strategically plan our role in propelling forward hydrocephalus research.

The Association is now considering that our strongest role may include rais-

The Association is now considering that our strongest role may include raising money to directly fund hydrocephalus research.

ing money to directly fund hydrocephalus research. Our process is guided by experts in focusing resources on research: a professional consultant, Jon Tullis, who has helped similar organizations along this path; the National Health Council; the FasterCures center for accelerating medical research; and other patient advocacy groups like ours that have had success in directly funding research. This is a question we have pondered long and hard, and are continuing to think through. All of us share a commitment to finding a role and designing processes that will:

- continue to strengthen our core services of support and education;
- enhance our national advocacy efforts to encourage more federal support of hydrocephalus research through the NIH and other agencies;

- leverage HA's role in the community to draw significant new money to the table to take advantage of the “hydrocephalus research renaissance” currently under way;
- support and collaborate with the private research organizations already contributing so much to hydrocephalus research; and
- build on HA's reputation as an organization of high integrity among private research funders, community members, researchers and federal research agencies.

As a trusted patient advocacy organization, we are in a unique position to connect individuals who have an interest in funding hydrocephalus research with both organizations that fund such

research and individual researchers in need of funding. Already, over the past few years, we have successfully directed hundreds of thousands of dollars to research in this way. After lengthy dialogue throughout our community, as well as soliciting professional advice from outside counsel, it is now my belief that we can direct significantly more much-needed capital to hydrocephalus research if we take an active role in driving and supporting the national research agenda by directly funding researchers.

We are in the process of identifying individuals who are motivated by this vision to participate actively in this exciting dialogue. Please let me hear from you if you are one of those people (415-732-7040; dory@hydroassoc.org). As we continue to explore and refine our role, we welcome your feedback, your guidance and your support. ■

HA Conference—Finding Funding to Attend

The following article is reprinted from *Insights Into Spina Bifida* with the permission of the Spina Bifida Association, 4590 MacArthur Blvd. NW, Washington, DC 20007; (800) 621-3141; www.sbaa.org.

IT WOULD be difficult to put a price tag on the experiences that will be an integral part of the upcoming conference: meeting new friends and old, gaining expanded knowledge and a broader perspective, even fostering new dreams and ambitions for the future. Unfortunately, airlines, hotels, restaurants and conferences do have price tags. But if you start now, there are many avenues to funding, and one of them is almost certain to work for you.

Scholarships

Your state's Developmental Disability Council may offer scholarships to self-advocates and parents or other family members for conferences related to their disability. In Wyoming, for example, the Developmental Disability Council will cover 100 percent of conference costs for self-advocates and 50 percent of the costs for family members. Some parents have obtained funds from their child's school to attend SBAA's Annual Conference.

Grants

Gail Donkers, mother of 8-year-old Abby, has received help from a couple different sources for conference funding. The Elks Lodge once paid the entire cost of her attendance at an SBAA Annual Conference. In return, Gail wrote a summary of the trip and conference, and volunteered to share what she learned. She also received some help from Three Rivers, which was suggested by her county and school social worker. The same social worker also suggested that Gail try People in Business Who Care, which provided funding help without requiring documentation!

Gail said, "In the future, I would like to at least get Abby's way paid, since she is the reason we go! I believe that Kids!Camp is very important for Abby." According to Lisa LeBlanc, who has considerable experience with obtaining

funding for conferences, there are many agencies that may be willing to help, especially if you ask for relatively small amounts from several agencies. Some agencies are willing to pay costs for the child or adult with the disability, but not for family members. Large-scale agencies that are worth trying include Shriners, Kiwanis International and Optimist International. Churches can be a good source of help. Also, there are countless local service organizations and businesses that may be willing to step up with a donation for a good cause. If you can hook up with a nonprofit organization, there are several avenues for funding. You can establish a scholarship fund and then ask corporations to contribute. Local businesses often offer grants to local nonprofit organizations. One mother of a child with spina bifida said that she asks businesses from which she purchases disability-related products to donate toward her conference attendance, and many have responded generously.

Tax Write-Off

For those who itemize deductions, much of the cost of attending the conference is tax-deductible. That helps. In Ruling 2000-24, the IRS ruled that amounts paid by an individual for expenses of admission and transportation to a medical conference relating to a chronic disease of the individual's dependent are deductible as medical expenses under Code Section 213. Consult with your tax adviser for confirmation.

Getting Started

Although people obtain funding from various sources, you need to start by figuring out exactly how much you need. No matter who you approach, they will need estimates of the cost of attendance, conference specifics and the benefits of attending.

1. Identify the conference and determine the costs associated with attendance. Estimate the total costs for registration fees, transportation, meals and any special partici-

pation aids that you will need.

2. Identify the potential benefits for you and/or your children. These may include medical knowledge, resources, employment advice and information, and much more.
3. Talk with your local chapter to see whether there are funds available or whether there are already plans afoot to secure funds for conference attendance.
4. Write to local organizations and corporations to see whether they can provide assistance and how much. Submit your estimated expenses, event description and benefits of attending along with your letter.

Start Now

There are many possibilities, but it's important to get an early start. Talk to people—social workers, school guidance counselors, nurses—for ideas. There are many organizations willing to help, but you have to meet them halfway. Lisa LeBlanc said, "The biggest thing is to ask. No one knows that you need funds if you don't ask. That is probably the hardest thing for parents to do. I have been setting up conferences and getting funding for quite a few years, so it's a littler easier for me now."

Now is the time to start. ■

New Website Launched

Thank you for all the feedback on our new website. It's wonderful to have the work we put in over the past year so well received. Here's what you are saying about the new site:

- "The new website is outstanding! Congrats on a job well done."
- "[The] new website flows well and is a nice update to the previous one. It was nice to see the various photos of people we have met over the years at the conferences."
- "The new site is wonderful! I pulled off a lot of information."

Please check out our new website at www.hydroassoc.org—and let us know what you think.

Marathon Mom Makes Hydrocephalus Her Mission

WHEN NIKKI SILVER found out that her husband, Brad, required open heart surgery two years ago, she made a surprising decision: She slipped into her sneakers and ran. Running, she discovered, was a great outlet for the anxiety that eroded her sleep as Brad slowly recovered.

It wasn't the first time the Manhattan mother of Harrison, 10, Jack, 8, and Justin, 4, has had to deal with a major health issue. Shortly after Harrison was born, Nikki and Brad made plans for a winter vacation in Puerto Rico. But first she took 3-month-old Harrison for a routine checkup with his pediatrician. It was a visit that would redefine the kind of mother Nikki is today.

The pediatrician measured Harrison's head and urged Nikki to take him immediately to a neurologist and neurosurgeon. Harrison was diagnosed with hydrocephalus and underwent shunt surgery. The couple was warned of problems ahead: possible shunt revisions, infections, learn-



ing delays and motor difficulties.

Against the odds, Harrison has flourished and has experienced no problems with his shunt. After an aggressive intervention in his preschool years, he has excelled academically and has been in the advanced math class for two years at Riverdale Country School, in New York City.

"He has always been very empathetic and when we joined the TEAM event in Edison, New Jersey, this September he decided he wanted to do more to help," says

Nikki, who works as a TV producer for the children's program *Reading Rainbow*.

Harrison and his brother Jack held bake sales every Sunday in the fall and raised more than \$1,000 for the Association. Meanwhile, Nikki had beefed up her training regimen in preparation for the New York City marathon. To her family's delight, she completed the 26.2-mile marathon in 4 hours and 25 minutes. In total the Silvers have raised an extraordinary \$40,000 for the Association, with donations still coming in.

To Nikki, the marathon was about demonstrating the importance of hard work and determination. These are qualities that she realized were essential for Harrison's future on that dark day 10 years ago when he got his diagnosis. They have become even more important now that he is excelling, she says.

"Harrison knows that he is very lucky. He knows the joy of receiving and now he is learning the joy of giving." ■

Daniel and Michael Jones Hold Birthday Party Fundraiser

PLANNING a 5-year-old's birthday party is always a challenge. No longer a toddler, the child already has expectations of cake, ice cream and lots of games. Yet, not quite a mature elementary student, she hasn't always learned the behaviors of sharing and gratitude. After attending a few parties with mounds of gifts, it became predictable that the whining was soon to follow. "I want one too! I already have that one! I only like the red Power Ranger!" I'm sure you've all been there, and I was ready for a better way.

A couple weeks before my twins turned 5, I asked the boys if they would like to do presents at home, and hold a fundraiser party to help raise money for people with hydrocephalus. A bit to my surprise, the boys immediately agreed with no coaxing at all. Daniel has hydrocephalus as a result of intraventricular hemorrhage following premature birth.



Left to right: America Miller, Ashley Moyle, Brooke Moyle, Ian Boswell, Michael Jones (birthday boy), Daniel Jones (birthday boy with hydrocephalus), and Reese Ward

Despite a poor prognosis at birth, Daniel is now a healthy, bright preschooler.

We've been members of the Hydrocephalus Association, but this was the first time we've done a fundraiser. The boys were so proud to be helping other "kids with tubes in their heads" and they enjoyed telling everyone about it.

On the party day, we had a big snowfall, but we still had 11 guests come to the party. The children had a great time, and we raised over \$200. However, that wasn't the only benefit. In addition, 11 children went home with necklaces, awareness bracelets, coloring books and information to share with their families. I got to sit and talk to several parents about how hydrocephalus has affected us, and how without a cure, Daniel will need surgeries throughout his life. That growing awareness is key to future fundraising efforts. For our family, my kids learned about treasuring their friendships instead of treasuring their gifts, which was very important to me. ■

2008 Scholarship Applications Available Now

By *Bonnie Hom*

WE ARE VERY PLEASED to offer 11 scholarships to young adults with hydrocephalus in 2008. The scholarships are \$500 each, and will be awarded in June. If you would like to apply, please call our office (888-598-3789) or email Bonnie (bonnie@hydroassoc.org) to request an application. We will mail or email you the application with instructions.

Eligibility requirements:

- Applicants must be between the ages of 17 and 30 and have hydrocephalus.
- Scholarship funds must be used for an educational purpose: a four-year or junior college; a high school post-graduate year to prepare for college, technical or trade school; an accredited employment-training program; or a postgraduate program.
- Scholarship funds may be used for tuition, books, housing or an expense directly related to the educational experience.
- The deadline for completed applications and recommendation forms is April 1, 2008. Applications received at our office after this date will not be considered, nor will applications that are incomplete (e.g., missing the recommendation form).

Gerard Swartz Fudge Memorial Scholarship

This fund was established in 1994 by the Fudge family. Their son, Gerard, had hydrocephalus and died in 1992 at the age of 22, in the midst of his college experience. Two scholarships are awarded each year from this fund.

Morris L. and Rebecca Ziskind Memorial Scholarship

This fund was established in 2001 by Rebecca Ziskind and her family in memory of her husband, Dr. Morris Ziskind, who had NPH. After Rebecca Ziskind's death in 2005, her three surviving children and their spouses—Carrie and Dee Norton, Jerome and Rosemary Ziskind, and Janet

and Charles Tarino—graciously funded one more scholarship in loving memory of their parents, so that two scholarships are now awarded from this fund.

Anthony Abbene Scholarship

This fund was established in 2002 by Anthony Abbene's extended family. Anthony is a teenager with hydrocephalus. This fund awards two scholarships in honor of Anthony and to help others with hydrocephalus with their education.

Justin Scot Alston Memorial Scholarship

Gloria M. Alston established this scholarship in loving memory of her son, Justin Scot Alston, who died in 2004. Justin received a Hydrocephalus Association scholarship in 2002 and is remembered for his tremendous upbeat attitude and for all that he accomplished during his short life.

Mario J. Tocco Hydrocephalus Foundation Scholarship

This scholarship was established in 2007 by Greg Tocco, executive director of the Hydrocephalus Foundation, Inc. of Saugus, Massachusetts, and his family in honor and in memory of Greg's grandfather, Mario J. Tocco.

Laura Beckley Barsotti Memorial Scholarships

The Beckley-Clark family established this scholarship in 2008 in loving memory of Laura Beckley Barsotti. Of particular interest are candidates who express an interest in education or social work. ■

New Newsletter Look for Spring

The next issue of our newsletter will have a new look and a new name. It will still be full of news about hydrocephalus and the community of people who are affected by this condition, but it will no longer have a pink banner! Please keep an eye out for our new look this spring.

Boozle Testing

BOZZLE THE HYDRO BEAR is a plush toy we introduced to our community as a wonderful teaching tool about hydrocephalus and shunt surgery. As sometimes happens to bears and people with shunts, Boozle had to go in for some testing. Instead of brain scans, neuropsychology tests and shunt-o-grams, Boozle was tested on Consumer Product Safety Commission (CPSC) regulations and other toy-safety standards.

The independent laboratory results show that Boozle complies with all of the applicable CPSC regulations. Boozle was age-graded by the laboratory at "over 4 years of age," and is intended only for children ages 4 and older.

Boozle did not meet one voluntary toy industry standard that applies only to plush toys intended for children 18 months or younger. Since Boozle is intended for children age 4 and older, we believe there is no health risk presented by Boozle's shunt when used as intended. But we want to remind our community members not to leave Boozle with children under age 4, unless the shunt is removed. In the future the shunt tubing will be shorter rather than leaving it long (to reflect how it can uncoil as a kid grows taller, which is what the real doctors do). If you already have a Boozle with extra-long shunt tubing, you might wish to cut it off about an inch below the belly incision. Even with a short cord, please remember that the bear is not intended for children under age 4. Please don't leave the shunt in the bear around younger children.

Pennsylvania, Ohio and Massachusetts have some additional plush-toy regulations, so we will not be distributing Boozle in those states until we are sure we meet the additional standards.

We appreciate your patience and apologize for the delay many of you experienced in receiving bears while this testing occurred. As anyone who has lived with a shunt knows, one might suddenly need to go in for testing at any time, so Boozle just had his first experience of a similar kind. ■

Advocacy Update: Report from Washington, DC

By *MaryBeth Godlewski*,
National Advocacy Director

ACCORDING to speakers at “Blue Skies & Brickwork: Access to Care—from the White House to the State House to Your House,” a conference sponsored by the National Health Council in Washington, DC in mid-October, the climate is ripe for national healthcare reform in this upcoming presidential cycle. Panelists representing political insiders and patient advocates were in agreement that all the major players in DC want to come to the table and work through critical issues around access to healthcare. Unfortunately the panelists did not agree as to how they would achieve universal access, but we take heart that some heavy hitters are at least engaged in the dialogue and we are hopeful that this cycle may produce some real change.

During our stay in Washington, Dory Kranz and I also made the rounds of key legislators, committee members and agency leaders in our efforts to push the levers on hydrocephalus research. Since we have received tremendous support this year, much of our time was spent saying thank you to those who championed our resolution and appropriations report language. We also reached out to new agencies, including the Veteran’s Administration and the Department of Defense, and organizations like the Biotechnology Industry Forum.

We had many friends to thank. For lead sponsorship and all their efforts on behalf of H. Con. Res. 74, the resolution calling for more federal support of hydrocephalus research that passed the House in February 2007, we thanked personally Congressman Mike Thompson and his Legislative aid Liz Thomas. Through his Director of Health Policy, Karen Nelson, we thanked Congressman Henry Waxman for his support of H. Con. Res 74 and his continuing support of our work with the NIH. For their leadership on inclusion of hydrocephalus report language in the Labor, Health and

Human Services (LHHS) 2008 Appropriations Bill, we thanked Senator Arlen Specter through his legislative aid, John Myers, as well as Congressman Jim Gerlach and his legislative aid Annie Foltz, and Congresswoman Rosa DeLauro and her legislative director, Leticia Mederos. They all reaffirmed their commitment to the hydrocephalus community.

As we reached out to new agencies and organizations we learned that using the language of traumatic brain injury (TBI) may be the best way to create research relationships with the Veteran’s Administration (VA) and Department of Defense (DoD). In our first meeting at the VA, Assistant Secretary for Congressional Affairs Thomas E. Harvey encouraged us to seek out clinical and basic research scientists active in hydrocephalus who are affiliated with VA hospitals and interested in exploring the connection between TBI and hydrocephalus. If you know anyone who fits this bill, please encourage them to apply for research grants through the VA. We also met with Sarah Young, legislative aid for Congressman Jack Murtha, Chair of the Appropriations Subcommittee on Defense, and she encouraged us to let researchers know about the Post Traumatic Stress Disorder and Traumatic Brain Injury Research Program (<http://cdmrp.army.mil/prmrp>). As researchers make strides in documenting hydrocephalus as an ongoing problem associated with some percentage of war-related TBI and confirm the unusually high incidence of hydrocephalus in children of military families, we will continue to explore a congressionally directed medical research program specifically for hydrocephalus.

At one very early morning meeting, we learned inadvertently that a simple box of donuts can be misconstrued as a potential bribe—even though a gift of value un-

der \$10 is technically allowed. The outside guards had a nice treat that day!

We met with the Vice President of the HA Board of Directors. Deborah Phillips, who lives in DC, to discuss tactics to further our work with the Centers for Disease Control (CDC). After a few exploratory phone conversations and a personal meeting which Deborah attended, it appears that the most promising avenue of initial approach with the CDC may be to mine the underlying data from their December 2006 *Congenital Malformations Surveillance Report*. Hydrocephalus is reported as a birth defect only when it is not secondary to another condition like spina bifida, cerebral palsy, prematurity or intraventricular hemorrhage. This means that hydrocephalus is grossly underreported. Unfortunately, the data is not publicly accessible, so we must find a qualified researcher who has—or is willing to get—permission to look at the underlying data so that we can

Hydrocephalus is reported as a birth defect only when it is not secondary to another. This means that hydrocephalus is grossly underreported.

understand the extent of the understatement of hydrocephalus in these important CDC reports. We are also working with the Spina Bifida Association to look at the Spina Bifida Registry they are creating with the CDC to see if it might be expanded to include hydrocephalus that is not secondary to spina bifida. The Hydrocephalus Clinical Research Network is also looking into how a hydrocephalus registry they are designing can complement and integrate with the CDC Spina Bifida registry so that data can be shared from the two sources.

Thanks to HA member Michael Ilions, we had the pleasure of meeting with Michelle Presson, Chief of Staff for New Jersey Congressman E. Scott Garret. On hearing about some exciting new research linking heart rate and hydrocephalus, Michelle suggested we approach pharmaceutical companies through the HealthCare Institute of New Jersey.▶▶

Board Member Profile: Deborah Phillips

By Deborah Phillips



I WAS INTRODUCED to the Hydrocephalus Association when my son, Elijah, was just 2 years old. The Association's biennial conference was being held in Alexandria, Virginia, that year and I had the wonderful opportunity to co-chair a session for parents with Elijah's pediatrician. In truth, most of the parents in the audience were much more informed than I, in large part because of the support provided to them by the Association. So, I jumped on the bandwagon, eagerly awaited each newsletter and acquired virtually every brochure that the

Association produced. Especially helpful was *A Teacher's Guide to Hydrocephalus*, which is now on the shelf in every one of Elijah's classrooms—our personal public education campaign.

Our family's involvement in the Hydrocephalus Association expanded when my husband, John Lawrence, worked with the Internal Revenue Service in 2000 to enable parents of children with chronic medical conditions to deduct some of the expenses associated with attending relevant conferences, such as the Association's conference.

Subsequently, John was invited to give the keynote speech at the 2006 conference in Baltimore. But it was Elijah who stole the show when, as part of John's talk, he sang "What a Wonderful World." I credit John and Elijah with my invitation to join the Association's Board of Directors two years ago. It has been my deep honor to bring my background as a developmental scientist, my experience as a federal advocate for children and my passion as a mother of a child with hydrocephalus to the work of this remarkable organization. ■

Deborah Phillips, PhD, is professor of psychology and associated faculty in the Public Policy Institute at Georgetown University. She is also co-director of the University's Research Center on Children in the US. Prior to this, she was the first executive director of the Board on Children, Youth, and Families of the National Research Council's Commission on Social and Behavioral Sciences and the Institute of Medicine. She coedited *From Neurons to Neighborhoods: The Science of Early Child Development*, and is a member of the organization that was created to continue the work of *Neurons to Neighborhoods*: the National Scientific Council on the Developing Child (based at Harvard University).

Her research focuses on the developmental effects of early childhood programs, including both childcare and pre-k settings. Her current studies focus on how children who vary in temperament are differentially affected by childcare experiences and on an evaluation of the Tulsa,

Oklahoma, pre-k program as it affects both cognitive and social-emotional development. As a Congressional Science Fellow of the Society for Research in Child Development, Dr. Phillips served as an analyst at the Congressional Budget Office and on the personal staff of Congressman George Miller. She was a midcareer fellow at Yale University's Bush Center in Child Development and Social Policy, and director of the Child Care Information Service of the National Association for the Education of Young Children. She has served on numerous task forces and advisory groups, including the Carnegie Corporation's Task Force on Meeting the Needs of Young Children and the Secretary's Advisory Committee on Head Start Quality and Expansion of the US Department of Health and Human Services. She is also vice-president of the Hydrocephalus Association Board of Directors. Dr. Phillips is a Fellow of the American Psychological Association and the American Psychological Society.

➤➤ This dialogue is just beginning. We had lunch with Michael Losow, Director of Outreach for the Biotechnology Industry Organization, and discussed the importance of banding together to speak for patients' rights during this current national conversation on comparative effectiveness research (CER). Through Michael, the Association became a signatory to a NORD-sponsored letter to

legislators Baucus and Grassley about how CER is addressed in the upcoming Medicare package.

Our very busy three-day trip to Washington was not without some fun. We celebrated with one of our great supporters, the Medtronic Foundation, as they launched their PBS series *The Mysterious Human Heart* with an awards ceremony at the Library of Congress. It was also

our pleasure to have dinner with Association members local to DC and strengthen our connections with this important constituency.

All this and more in three days makes us very hopeful that the near future will see greater national attention paid to hydrocephalus research. As always, your comments and involvement are welcome. ■

Medical Advisory Board Meets in Miami

FOURTEEN members of our Medical Advisory Board (MAB) joined with seven members of our Board of Directors (BOD) and two staff members for a very productive meeting on November 28, 2007, in Miami Beach, Florida.

As the Association grows, we ask more from our MAB. To this end, Bob Jacobsen, president of our Board of Directors, announced a new leadership and committee structure within the MAB to foster more strategic input and improve integration between the BOD and MAB. Dr. Marion L. “Jack” Walker of Primary Children’s Medical Center in Utah was appointed chair of the MAB. Dr. Walker will also sit on the BOD and serve as an active liaison between the two bodies. The committees, which are currently being constituted, will include pediatric, transition, adult, research and advocacy. The Association is excited about calling on smaller groups within the MAB for more active advice and counsel, especially as we seek to explore the highest leverage role we can play in hydrocephalus research.

Dr. Joe Piatt of St. Christopher’s Hospital for Children in Philadelphia provided an update on the transition issue. Since this issue made the top-10 list of the American Academy of Pediatrics (AAP) in March 2007, the AAP launched a “Step Up to the Plate” initiative, which



brings together many organizations that care about improving the quality of patient care during transitions. Jack Walker has been named an AAP representative to the Step Up to the Plate initiative and said that, although the age-related transition of care is part of the question that is

framed, it is not actually part of the conversation yet. The Association and the MAB are still committed to driving this issue forward and specific suggestions were made.

Dr. Rick Abbott of Montefiore Medical Center in the Bronx, past chair of the AANS/CNS section on Pediatric Neurological Surgery, shared highlights of Susan Durham’s report on the first phase of the AANS’s Pediatric Neurosurgery Workforce Study. Highlights of the findings: Only five or six pediatric neurosurgeons are trained and certified each year, and one-third of time is lost to nonclinical work. Questions were raised about defining the need and the net loss per year. This will need to be considered in a future project, which will depend on funding and staffing.

We are grateful to all of the outstanding professionals who serve on our Medical Advisory Board, especially now as they help us drive issues of importance to our community forward into the clinical and research communities. ■

Inside the Operating Room

AS PART OF a high-school advanced-placement psychology class, Association Medical Advisory Board member Dr. Mark Luciano, director of pediatric neurosurgery at the Cleveland Clinic, performed an endoscopic third ventriculostomy while 104 students from Medina High School in Cleveland viewed the procedure live on a screen in the school’s distance-learning lab.

Once the two-hour surgery was over, Dr. Luciano answered questions from the students, which were relayed to him through microphones scattered

throughout the room. Dr. Luciano took every question and gave answers in lay terms, explaining in basic language the complexity of the brain and of hydrocephalus, which was the infant’s condition.

“These surgeries are broadcast in the classroom through a partnership with the Cleveland Clinic’s Office of Civic Education Initiatives,” said Jeanne Hurt, communication coordinator for the school district. “In partnership with area schools, local businesses and fellow nonprofit organizations, the Of-

fice of Civic Education creates innovative programs designed to enhance children’s education in the areas of math, science, health and wellness, arts and innovations.”

Hurt said the teachers and students prepared ahead of time for the surgical broadcast with a teacher’s guide containing pre- and post-surgery lessons and discussions.

She added: “The lessons prepare students to view the surgeries and include ideas to extend the learning into other curricular areas.” ■

Introducing the Life Enhancement Project

By Bonnie Hom, Outreach Assistant

WE HAVE an exciting project under way at the Hydrocephalus Association, and we need your help.

The purpose of our Life Enhancement Project is to better understand quality-of-life issues pertaining to young adults with hydrocephalus. Some of the issues we're interested in are: transition from pediatric to adult-centered medical care, education, employment, insurance and emotional well-being.

Here are quotes we've received from several young adults:

"I am so excited about this project because I feel that as a young adult with hydrocephalus, there is a lack of information/resources regarding the transition from peds to adults. I felt this way especially during my college years where I was just sent out into the world without any support or tools. I learned to be an advo-

cate for myself and of my medical condition. I am more than happy to help out with this survey/project in any way that I can or even meet other young adults like myself. My mission is just to help others."

"I am now 38, and would gladly participate in any survey or study that can help someone else with hydrocephalus. I myself had never heard of it until my diagnosis."

"I would like to become more involved and get famous enough to get this condition on the map, because it is not right now. I will help you in any way I can."

"Hydrocephalus has certainly impacted aspects of my life more than I ever desired. I am more than happy to take the survey."

"Thank you very much in wanting to update my file. As a biologist and high school teacher, I do know that we are a small community in this big world in front of us."

If you are a young adult between the ages of 18 and 40 and are interested in participating in the Life Enhancement Project Survey, please email Bonnie (bonnie@hydroassoc.org) no later than **Friday, March 14**. Please include your full name and current email address in the body of the email and "Life Enhancement Survey" in the subject line. After we receive this information, we will send you a link to the online survey. You can then go to the website and complete the survey, and if you wish, you can remain anonymous. If you don't have internet access, you can drop us a note by regular mail with your current mailing address and we will send you a paper survey to complete.

We strive to stay current with the needs of our diverse community and it's time to get an update from our young adults with hydrocephalus. Please take this unique opportunity to lend your voice because it needs to be heard. ■

Getting Patients and Physicians on the Same Page

WITH MANY VISITS to the doctor averaging just 11 minutes, how can we ensure that our medical needs are adequately met? That is the question posed by reporter Laura Landro in an article that appeared in the *Wall Street Journal* on October 31, 2007.

Although medical information has never been more accessible, many of us flounder in the doctor's office, cramming all our questions into a single visit, ignoring information we don't understand and saving any delicate but important issues until the end of the appointment, just as the physician is preparing to make a getaway.

But thanks to concerns about patient safety and malpractice liability, doctors, too, are feeling the need to get up to speed on communication with patients. Researchers at the University of

California, Los Angeles, have suggested that subtle differences in bedside manner can affect patient satisfaction. For example, patients who were asked at the end of a visit if there was "anything else" that needed attention were more likely to leave with unmet concerns than those who were asked if there was "something else." The researchers explain this is because "any" tends to be used in a negative context, prompting patients to answer negatively.

According to Landor's article there are several steps we can take to get the most out of our doctor's visit. Among them:

➤ Prepare questions prior to your visit. (The Association can help you put together a list of pertinent questions for your physician.)

- If it's a diagnostic visit, write down a detailed summary of your symptoms.
- Bring a list of current medications and dosages.
- Avoid misunderstandings about the purpose of your visit by addressing your primary concern first.
- Before your appointment, check that your doctor's office has received all test results and reports from other physicians and labs.
- Consider taking notes or even asking your doctor if you can record the session for subsequent review. ■

Way to Go TEAM Hydrocephalus 2007!

THANKS to the efforts and leadership of 35 amazing members of the HA, we have received over \$400,000 in donations through TEAM Hydrocephalus and other hydrocephalus fundraising events in 2007. Our TEAM Hydrocephalus leaders cultivated committee members, volunteers and donors, creating not only funding but awareness and support of hydrocephalus from their communities, local hospitals/medical professionals and legislators.

The number of TEAM supporters we need to acknowledge individually and thank for contributing to the 2007 TEAM accomplishments are far too great to do

so in the newsletter. You know who you are, please accept our heartfelt thanks for your amazing support. However, we would like to give a big round of applause to our 2007 TEAM Leaders:

Kathy Carrillo, Albuquerque, NM; Kerry Houghton and Debbie Crandall, Atlanta, GA; Terri Smith, Baltimore, MD; Sherry Reising and Debi Rabick, Chicago, IL; Phyllis Rogers, Denver, CO; Denise Bechard, Detroit, MI; Kim and Michael Illions, Edison, NJ; April Brantley, Greensboro/Durham, NC; Amy Maynard, Jack Ginnity and Jim and Beth Walsh, Fitchburg, MA; Sherry Veillieux, International Falls, MN; Janine Melomo

and Doris Kahler, Long Island, NY; Elizabeth and Richard Gladden, Louisville, KY; Hilary Rossen, Monica Ferrante and Stephen Dombrowski, Cleveland, OH; Kelly Rambo, Erica Stivaletti and MaryBeth Godlewski, Philadelphia, PA; Jodi Lawrence, Sacramento Valley, CA; Kelly Varga and Vicki Bell, Salt Lake City, UT; Sheri Burdine, San Antonio/Austin, TX; Pip Marks and Emily Fudge, San Francisco, CA; Abby Puckett, St. Louis, MO; Paula Keyser, Tampa Bay, FL and Mimi Kramer-Roberts, Washington, DC

Please consider joining these amazing people in 2008.



Albuquerque, NM



Baltimore, MD



Chicago, IL



Cleveland, OH



Denver, CO

Not pictured:

Sacramento Valley (CA)

International Falls (MN)

Another Outstanding Success!



Detroit, MI



Edison, NJ



Fitchburg, MA



Greensboro–Durham, NC



Louisville, KY



New York, NY



Philadelphia, PA



Salt Lake City, UT

TEAM Hydrocephalus 2007!



San Francisco, CA



San Antonio/Austin, TX



St. Louis, MO



Tampa Bay, FL



Washington, DC

TEAM Leaders

THE HYDROCEPHALUS ASSOCIATION could not accomplish all the work it does without the dedication of our volunteers at the local and national levels.

The staff and board of the Hydrocephalus Association would like to take this opportunity to recognize and thank our TEAM Leaders, who volunteer their time, effort and talents to make these events run so smoothly. The enthusiasm and passion each of them displays make our TEAMS successful, and we thank them one and all for a job exceptionally well done!

HA's TEAM Leaders are worth their weight in gold and they are the driving force behind our success in our local communities. We know each of them made the commitment to long hours and hard work because their lives have been touched by hydrocephalus. Whether a parent, a child, a sibling, a spouse or a friend to someone living with hydrocephalus, they know how very important raising the visibility of this condition is.

Go TEAMS!

New Research 2007: A Summary

The following summaries are a small sample of research papers appearing in peer-reviewed medical and scientific journals in 2007. Due to space limitations resulting from the exciting abundance of articles relating to hydrocephalus, we have collapsed the abstracts to include only the purpose of the studies. For more information on these and other articles, please utilize our new web page where you can search PubMed articles (www.hydroassoc.org/research_advocacy/search-pubmed). You may also call our office for further help accessing these articles.

A FEW KEY ORGANIZATIONS are spearheading this renaissance in hydrocephalus research and we would like to acknowledge and thank them for their leadership. The names of researchers who have received support from these organizations are marked with an asterisk. Although the particular research projects marked may not be funded by the organizations, we want to begin to familiarize the community with the organizations and the cutting-edge researchers who are poised to change for the better the reality of living with hydrocephalus. These are the organizations with whom we are working to redefine the Association's highest-leverage role in research as described in the letter from the editor.

***B**: Indicates that one or more of the authors is currently supported in part by **The BrainChild Foundation**, which continues to expand its innovative hydrocephalus research program in pursuit of the organization's mission to improve the lives of children with hydrocephalus by supporting research to enhance treatment and find a cure for the disease. The research team is now international in scope and is led by excellent clinicians and basic scientists from the State University of New York–Stony Brook, the University of Toronto, the University of Utah and Harvard University. The research team has focused on the innovative theory of pulsatile dynamics within the brain as a better way to understand both the cause and the effects of hydrocephalus. Important recent advances have been made in the development of

clinically relevant animal models to better study hydrocephalus, the use of MRI to quantify CSF flow during hydrocephalus, improved understanding of CSF absorption sites and understanding the change in cell structure and function in the hydrocephalic brain.

***H**: Indicates that one or more of the authors is currently involved with the **Hydrocephalus Clinical Research Network (HCRN)**, a pediatric-focused clinical research network which developed out of an MBA project and was influenced by the NIH Hydrocephalus workshop in 2005. It is modeled after other successful multicenter research networks, including the Children's Oncology Group. The mission of HCRN is to dramatically improve the lives of children with hydrocephalus by conducting important and field-changing multicenter clinical research. The vision of HCRN is that, in 5 to 10 years, doctors will use HCRN-research-based evidence to improve the diagnosis, treatment and outcomes of hydrocephalus patients, and that these patients will live longer, more trouble-free lives. Over that same time frame, HCRN envisions greater attention and financial resources directed toward hydrocephalus research and treatment.

***S**: Indicates that one or more of the authors has received support from **STARS-kids** (Seeking Technology Advancing Research in Shunts) of Detroit, MI, a tax-exempt public charity whose mission is to raise awareness and funds for shunt and hydrocephalus research. Funds are acquired from private sources through donations and fundraising events. The STARS-kids grants provide seed funding for two-year projects. Their goal is for these seed grants to support research that generates pertinent data to sustain additional publicly funded studies.

***N**: Indicates that one or more of the researchers has received hydrocephalus research funding from the **National Institutes of Health (NIH)**. The NIH, a part of the U.S. Dept. of Health and Human Services, is the primary federal

agency conducting and supporting medical research. Helping to lead the way toward important medical discoveries that improve people's health and save lives, NIH scientists in Bethesda, MD, as well as NIH-funded scientists throughout the country, investigate ways to prevent disease as well as the causes, treatments and even cures for common and rare diseases. Four of the 27 Institutes and Centers within the NIH (NINDS, NIA, NICHD, NIA) and the Office of Rare Diseases sponsored the 2005 workshop "Hydrocephalus: Myths, New Facts, Clear Directions," which inspired the HCRN.

Adults

Changes in Aqueeductal CSF Stroke Volume and Progression of Symptoms in Patients With Unshunted Idiopathic Normal Pressure Hydrocephalus. *AJNR Am J Neuroradiol.* 2007 Oct 9; Scollato A, Tenenbaum R, Bahl G, Celerini M, Salani B, Di Lorenzo N.; Dept.s of Neurosurgery and Radiology, and Emergency Dept., Geriatric Agency, University of Florence, Florence, Italy; and Dept. of Radiology, University of California, San Diego

In this study, the authors evaluated the changes in stroke volume (SV) during the progression of clinical symptoms in patients with suspected NPH. The progressive reduction of the SV in untreated patients with worsening clinical symptoms may be a sign of a progressive cerebral ischemic injury, which renders the NPH irreversible.

Characteristics and reversibility of dementia in Normal Pressure Hydrocephalus. *Behav Neurol.* 2007;18(3):149-58; Chaudhry P, Kharkar S, Heidler-Gary J, Hillis AE, Newhart M, Kleinman JT, Davis C, Rigamonti D, Wang P, Irani DN, Williams MA; Johns Hopkins University, School of Medicine, Baltimore, MD

The authors prospectively studied performance of 60 patients with NPH on a comprehensive battery of neuropsychological tests before and after shunt surgery to determine which cognitive functions improve with shunt insertion. Results indicate that testing before and after temporary drainage may be useful in predicting which patients are less likely to improve in memory with shunting.

Clinical value of constructional skill testing in patients with secondary normal pressure hydrocephalus—two case reports. *Neurol Med Chir (Tokyo).* 2007 Jul;47(7):322-4; Takeuchi M, Hayashi N, Takaiwa A, Hamada H, Kuwayama N, Hirashima Y, Matsui M, Endo S; Dept. of Neurosurgery, University of Toyama, Japan

Cognitive functions are frequently impaired in patients with NPH. Dysfunction of constructional skill should be added to the important clinical features of NPH. The geometric test can be used as a practical tool for evaluation of parietal lobe function in patients with NPH.

Estimated incidence of normal pressure hydrocephalus and shunt outcome in patients residing in assisted-living and extended-care facilities. *Neurosurg Focus.* 2007 Apr 15;22(4):E1: Marmarou A, Young HF, Aygok GA; Dept. of Neurosurgery, Virginia Commonwealth University Medical Center, Richmond, VA

The primary objective of this study was to estimate the prevalence of idiopathic NPH, both diagnosed and undiagnosed, among residents of assisted-living and extended-care facilities, by using a practical screening tool. A secondary objective was to evaluate prospectively the diagnosis and outcome of surgical treatment in a subset of patients residing in healthcare facilities who were at risk for idiopathic NPH.

Extrapyramidal signs in normal pressure hydrocephalus: an objective assessment. *Cerebrospinal Fluid Res.* 2007 Aug 13;4:7: Mandir AS, Hilfiker J, Thomas G, Minahan RE, Crawford TO, Williams MA, Rigamonti D; Johns Hopkins University, Dept. of Neurology and Neurosurgery, Baltimore, MD

Beyond the classic NPH triad of gait disturbance, incontinence, and dementia are characteristic signs of motor dysfunction in NPH patients. The researchers used highly sensitive and objective methods to characterize upper limb extrapyramidal signs in a series of NPH subjects compared with controls.

Influence of shunt surgery on healthcare expenditures of elderly fee-for-service Medicare beneficiaries with hydrocephalus. *J Neurosurg.* 2007 Jul;107(1):21-8: Williams MA, Sharkey P, van Doren D, Thomas G, Rigamonti D; Dept. of Neurology, Johns Hopkins School of Medicine, Baltimore, MD

The goal in this study was to determine the percentage of patients with hydrocephalus who were treated with shunt surgery and to assess Medicare expenditures for those with and without shunt surgery.

Guide to Abbreviations

AIS: antibiotic-impregnated shunts
CSF: cerebrospinal fluid
ETV: endoscopic third ventriculostomy
iNPH: idiopathic NPH
MRI: magnetic resonance imaging
NPH: normal pressure hydrocephalus
VP shunt: ventriculoperitoneal shunt
VSG shunt: ventriculosubgaleal shunt

Longstanding overt ventriculomegaly in adults: pitfalls in treatment with endoscopic third ventriculostomy. *Neurosurg Focus.* 2007 Apr 15;22(4):E6: Rekate HL; Pediatric Neurosciences, Barrow Neurological Institute, Phoenix, AZ

The purpose of this review was to evaluate the role of endoscopic third ventriculostomy (ETV) in the treatment of longstanding overt ventriculomegaly in adults (LOVA).

Mechanism of bladder dysfunction in idiopathic normal pressure hydrocephalus. *Neurourol Urodyn.* 2007 Dec 18: Sakakibara R, Kanda T, Sekido T, Uchiyama T, Awa Y, Ito T, Liu Z, Yamamoto T, Yamanishi T, Yuasa T, Shirai K, Hattori T; Neurology Division, Dept. of Internal Medicine, Sakura Medical Center, Toho University, Japan

The aim was to elucidate the mechanism of bladder dysfunction in idiopathic normal pressure hydrocephalus (iNPH) by a urodynamic study.

Normal pressure hydrocephalus. *Neurol Clin.* 2007 Aug;25(3):809-32, vii-viii: Graff-Radford NR; Mayo Clinic Jacksonville, FL

This article discusses the epidemiology, reasons why the diagnosis is difficult, differential diagnosis, features of the history, examination, neuropsychologic assessment, radiologic evaluation, and special tests that may help clinicians with management.

Normal pressure hydrocephalus: a case report by a physician who is the patient. *Clin Med.* 2007 Jun;7(3):296-9: Conn HO; Yale University School of Medicine, New Haven, CT

This report describes the case of an elderly physician who endured a slowly progressive, ambulatory illness, which was erroneously diagnosed as Parkinson's disease.

Pathophysiology of cerebral circulatory disorders in idiopathic normal pressure hydrocephalus. *Neurol Med Chir (Tokyo).* 2007 Jul;47(7):299-306: Takeuchi T, Goto H, Izaki K, Tamura S, Tomii M, Sasanuma J, Maeno K, Kikuchi Y, Koizumi J, Watanabe Z, Numazawa S, Itoh Y, Watanabe K, Kojima M, Mishima M, Onishi Y, Okada T, Arai T; Dept. of Neurosurgery, Gyoda General Hospital, Saitama, Japan

This study was conducted to elucidate the pathologic conditions of cerebral circulatory disorders in iNPH.

Predictive assessment of shunt effectiveness in patients with idiopathic normal pressure hydrocephalus by determining regional cerebral blood flow on 3D stereotactic surface projections. *Acta Neurochir (Wien).* 2007 Oct;149(10):991-7: Murakami M, Hirata Y, Kuratsu JI; Dept. of Neurosurgery, Kumamoto Takumadai Hospital, Japan

Using single-photon emission computed tomography (SPECT), these investigators compared the characteristic rCBF patterns in iNPH patients who did, or did not, respond to shunt operations.

Striatal D2 Receptor Availability After Shunt-

ing in Idiopathic Normal Pressure Hydrocephalus. *J Nucl Med.* 2007 Dec; 48(12):1981-1986. Epub 2007 Nov 15; Nakayama T, Ouchi Y, Yoshikawa E, Sugihara G, Torizuka T, Tanaka K; Dept. of Neurosurgery, Hamamatsu Medical Center; Positron Medical Center, Hamamatsu Medical Center; Central Research Laboratory, Hamamatsu Photonics K.K.; and Dept. of Psychiatry, Hamamatsu University School of Medicine, Japan

The authors investigated the plasticity of D(2) receptor in treating iNPH patients with VP (VP) shunting using PET with (11)C-raclopride and discuss the contribution of D(2) receptor to the pathophysiology of iNPH.

The neuropsychology of patients with clinically diagnosed idiopathic normal pressure hydrocephalus. *Neurosurgery* 2007 Dec; 61(6):1219-26; discussion 1227-8: Hellström P, Edsbacke M, Archer T, Tisell M, Tullberg M, Wikkelsö C.; Institute of Neuroscience and Physiology, Göteborg University, Sweden

The objective of this study is compare the neuropsychological performance of patients with iNPH with that of healthy individuals and to examine its relation to neurological signs, vascular comorbidity, and background factors.

The Pathophysiology of Idiopathic Normal Pressure Hydrocephalus: Cerebral Ischemia or Altered Venous Hemodynamics? *AJNR Am J Neuroradiol.* 2007 Oct 9: Bateman GA; Dept. of Medical Imaging, John Hunter Hospital; and the University of Newcastle, Callaghan Campus, Australia

This study sought to compare cerebral blood flow and compliance measures in a cohort of patients with NPH selected for having arterial inflows above the normal range to see if deep brain ischemia or superficial hemodynamic changes contribute to the pathophysiology of NPH.

Ventricular cerebrospinal fluid neurofilament protein levels decrease in parallel with white matter pathology after shunt surgery in normal pressure hydrocephalus. *Eur J Neurol.* 2007 Mar;14(3):248-54: Tullberg M, Blennow K, Månsson JE, Fredman P, Tisell M, Wikkelsö C.; Institute of Clinical Neuroscience, The Sahlgrenska Academy, Göteborg University, Sweden

The researchers' aim was to explore the relationship between ventricular CSF markers, periventricular WML and postoperative clinical outcome in patients with NPH. They analyzed lumbar and ventricular concentrations of 10 CSF markers, 12 clinical symptoms and signs, periventricular white matter hyperintensities (PVH) using MRI, and ventricular size before and 3 months after shunt surgery in 35 patients with NPH.

Basic Science

CSF pathways: a review. *Br J Neurosurg.* 2007 Oct;21(5):510-20: Brodbelt A, Stoodley M.; The Walton Centre for Neurology and Neurosurgery, Liverpool, UK

This article reviews current concepts of CSF

function and pathways, following the journey of CSF from conception to absorption.

***B Impact of ageing on lymphatic cerebrospinal fluid absorption in the rat.** *Neuropathol Appl Neurobiol.* 2007 Dec;33(6):684-91: Nagra G, Johnston MG^{*B}; Neuroscience Program, Dept. of Laboratory Medicine and Pathobiology, Sunnybrook Health Sciences Centre, University of Toronto, Canada

Several parameters associated with CSF system show a change in the later stages of life, including elevated CSF outflow resistance. The latter implies a CSF absorption deficit. As a significant portion of CSF absorption occurs into extracranial lymphatic vessels located in the olfactory turbinates, the purpose of this study was to determine whether any age-related impediments to CSF absorption existed at this location.

***B*^S Reduction of astrogliosis and microgliosis by cerebrospinal fluid shunting in experimental hydrocephalus.** *Cerebrospinal Fluid Res.* 2007 Jun 7;4:5: Miller JM^{*S}, McAllister JP 2nd ^{*B*^S}; Dept. of Neurosurgery, Wayne State University, Detroit, MI Reactive astrogliosis and microgliosis, injury-related processes that contribute to scar formation in the brain, were evaluated as the severity of hydrocephalus increased with age in hydrocephalic H-Tx rats and control littermates.

***B*^{H*^S} Effects of congenital hydrocephalus on the hypothalamic gonadotrophin-releasing hormone system.** *Neurosurg Focus.* 22(4), E4: McAllister JP 2nd ^{*B*^S}, Abdolvahabi RM, Walker ML ^{*B*^H}, Mitchell JA, Jones HC. (2007); Dept. of Neurosurgery, Division of Pediatric Neurosurgery, Primary Children's Medical Center and the University of Utah, Salt Lake City, UT

This study, performed in neonatal rats with congenital hydrocephalus, was designed to identify the brain pathology that causes precocious puberty and impaired reproductive function in hydrocephalus. The authors found retarded development of the gonadotrophin releasing hormone system in the hypothalamus of untreated brains, and showed that early shunting was more effective than late shunting in reverse the pathology.

ETV

***B Audits can improve neurosurgical practice—illustrated by endoscopic third ventriculostomy.** *Pediatr Neurosurg.* 2007;43(6):482-7: Meling TR, Tiller C, Due-Tønnessen BJ, Egge A, Eide PK^{*B}, Frøslie KE, Lundar T, Helseth E.; Dept. of Neurosurgery, The National Hospital, Oslo, Norway
A single-center, retrospective study was performed to evaluate the effect of audit on the patient selection for ETV.

Complications following endoscopic intracranial procedures in children. *Childs Nerv Syst.* 2007 Jun;23(6):633-44: Cinalli G, Spennato P, Ruggiero C, Aliberti F, Trischitta V, Buonocore MC, Cianciulli E, Maggi G.; Dept. of Pediatric Neurosur-

gery, Santobono Children's Hospital, Naples, Italy
Complications recorded in a prospectively collected database of pediatric patients undergoing neuroendoscopic procedures were analysed; the medical histories of the patients and the surgical procedures were reviewed.

Delayed endoscopic intraventricular hemorrhage (IVH) removal and endoscopic third ventriculostomy may not prevent consecutive communicating hydrocephalus if IVH removal was insufficient. *Minim Invasive Neurosurg.* 2007 Aug;50(4):209-11: Nishikawa T, Takehira N, Matsumoto A, Kanemoto M, Kang Y, Waga S; Dept. of Neurosurgery, Saiseikai-Izuo Hospital, Osaka, Japan
The aim of this study was to investigate whether delayed endoscopic treatment of intraventricular hemorrhage (IVH) can prevent consecutive communicating hydrocephalus.

***H Endoscopic biopsy for intraventricular tumors in children.** *J Neurosurg.* 2007 May;106(5 Suppl):340-6: Depreitere B, Dasi N, Rutka J, Dirks P, Drake J^H; Division of Neurosurgery, The Hospital for Sick Children, Toronto, Canada
The authors performed a retrospective analysis of biopsy accuracy, complication rate, and success rate of ETV in a series of 31 endoscopic biopsy procedures.

Endoscopic Management of Hydrocephalus in Pediatric Patients: A Review of Indications, Techniques, and Outcomes. *J Child Neurol.* 2007 Dec 3: Sandberg DL.

This article reviews modern endoscopic techniques available to treat hydrocephalus, with a focus on selection criteria and outcomes.

Endoscopic third ventriculostomy for treatment of obstructive hydrocephalus. *Arch Iran Med.* 2007 Oct;10(4):498-503: Rezaee O, Sharifi G, Samadian M, Haddadian K, Ali-Asgari A, Yazdani M.; Dept. of Neurosurgery, Loghman Hakim Hospital, Shaheed Beheshti University of Medical Sciences, Tehran, Iran

ETV has become the preferred treatment for obstructive hydrocephalus. The purpose of this paper was to present the experience of these clinicians with ventriculostomy at their center.

Hygromas after endoscopic third ventriculostomy in the first year of life: incidence, management and outcome in a series of 34 patients. *Childs Nerv Syst.* 2008 Jan;24(1):57-63: Wiewrodt D, Schumacher R, Wagner W.; Neurochirurgische Klinik und Poliklinik, Bereich Pädiatrische Neurochirurgie, Johannes Gutenberg-Universität, Mainz, Germany

Overdrainage in shunted patients is a known predisposing factor for the formation of hygromas, but little is known about risk factors in ETV. The researchers retrospectively analyzed data of 34 patients younger than 1 year with obstructive hydrocephalus, undergoing ETV, with respect to incidence, management, outcome and possible risk factors for the formation of hygromas.

Long-term outcome of endoscopic third ventriculostomy in obstructive hydrocephalus. *Minim Invasive Neurosurg.* 2007 Oct;50(5):265-9: Gangemi M, Mascari C, Maiuri F, Godano U, Donati P, Longatti, PL.; Dept. of Neurological Sciences, Neurosurgical Clinic, "Federico II" University, Naples, Italy

This multicentric study reports on 140 patients who underwent ETV for obstructive hydrocephalus in four Italian neurosurgical centers between 1994 and 1999. Its aim is to define the long-term outcome of these patients many years (6–12) after the initial procedure.

Lumbar elastance and resistance to CSF outflow correlated to patency of the cranial subarachnoid space and clinical outcome of endoscopic third ventriculostomy in obstructive hydrocephalus. *Minim Invasive Neurosurg.* 2007 Aug;50(4):189-94: Bech-Azeddine R, Nielsen OA, Løgager VB, Juhler M.; University Clinic of Neurosurgery, The Neuroscience Center, Rigshospitalet, Glostrup, Denmark

The purpose of this study was to elucidate the value of the lumbar and intraventricular infusion tests in the selection of patients with obstructive hydrocephalus for ETV, and whether the presence of a diminished cranial subarachnoid space was a source of error in the interpretation of the results.

Prior CSF shunting increases the risk of endoscopic third ventriculostomy failure in the treatment of obstructive hydrocephalus in adults. *Neurol Res.* 2007 Jan;29(1):27-31: Woodworth G, McGirt MJ, Thomas G, Williams MA, Rigamonti D; The Johns Hopkins School of Medicine, Baltimore, MD

ETV is accepted as an effective treatment for obstructive hydrocephalus; however, its benefit in patients previously treated with CSF shunting remains unclear. The value of concurrent ETV and VP shunting in patients with frequent shunt failure remains unstudied.

Pulse pressure waveform in hydrocephalus: what it is and what it isn't. *Neurosurg Focus.* 2007 Apr 15; 22(4):E2: Czosnyka M, Czosnyka Z, Keong N, Lavinio A, Smielewski P, Momjian S, Schmidt EA, Petrella G, Owler B, Pickard JD; Academic Neurosurgical Unit, Addenbrooke's Hospital, Cambridge, UK

Apart from its mean value, the pulse waveform of intracranial pressure (ICP) is an essential element of pressure recording. The authors reviewed their experience with the measurement and interpretation of ICP pulse amplitude by referring to a database of recordings in hydrocephalic patients.

Simultaneous endoscopic third ventriculostomy and ventriculoperitoneal shunt for infantile hydrocephalus. *Childs Nerv Syst.* 2007 Nov 10: Shim KW, Kim DS, Choi JU; Brain Korea 21 Project for Medical Science, Pediatric Neurosurgery, Dept. of Neurosurgery, Severance Children's Hospital, Yonsei University College of Medicine, Seoul, Korea

The authors analyzed a series of consecutive hydrocephalic infants treated with implantation of a VP shunt and ETV simultaneously.

Pediatric

An alternative approach for management of abdominal cerebrospinal fluid pseudocysts in children. *Childs Nerv Syst.* 2007 Jan;23(1):85-90: de Oliveira RS, Barbosa A, Vicente YA, Machado HR; Division of Pediatric Neurosurgery, Ribeirão Preto School of Medicine, University of São Paulo, Campus Universitário, São Paulo, Brazil

CSF abdominal pseudocyst is an uncommon but important complication of VP shunts. From the collected series, several features about the etiology and management become apparent. Retrospective data were obtained from 12 children treated with CSF abdominal pseudocyst defined an alternative approach for management of these patients.

Anomalous venous drainage preventing safe posterior fossa decompression in patients with chiari malformation type I and multilateral craniosynostosis. Report of two cases and review of the literature. *J Neurosurg.* 2007 Jun;106(6 Suppl):490-4: Sandberg DI, Navarro R, Blanch J, Ragheb J; Dept. of Neurosurgery, University of Miami Miller School of Medicine and Miami Children's Hospital, FL

The authors report on two children in whom an anomalous posterior fossa venous drainage pattern prevented safe posterior fossa decompression.

Arachnoid cysts: case series and review of the literature. *Neurosurg Focus.* 2007 Feb 15;22(2):E7: Pradilla G, Jallo G.; Dept. of Neurosurgery, The Johns Hopkins School of Medicine, Baltimore, MD

The authors report on a case series that illustrates the diverse forms of presentation and the treatment modalities commonly used for arachnoid cysts.

Ascites and abdominal pseudocysts following ventriculoperitoneal shunt surgery: variations of the same theme. *J Neurosurg.* 2007 May;106(5 Suppl):350-3: Kariyattil R, Steinbok P, Singhal A, Cochran DD; Division of Pediatric Neurosurgery, Dept. of Pediatric Surgery, British Columbia Children's Hospital, Children's and Women's Health Centre, Vancouver, Canada

Ascites and abdominal pseudocysts are two complications that can occur following placement of a VP shunt. Although various factors have been implicated, the exact pathogenesis of the two conditions remains elusive. The authors retrospectively reviewed the cases of children with abdominal complications caused by a VP shunt.

***H Assessment of mother and father concern in childhood hydrocephalus.** *Qual Life Res.* 2007 Nov;16(9):1501-9: Kulkarni AV^{*H}; Division of Child Health and Evaluative Sciences, Hospital for Sick Children, University of Toronto, Canada

Parental concern can play an important role in overall management of children with serious chronic illness. The researchers quantitatively as-

sessed the concerns of parents of children with hydrocephalus, using the Hydrocephalus Concerns Questionnaire for parents (HCQ-P).

Comparative evaluation of 5-HIAA (5-hydroxy indoleacetic acid) and HVA (homovanillic acid) in infantile hydrocephalus. *Childs Nerv Syst.* 2007 Dec 12: Gopal SC, Pandey A, Das I, Gangopadhyay AN, Upadhyaya VD, Chansuria JB, Singh TB; Dept. of Pediatric Surgery, Institute of Medical Sciences, Banaras Hindu University, India

Infantile hydrocephalus is a common congenital problem. Functional and behavioral disturbances associated with hydrocephalus may be due to altered neurotransmitters in the brain. The authors decided to study the role of 5-hydroxy indoleacetic acid (5-HIAA) and homovanillic acid (HVA) in CSF of hydrocephalic patients as diagnostic and prognostic marker.

***H Death in shunted hydrocephalic children: a follow-up study.** *Childs Nerv Syst.* 2007 Jun 27: Acakpo-Satchivi L, Shannon CN^{*H}, Tubbs RS, Wellons JC 3rd^{*H}, Blount JP, Iskandar BJ, Oakes WJ^{*H}; Pediatric Neurosurgery, Children's Hospital, Birmingham, AL

The authors previously conducted a retrospective study regarding deaths from CSF shunt failure to identify circumstances surrounding shunt malfunction-related deaths in children in the modern era. This follow-up study was designed to determine whether recent policy and procedural changes instituted since the time of the first study had effected a change in the mortality rate of their shunted patient population.

Diagnosis of congenital hydrocephalus and delivery of its patients in Japan. *Brain Dev.* 2007 Dec 26: Moritake K, Nagai H, Nagasako N, Yamasaki M, Oi S, Hata T; Dept. of Neurosurgery, Shimane University School of Medicine, Japan

The study population included 193 patients with prenatally diagnosed (fetal) hydrocephalus and 181 with postnatally (12 or less than 12 months after birth) diagnosed (infantile) hydrocephalus identified by a nationwide questionnaire survey of congenital hydrocephalus performed in 2000.

***B^H Evaluation of the necessity of postoperative imaging after craniosynostosis surgery.** *J Neurosurg.* 2007 Jul; 107(1 Suppl):43-5: Binning M, Ragel B, Brockmeyer DL, Walker ML^{*B^H}, Kestle JR^{*H}; Dept. of Neurosurgery, Primary Children's Medical Center, University of Utah, Salt Lake City, UT

Neurological evaluation of patients after cranial vault reconstruction for synostosis repair is often complicated by pain medication, sedation, intubation, swelling, and dressings; therefore CT scans are routinely ordered by some surgeons on the 1st postoperative day. The object of this study was to evaluate the utility of these scans.

Hydrocephalus in children born in 1999-2002: epidemiology, outcome and ophthalmological findings. *Childs Nerv Syst.* 2007 Oct;23(10):1111-8.

Epub 2007 Apr 12: Persson EK, Anderson S, Wiklund LM, Uvebrant P; Dept. of Paediatrics, Halmstad County Hospital, Sweden

The purpose of this study was to monitor incidence and outcome in children with hydrocephalus. This is a population-based prospective study of all the children with hydrocephalus born in western Sweden in 1999-2002.

Idiopathic hydrocephalus in children and idiopathic intracranial hypertension in adults: two manifestations of the same pathophysiological process? *J Neurosurg.* 2007 Dec; 107(6 Suppl):439-44: Bateman GA, Smith RL, Siddique SH; Dept. of Medical Imaging, John Hunter Hospital, Newcastle, Australia

Both idiopathic intracranial hypertension (IIH) in adults and idiopathic hydrocephalus in children have been shown to involve elevations in venous pressure that resolve once the CSF pressure is reduced. It has been assumed that the venous pressure elevations in both conditions are not hemodynamically significant, but measurement of venous collateral flow in IIH has shown these pressure elevations to be of consequence. The authors used the same methodology to see if the venous pressure elevations noted in childhood hydrocephalus are important.

Is endoscopic third ventriculostomy an internal shunt alone? *Minim Invasive Neurosurg.* 2007 Feb;50(1):47-50: Gangemi M, Maiuri F, Colella G, Magro F, Seneca V, de Divitiis E; Dept. of Neurological Sciences, Section of Neurosurgery, Federico II University School of Medicine, Naples, Italy

This study was made to define the mechanism of ETV in the various forms of hydrocephalus.

Is intracranial pressure waveform analysis useful in the management of pediatric neurosurgical patients? *Pediatric Neurosurgery* 2007; 43:472-480: Eide P, Egge A, Due-Tønnessen BJ, Helseth E; Dept. of Neurosurgery, The National Hospital (Rikshospitalet), Rikshospitalet-Radiumhospitalet HF, Oslo, Norway

These authors report casuistic observations that ICP waveform analysis may be useful in the management of pediatric patients. They studied 65 children undergoing ICP monitoring during the years 2002-2005. The main observations were that the mean ICP wave amplitude (not mean ICP) was increased in those that improved from clinical symptoms/findings after treatment and in those that were unchanged/worse after not being treated.

Long-term outcomes in patients with treated childhood hydrocephalus. *J Neurosurg.* 2007 May;106(5 Suppl):334-9: Gupta N, Park J, Solomon C, Kranz DA, Wrensch M, Wu YW; Dept. of Neurological Surgery, University of California, San Francisco, CA

The goal in this study was to determine the long-term effects of childhood hydrocephalus. A patient-reported survey completed by 1,953 participants was used to collect data in a subgroup

of 1,459 individuals who had been treated for hydrocephalus in childhood.

Low-dose protocol for head CT in monitoring hydrocephalus in children. *Med Sci Monit.* 2007 May 18;13(S1):147-151: Rybka K, Staniszewska AM, Biegański T; Dept. of Diagnostic Imaging, Polish Mother's Memorial Hospital-Research Institute, Łódź, Poland

Children with hydrocephalus and increased ICP were treated with ventricular shunts and multiple head CT was used to assess shunt malfunction and changes in ventricular size (volume). The aim of the study was to assess the implemented protocol in categories of radiation risk to the patients.

Macrocephaly, increased intracranial pressure, and hydrocephalus in the infant and young child. *Top Magn Reson Imaging.* 2007 Feb;18(1):31-51: Vertinsky AT, Barnes PD; Stanford University Medical Center, CA

In this review, a general overview is provided, and the more common causes of hydrocephalus are presented, including posthemorrhage, postinfection, developmental malformations, and masses. Imaging guidelines are also outlined for initial evaluation and follow-up, along with a discussion of the imaging features of shunt malfunction.

Management of neonatal hydrocephalus: feasibility of use and safety of two programmable (Sophy and Polaris) valves. *Childs Nerv Syst.* 2007 Oct 9: Martínez-Lage JF, Almagro MJ, Del Rincón IS, Pérez-Espejo MA, Piqueras C, Alfaro R, Ros de San Pedro J; Regional Service of Neurosurgery, Virgen de la Arrixaca University Hospital, Murcia, Spain

In this review, a general overview is provided, and the more common causes of hydrocephalus are presented, including posthemorrhage, postinfection, developmental malformations, and masses. Imaging guidelines are also outlined for initial evaluation and follow-up, along with a discussion of the imaging features of shunt malfunction.

Pathogenesis and treatment of intracranial arachnoid cysts in pediatric patients younger than 2 years of age. *Neurosurg Focus.* 2007;22(2):E1: Zada G, Krieger MD, McNatt SA, Bowen I, McComb JG; Dept. of Neurosurgery, Childrens Hospital Los Angeles, Keck School of Medicine of University of Southern California, Los Angeles, CA

The authors sought to determine whether the clinical presentation of pediatric patients younger than 2 years old and harboring arachnoid cysts influenced the type of intervention that would be required.

Pre-conceptional vitamin/folic acid supplementation 2007: the use of folic acid in combination with a multivitamin supplement for the prevention of neural tube defects and other congenital anomalies. *J Obstet Gynaecol Can.* 2007 Dec;29(12):1003-26: Wilson RD, Johnson JA, Wyatt P, Allen V, Gagnon A, Langlois S, Blight

C, Audibert F, Désilets V, Brock JA, Koren G, Goh I, Nguyen P, Kapur B; Philadelphia, PA

The objective of this review is to provide information regarding the use of folic acid in combination with a multivitamin supplement for the prevention of neural tube defects and other congenital anomalies, so that physicians, midwives, nurses and other health care workers can assist in the education of women in the pre-conception phase of their health care.

***B*H Predicting slitlike ventricles in children on the basis of baseline characteristics at the time of shunt insertion.** *J Neurosurg.* 2007 May;106(5 Suppl):347-9: Kan P, Walker ML^{*B} ^{*H}, Drake JM^{*H}, Kestle JR^{*H}; Dept. of Neurosurgery, Primary Children's Medical Center, University of Utah, Salt Lake City, UT

Slit ventricle syndrome (SVS) is a delayed complication of shunt insertion and occurs only in children with slitlike ventricles after shunt placement. Although SVS appears to be related to early shunt placement, its predisposing factors are largely unknown.

Radiation doses to children with shunt-treated hydrocephalus. *Pediatr Radiol.* 2007 Dec;37(12):1209-1215: Holmedal LJ, Friberg EG, Børretzen I, Olerud H, Lægveid L, Rosendahl K; Dept. of Radiology, Stord Hospital, Helse Fonna, Norway

This study was designed to estimate the effective dose, brain and lens doses from these examinations during childhood, and to assess dose variation per examination.

Relevance of surgical strategies for the management of pediatric Chiari type I malformation. *Childs Nerv Syst.* 2007 Jun;23(6):691-6. Epub 2007 Jan 25: Galarza M, Sood S, Ham S.

In the face of continuing controversy over the optimal treatment of Chiari type I malformation, the authors analyzed three different surgical strategies.

Strabismus, binocular functions and ocular motility in children with hydrocephalus. *Strabismus.* 2007 Apr-Jun;15(2):79-88: Aring E, Andersson S, Hård AL, Hellström A, Persson EK, Uvebrant P, Ygge J, Hellström A; Dept. of Ophthalmology, Institute of Clinical Neuroscience, The Sahlgrenska Academy of Göteborg University, Sweden

To investigate heterotropia, heterophoria, head posture, nystagmus, stereo acuity, ocular motility and near point of convergence (NPC) in children with hydrocephalus treated surgically before 1 year of age. In addition, the effects of being born with hydrocephalus, the effect of the etiology of hydrocephalus, number of shunt revisions and the size of the ventricles on these variables were studied.

The changing face of paediatric hydrocephalus: A decade's experience. *J Clin Neurosci.* 2007 Nov;14(11):1049-54: Green AL, Pereira EA, Kelly D, Richards PG, Pike MG; Dept. of Neurosurgery, The

Radcliffe Infirmary, Woodstock Road, Oxford, UK
All 253 children receiving neurosurgical intervention for hydrocephalus (HCP) at a single British Neurosurgical Unit over a decade were investigated by retrospective case note review. Referral rates and mean age at presentation remained stable throughout, as did proportions of children presenting due to myelomeningocele or meningitis.

Ventriculosubgaleal shunts at Columbus Children's Hospital: Neurosurgical implant placement in the neonatal intensive care unit. *J Neurosurg.* 2007 Sep;107(3 Suppl):220-3: Karas CS, Baig MN, Elton SW; Dept. of Neurological Surgery, Columbus Children's Hospital and Ohio State University Medical Center

The authors review all cases in which ventriculosubgaleal (VSG) shunts were placed at Columbus Children's Hospital for the treatment of posthemorrhagic hydrocephalus in order to assess the surgical procedure, effectiveness of surgery, and complications of CSF diversion to the subgaleal space. The purpose of the review was to make a comparison between cases in which shunts were placed in the operating room and those in which they were placed in the neonatal intensive care unit.

Shunts

A mathematical model of survival in a newly inserted ventricular shunt. *J Neurosurg.* 2007 Dec;107(6 Suppl):448-54: Stein SC, Guo W; Dept. of Neurosurgery, University of Pennsylvania School of Medicine, Philadelphia, PA

The object of this study was to mathematically model the prognosis of a newly inserted shunt in pediatric or adult patients with hydrocephalus. A structured search was performed of the English-language literature for case series reporting shunt failure, patient mortality, and shunt removal rates after shunt insertion.

***N Adjustable shunt valve reprogramming at home: safety and feasibility.** *Neurosurgery.* 2007 Feb;60(2):333-6; discussion 336-7: Sikorski CW, Rosen DS, Frim DM^{*N}; Section of Neurosurgery, The University of Chicago, IL

Shunt valve resistance changes using a specialized magnetic programming device permit noninvasive changes to CSF drainage. In selected cases between 2001 and 2005, patients and families used shunt valve programming devices at home. This study examined the safety and efficacy of this practice.

Analysis of a nationwide survey on treatment and outcomes of congenital hydrocephalus in Japan. *Neurol Med Chir (Tokyo).* 2007 Oct;47(10):453-60: Moritake K, Nagai H, Miyazaki T, Nagasaki N, Yamasaki M, Sakamoto H, Miyajima M, Tamakoshi A; Dept. of Neurosurgery, Shimane University School of Medicine, Izumo, Japan

A nationwide questionnaire survey of congenital hydrocephalus in 2000 investigated the treatment and clinical outcomes for congenital

hydrocephalus in Japan to evaluate the factors influencing clinical outcome.

Antibiotics for the eradication of *Propionibacterium acnes* biofilms in surgical infection. *J Antimicrob Chemother.* 2007 Dec;60(6):1298-301: Bayston R, Nuradeen B, Ashraf W, Freeman BJ; Biomaterials-Related Infection Group, School of Medical and Surgical Sciences, University of Nottingham, UK

Propionibacterium acnes is increasingly recognized as a cause of delayed infection after spinal instrumentation or shunting for hydrocephalus. Biofilm development by this organism has recently been demonstrated. The authors therefore investigated the effect of two different courses of three antibiotics (penicillin, rifampicin and linezolid) on mature *P. acnes* biofilms in vitro.

Cerebrospinal shunt malfunction: recognition and emergency management. *Br J Hosp Med (Lond).* 2007 Dec; 68(12):651-5: Khan AA, Jabbar A, Banerjee A, Hinchley G; Emergency Dept., Chase Farm Hospital, Enfield

Indwelling shunts to divert CSF flow are essential in treating hydrocephalus. There is a high incidence of shunt malfunction, which accounts for the increasing popularity of ETV. Failure to recognize and act on symptoms and signs of shunt malfunction may lead to loss of life or to permanent neurological dysfunction. This review provides the basis for assessment and management based on updated clinical knowledge.

Clinical application of a laparoscope in ventriculoperitoneal shunting. *Minim Invasive Ther Allied Technol.* 2007 Oct 17;1-3: Li B, Zhang Q, Liu J, Yu H, Hu S; The Second Hospital of Shandong University, Jinan, Shandong Province, China
A new laparoscopic method was used for percutaneous placement of the peritoneal end of CSF shunts in patients with obstructive or normal-pressure hydrocephalus. The peritoneal ends of shunts were placed and fixed upward between the liver and the diaphragm by a two-trocar method under direct laparoscopic vision.

Complications of lumboperitoneal shunts. *Neurosurgery.* 2007 Jun;60(6):1045-8: Wang VY, Barbaro NM, Lawton MT, Pitts L, Kunwar S, Parsa AT, Gupta N, McDermott MW; Dept. of Neurological Surgery, University of California, San Francisco
Placement of a lumboperitoneal (LP) shunt is a method for treating communicating hydrocephalus. These shunts can be placed with or without valves. The authors sought to review the complications associated with the use of LP shunts with the increasing use of horizontal-vertical (HV) valve systems.

Continuous intracranial pressure monitoring via the shunt reservoir to assess suspected shunt malfunction in adults with hydrocephalus. *Neurosurg Focus.* 2007 Apr 15;22(4):E10: Geocadin RG, Varelas PN, Rigamonti D, Williams MA; Dept. of Neurology and Neurosurgery, Johns

Hopkins Medical Institutions, Baltimore, MD
The authors attempted to determine whether continuous ICP monitoring via the shunt reservoir identifies VP shunt malfunctions that are not identified by radionuclide shunt patency study or shunt tap in adults with hydrocephalus.

Do antibiotic-impregnated shunts in hydrocephalus therapy reduce the risk of infection? An observational study in 258 patients. *BMC Infect Dis.* 2007 May 8;7:38: Ritz R, Roser F, Morgalla M, Dietz K, Tatagiba M, Will BE; Dept. of Neurosurgery, University Hospital Tübingen, Germany
The study was performed to analyze if antibiotic-impregnated shunts (AIS) can diminish the rate of shunt infection. The pathogenic nature of shunt infection in patients with AIS systems and those without antibiotic impregnated shunts (non-AIS) was compared.

***N Endoscope-assisted placement of a multi-perforated shunt catheter into the fourth ventricle via a frontal transventricular approach.** *Neurosurg Focus.* 2007 Apr 15;22(4):E8: Upchurch K, Raifu M, Bergsneider M^{*N}; Division of Neurosurgery, Dept. of Surgery, UCLA Medical Center and David Geffen School of Medicine at UCLA, Los Angeles, CA

The authors report on their experience with the treatment of symptomatic adult patients by endoscope-assisted placement of a fourth ventricle shunt catheter via a frontal transventricular approach.

Endovascular placement of a ventriculoatrial shunt. Technical note. *J Neurosurg.* 2007 Apr;106(4 Suppl):319-21: Gonzalez LF, Kim L, Rekatte HL, McDougall CG, Albuquerque FC; Division of Neurological Surgery, Pediatric and Congenital Neurosurgery, Barrow Neurological Institute, St. Joseph's Hospital and Medical Center, Phoenix, AZ

Atrial shunt revision surgeries are sometimes difficult due to venous occlusion and neck scarring. A direct approach guided by venography facilitates exposure and guarantees accurate placement of the distal catheter. Five patients with complicated histories of shunt malfunction were treated using an endoscope-assisted technique.

Factors contributing to the medical costs of cerebrospinal fluid shunt infection treatment in pediatric patients with standard shunt components compared with those in patients with antibiotic impregnated components. *Neurosurg Focus.* 2007 Apr 15;22(4):E9: Sciubba DM, Lin LM, Woodworth GE, McGirt MJ, Carson B, Jallo GI; Dept. of Neurosurgery, Baltimore, MD

In the present study the authors evaluated factors contributing to the medical costs associated with the treatment of CSF shunt infections in a hydrocephalic pediatric population, those implanted with AIS systems compared with those implanted with standard shunt systems.

Interaction of ventriculoperitoneal shunt and baclofen pump. *Childs Nerv Syst.* 2007

Jul;23(7):733-8: Fulkerson DH, Boaz JC, Luerssen TG; Pediatric Neurosurgery Service, James Whitcomb Riley Hospital for Children, Indiana University School of Medicine, Indianapolis, IN

The authors present three cases of children with shunted hydrocephalus and intrathecal delivery of baclofen via an implanted pump. Each case illustrates a potential interaction of these devices.

Laboratory study on "intracranial hypotension" created by pumping the chamber of a hydrocephalus shunt. *Cerebrospinal Fluid Res.* 2007 Mar 26;4:2: Bromby A, Czosnyka Z, Allin D, Richards HK, Pickard JD, Czosnyka M; Academic Neurosurgical Unit, Addenbrooke's Hospital, Cambridge, UK
It has been reported that pumping a shunt in situ may precipitate a proximal occlusion, and/or lead to ventricular overdrainage, particularly in the context of small ventricles. In the laboratory the effect of pumping the pre-chamber of hydrocephalus shunts on intracranial hypotension was measured.

***H Lack of efficacy of antibiotic-impregnated shunt systems in preventing shunt infections in children.** *Childs Nerv Syst.* 2007 Jul;23(7):773-7: Kan P, Kestle J^{*H}; Dept. of Neurosurgery, Primary Children's Medical Center, University of Utah, Salt Lake City, UT

Recent studies indicate that the use of AIS systems may reduce the risk of postoperative shunt infections. These authors evaluated the incidence of shunt infections associated with the use of AIS catheters and compared it with the incidence associated with standard non-AI catheters.

Laparoscopic management of ventriculoperitoneal and lumboperitoneal shunt complications. *JSLs.* 2007 Jan-Mar;11(1):14-9: Kavic SM, Segan RD, Taylor MD, Roth JS; Dept. of Surgery, University of Maryland School of Medicine, Baltimore, MD

A laparoscopic approach has multiple advantages over open techniques, including decreased morbidity, more rapid recovery, and ability to visually assess catheter function. However, few series have addressed the role of laparoscopy in the management of VP and LP shunt complications.

Laparoscopic placement of ventriculoperitoneal shunts: an innovative simplification of the existing techniques. *Minim Invasive Neurosurg.* 2007 Feb;50(1):62-4: Konstantinidis H, Balogianis I, Foroglu N, Spiliotopoulos A, Magras I, Kesisoglou I, Selviaridis P; 1st Neurosurgical Dept. of Aristotelian University of Thessaloniki, AHEPA Hospital, Greece

VP shunting remains one of the alternative choices for the surgical treatment of hydrocephalus. During the last two decades laparoscopy has been utilized to facilitate the placement of the abdominal portion of the shunt. These authors describe a minimally invasive laparoscopic technique, which facilitates the rapid, safe and direct placement of the peritoneal component of the VP shunt.

Laparoscopic versus non-laparoscopic-assist-

ed ventriculoperitoneal shunt placement in adults. A retrospective analysis. *Surg Neurol.* 2007 Aug;68(2):177-84: Roth J, Sagie B, Szold A, Elran H; Dept. of Neurosurgery, Tel-Aviv Sourasky Medical Center, affiliated to the Sackler Faculty of Medicine, Tel Aviv University, Israel

The researchers performed laparoscopy-guided distal shunt placement or revision for patients with and without a positive abdominal history. They review the indications, techniques, complications, and long-term outcomes of these cases and compare the results to those of patients operated without laparoscopic guidance.

Monte Carlo simulation of cerebrospinal fluid shunt failure and definition of instability among shunt-treated patients with hydrocephalus. *J Neurosurg.* 2007 Dec;107(6 Suppl):474-8:Piatt JH Jr, Cosgriff M; Section of Neurosurgery, St. Christopher's Hospital for Children, Philadelphia, PA

The authors undertook the present study to estimate the number of operations that patients with hydrocephalus will require within 10 years of diagnosis based on published survival data for CSF shunts.

***N Observations regarding failure of cerebrospinal fluid shunts early after implantation.** *Neurosurg Focus.* 2007 Apr 15;22(4):E7: Ferguson SD, Michael N, Frim DM^{*N}; Section of Neurosurgery, The University of Chicago, IL

The aim of this study was to evaluate the independent predictors of early shunt survival after implantation in a large cohort of patients. The authors retrospectively reviewed the records of all patients who had undergone shunt implantation procedures at their institution during an 8-year period.

Pediatric gravitational shunts: initial results from a prospective study. *J Neurosurg.* 2007 Mar;106(3 Suppl):179-84: Eymann R, Steudel WI, Kiefer M; Dept. of Neurosurgery, Saarland University Medical School, Germany

The authors' goal was to evaluate prospectively the efficacy and safety of a new pediatric gravitational shunt to determine whether it warrants inclusion in a randomized, controlled trial with other shunts.

Reduction in shunt infection using antibiotic impregnated CSF shunt catheters: an Australian prospective study. *J Clin Neurosci.* 2007 Jun;14(6):526-31: Pattavilakom A, Xenos C, Bradford O, Danks RA; Dept. of Neurosurgery, Monash Medical Centre, Clayton, Victoria, Australia

Antibiotic impregnated shunt catheters have emerged as a promising tool against the continuing challenge of shunt infection. The authors present their prospective evaluation of the efficacy of antibiotic (rifampicin and clindamycin) impregnated CSF shunt catheters in a mixed pediatric and adult Australian population.

Severe constipation: an under-appreciated cause of VP shunt malfunction: a case-based update.

Childs Nerv Syst. 2007 Oct 10: Martínez-Lage JF, Martos-Tello JM, Ros-de-San Pedro J, Almagro MJ; Regional Service of Neurosurgery, "Virgen de la Arrixaca" University Hospital, Murcia, Spain

The authors briefly review the etiopathogenesis, diagnosis and management of severe constipation leading to VP shunt malfunction. Their aim is to draw the attention of pediatric neurosurgeons towards severe constipation as a possible cause of VP shunt failure thus avoiding unnecessary surgical valve revisions, to which children with hydrocephalus are often submitted to.

Shunt infection: is there a near-miss scenario? *J Neurosurg.* 2007 Jan;106(1 Suppl):15-9: Thompson DN, Hartley JC, Hayward RD; Dept. of Neurosurgery, Great Ormond Street Hospital for Children, NHS Trust, London, UK

The aim of this study was to establish whether microbiological contamination at the time of shunt insertion can be detected and used to predict the likelihood of subsequent shunt infection.

Siphon regulatory devices: their role in the treatment of hydrocephalus. *Neurosurg Focus.* 2007 Apr 15;22(4):E5: Kurtom KH, Magram G; Dept. of Neurosurgery, George Washington University Hospital Washington, DC

In this paper the authors discuss the pathophysiology of CSF siphoning as well as the various devices used to treat this problem. The pros and cons of each device are discussed, as are the key differences among them. Future concepts are also introduced with an emphasis on upcoming device designs.

Sterile surgical technique for shunt placement reduces the shunt infection rate in children: preliminary analysis of a prospective protocol in 115 consecutive procedures. *Childs Nerv Syst.* 2007 Nov;23(11):1251-61: Pirotte BJ, Lubansu A, Bruneau M, Loqa C, Van Cutsem N, Brotchi J; Dept. of Neurosurgery, ERASME Hospital, Université Libre de Bruxelles, Belgium

The objective of this study was to evaluate whether the rigid application of a sterile protocol for shunt placement was applicable on a routine basis and allowed the reduction of shunt infections in children.

***B*S The effect of self-assembled layers on the release behavior of rifampicin-loaded silicone.** *J Biomater Sci Polym Ed.* 2007;18(6):687-700: Liang X, Wang A, Tang H, Cao T, McAllister JP 2nd*B*S, Salley SO, Ng KY; Dept. of Chemical Engineering and Materials Science, Wayne State University, Detroit, MI

Providing a long period of sustained antibiotic release is one of the important challenges in the development of clinical shunts for long-term implantation. A cast-molding approach was used to load rifampicin into the silicone precursor before curing.

The Hakim programmable valve: reasons for reprogramming failures. *J Neurosurg.* 2007

Oct;107(4):788-91: Mauer UM, Schuler J, Kunz U; Dept. of Neurosurgery, Armed Forces Hospital, Ulm, Germany

In patients with hydrocephalus, the pressure settings of a Medos Hakim programmable valve may require adjustments even months after implantation. In some cases, however, adjustment proves to be impossible. The object of this study was to illuminate the reasons for reprogramming failures.

The impact of antibiotic-impregnated catheters on shunt infection in children and neonates. *Childs Nerv Syst.* 2007 Oct 26: Hayhurst C, Cooke R, Williams D, Kandasamy J, O'Brien DF, Mallucci CL; Dept. of Neurosurgery, The Walton Centre for Neurology and Neurosurgery, Lower Lane, Fazakerley, Liverpool, UK

Infection remains a significant problem with CSF diversion procedures. AIS catheters have been introduced to prevent infection, mainly in the early postoperative period when most infections occur. The authors evaluate the impact on infection rates in children following the introduction of catheters impregnated with rifampicin and clindamycin.

Trans-anal protrusion of ventriculo-peritoneal shunt catheter with silent bowel perforation: report of ten cases in children. *Pediatr Surg Int.* 2007 Jun;23(6):575-80: Ghritlaharey RK, Budhwani KS, Shrivastava DK, Gupta G, Kushwaha AS, Chanchlani R, Nanda M; Dept. of Paediatric Surgery, Gandhi Medical College and Associated, Kamla Nehru & Hamidia Hospitals, India

This is a retrospective study of 10 patients who had VP shunt catheter protrusion from anus, admitted in the Dept. of Pediatric Surgery between Jan. 1996 and Dec. 2005.

Trans-umbilical access and ventriculoperitoneal shunt in adults: preliminary results [Article in French]. *Neurochirurgie.* 2007 Aug;53(4):307-11: Litré CF, Noudel R, Scavarda D, Pech-Gourg G, Fuentes S, Scherpereel B, Rousseaux P; Service de neurochirurgie, hôpital Maison-Blanche, Reims, France

Treatment Approaches for Abdominal Migration of Peritoneal Catheter of Ventriculoperitoneal Shunt. *Turk Neurosurg.* 2007;17(2):158-162: Kaplan M, Ozel SK, Dönmez O, Kazez A; Firat University School of Medicine, Neurosurgery, Elazığ, Turkey

Migration of peritoneal catheter into the abdominal cavity is rare. The authors have discussed and presented the treatment options in two cases with accompanying literature. Abdominal migration of peritoneal catheter appears as a result of shunt fracture and disconnection.

Ventriculoperitoneal shunt complications in California: 1990 to 2000. *Neurosurgery.* 2007 Sep;61(3):557-62; discussion 562-3: Wu Y, Green NL, Wrench MR, Zhao S, Gupta N; Dept. of Neurology, University of California, San Francisco

Risk factors for VP shunt complications have not

been assessed with population cohort data since the advent of modern surgical techniques. The authors examined demographic factors and VP shunt complications in a population-based retrospective cohort study of all nonfederal California hospital admissions between 1990 and 2000.

Ventriculostomy shunts at Columbus Children's Hospital: Neurosurgical implant placement in the neonatal intensive care unit. *J Neurosurg.* 2007 Sep;107(3 Suppl):220-3: Karas CS, Baig MN, Elton SW; Dept. of Neurological Surgery, Columbus Children's Hospital and Ohio State University Medical Center

The authors review all cases in which VSG shunts were placed at Columbus Children's Hospital for the treatment of posthemorrhagic hydrocephalus in order to assess the surgical procedure, effectiveness of surgery, and complications of CSF diversion to the subgaleal space. The purpose of the review is to make a comparison between cases in which shunts were placed in the operating room and those in which they were placed in the neonatal intensive care unit.

Other

Concept and treatment of hydrocephalus in the Greco-Roman and early Arabic medicine. *Minim Invasive Neurosurg.* 2007 Oct;50(5):253-64: Grunert P, Charalampaki P, Ayyad A; Dept. of Neurosurgery, Johannes Gutenberg University, Mainz, Germany

In the ancient medical literature hydrocephalus was not often described although its existence and symptomatology were well known. Most detailed descriptions of hydrocephalus including the surgical treatment are extant in the encyclopaedic works on medicine of the physicians Oreibasios and Aetios from Amida from the 4th and 6th centuries AD, respectively.

***B*H*N*S Priorities for hydrocephalus research: report from a National Institutes of Health-sponsored workshop.** *J Neurosurg (5 Suppl Pediatrics)* 107:345-357, 2007: Williams MA, McAllister JP II^{*B*H}, Walker ML^{*B*H}, Kranz DA, Bergsneider M^{*N}, Del Bigio MR, Fleming L, Frim DM^{*N}, Gwinn K, Kestle JRW^{*H}, Luciano MG, Madsen JR^{*B}, Oster-Granite ML, Spinella G
This "white paper" summarized the key issues and recommendations from the 2005 NIH workshop "Hydrocephalus: Myths, New Facts, Clear Directions." It is a critical paper for all types of future hydrocephalus research, and will raise awareness for the need to fund these studies.

The history of mathematical modeling in hydrocephalus. *Neurosurg Focus.* 2007 Apr 15;22(4):E3: Clarke MJ, Meyer FB; Dept. of Neurologic Surgery, Mayo Clinic, Rochester, MN
The mathematical modeling of hydrocephalus is a relatively young field. The discipline evolved from Hakim's initial description of the brain as a water-filled sponge. ■

Meet Suzanne, Our New Public Affairs Manager



By Suzanne Leigh

WHEN Ronald Reagan disclosed that he had Alzheimer's disease in 1994, the nation reflected on a former head of state who had been as captivating as he had been controversial. Reagan's admission served a far-reaching purpose: it put a human face on a medical condition that, 14 years ago, many Americans knew little about.

Since joining the Association in August, my mission has been to find the "Ronald Reagans" among the one million Americans living with hydrocephalus. These are people who are willing to share their story with the public—just as Reagan did—so that they can learn what hydrocephalus is, how it affects lives and what needs to be done to optimize diagnosis and treatment.

"Hydro what?" is a common response to those individuals who divulge their diagnosis to friends and acquaintances. Getting the word out about hydrocephalus means that one day this will not be a typical reaction. Getting the word out is what we have been doing.

As a former health reporter who has covered countless medical disorders for newspapers, magazines and TV, I know that what grabs the public's attention is not data about clinical trials or statements from the CDC. It's the families and individuals living with these conditions who articulate their challenges, their fears, their aspirations and their triumphs.

In three months, the Association has

placed more than 20 stories about our members in newspapers throughout the nation. I have been humbled by the generosity and the honesty with which families have talked about their lives—using me as a conduit to the media.

There's the young man in a wheelchair who has never known the primal joy of splashing in a puddle or running barefoot and unfettered on a soft sand beach, but instead celebrates his "great family and friends"; the child who has undergone more than 30 shunt surgeries and longs for relief from pain; and the adult children of a woman with normal pressure hydrocephalus who "got our mother back" after months of witnessing her descent into darkness. Most poignant of all is the mother whose 5-year-old daughter died following complications of hydrocephalus. Once she had moved past her raw grief, this mother dealt with her bereavement by becoming an advocate for patients' rights.

These individuals' stories have resulted in articles in newspapers like the *Marin Independent Journal*, the *Suffolk County News* and the *Roxborough Review*.

If you or your family member has hydrocephalus, consider telling me your story. Together we will see if we can raise media interest. Getting the public to care about hydrocephalus is the first step to securing the funding we need to develop better diagnostic protocols and safer, more effective treatments.

In the letter informing the country of his Alzheimer's, Reagan wrote that he and Nancy had wrestled with the decision of whether to make his diagnosis public but decided that "opening our hearts" would "promote greater awareness of this condition." You don't have to be a Republican to applaud that decision.

Editor's Note: We are sad to report that Suzanne's 7½-year-old daughter, Natasha, recently had emergency surgery to remove a brain tumor. The prognosis and treatment program are not yet clear. Please be patient during this time of uncertainty. ■

Kids' Corner! Hydrocephalus Mad Libs

By Bonnie Hom

To begin, fill in the lists below—without peeking at the story! Then transfer your answers to the corresponding numbers in the story.

Zach Saves the Day

- (1) Your school name _____
- (2) Planet _____
- (3) Action verb ending in -ing _____
- (4) School subject _____
- (5) Large animal _____
- (6) Color _____
- (7) Loud noise _____
- (8) Kitchen item _____
- (9) Favorite food item _____
- (10) Flower _____
- (11) Insect _____

Zack is an 8-year-old boy with hydrocephalus who goes to (1)_____. School on (2)_____. One day, Zack was (3)_____ in his (4)_____ class when suddenly, a giant (5)_____ burst through the classroom door. It had (6)_____ bumps all over it and made (7)_____ sounds, which caused Zack to have a terrible headache. Zach wasn't scared though because he had a (8)_____ and (9)_____ which frightened it away. Zach has never had a headache since then. Zach's classmates were so happy because Zach saved the day that they each gave him a (10)_____ and a (11)_____.

And the Winner Is ... Caroline!

- (1) Favorite singer _____
- (2) Cartoon character _____
- (3) Time you wake up in the morning _____
- (4) Action verb _____
- (5) Body part _____
- (6) Animal _____
- (7) A school supply _____
- (8) Action verb _____
- (9) Item found at the beach _____
- (10) Kitchen appliance _____
- (11) A breakfast item _____
- (12) A superpower that starts with an action verb _____

Caroline, who has hydrocephalus and has had a shunt since birth, attends (1)_____ School of the Arts. She is excited because Principal (2)_____ announced this morning that there will be a talent show at (3)_____ a.m. next Friday. However, Caroline has so many talents she doesn't know which one to perform. She could (4)_____ on one (5)_____ or she could pull a (6)_____ out of a (7)_____. She might even be able to (8)_____ on a (9)_____. Friday rolls along and as soon as the (10)_____ goes off, Caroline leaps out of bed and runs to school. She's in such a hurry that she forgets her glasses. She can't see very well without them because the hydrocephalus has caused her blurry vision. She makes it the auditorium just in time and grabs the first thing she sees, which is a (11)_____. She takes it and (12)_____ and wins the talent show!

New: Parents' Guide to IDEA

The National Center for Learning Disabilities has created a *Parent Guide to the Individuals with Disabilities Education Act (IDEA)* so you can become an informed and effective partner with school personnel in supporting your child's special learning and behavioral needs. This guide will help you to understand:

- How the federal law generally works in most states
- What the law requires to determine whether your child has a learning disability
- What is new to IDEA since Congress last updated the law in 2004
- What questions you should ask and what information you should prepare in order to be a full and active advocate for your child
- What resources are available to you

In developing this guide, the authors worked with parents of students with learning disabilities from around the country and tried to address the questions, challenges and barriers parents face as they navigate their way through the special-education process. Parents have also contributed their own personal stories so that you can hear firsthand that you are not alone in this journey. To download this wonderful resource go to www.ncl.org/content/view/972/456224/.

Sherman Alexie Wins National Book Award

Sherman Alexie's autobiographical novel for young people, *The Absolutely True Diary of a Part-Time Indian*, won for best book in the young people's literature category. The National Book Award is one of the most prestigious awards in literature. When Alexie was named a finalist in October, he said the "very, very autobiographical" nature of the book made the attention it has received even more gratifying.

Alexie, 41, has been critically ac-

claimed for his work, a mix of insight and honesty, compassion and outrageous humor. He also has had a successful career as a filmmaker, playwright and teacher, and other books and films have drawn on his Indian heritage. But *Absolutely True Diary* may be the book that's closest to the life he led.

Like Alexie, 14-year-old Arnold Spirit survives being born with hydrocephalus, becomes an honors student and ultimately leaves the Spokane Indian reservation for a white school. He battles the alcoholism of his parents, the death of family members, poverty and despair.

In a September interview, Alexie called himself a "reluctant role model.... I write aware of that. Especially with this book, certainly, whose theme is about escape, I hope it encourages all sorts of trapped people to feel like they can escape."

Shunt Pins

Ribbon pins are made from actual shunt tubing and come on a card that outlines a few key statistics about hydrocephalus. Educate your friends—and your government representatives. Be an advocate for your condition. Show your friends what you have implanted in your body. Let them feel how soft and flexible it is. Nurses and doctors can wear it so you always have some shunt tubing handy to show families who are curious.

Buy a set of 10 pins on informative cards for \$30 and give them to your friends and relatives. Help us raise awareness so hydrocephalus becomes a household word.

We make each pin by hand, so forgive us if it takes a little while to fill your order!

Our heartfelt thanks go to the following shunt companies for donating shunt tubing: Codman, a Johnson & Johnson company; Medtronic Neurologic Technologies; Integra Neurosciences.

Latina Author Writes Bilingual Children's Book on Growing Up With Hydrocephalus

In her first children's book, *My Brain Won't Float Away/Mi cerebro no va a salir flotando*, Puerto Rican author Annette Pérez tells her true story of growing up with hydrocephalus.

Pérez narrates her tale through the voice of Annie, an 8-year-old girl who is the target of ridicule by the children at her school. Despite being ostracized at school for being different, Annie overcomes her fear of not being accepted by her peers through the realization that her condition is her strength rather than her weakness. Annie's optimism story leaves readers inspired and hopeful.

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

The book can be ordered from www.editorialcampana.com.

SpinaBifidaConnection.com

This is a person-to-person support website where the ups, downs, positives and negatives of living with spina bifida are discussed. This site offers resources, personal experiences and support so that visitors can discover options and make decisions for themselves.

The site has been reopened with a small structure to allow members to dictate what topics are the most important to their community. You will need to register your account but it is simple, quick and, of course, free. If you have any questions or comments, feel free to email barb@spinabifidaconnection.com.

2008 Membership Form

Name: _____ Telephone: _____

Address: _____

_____ Email: _____

Name of person with hydrocephalus: _____ Birth date _____ Age at diagnosis _____

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

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

\$30 \$50 \$100 Other \$ _____

How would you like to receive your quarterly newsletter?

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

Please send my newsletter via email to: _____

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

Charge my: VISA MasterCard Discover

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Signature _____

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Please check all that apply:

I am on SSI or Disability.

My medical bills have exhausted my finances.

My income is below \$30,000 per year.

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

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HYDROCEPHALUS ASSOCIATION RESOURCES AND FACT SHEETS

The following resources are available free to our members:

About Hydrocephalus—A Book for Families (in English or Spanish)

About Normal Pressure Hydrocephalus (Adult-Onset)

Prenatal Hydrocephalus—A Book for Parents

Hydrocephalus Diagnosed in Young to Middle-Aged Adults

A Teacher's Guide to Hydrocephalus

Health-Care Transition Guide for Teens and Young Adults

Directory of Pediatric Neurosurgeons

Directory of Neurosurgeons for Adults

Fact Sheets:

Primary Care Needs of Children with Hydrocephalus

Learning Disabilities in Children with Hydrocephalus

Hospitalization Tips

Headaches and Hydrocephalus

Social Skills Development in Children with Hydrocephalus

Eye Problems Associated with Hydrocephalus

Survival Skills for the Family Unit

Durable Power of Attorney for Health Care Decisions

Endoscopic Third Ventriculostomy

Cerebrospinal Fluid Shunt Systems for Management of Hydrocephalus

Nonverbal Learning Disorder Syndrome

How to Be an Assertive Member of the Treatment Team

Second Opinions

College & Hydrocephalus

Understanding Your Child's Education Needs/IEP Resource Packets

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