

HYDROCEPHALUS

• ASSOCIATION •

SUPPORT EDUCATION ADVOCACY

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My Hydrocephalus Stories

By Debra Howell

Several months ago, we at the Hydrocephalus Association asked you to complete and return My Hydrocephalus Story forms. We hope to use them in our legislative work together. At the same time, readers requested more newsletter stories about other people who have or are affected by hydrocephalus.

You responded to our call for personal stories by sending 88 stories from 34 states and 2 Canadian provinces representing all ages and stages of hydrocephalus.

The excerpts below are from people whose stories were representative of others' experiences. Several common themes that resonated through the stories were about the positive and negative aspects of living with hydrocephalus: concerns about shunt malfunction, difficulties with healthcare coverage, and the challenges and joys of work, school and social activities.

We were deeply touched by your stories. They showed that people in the hydrocephalus community are resilient, strong, and vital. You have faced tremendous challenges and still persevere.

These are your stories.

Stories from Different Diagnostic Stages

Ten individuals were diagnosed prenatally. Christal's son is now 22 years old.

Wow! Finding out your unborn child is hydrocephalic and may not survive childbirth is an incredibly emotional challenge for anyone. . . I carried an incredible amount of guilt. I'm not sure why; (my husband and I) had nothing to feel guilty for. I just thought I was being punished for something that I did wrong. Another overwhelming emo-

tion was loneliness. We had a great support group with our families, but if we could have communicated with other parents going through the same thing, it could have made our journey a little easier.

—Christal G., Arizona

Fifty-four people were diagnosed at birth or in childhood. This mother of a two-year-old girl expressed the most common emotional challenge faced by parents and also expressed by many people affected by other types of hydrocephalus.

The biggest emotional challenge is trying not to think that something is wrong with Julia's shunt every time she cries or

ily support (empathy) that I need to manage these difficult times. I am a school nurse. (Since having hydrocephalus), I have much more patience and empathy for my students with chronic illnesses.

—Amy H., New Jersey

Eleven people were diagnosed as older adults with normal pressure hydrocephalus (NPH).

I constantly worry that (my friend's) shunt will malfunction and that the dementia, abnormal walking gait and incontinence symptoms will return. At times, I can't help but be overprotective. It gives me the greatest joy to see him live a nor-

The fact that the research is expanding and...the Hydrocephalus Association exists is a constant reminder of the hope...that(hydrocephalus) may one day become much more widely recognized and researched.

expresses unhappiness and/or sickness. It makes every little thing seem like a potential disaster. It is a constant challenge to not overreact.

—Debra H., Ohio

Twelve people were young- or middle-aged when diagnosed, including Amy, who was diagnosed when she was 43 years old. She is now 48 years old.

At times when I am feeling badly with hydrocephalus symptoms (severe headaches, poor short-term memory, balance problems) often I do not have the fam-

mal and active life out of the nursing home where he had to reside for several months before surgery.

—Carole R., New York

Staggering Statistics

This group of 88 people with hydrocephalus represents a total of 897 hospital stays and 611 surgeries. The 35 people who were able to estimate costs had a combined total of over \$1 million dollars out-of-pocket (an average of \$28,000 per person). Costs paid by private and public insurance for this group were over \$16 million (continues on page 7)

From the Editor: Advocacy and Newsletter Updates

By *Debra Howell, Advocacy and Adult Services Director*

Advocates Take Action

Over 180 people with hydrocephalus, their family members, friends and supporters have signed up to be advocates for our work to direct federal attention and resources to hydrocephalus. We are currently working on garnering support for a Congressional resolution requesting more federal support of hydrocephalus research.

Thank you to the many members and supporters who received the Association's email Advocacy Alerts and responded by writing letters and/or visiting your legislators. I was heartened by the many emails I received which shared correspondence, contacts and successes with legislators. You all did a tremendous job!

Update on Advocacy: Resolution is Introduced to the House of Representatives

As a result of everyone's efforts, Congressman Mike Thompson introduced

our resolution as H. Con. Res. 465 to the House on July 28, 2006. It was assigned to the Committee on Energy and Commerce for consideration and action just before the August recess. It has bipartisan (Democratic and Republican) support with 12 co-sponsors so far.

We are working to secure a lead sponsor in the Senate.

Our work continues as legislators reconvened last week. We are busy working with Congressional advisors on future strategy, so stay tuned. In the meantime, please contact your representatives and ask for their support if you have not already done so. See the Advocacy Pages on our website for more details.

Advocacy Pages Now Available on the Association Website

Click on the new Advocacy tab on the homepage to learn more about our resolution, how to be an advocate and what you can do to help. Visit often to get the latest news and information on advocacy.

To join the advocacy email list or request more information, visit the As-

sociation website at www.hydroassoc.org or contact me at (888) 598-3789 or debra@hydroassoc.org.

New Newsletter Feature and Stories

We are introducing a new feature in this newsletter, Kids Corner. Tell me how your kids like it!

Also new in this issue is an article on the My Hydrocephalus Story forms that 88 people sent to us. We will feature more excerpts in the coming months. The data from these stories—the staggering statistics about the financial burden and number of surgeries along with the poignant narratives—will help us make our case with legislators.

If you would like to contribute your story to our common cause, please use the My Hydrocephalus Story form on pages 11–12 and mail or fax it to the Association.

As always, feel free to let me know any feedback about the newsletter and what you would like to see covered in these pages. ■

Medical Advisory Board Member News

By *Dory Kranz and Pip Marks*

Congratulations to **Dr. John Kestle** on his promotion to Chief of the Division of Pediatric Neurosurgery at Primary Children's Medical Center at the University of Utah. A native of Canada, Dr. Kestle brings to this position his gifts in neurosurgery and patient care as well as his considerable research experience, especially in clinical trials. The hydrocephalus community is fortunate that Dr. Kestle chooses to focus many of his research efforts on hydrocephalus.

* **Dr. Michael A. Williams**, Co-Director of the Adult Hydrocephalus Program at Johns Hopkins Hospital in Baltimore, MD, appeared on ABC's World News Tonight on July 3, 2006. He was interviewed regarding the

brain's ability to "re-wire" itself for a story called "Medical Miracle of the Brain: A Man's Recovery from Head Trauma Sheds Light on Healing Powers of the Brain," which was about a man who awoke from a 10-year coma.

* The Hydrocephalus Association congratulates **Dr. Roger Hudgins** on his promotion to Chief Medical Officer of the Neurosciences program at Atlanta Children's Hospital. Dr. Hudgins was on our Medical Advisory Board for many years and has been a great friend and supporter to the Association. He will be responsible for executive oversight, vision and leadership in all aspects of the neurosciences program at Atlanta Children's.

* **Dr. Richard Ellenbogen**, Chief of Pediatric Neurosurgery at Children's

Hospital and Regional Medical Center in Seattle, WA, is the president of the Congress of Neurological Surgeons (CNS) this year. He will give the presidential address at the 2006 Annual Meeting in Chicago in October on the theme of "Transcendent Leadership: Scientific Inquiry, Patient Advocacy, Surgical Mentorship."

* **Dr. Rick Abbott** is Chair of the AANS/CNS Section on Pediatric Neurosurgery. As Chair, he created an Education Committee to allow the Pediatric Section and its members to better assist the AANS and CNS to advance education, research and patient care in pediatric neurosurgery. Under Dr. Abbott's leadership, this commitment to education will infuse the Annual Meeting of the Pediatric Section of the AANS in Denver November 28–December 1. ■

The Parent Teacher Team: Establishing Communication Between Home and School

By Margaret Rice

This article, reprinted from Exceptional Parent, was written for parents of children with special needs who have Individualized Education Plans (IEP's). Much of the advice is relevant for all parents of school-age children.—Ed.

It is the time for annual reviews where planning begins for the new school year. Parents, student and teachers have excitement and anxiety about changing current programs.

For parents of children with special needs it can be an especially fearful time. Students with special needs may be facing new teachers, new teacher's assistants, new classmates, new schools, new nurses and new therapists often resulting in confusion. It can be particularly strenuous if your child has difficulties relaying to you what occurred during the course of the day.

One very important means to ease this transition is effective communication between home and school. As a parent you will be helping your child do well in school by maintaining good communication with the teacher and the special education team. Here are several suggestions that will assist parents in establishing valuable communication.

The first step that parents can take is to do your homework. Learn all that you can about your child's school or summer program by talking to other parents, nurses, etc. or by observing the actual programs. Become active members of the parent teacher team by learning what goes on in the classroom during the course of the day including the class routine, rules and goals. Parents are the team leaders—you know all the past medical and educational history and can provide the best overview of your child. Provide all the special education team members with your contact information including your phone number, email and the best time to reach you. Request a list of names, numbers and emails of all the

team members including teacher, therapists and nurses and the best time to reach them.

There are some basic tips that will help you establish good communication with your child's teacher and other providers. First and foremost, begin your communication as early as possible and with a positive attitude. Let the teacher know from the start of the academic program that you would like an open line of communication. Try to define with the teacher how often you would like to communicate—daily, weekly, monthly or quarterly. Of course, if there is a problem and concern at school, you would like to know about it right away and you will offer the same in return. Always respond to any notes sent home from school so that the team members are aware that you read and validated their comments. By keeping the lines of communication open you can prevent a small problem from becoming a much larger problem. By working as a team with your child's special education team you will be able to accomplish much more.

It is important to establish how you will communicate with the special education team such as phone contact, written notes, and emails or in person. Perhaps you would like to request a monthly phone call from your child's teacher to determine if your child is progressing toward his or her goals. Communication journals and logs can offer an effective way to communicate between home and school personnel. You can request a notebook to be sent back and forth with your child to write comments in throughout the school year. Another option for some students is a specialized log such as *My School Journal* published by Your Therapy Source (www.yourtherapysource.com). This is a weekly or daily communication notebook for students with special needs that allows for quick, simple written documentation from students' parents, teachers, therapists and other staff members all in one organized

log. Another effective means of communication is to plan monthly team meetings with all the members of the special education staff that work with your child. This is a great way for all members to address current goals, concerns and make any necessary changes. If you cannot meet in person ask for a follow up phone call or written notes on what occurred at the team meetings. Whichever method of communication you decide on, add it to your child's Individualized Education Plan (IEP) so that all team members know what is requested of them.

Try to be an active parent throughout the school year. Attend open house nights, parent teacher meetings and other school-sponsored events. If possible, be involved in the school by volunteering in the classroom, parent teacher association or in some other manner. This allows you to feel more comfortable in the school environment. In addition, you will be able to establish a good relationship on a personal and professional level with your child's teachers and other staff members.

Finally, fulfill the requests made of you; that way you can expect the same in return from the special education team. Ask for suggestions to carry over at home what your child is learning in school. In addition, remember to not always offer criticism, if your teacher or school has done a good job let them know about it. Keeping your outlook positive and helpful will make for an easier school year for the student and the parent. ■

Margaret Rice is a licensed physical therapist and owner of Your Therapy Source (www.yourtherapysource.com). She has published several books to improve communication between school and home for students with special needs and therapists. Email srice4@nycap.rr.com or contactus@yourtherapysource.com.

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Searching For and Evaluating Doctors

By Dory Kranz, Executive Director

Whether it is for an initial diagnostic appointment, a second opinion or to schedule a surgery, there are many reasons to find doctors and evaluate their experience and abilities. On the Hydrocephalus Association's website, there is a limited database of neurosurgeons and neurologists who have let us know that they treat children or adults with hydrocephalus. However, this is not an exhaustive list and you may need to find another kind of doctor in the course of managing hydrocephalus. Here are some websites we have found helpful in locating and evaluating doctors.

Locating Doctors:

American Association of Neurological Surgeons (AANS)

1. Go to www.neurosurgerytoday.org
2. Select "Find a Board-Certified Neurosurgeon" from the left-hand menu.
3. Enter search criteria and click on "Find." You can search by name, area code, city, state, zip and specialty.
4. The results will show members of the AANS and identify whether the neurosurgeon is certified by the American Board of Neurological Surgery which has been certifying neurosurgeons since 1940.

Congress of Neurological Surgeons (CNS)

1. Go to www.neurosurgeon.org
2. Select "Find a Neurosurgeon" from the left-hand menu.
3. Enter search criteria and click on "Search." You can search by name, city, state, and member section.
4. The results will show neurosurgeons who are members of the Congress of Neurological Surgeons.

International Society for Pediatric Neurosurgery (ISPN)

1. Go to www.ispneurosurgery.org
2. Select "Membership" from the left-hand menu.
3. Click on "Find a Member by Country" at the bottom of the page.

4. Select a country and click and click on "Submit."
5. The results will show the name and city of ISPN members in that country.

Medicare Participating Physicians

1. Go to www.medicare.gov
2. Under "Search Tools" on the left hand menu, select "Find a Doctor."
3. Click on the search criteria you would like to use: State, County, City, Zip Code or Name.
4. Enter the search criteria.
5. Check a Specialty Group. If appropriate, check one or more Specialty Types. (Neurosurgery is under the Specialty Group "Neurology" and the Specialty Type "Surgery, Neurological.")
6. Click on "Find a Physician."
7. Results list the name and location of Medicare Participating Physicians.

LifeNPH

1. Go to www.lifenph.com
2. Under "My Checkup" on the top menu, select "Find a Specialist."
3. Fill in zip code and search radius.
4. Results list neurosurgeons and neurologists in that area. Doctors that are certified in Codman's Hakim Programmable Valve are identified.

Checking Certifications

American Board of Medical Specialties (ABMS)

1. Go to www.abms.org
2. Click on "Who's Certified."
3. The first time you must click on "Register for Search Service." Enter your email address and name. They will email you a password.
4. Once you receive your password, go to www.abms.org, login and accept the agreement. Public searches are limited to 5 searches per 24 hour period.
5. You can search by Name/Location or Specialty/Location. Specialties include Neurodevelopmental Disabilities, Neurological Surgery, Neurology and Neurology with Special Qualifications in Child Neurology.

6. Results list the name and city for doctors that meet the search criteria. If you click on the name, there is a list of ABMS General and Subspecialty certificates held by that doctor.

Castle Connolly Medical Ltd. (private list of peer-nominated doctors)

1. Go to www.castleconnolly.com
2. You can choose to find a doctor, find a hospital or look up a doctor's disciplinary record.
3. You must join in order to use the services. Click on "Find a Doctor," then click on "click here to join." You can then select to "Become a Registered Member" which is free. This allows you to see about 20% of the doctors on their database—only those who are associated with hospitals in their Partnership for Excellence program.
4. Fill out the required information and click "Continue." You can start using the site immediately.
5. Select "Find a Doctor," "Find a Hospital" or "Doctor Disciplinary Information" from the left-hand menu. Enter search criteria.
 - i. Results for "Find a Doctor" include name, hospital affiliation, phone number and board certifications.
 - ii. Results for "Find a Hospital" include contact information and lists Centers of Excellence for the hospital.
 - iii. Results for "Doctor Disciplinary Information" include license number, expiration date and any disciplinary action associated with that license number.

US Department of Health and Human Services Hospital and Hospital Quality Alliance project

1. Go to www.hospitalcompare.hhs.gov
2. Click on the "Geography" category you want to search by or "Hospital Name."
3. Enter the geographic or name information.
4. Results list hospitals which you can then select to see their quality comparison on specific conditions. ■

NPH Getting Noticed!

Dr. Katrina Firlik, one of about 200 female neurosurgeons in the country, devotes four pages to Normal Pressure Hydrocephalus in her new book, "Another Day in the Frontal Lobe." Of her experience treating NPH, she says, "The shunt procedure, even though it takes only an hour or so, can actually be one of the most satisfying in neurosurgery when it works well, which is most of the time but not all of the time."

She also mentions the effect that media attention to NPH has had over the last few years. "I have seen elderly patients coming out of the woodwork recently—usually accompanied by an internet-savvy daughter or son—with the potential diagnosis of NPH," she said.

The book is an insider's look at the profession of neurosurgery written for lay people. It may prove to be an interesting read for those with hydrocephalus. ■

Share your Story with the American Brain Coalition

The American Brain Coalition (ABC) is launching a new effort to achieve more public awareness and support for disorders of the brain, including hydrocephalus. Personal stories from real people have great potential to strike a chord with policymakers, so ABC is collecting stories from patients and their caregivers chronicling the difficulties they face in accessing appropriate and timely healthcare.

The stories needed for the new project include problems with the following healthcare-access issues: getting a doctor's appointment, paying for critical services and treatments, finding insurance that will cover your medical needs, or seeing a specialist. All information will be kept anonymous and may be used in future advocacy activities.

The ABC is a group of nearly 50 professional societies, patient advocacy groups and foundation representatives that have

joined forces to reduce the burden of brain disorders and advance our understanding of the brain. It was co-founded in 2004 by the American Academy of Neurology and the Society for Neuroscience. The Hydrocephalus Association is a proud member of the ABC.

Please submit your story via email to stories@americanbraincoalition.org.

Stories can also be mailed to: Attn: ABC, 1121 14th Street, NW, Suite 1010, Washington DC, 20005. Please also send a copy of your story to the Hydrocephalus Association via email (debra@hydroassoc.org) or regular mail. For more information, visit ABC at www.americanbraincoalition.org. ■

Tax-Free giving opportunity for those over 70 ½ with IRA

The Pension Protection Act of 2006 was signed into law by President Bush on August 17. The act includes a provision which allows individuals age 70½ or older to directly transfer up to \$100,000 a year from a traditional or Roth Individual Retirement Account (IRA) to tax-exempt charitable organizations like the Hydrocephalus Association. This giving opportunity applies to gifts made from qualified IRAs to eligible charities in 2006 and 2007.

Previously, any lifetime distribution from an IRA was subject to federal income tax even if it was gifted to a charity. Under the Charitable Rollover provision of the Act, such a gift—up to \$100,000 per donor per year—will not be subject to federal income tax. To qualify, the owner of the IRA account must be age 70½ or older, and the gift must be made in a way that it would otherwise be fully deductible. For someone in the 35% income tax bracket, rolling over \$100,000 in IRA assets to the Hydrocephalus Association could mean a tax savings of \$35,000 and the ability to gift the entire amount.

Please consult your tax advisor if you think this may apply to you as you consider your year-end giving to the Hydrocephalus Association. ■

Kid's Corner!

Here is a riddle made especially for you. Written below is a simple clue. Make a guess and have some fun. Turn this paper upside down when you're done!

Riddle: What is small enough to hold in your two hands, squishy, wrinkly and one of the most powerful tools on earth?

Answer: Your Brain

Unscramble these words about hydrocephalus:

1. CORDOT
2. ABINR
3. HNTUS

Hints: (Only read this if you really need it!)

1. This type of person often wears a white coat.
2. It helps you think.
3. You have to go to the hospital to get this.

3. SHUNT
2. BRAIN
1. DOCTOR

In Memoriam: Fred J. Epstein, MD

By Emily Fudge with excerpts from *Greenwich Time*

The hydrocephalus community mourns the loss of a great supporter, Dr. Fred J. Epstein, a world-renowned pediatric neurosurgeon who died July 9, 2006 at his home in Greenwich, CT, of metastatic malignant melanoma. He was 68 years old.

Dr. Epstein was a committed and compassionate pediatric neurosurgeon who blazed many trails during his career. He was an early member of our Medical Advisory Board and, along with Dr. Michael Edwards, he was one of the keynote speakers at our first hydrocephalus conference in 1988. He was a champion of long-term care planning and was deeply committed to the quality of life of his patients.

Quoting from his chapter entitled, "How to Keep Shunts Functioning, or 'The Impossible Dream,'" from the 1985 edition of *Clinical Neurosurgery*, he wrote: "It must be emphasized that any neurosurgeon that accepts the responsibility of caring for a hydrocephalic infant is making a long-term commitment to the well-being of the child that in all likelihood will continue throughout the professional career of the neurosurgeon. While many of the long-term complications may not be related to shunt obstruction, it is the responsibility of the neurosurgeon to make that assessment and to assume responsibility for making

the proper referral should other expertise be necessary...A neurosurgeon who is devoted to both the patient and the family and is committed to understanding and treating complications associated with shunts and shunt dependency will be the best insurance of the future of the patient..."

In 1996, Dr. Epstein was the founding director of the Hyman-Newman Institute for Neurology and Neurosurgery (INN) at Beth Israel Medical Center. The creation of the INN was the fulfillment of Dr. Epstein's dream of a special place of hope and comfort for patients and families dealing with the most serious neurological illnesses. Whether performing the most delicate neurosurgical procedure or holding the hand of a parent who had just lost a child, he set an example of care and compassion that serves as a mark of excellence in all of medicine. In a special effort to recognize Eastern religious beliefs in healing, Dr. Epstein hosted His Holiness the Dalai Llama at the INN in 1999. His unconventional and holistic approach to health as well as his charismatic demeanor made him a medical icon recognized world-wide.

In his lifetime, he published more than 175 scholarly papers, and in 2001 received a Lifetime Achievement Award from the American Association of Neurological Surgeons. He was the author of two books, "Gifts of Time" and "If I Get to Five: What Children Can Teach Us About Courage and Character." ■

Watermarks

By Esther Mills

I trace my finger down the ridges,
Seams of skin stark against your hair
Where hair will never grow again,
Cords of healing from wounds that
saved you—
Saved you for me.
I kiss the scars in gratitude.

"Does it hurt?" I ask.
"It never hurts," you say. "It just feels
strange."
I kiss them again,
Lips pressed to their thickness,
Glad you wear them unashamed,
These testaments to the deluge within;
You were so near to drowning
inside yourself.

I close my eyes before the visions
Of a boy alone, bewildered,
Struggling in seeping darkness
Amid the taunts of brainless children.

I will not imagine your skull pierced
by surgeon's knives
Or the flood receding in shunted tides;
But these—
Watermarks on a recovered landscape—
These I adore,
Flesh binding proudly, strongly,
The signature of your soul.

LINK Update Reminder!

Due to a database change, we are updating our entire LINK Directory designed to facilitate peer-to-peer networking and support.

If you would like to continue to appear in the LINK Directory or be added as a new LINK member, please contact our office to request a LINK form. If you have already received a

LINK update form by mail or email, please fill it out and return it to us.

Once we receive enough of these updated forms and add them to the new database, we will publish and send a new and more accurate LINK Directory. During this transition, feel free to call or email our office to connect with other LINK members. ■

Designate the Hydrocephalus Association for your Workplace Giving

Combined Federal Campaign:
Code #1061

Community Health Charities:
Code #36

United Way:
Write in Hydrocephalus Association

Upcoming TEAM Hydrocephalus 2006 Walkathons

By Gina DeGennaro, Development Director

It is shaping up to be an amazing year for TEAM Hydrocephalus 2006! This year we have 12 TEAM events planned in 11 states in the nation! Most of our events took place in September. You will see their results in an upcoming issue of our newsletter. In the meantime, here is a look ahead at the upcoming TEAM events with leader contact information.

TEAM Illinois: Chicago Area, October 7, 2006

Sherry Reising (708) 560-0460

TEAM New Mexico: Albuquerque area, October 21, 2006

Kathy Carrillo (505) 440-3573

TEAM New Jersey (Liberty): October 22, 2006

Chris Riccio (973) 661-4291

TEAM Pennsylvania: November 5, 2006

MaryBeth Godlewski (610) 664-1355

Kelly Rambo (610) 277-7339

Online registration is available, or to donate to a TEAM event, at www.hydroassoc.org/TEAM.htm and follow the link to your specific TEAM.

We are truly grateful to our very special TEAM leaders who have put their time and dedication into organizing their event and creating an opportunity to network with other families. We are also grateful for all TEAM participants who go the extra mile for promoting awareness of hydrocephalus by raising funds to allow us to provide personal support, education, and advocacy to people with hydrocephalus and their families. ■



TEAM Hydrocephalus 2006

My Hydrocephalus Stories Continued

(continued from page 1) dollars (an average of \$457,000 per person).

Causes

59 people listed a cause for their hydrocephalus and 29 were of unknown cause.

15 different causes were listed. The most common causes were aqueductal stenosis (10), intraventricular hemorrhage (IVH: 7), Dandy Walker syndrome (5), arachnoid cyst (3), and an accident or fall (3). Other causes included arterial-venous malformation (AVM), birth trauma, intrauterine stroke, concussion, complications of cranial surgery, meningitis, seizure, spina bifida, stroke, and tactile glioma tumor.

Jerri and her 7-year-old son Philip wrote his story together. Philip was one year old when he was diagnosed. His hydrocephalus was caused by aqueductal stenosis. Philip wrote:

People like me with hydrocephalus think better (with a shunt), not like when their brain is clogged.

—Philip B., Maryland

Kate D. was diagnosed at birth and has Dandy-Walker syndrome. She is now 16 years old.

Being a teen with hydro, I find one of my greatest challenges is going to school every day. My peers aren't very accepting (of me). I don't have many friends...(One thing that brings me joy is) having friendships that don't disown me but embrace my difference. —Kate D., Michigan

Difficulties with Healthcare Coverage

Many people had difficulty affording or accessing healthcare coverage. Debra and Kimberly wrote about the most often cited problem: difficulties getting insurance companies to pay for healthcare services.

(The biggest challenge is) having to play by the insurance company's rules even though it is not what is best for our daughter. (Her healthcare) costs are unaffordable without insurance coverage.

—Debra H., Ohio

(There are) constant disagreements and hours of time fighting for coverage.

—Kimberly C., Michigan

We Hope and Work for Change

We in the hydrocephalus community hope for more hydrocephalus research to unravel the mysteries of hydrocephalus. We work together with federal legislators to gain more funding for that research. Together, we can make a difference.

Darrill, diagnosed at 22, expresses the hope we all share.

The fact that the research is expanding and that a group such as the Hydrocephalus Association exists is a constant reminder of the hope and... visualization that this may one day become a much more widely recognized and researched/studied disorder. —Darrill G, Florida

Look for more from My Hydrocephalus Stories in future newsletters. ■

Conference

More Photos from the 2006 National Conference in Baltimore, Maryland

*All of the photos from the conference can be viewed online through Snapfish.com
Call or email the office and we will email you an invitation to view them.*



Thanks to Dr. Janet Miller and graduate student Kelley Brabant from Wayne State University, participants got a hands-on lesson in brain anatomy and physiology and were able to try inserting a shunt catheter into a specially-made gel brain.



We made new friends...and reconnected with friends from past conferences.



Save the Date: 10th National Conference

June 19-22, 2008 (Yes, we are moving it a month later than usual)

The Canyons Resort, Park City, UT

Plan to bring the family and enjoy Utah's beautiful mountains and National Parks



One lovely couple celebrated their ability to dance together again at our family dinner dance.



With all of the outstanding speakers, people couldn't take notes fast enough.



A panel of people whose lives are touched by hydrocephalus shared the meaning of this conference in their lives.



They left us reaching for a tissue and standing to applaud.

Thank you to the incomparable faculty, staff, and Board members, our wonderful volunteers and especially our exhibitors and sponsors for making this conference such a great experience for all of us.

Board Member Profile: Sally Baldus



When I moved to San Francisco in 1994, my sister Emily Fudge, the founder and then Executive Director of the Hydrocephalus Association, said to me, "I have one favor to ask. I would like you to join the Hydrocephalus Association Board of Directors." Well, how could I say no to that!

In 1994, the Board's members were all local and the Association's office had only recently moved from the Fudge dining room table to its current location

in the Flood Building. Our budget was less than an eighth of what it is today. However, the Association's mission was thriving—to provide support, education and advocacy.

My first Board assignment was to chair the Association's Scholarship Committee on behalf of the Fudge family. At that time, we awarded the annual Gerard Swartz Fudge (named for my nephew) Scholarship to one young adult for education beyond high school. From the beginning, we had many qualified applicants and one of my most meaningful experiences as a Board member has been to see that funds have increased to the point that, in 2006, we were able to give out seven scholarships. To me this is still not enough, but a move in the right direction.

My entire professional career has been in the non-profit sector and for the past 20 years I have focused on major gift and planned giving fundraising. So, after

a few years on the Board, I was asked to take on its presidency.

I felt and still feel enormously privileged to have served the Hydrocephalus Association at a time when it was poised to take its next step: developing into a truly national organization with an increased budget, staff and commitment to professionalism. This was possible because of the vision of all of us involved. It was not only my vision; the time was right, and I simply helped steer the course.

Twelve years later I am something of a "lifer." I still chair the scholarship committee and am currently serving as the second vice-president. It's been incredibly meaningful to me that I can give back in this way to my family and to my late nephew, Gerard Swartz Fudge, whose diagnosis of hydrocephalus made this all possible for the thousands of other families who have sought us out over the past 22 years. ■

Volunteer Focus: Jim Luedde

By *Chris Neira, Executive Assistant*



Meet our star volunteer, Jim Luedde! Jim volunteers on Thursdays and helps us process information from the web, fax, mail and phone.

Jim is prompt, courteous and mild-mannered and has been a wonderful addition to the Hydrocephalus Association since he first began volunteering. Jim hand-picked the Association as the organization he wanted to work with when he signed up at the Volunteer Center of San Francisco a year ago and we have been grateful ever since.

Jim enjoys working for the Hydrocephalus Association because he has seen how much information, education and support we provide for those affected by hydrocephalus. This has inspired him to contribute in any way he can. Jim has also said he enjoys working with the staff, adding, "Everyone is so nice here!"

When Jim is not volunteering at the office, he sings in his church choir and volunteers twice a week at Most Holy Redeemer Catholic Church in San Francisco's Castro district where he counts collections and makes sandwiches for

dinners serving the homeless.

Jim comes to us with an interesting background. He has lived in San Francisco for 24 years, but is originally from St. Louis, Missouri. Jim also served 16 years in the Air Force Band playing the clarinet, flute, piano and saxophone. Once stationed in Germany, Jim then made his home in Europe for three years traveling from North Africa to Scandinavia. Prior to volunteering with the Hydrocephalus Association, Jim was a facilities manager for a midsize law firm in San Francisco.

In his spare time, Jim also enjoys spending time with his two new 5-month-old toy poodles, Bruno and Duke.

We are very fortunate to have Jim as part of the Hydrocephalus Association team! ■

My Hydrocephalus Story

What are the biggest emotional challenges of being, raising or living with a person with hydrocephalus? Tell a story or give an example.

What is something about being or living with this person with hydrocephalus that brings you happiness and joy. Tell a story or give an example.

Release:

I give my permission to the Hydrocephalus Association to use this information without attribution in any way that will help find a cure, advance understanding, raise awareness or advance diagnosis and treatment for hydrocephalus.

Date: _____

Signature: _____ Printed Name: _____

I give permission to use the story with attribution in communication with legislators:

Person filling this out: _____ City & State of residence: _____

Person with hydrocephalus: _____ City & State of residence: _____

What is the greatest obstacle you or the person with hydrocephalus has overcome? Tell a story or give an example.

What is the most common daily task with which the person with hydrocephalus needs assistance?

Please provide a subjective assessment of development of the person with hydrocephalus at this time by putting a check in the appropriate box.

	Over Achiever	On par w/ age peers	Delayed & Challenged	Severely Impaired
Cognitive				
Social/Emotional				
Physical				
Other (please explain)				

Age at Diagnosis _____ Cause of hydrocephalus (if known) _____

Age now _____ Grade level in school _____

of surgeries for hydro _____ # of hospital visits _____

of shunt infections _____ # of Sleepless nights (for caregivers) _____

Is the person with hydrocephalus employed? No Yes Part time Full time

The biggest challenges to affording or accessing needed healthcare are:

Is the person with hydrocephalus on SSI, SSDI, Medicaid, Medicare or State Children's Health Insurance Program? _____ If so, how long has the person received it? _____

Reason for approval? _____

Did you apply and get denied? _____ Reason for denial? _____

Total cost of all surgeries, doctor visits, special equipment, therapy, tutoring, etc. (If you don't have this information at hand, you may get it to us later.)

Out-of-pocket paid by family: _____

Paid by private insurance: _____

Creative Fundraising Events for which we are Grateful

By Gina DeGennaro and Pip Marks



San Francisco Marathon

Jennifer Jimenez Marana ran in the San Francisco Marathon on July 30, 2006 and raised over \$4,000 for the Association. Her son, William, was born premature and diagnosed with hydrocephalus. While doctors predict that William may not be able to walk, Jennifer and her husband Joe believe otherwise. Jennifer describes the half-marathon as “the most rewarding and memorable run I’ve ever done. Until William can run with me, I will ‘Run for Will.’” Thank you, Jennifer, for all of your hard work and dedication! And thank you to all those who supported her!



Happy Birthday!

Grace Metts celebrated her ninth birthday on July 8 and in lieu of birthday gifts she asked for donations to be made to the Association in honor of her brother Waylon who is four years old and has hydrocephalus. Thank you Grace for your wonderful donation and happy belated birthday!



1st Hydrocephalus Golf Outing

Nicole Russo hosted the first-ever golf outing for the Hydrocephalus Association August 1, 2006 at Eisenhower Park Golf Course in Long Island, NY, which raised over \$3,300 for the Association. Nicole said, “Planning the outing

was many hours of hard work, but the outcome was amazing. Even though temperatures reached 100 degrees, it was worthwhile when I met all of the participants and heard their stories about how hydrocephalus affected their lives.” Nicole’s father was diagnosed with NPH this year and is now at home with a complete recovery. Congratulations, Nicole, on your success, and many thanks to the golfers who came out to support us and enjoy the day!

Birthday Bash

Natasha Jackson, mother of triplets Brianna, Larry III, and Izaiah (who has hydrocephalus), threw a birthday bash in July and in lieu of gifts for herself asked family and friends to make donations to the Hydrocephalus Association. She also had a raffle at the party, and proceeds also benefited the Association. We thank Natasha for raising \$300 in honor of her son Izaiah, and for her hard work and dedication. Happy belated birthday Natasha!



Birthday on Angel Island

Will Kelly celebrated his 9th birthday on September 10th during our TEAM walk-run-wheel-a-thon on Angel Island in California. Will surpassed his goal of \$1,000 in donations, making him the number one fundraiser under 16 years old. Happy birthday and way to go Will!

A Fundraising Family

Tom and Margo Graham along with their adult children Tom Jr., Jonathon and Jessica (who has hydrocephalus), raised funds for the Association by managing a refreshment stand at a local home and garden show in Chico, CA. But that’s not all—in April 2007, the Grahams are planning a golf outing in the Chico, CA, area, so be on the watch for details. A special thanks to the entire Graham family!

Able Play

As a parent, do you struggle to find just the right toys for your child with special needs? As a professional, are you able to find the best toys, educational products and information for special needs children you work with? There is a great new website called Able Play which provides independent ratings and product reviews on play products in four disability categories: physical, sensory, communicative and cognitive. Visit their website at www.ableplay.org.

Resource for College-Bound Students with Disabilities

An online mentoring program brings students and professionals together via the internet to increase the participation of individuals with disabilities in challenging academic programs and careers. DO-IT (Disabilities, Opportunities, Internetworking, and Technology) is a networking program supported by the University of Washington. It promotes the use of computer and networking technologies to increase independence, productivity and participation in education and employment by offering electronic mentoring and discussion lists. Topics focus on access issues for people with disabilities, including access to adaptive technology, postsecondary education, and career fields such as science, mathematics, engineering and technology. To contact staff, request publications or apply to be a DO-IT Scholar, Pal, Mentor, or volunteer, email: doit@u.washington.edu. For more information, visit <http://www.washington.edu/doit/>.

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care ADvantage™ Magazine

care ADvantage™ is a free quarterly magazine for family members and caregivers of people with all forms of dementia, whether from normal pressure hydrocephalus, Alzheimer's disease or another health condition. It is published by the Alzheimer's Foundation of America. AFA's mission is "to provide optimal care and services to individuals confronting dementia, their caregivers and families, through member organizations dedicated to improving quality of life."

care ADvantage™ is designed to provide a new vantage point and voice to dementia caregivers. Each issue presents articles by experts offering information and perspective into topics of interest to caregivers. *care ADvantage™* welcomes contributions from caregivers and other readers. For a free subscription, call (866) 232-8484 or visit www.alzfdn.org.

Taking Charge of the Future: A Financial Guide for People with Spina Bifida and Their Families

A new online publication, *Taking Charge of the Future: A Financial Guide for People with Spina Bifida and Their Families*, suggests reader-friendly advice on ways to take charge of your financial health. Published by the Spina Bifida Association (SBA), the guide provides straightforward answers to financial questions such as "How can I pay for college or independent living?" and "How can I leave money to my child with spina bifida without jeopardizing her future government benefits?" The guide is also useful for those with hydrocephalus who do not have spina bifida. The publication is divided into two sections: one for parents and caregivers and one for adults living with spina bifida. The guide can be found under the "What's New" section on the right side of SBA's home page at www.sbaa.org or go directly to www.sba-resource.org/NEFE/.

Emergency Guide Useful for Older Adults and People with Disabilities

The Administration on Aging's National Family Caregiver Support Program and Caresource Healthcare Communications Inc. have collaborated to produce a new consumer guide, *Just in Case: Emergency Readiness for Older Adults & Caregivers*. It is a free consumer resource which includes a 12-page fact sheet and checklist aimed at helping older adults and caregivers prepare for emergencies.

Special emphasis is placed on issues affecting older adults, people with disabilities and their caregivers, and those affected by medical conditions, physical challenges, assistive devices and mobility issues. It can be found at www.aginginstride.org/emergencyprep/default.htm.

Change in Spanish Support

Our Spanish outreach staff member, Daniela Salas, has left our organization. At this time, we no longer have full-time Spanish support in the office. However, we still offer Spanish publications and resources as well as several members across the U.S. who are fluent in Spanish who are willing to provide one-on-one support by phone or email.

Daniela, la persona que ha estado a cargo de comunicaciones en español, no es parte ya mas de nuestra organización. En este momento, no tenemos ninguna persona trabajando en nuestras oficinas quien hable español. Sin embargo, continuaremos ofreciendo publicaciones e información en español. También contamos con varios miembros bilingües de nuestra organización que residen en los Estados Unidos disponibles para ofrecer asistencia en español por teléfono o correo electrónico.

2006 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 2006. Enclosed is my unrestricted donation of:

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

How would you like to receive your quarterly newsletter?

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

Please send my newsletter via email to: _____

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

Charge my: VISA MasterCard Discover

Amount Charged \$ _____

Card No. _____ - _____ - _____ - _____

Exp. Date ____ / ____ VIN # _____

Print Name _____

Signature _____

Please remove my name from your mailing list.

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

Please check all that apply:

I am on SSI or Disability.

My medical bills have exhausted my finances.

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

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

**Hydrocephalus Association • 870 Market St. #705 • San Francisco, CA 94102
Tel. 415-732-7040 • Toll-Free 888-598-3789 • Fax 415-732-7044 • Email: info@hydroassoc.org**

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Hydrocephalus Association

serving individuals, families and professionals since 1983
870 Market Street #705 • San Francisco, California 94102
(415) 732-7040 Telephone • (415) 732-7044 Fax • Toll-Free (888) 598-3789
Website: www.hydroassoc.org • Email: info@HydroAssoc.org

HYDROCEPHALUS ASSOCIATION RESOURCES AND FACT SHEETS

The following resources are available free to our members:

About Hydrocephalus—A Book for Families (in English or Spanish)
About Normal Pressure Hydrocephalus (Adult-Onset)
Prenatal Hydrocephalus—A Book for Parents
Hydrocephalus Diagnosed in Young to Middle-Aged Adults
A Teacher's Guide to Hydrocephalus
Health-Care Transition Guide for Teens and Young Adults
Directory of Pediatric Neurosurgeons
Directory of Neurosurgeons for Adults

Fact Sheets:

Primary Care Needs of Children with Hydrocephalus
Learning Disabilities in Children with Hydrocephalus
Hospitalization Tips
Headaches and Hydrocephalus
Social Skills Development in Children with Hydrocephalus
Eye Problems Associated with Hydrocephalus
Survival Skills for the Family Unit
Durable Power of Attorney for Health Care Decisions
Endoscopic Third Ventriculostomy
Cerebrospinal Fluid Shunt Systems for Management of Hydrocephalus
Nonverbal Learning Disorder Syndrome
How to Be an Assertive Member of the Treatment Team
Second Opinions
College & Hydrocephalus
Understanding Your Child's Education Needs/IEP Resource Packets

HYDROCEPHALUS

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SUPPORT EDUCATION ADVOCACY

870 MARKET STREET
SUITE 705
SAN FRANCISCO, CALIFORNIA 94102
