

HYDROCEPHALUS

ASSOCIATION

SUPPORT EDUCATION ADVOCACY

FALL 2007

VOL. 25, NO. 4

Anticipation: Association Designs New Website

After nearly 10 months of dreaming, designing and building, the Hydrocephalus Association is proud and excited to announce the launch of our new website. Soon when you go to www.hydroassoc.org, the familiar purple and gold pages will give way to a new communication and information portal in shades of teal and white. The new site offers an enriched assortment of tools and resources to help you learn about hydrocephalus, request and offer support, understand and advance research, gain the interest of the media and get involved with our community. We invite you to visit, explore and let us know what you think.

The site debuts our new logo which evolved from images of flow and change: the flow of information and feedback and the ability to move through and adapt to different pathways during change. This cosmetic update marks our expanding view of our mission to include more channels of local support and community connection, provide additional educational resources accessible over the Internet and enroll members in our growing national advocacy work to advance research and find a cure.

The site was designed to feel approachable and personal. A professional writer helped us present content in a way that is accessible, understandable and appropriate to people in many different situations related to hydrocephalus. And, the site is full of photos of people in our community. You can upload your photos at www.hydroassoc.org/12hna.com/flickr. View photos that have been uploaded by our

community at www.flickr.com and search for 'Hydrocephalus Association.'

The content of the new website is organized according to the services we offer

lets and fact sheets. Here, we also direct people seeking support to our national toll-free hotline and our newly developing local support groups.

We are also excited about a new social networking site www.gabrielslife.org that will be closely linked to our HA website. However, the content on GabrielsLife will come from you. Here you will share experiences, knowledge and support with each other directly. This community will be available every hour of the day from any location. You can read the moving story behind GabrielsLife.org when you visit the site.

On our pages devoted to 'Research and Advocacy,' you can browse a database of research projects or learn how you can join our national advocacy efforts to advance hydrocephalus research. On our 'Media' pages, we invite inquiries from reporters and encourage your help in reaching out to local press with your personal stories.

Through the 'How You Can Help' pages you will find ways to donate and volunteer to strengthen the work we do as a community.

The websites were created by Twelve Horses, www.twelvehorses.com, a website and relationship management company in Reno, Nevada. Through Twelve Horses' progressive design, the Hydrocephalus Association may

become the first health advocacy nonprofit organization to embrace the power of social networking to encourage their membership to reach out and connect with each other and give them the tools to do it. ■



The Hydrocephalus Association would like to thank one of our members, Leilani Schweitzer, for her vision and passion, the people at Lucile Packard Children's Hospital, who recognized the importance of hydrocephalus education and generously funded these websites, and Twelve Horses, whose expertise enabled us to use the latest technologies to create a place of support, advocacy, community and hope.

—Dory Kranz, Executive Director

and audiences we seek to engage. Pages devoted to 'Education and Support' provide information about hydrocephalus diagnosis, treatment and ongoing management along with links to downloadable files of our full library of educational book-

From the Executive Director

By Dory Kranz

Leveraging our strength as an advocacy organization, the Hydrocephalus Association has been centrally involved in bringing increased attention to hydrocephalus: through our pilot program to strengthen and unify local support groups in affiliation with the Association; through a growing cadre of volunteers leading TEAM networking and fundraising events in 22 states; and through our advocacy efforts around hydrocephalus awareness, research and health policy. Critical to attaining this objective are the Association's efforts to generate excitement and engender a collaborative spirit among researchers, members of the healthcare community and health policy

makers. Our work as a catalyst, facilitating alignment, and unifying and amplifying the voice of hydrocephalus nationally has been making great strides.

I am pleased to announce that a paper summarizing the NIH-sponsored 2005 research workshop, "Hydrocephalus: Myths, New Facts, Clear Directions" has been accepted for publication in the peer-reviewed *Journal of Neurosurgery: Pediatrics*. We expect this will be published in the November issue which will be distributed at the Annual Meeting of the Pediatric Section of the American Association of Neurological Surgeons and Congress of Neurological Surgeons. November publication will also allow our colleagues at NIH to begin using this as a template for hydrocephalus research.

As this newsletter was going to press, our National Advocacy Director, MaryBeth Godlewski, and I have just attended a town hall meeting in New Hampshire in support of the National Health Council's agenda to raise national healthcare issues to the highest levels of the presidential debates. Your participation through legislative visits and letters makes a huge contribution to the success of our advocacy efforts and I encourage you to continue to be responsive to our advocacy alerts. I hope you enjoy reading throughout this newsletter about our advocacy efforts at the state and national level to increase government awareness of hydrocephalus, increase federal investment in hydrocephalus research and improve national health policy for all people with chronic medical conditions. ■

Medical Advisory Board News

At the Hydrocephalus Association's Medical Advisory Board (MAB) meeting in July, 2007, members explored how the MAB could become more active strategic advisors during this exciting period of growth. The MAB is committed to helping the Association protect our integrity and high quality of personal support and educational materials as we expand support locally through our Affiliate Pilot Program and accelerate research advocacy efforts at the national level. We took time out to celebrate two recent successes: raising the issue of transition of care within professional organizations (described in the summer, 2007 newsletter) and acceptance of a paper that summarized the NIH-sponsored 2005 research workshop, "Hydrocephalus: Myths, New Facts, Clear Directions" in the *Journal of Neurosurgery: Pediatrics*. We are grateful for the outstanding medical and research professionals who grace us with their energy, expertise and commitment.

We congratulate MAB member, Michael A. Williams, MD, on his recent appointment as medical director of the newly-created LifeBridge Health Brain and Spine Institute at Sinai Hospital of

Baltimore, MD. Dr. Williams will continue to evaluate and treat hydrocephalus patients and be a strong advocate for adult hydrocephalus within the medical community as Director of the Adult Hydrocephalus Center at the Brain & Spine Institute. Robin K. Wilson, MD, will serve as Associate Director of the Adult Hydrocephalus Center. Announcing their appointments, Sinai Hospital President and COO, Neil Meltzer, said, "We are excited to welcome Drs. Williams and Wilson who will be leading Sinai into the future of hydrocephalus diagnosis, treatment and research." Of his new appointment, Dr. Williams said, "Dr. Wilson and I are delighted to be at LifeBridge Health, where in our first two months, we already have established a full range of neurology, neurosurgery and rehabilitation services that are so important in the care of adults with hydrocephalus. It's our hope that we will be able to serve more patients and families more efficiently than we ever have before; and we will continue to conduct research that will help to advance our understanding of hydrocephalus and its treatment outcomes."

We also congratulate MAB member, James P. 'Pat' McAllister, PhD, who was recently appointed Professor of Neurosurgery, Division of Pediatric Neurosurgery, University of Utah School of Medicine, with adjunct appointments in the Departments of Bioengineering and Neurobiology and Anatomy. With the generous support of fellow MAB members Drs. John Kestle and Marion 'Jack' Walker, and William Couldwell, all affiliated with the Primary Children's Medical Center, Dr. McAllister was able to move his entire laboratory and several members of his staff, enabling them to continue the basic research they have performed for the past 23 years on the pathophysiology of pediatric hydrocephalus at in the Children's Hospital of Michigan and Wayne State University School of Medicine, Detroit, MI. Dr. McAllister says that he "regrets being separated from his friends in Michigan, especially the STARS Support Group which continues to provide funding and inspiration for his experiments, but he and his colleagues are very excited about the prospect of working at the University of Utah." ■

Hydrocephalus Association Posts Legislative Victory Thanks to Outpouring of Grass Roots Support from Members

By MaryBeth Godlewski

Congress read our letters and answered our calls! Our suggested report language is included in the House and Senate 2008 appropriations bills, bringing us one step closer to increased federal support for hydrocephalus research.

This action on Capitol Hill is a testament to the hard work of scores of patients, families and health professionals who worked to convince Congress that the National Institutes of Health (NIH) needs to focus more on hydrocephalus research. One such family is Gerry McMahon's who responded to an email seeking constituents in strategic congressional districts. Gerry's efforts resulted in the support of Rep. Rosa DeLauro (D-CT) whose leadership was essential to securing report language in the House. Every voice and letter was important and we thank and congratulate you all.

NIH Encouraged to Increase Hydrocephalus Research Funding

Specifically, the report language encourages NIH to "...significantly strengthen funding for hydrocephalus research along with actively soliciting grant applications based on the findings from the workshop. The Committee also encourages NINDS [National Institute of Neurological Disorders and Stroke] to seek opportunities to collaborate with other institutes and offices at NIH [and] to support



Gerry McMahon and her family responded to an email alert looking for constituents of specific members of Congress. Gerry's efforts resulted in the support of Rep. Rosa DeLauro (D-CT). Pictured are Kaitlin, Gerry, Kaitlin's twin sister Molly and Michael. Kaitlin has had hydrocephalus and a shunt since she was one year old.

research collaboratively in epidemiology, pathophysiology, disease burden and improved treatment for hydrocephalus."

The Significance of Report Language

Report language is a key avenue for members of Congress and their constituents to influence the ways federal agencies, including the NIH, spend federal funds. Report language does not have statutory force; departments and agencies are not legally bound by their directives. However, these documents express congressional intent and executive branch departments take them seriously. ■

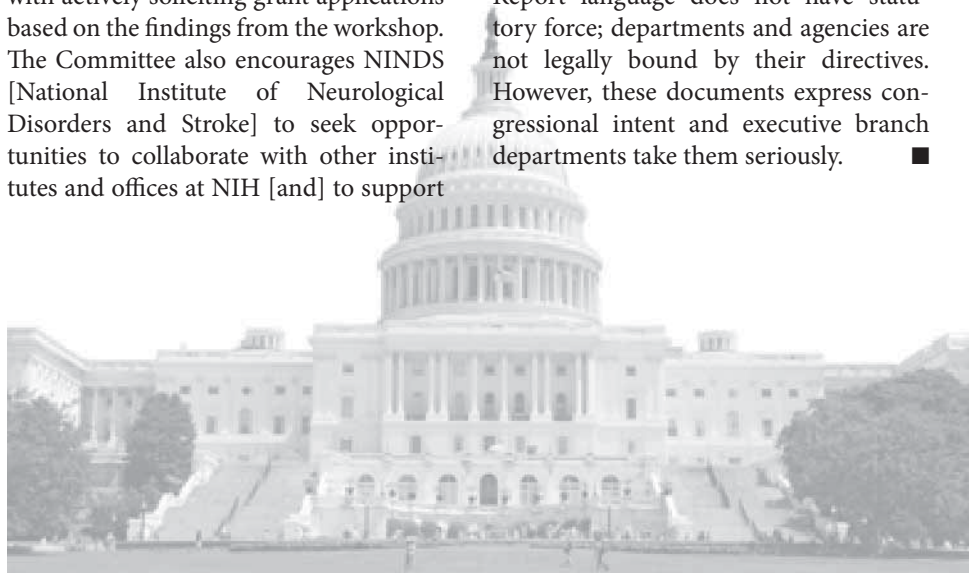
Keep Up The Good Work!

The grassroots movement has been critical to our legislative success—and we encourage you to keep up the good work.

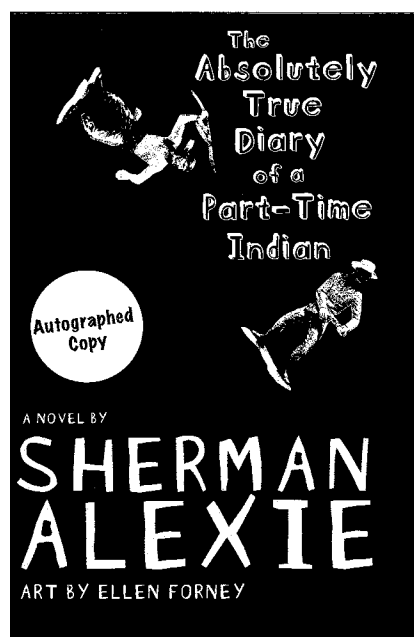
We need you to help us seal our legislative victory. More remains to be done to move the 2008 Appropriations Bill with our report language attached through the combined House and Senate Conference Committee with the two-thirds majority vote needed to overcome a threatened Presidential veto.

Lend your voice, your letters and your emails to help convince Congress that this appropriations bill with the report language is important to you.

Get involved! Please call or email MaryBeth at 484-270-8523 or marybeth@hydroassoc.org.



Sherman Alexie Chronicles Story of Young Spokane Indian with Hydrocephalus



Sherman Alexie, noted author, poet and screen writer, has just published his most recent novel, *The Absolutely True Diary of a Part-time Indian*. Written for young adults, the novel features Junior, a 14-year-old Spokane Indian who has hydrocephalus. This plucky teenager leaves the reservation and attends an all-white school where the only other Indian is the school mascot. Although Junior endures great tragedies, he attacks life with wit and humor and discovers strengths inside of himself that he never knew existed.

Many of you have been fortunate to have met and heard Sherman as the keynote speaker at our national conferences. His new book is a must read for all parents and teens living with hydrocephalus. It chronicles the contemporary adolescence of one unlucky boy trying to rise above the life everyone expects him to live. This book is available in major bookstores and on Amazon.com. ■

HA Helps Influence Presidential Candidates to Address Adequate Healthcare Coverage

By Dory Kranz

Even if we achieve great strides in raising awareness and increasing research funding, too many Americans with hydrocephalus still live with unaffordable, inaccessible or insufficient health insurance coverage. The hydrocephalus community is not alone. We share this struggle with everyone who has a chronic medical condition. Raising our voices together with the 100 million people in the US who live with chronic disease or disability is our best chance to change this reality for the better. Thankfully, the National Health Council recognizes this issue and is uniting us to inspire change.

Under the guidance of the council, the leaders of 48 of the nation's patient advocacy groups recently agreed on a powerful statement and plan to call the presidential candidates to task on healthcare policy. At a September 6 press conference held in Nashua, New Hampshire, the first step of that plan was realized by the release of the following joint statement:

"The lack of effective healthcare coverage is one of the most important issues facing our nation. Nearly 50 million Americans have no coverage at all. Many more have coverage that does not provide for their basic health and long-term care needs. The problem is especially acute for Americans with a chronic disease or disability—the people we represent. We urge you to propose specific solutions

that guarantee effective and affordable health and long-term care coverage for all Americans."

This effort represents the first time that the nation's leading patient advocacy groups have joined forces in support of improving health coverage for all Americans. "We're facing a grave cri-



HA National Advocacy Director MaryBeth Godlewski, National Health Council Chair Jim Williams and HA Executive Director Dory Kranz at the September 6 press conference in Nashua, NH.

Photo credit Daniel J. Splaine/National Health Council

sis that demands action," said National Health Council Chair Jim Williams who is also President and CEO of Easter Seals. "Many are at risk, but none more so than the 100 million Americans we represent. We hope to not only educate candidates, but compel them to act on this vital issue."

The National Health Council, founded in 1920, is leading the effort to educate presidential candidates and the media about the importance of ensuring that all Americans have coverage. We are proud to join with the American Cancer Society, American Diabetes Association, Alzheimer's Association, Spina Bifida Association, Easter Seals, American Heart Association and other prominent and influential organizations across the

nation in this important effort.

You can support this effort by sending a letter to the editor of your local newspaper in response to any article or story relating to healthcare and the 2008 presidential campaign explaining how this problem affects you and your

family. Please also send a copy of your letter to the presidential candidates and ask them what they plan to do about this. For more information about the National Health Council, please visit their website at www.nationalhealthcouncil.org. ■

**(Sample letter to the editor
modify for presidential candidates)**

Dear Editor,

I read your recent article about _____. As a person affected by the chronic neurological condition of hydrocephalus, I am very interested in what the candidates are saying about the lack of health coverage for millions of Americans.

(Include a brief paragraph about your experiences, such as:)

- My child has hydrocephalus and, at the tender age of 9, has already endured 32 brain and skull surgeries. Our health insurance costs \$1,200 per month which is quite a hardship for us financially. But, we cannot afford to be without health insurance.
- I am a college student with hydrocephalus and spina bifida. Although I'm doing really well in my life, I am very afraid of being without healthcare coverage when I am too old to be covered under my parent's insurance. What will happen to me if I cannot find a job right away?
- I am an adult living with hydrocephalus and unable to obtain health insurance because of my pre-existing condition. I worked for many years, but had a series of seven surgeries in one year and lost my job as a result of all of the lost time. Despite the fact that I now live with debilitating headaches almost daily, I have been denied disability insurance. I live in constant fear that I will need another brain surgery. At an average cost of \$35,000 per surgery, this would be financially devastating for me.
- My wife is 58 years old and has hydrocephalus. Nine months after her first brain surgery to implant a shunt to drain the excess fluid from her brain to another part of her body, her symptoms are returning. She has no insurance, cannot work and has been denied twice for SSI.

I am not alone. According to the National Health Council, more than 100 million Americans have a chronic disease, condition or disability. Like me, many lack the coverage they need to stay healthy and feel secure.

Nearly 50 of the country's leading patient advocacy groups have issued a statement highlighting this problem and the need to solve it. I strongly support these efforts and urge candidates to propose specific solutions to address this problem.

Sincerely yours,

**(Your name
Address and
Daytime phone number)**

Special Thanks for Special Birthdays

By Gina DeGennaro



James Moroz celebrated his 10th birthday with family and friends in August by having a party where he asked for donations to be made to the Hydrocephalus Association in lieu of gifts. He raised \$900! James was diagnosed with hydrocephalus at seven months. James' mom, Janyce, said, "Our party was great!" We believe it! Happy 10th Birthday James and thank you for your very generous gift! ■

William Boyce of New York has a friend with hydrocephalus. Hearing recently of his friend's condition and wanting to help raise more awareness and funds for hydrocephalus William hosted a birthday bash at Wicker Park in Manhattan for family and friends in July. William raised \$500 to help support the mission of the Hydrocephalus Association. Happy Birthday, William, and thank you for all your support! ■



New Tampa Bay Affiliate Gathers TV, Newspaper Coverage

By Paula Keyser

One of the goals I set when we started our local support group in 2004, and that I hoped to strengthen by becoming an affiliate of the Hydrocephalus Association, was to gain greater exposure in the local media so that more people would become aware of hydrocephalus. In August, 2007, just a few months after officially becoming an affiliate, I was able to achieve a 'trifecta' of media coverage in local television, daily newspapers and periodicals.

Much of our success can be attributed to following up on old acquaintances, lucky timing and simply perseverance. I have learned that success in working with local media involves regular contact which may not always result in an article being written and using access to people 'who know people' to get close to those who control the airwaves.

Timing is critical. General feature stories such as ones about hydrocephalus patients and their families often find a more receptive audience among reporters who need copy to feed their newspapers and television station's 'news holes' in August and around the Christmas holidays.

Our first success this summer involved our family, along with fellow HA member Bill Vincent, who appeared as guests on the local CBS affiliate 'Studio 10' live interview show. Our segment was about seven minutes long and generated several phone calls from the local hydrocephalus community who were not even aware that we existed. Our appearance was made possible by a 'Studio 10' producer with whom I used to work and had kept in touch when she became a TV producer.

Second, a friend made introductions to a local direct-mail boutique magazine,



(Left to right) Paula Keyser, her husband Mark and HA member Bill Vincent gather behind Studio 10 Co-hosts Michelle Phillips, who is holding Jeremy, and Tim Wilkins.

distributed to 70,000 homes and businesses, which donated a full-page display ad about our chapter and walkathon. The magazine also ran a story about our son Jeremy and all the medical procedures he has endured. As it turns out, they printed the story in all three of their publications resulting in over 210,000 households and businesses receiving the issue.

And just when I thought it could not get any better, I received a phone call from a local newspaper reporter who was interested in writing a story about Jeremy and our upcoming TEAM walk. I have been pursuing this newspaper for a local story for about three years! We spoke to the reporter in great detail for about two and

a half hours, and then a photographer came out to take pictures of us. The story was 'cinched' when the reporter interviewed Sarah Gaskill, MD, who explained the clinical details behind Jeremy's surgeries. On Sunday, August 19th, the *St. Petersburg Times* ran a front page article in the local sections complete with photographs.

Don't let anyone ever tell you that persistence does not pay off. Keep in touch with producers and reporters and let them know what good works you are performing in the community. Two of these media contacts have known

about our local support group for years but it was the recent announcement of our affiliation with the national Association that sparked this recent media interest.

Let's celebrate the power of unifying and amplifying our voice through affiliation and collaboration. You can check out all of these publicity links and view photos of our events on our local support group website at www.gothydro.org. ■

North Pinellas Times
 Their support for son launches goal
 The parents' effort to learn more about his condition leads to a pilot expansion program.
 Three Days' Drive
 Paula Keyser learned their son's condition was not a rare one. She learned that many other families are struggling with the same condition. She learned that many other families are struggling with the same condition. She learned that many other families are struggling with the same condition.

Parents' efforts extend far beyond their son's condition
 A family's journey to find answers for their son's condition leads to a pilot expansion program.
 Paula Keyser learned their son's condition was not a rare one. She learned that many other families are struggling with the same condition. She learned that many other families are struggling with the same condition. She learned that many other families are struggling with the same condition.

Hydrocephalus Association 10th National Conference

Join us on June 19–22, 2008 in Park City, Utah for the Hydrocephalus Association’s 10th national conference, ‘It’s About Life.’ The conference promises to offer inspiration, education and enjoyment along with abundant opportunities to connect with other people with hydrocephalus, families and professionals.

To help with your planning, a conference schedule is provided along with information on accommodations and transportation. In conference sessions, at meals, by the pool or on the mountain trails with the local wildlife—we hope to see you there!

Conference Registration

Registration forms will be available in early January, 2008.

Accommodations

It is not too early to book your hotel rooms; you can always cancel if it turns out you can not attend. Call The Canyons Resort at 888-226-9667 and let them know you are with the Hydrocephalus Association group. Our block of rooms is split between two properties: typical hotel rooms at the slightly more upscale Grand Summit Lodge where the meeting rooms are located (about \$139 plus taxes/fees per night); and more casual, family-friendly rooms with full kitchen and free washer/dryer at the Sundial Lodge a short distance across the square (about \$109–\$119 plus taxes/fees per night).

Kids Camp

The Canyons offers Adventure Camp for children 3–12 years of age from 9:00 a.m. to 4:30 p.m. Pre-registration is required at least one month prior to arrival. Mention the HA conference to receive a five percent discount. Call the Canyons Daycare Center at 435-615-3402 in advance to reserve one of the 50 spaces available.

Transportation

Driving from Salt Lake City Airport to The Canyons Resort in Park City takes 45 minutes to an hour. We have contracted with All Resort Group to provide shared-ride van service from Salt Lake City airport to The Canyons resort at a discounted rate. The Shared shuttle

Tentative Conference Schedule | June 19-22, 2008

Thursday June 19

4:00–5:30 p.m. (MT)

Kickoff educational session. Back by popular demand, as preparation for the medical and shunt technology sessions throughout the weekend, James P. ‘Pat’ McAllister, PhD, and his team will present, “Anatomy & Physiology of the Brain,” complete with a hands-on demonstration of shunt implantation in a gel-model of the brain. This is one session you won’t want to miss.

7:00–9:00 p.m.

Gondola ride and dessert reception at Mid Mountain lodge

Friday

8:00–9:00 a.m.

Scientific Keynote address—The inaugural Hydrocephalus Association Robert Pudenz Lecture sponsored by the Rudi Schulte Research Foundation

9:15–10:45 a.m.

Interpersonal Connection Sessions

11:00 a.m.–2:30 p.m.

Medical and clinical presentations followed by question and answer sessions with physicians

2:45–4:00 p.m.

Concurrent research, clinical and support sessions

4:15–5:15 p.m.

Creative keynote address—Sherman Alexie

Dinner on your own

Saturday

8:30–9:30 a.m.

How Shunts Work

9:45 a.m.–3:00 p.m.

Concurrent research, clinical and support sessions

3:30–4:30 p.m.

Research Advocacy Progress—climbing Hydrocephalus’ Everest

4:45–5:15 p.m.

Inspirational keynote address—Doug Brockmeyer, MD, first neurosurgeon to reach the summit of Mount Everest—the real one in Nepal!

6:30 p.m.

Family dinner dance outside in the central square, weather permitting

Sunday

8:30–9:45 a.m.

Favorite research, clinical and support sessions voted by participants

10:15 a.m.–12:00 p.m.

Inter-generational panel and wrap-up

is \$28 per person and leaves every 20–30 minutes. All Resort Group also has rental cars that can be rented right in Park City. Contact them at 800-457-9457 and www.allresort.com. Use the Hydrocephalus Association group number 5350 to obtain

the discounted rate.

Most flights from major U.S. cities arrive before 1:30 p.m., allowing you to easily get to The Canyons for the starting session at 4:00 p.m. ■

HAMS—Are Being Served Up All Over!

All across America, members of the Hydrocephalus Association (HA) are reaching out to their local and state legislators to create greater public awareness of hydrocephalus. We encourage everyone to join us and put your town on our Hydrocephalus Awareness Month (HAM) map. To get started, contact MaryBeth Godlewski, National Advocacy Director, at marybeth@hydroassoc.org or 484-270-8523.

Nevada

Nora McGinley, an adult who was misdiagnosed with hydrocephalus, is starting legislative efforts in her community and state to raise awareness about the need to improve diagnosis.

California

Dory Kranz, Association Executive Director, has worked with State Assemblywoman Ma and Senator Migden on a HAM Resolution, ACR66, which passed the house and senate with overwhelming support in early September.

Los Angeles

Michael Antonovich, supervisor on the Los Angeles County Board of Supervisors, presented HA member, Sharon Raghavachary, with a proclamation on hydrocephalus. Sharon's advocacy efforts are motivated by her 3-year-old son Josh who developed hydrocephalus at seven months.

Colorado

Shannon Christian, motivated by her 2-year-old son Reece, was responsible for obtaining a HAM Resolution and Proclamation from CO's Governor. She also visited her Congressional delegation. Now she is speaking to groups in CO on the need for improved diagnosis and treatment options and greater public awareness.

New Mexico

Kathy Carrillo, chair of TEAM New Mexico, plans to incorporate state legislative awareness within the 2007 TEAM event.

Florida

Bill Vincent, an adult with hydrocephalus, is committed to gaining legislative awareness within his community and state where he relocated just this spring.

Missouri

Robin Holloway, who was diagnosed with hydrocephalus in 1961, was so excited about the opportunity to create awareness in her community and state that she bought a home computer to enable her to get the job done right.

Massachusetts

Cathy Thibeault has contacted her Congressional delegation to gain support on the federal level.

New Jersey

Michael Illions, on behalf of his 2-year-old son Cole, born with congenital hydrocephalus, received a resolution on hydrocephalus from the Edison, NJ Town Council, declaring September 9 Hydrocephalus Awareness Day! Michael is actively seeking state legislation in NJ as well.

Pennsylvania

New HA member Ashley Manthely is working diligently to obtain a second HAM in PA. Ashley's son Drake, 9-months old, was diagnosed with hydrocephalus in April 2007.

7-year-old Pioneers TEAM Events Outside of San Francisco

It took a courageous and engaged 7-year-old named Molly Roberts to open our eyes to the possibility of Team Events outside of San Francisco. We are so grateful to Molly and her parents Mimi and John for showing us the way. Now we have TEAM events in 20 states. What a great legacy to Molly's courage and foresight!

—Dory Kranz

When Molly heard about people walking around Angel Island in 2002 to raise money for hydrocephalus, she insisted upon walking despite her tender age. And when told that Angel Island was all the way across the country, she persisted to the point that we identified a similar walk in suburban Washington, DC. Molly and a small group of friends and family walked five miles around beautiful Burke Lake and raised \$200 that year.

In 2006 a generous corporate donation enabled use to provide T-shirts and wristbands for all sponsored walkers. For the first time, we had over 100 participants. Now five years later we are using a planning committee to organize our TEAM walk. This year we plan on using a larger covered picnic shelter and will once again be able to provide T-shirts for sponsored walkers.

—Mimi Kramer-Roberts

How TEAM Hydrocephalus Began

By *Evan Marks*

It all started over 10 years ago with my wanting to walk across the San Francisco-Oakland Bay Bridge and thinking that others might like to as well. I was inspired by a United Way fund-raising project that involved closing the bridge for runners and walkers. As an engineer, I thought I would gladly pay for a chance to walk across the bridge and see all those structural details. I also thought that this might be a good way to raise funds for the Hydrocephalus Association from a different pool of volunteers than we had been approaching.

The result of my initial brain storm was a hardy crew of neighbors, friends, neurosurgeons and some engineers who made an early start to walk the 10 kilometers across the bridge from Oakland to end up at the Yerba Buena Gardens in

San Francisco. The day dawned clear and unusually warm with endless views of the sunrise on the cityscape and water. Our trek began at the closed toll booths where we were set loose among the throngs of runners and walkers. I was with my 10-year-old son Sam who has hydrocephalus and uses a wheelchair. He took off alongside our jogging neighbors and that was the last I saw of him until the bagels and orange juice were served to the HA troupe in San Francisco! Our group's breakfast and gathering at the end was warm and cheerful with a great sense of achievement.

The closing of the bridge turned out to be a one-time event. Liability issues made it impossible for United Way to afford it again. But with our great bridge walk in mind, the next year a group of good folks from the Hydrocephalus Association walked across the Golden Gate Bridge

and back, followed by a picnic. The event continued to evolve. We moved to Angel Island where we offered a lunch as well as a breakfast, supplied T-shirts, hats and prizes.

These were the first of what turned out to be called 'TEAM Events.' It was a departure from the social events we had organized up to that point and succeeded in attracting a broader range of people who were interested and happy to support the Association. We raised close to \$3,000 the very first year. Throughout the 14 years of TEAM San Francisco events, we continue to provide a wonderful opportunity for the greater hydrocephalus community to share in a day of interaction and physical challenge at whatever level one chooses.

It is heartwarming to see TEAM events now growing through a network of dedicated volunteer leaders all around the country. ■

Mark Your 2007 Calendar for Upcoming TEAM Hydrocephalus Walkathons

This year our TEAM Hydrocephalus Walkathons are getting bigger and growing stronger. We have events scheduled in over 20 states with more to come. TEAM provides a great opportunity to network with other families and promote hydrocephalus awareness while raising funds for a great cause.

These events are hosted by amazing people who generously put their time, commitment and determination into running these outstanding events. We truly thank them for all of their hard work. Please come and show your support if an event is planned in your geographic area. To register or donate to these events or to learn how to start your own event, visit our website at www.hydroassoc.org/TEAM.htm.



TEAM Hydrocephalus 2007

Albuquerque, NM

October 20, 2007
Village of Los Ranchos Park
Contact: Kathy 505-440-3575,
kdllc@netzero.net

Baltimore, MD

October 7, 2007
Centennial Park
Contact: Terri 410-719-2272,
hydrotsmith@comcast.net

Chicago, IL

October 6, 2007
Lake Arlington Park
Contact: Sherry 708-574-5790,
sherryiab@yahoo.com

Louisville, KY

October 6, 2007
Otter Creek Park in Brandenburg
Contact: Elizabeth 502-548-3817

Philadelphia, PA

November 4, 2007
Norristown Farm Park
Contact: Kelly 610-764-7720,
Keli693@aol.com; or
Erica 215-704-3198,
divacantor5@yahoo.com

San Antonio/Austin, TX

October 20, 2007
Landa Park in New Braunfels
Contact: Sheri 830-620-9999,
texashydrowalk@wmconnect.com

When a Carrier Just Says No: Helping Patients Appeal Denials of Care

By: Christin Engelhardt, Outreach and Publications, Health Assistance Partnership

Mike Klug, Volunteer Program Development Consultant, Health Assistance Partnership; Consultant, National SHIP (State Health Insurance Assistance Program) Resource Center; Consultant, Caregiver Training and Support Program

Jane Smith, Retired Benefits Specialist, Department of Labor; Volunteer, Health Assistance Partnership

Basics of an Appeal After a Consumer Is Denied Care

All consumers—whether insured by Medicare, Medicaid or private insurance—can appeal denials of care, yet there are different rules and processes, depending upon the type of insurance and the state. Federal law covers some aspects of private insurance appeals, state laws other aspects. Sometimes states give you additional rights and protections, but not always. For those insured by a group plan, the appeal process varies further, depending upon whether the plan is self-insured or not. Despite these differences, there are many commonalities to appeals that are outlined here.

Remember to document all actions in one file. Record dates and times of conversations with all parties, including your healthcare professionals and customer service representatives at the insurance carrier. Summarize all conversations and keep all correspondence received and copies of all correspondence sent.

1 You are notified of a denial of care. If the denial is not given in writing, request that the denial be put in writing. If you have already received the care, resubmit the claim with more information on the necessity of the treatment.

2 Examine the reason for the denial against your specific plan benefits and determine if the denial is based on medical grounds or on plan rules. Plan rules include limitations and exclu-

sions and are stated in the summary plan document which you get each year from the employer—if insured through an employer—or plan—if self-insured. If you have lost yours, immediately request a new copy from your human resources department or from the plan.

- a. Unsupported therapy?
- b. Experimental therapy?
- c. Not a covered service? (e.g., the plan does not cover durable medical equipment)

3 Ask your healthcare provider to speak informally, on your behalf, to the medical director or other appropriate personnel at the carrier responsible for the denial.

- If your plan is self-insured, speak to the benefits administrator (who must protect patient confidentiality) and/or ask your healthcare provider and/or other advocates to speak to the administrator. The administrator can help reverse a denial, especially after considering indirect costs to the employer (such as longer sick leave, replacement costs, etc.).
- If your plan is not self-insured but is provided through your employer, your employer may still be able to help. Speak to the human resources director and ask him/her to contact the plan on your behalf. He/she may be able to persuade the plan, which views the company as a customer, to reverse the denial.

4 If the informal routes fail, begin the formal process of appealing. First and foremost, understand the appeal process, including timelines (e.g., 30 days for a first appeal to be filed in writing) and what rights you have under it.

5 Get letters of support from your providers (physicians, nurse practitioners, psychologists, physical therapists and others involved in your care) that also, if necessary, address any risks of the therapy. The stronger the letter, the better and, further, the more letters, the better. Letters from practitioners who do

not benefit financially from the requested treatment are particularly helpful.

6 Formulate your argument in response to the reason for the denial. You must make a solid and focused case, based on medical necessity and/or plan rules, for why your insurance company should cover this care.

7 Research your position and compile evidence to support your argument. If there is an organization for your condition, that group may be able to help prepare your medical necessity argument. Put your strongest arguments first, and, without overwhelming the reviewers, use the following if they support your case:

- plan benefits and plan rules
- your medical records. Remember that the Health Insurance Portability and Accountability Act or HIPAA gives patients a right to review and to make changes to them
- standards of care/guidelines/options (sometimes called practice parameters or practice guidelines) or consensus statements from professional societies
- position statements or guidelines or educational material from patient organizations (although these do not carry as much weight as positions from professional societies)
- statements or publications from the National Institutes of Health (which are viewed as authoritative but are often slow to be issued)
- approvals from the Food and Drug Administration and accompanying approved labeling text (e.g., indications and usage, contraindications, precautions, adverse reactions)
- articles published in peer-reviewed scientific journals (read the full article, not just the abstract and be mindful of the date as older articles may be disregarded)
- Medicare coverage
- accepted off-label use as noted in certain publications
- cost/benefit ratio of the treatment.

8 Address any risks, such as high blood pressure, or other disadvantages to the care desired. Explain, if possible, that these are minimal risks or irrelevant, given your medical history.

9 Simultaneously understand the insurance company's opposing argument so that you can argue against it.

10 In a professional manner, write your own statement of appeal. Reference the plan rules plus the science, the clinical evidence on the expected benefits, etc., while you make your argument clear and concise. Use a firm tone that indicates you plan to pursue your case until you succeed. Copying elected officials and government employees of relevant agencies, such as the state insurance commissioner's office, can be helpful. You may also consider cc'ing representatives of the media, but only if you are certain that you want your fight to be public.

11 Submit all of the information in the required time frame in a way that provides you with a confirmation of receipt such as certified mail, and make sure the insurance carrier responds within the appropriate timeframe.

12 If your appeal is successful, notify your healthcare professionals. If unsuccessful, take the next allowable step which may be a face-to-face appearance before a panel of individuals chosen by the carrier.

13 Address any issues raised in denial of appeal; if allowed in the claims procedure, submit second appeal according to the timelines. If possible, submit any new information omitted in the original appeal.

14 If your appeal is successful, notify your healthcare professionals. If unsuccessful, take the next allowable step which may be to a third party such as a state's insurance department.

Not all appeals are successful, but many are. If you do not succeed and after

Tips for Handling Denials of Care

- Read carefully any papers you receive about your health insurance or Medicare coverage.
 - Store all papers in a place where you and/or a trusted family member or friend will always know to look.
 - Always make requests for medical services or requests for review of denials, reductions or terminations in writing; when you make requests over the phone or in person, always follow up with a written request.
 - Keep copies of any letters, forms or other writings you submit regarding your health insurance or Medicare coverage.
 - When in doubt about the validity of a health insurance determination about coverage or payment, go through the informal process of resolution. If that fails, file an appeal.
- When in doubt about a Medicare determination, file an appeal.
- Consult and get help from attorneys, paralegal assistants, family members or friends.
 - Obtain necessary supporting documentation for the positions you assert, including the support of physicians and other healthcare providers.
 - Establish good relationships with your healthcare providers and suppliers so that they become partners with you in support of your claims for medically necessary services and payments where applicable.

Adapted from "Due Process in Medicare Appeals: A Primer," copyright 2002 by the Center for Medicare Education.

Resources on Health Insurance and Your Healthcare Rights

- Families USA, Consumer Information: <http://familiesusa.org/consumer-info/>
- State Health Insurance Assistance Program (SHIP) for information and assistance with Medicare cases: 800-633-4227 or <http://www.hapnetwork.org/ship-locator/> or <http://www.medicare.gov/> and click on 'Find Helpful Phone Numbers and Websites.'
- Publications on Medicare Appeals and Grievances can be found on the Medicare website: <http://www.medicare.gov/> and click on 'Find a Medicare Publication' under 'Search Tools' in the body of the main page. The following two publications may be helpful. Find them by entering the CMS Pub no. in the box under 'Search by Publication ID':
 - Medicare Advantage Plans and Medicare Cost Plans: How to File a Complaint (Grievance or Appeal) (CMS Pub no. 11312)
 - How to file a Medicare Part A or Part B Appeal in the Original Medicare Plan (CMS Pub no. 11316)

you have exhausted all of the appeal channels, depending on the type of insurance and the state where you live, you may be able to sue. If you reach this point, seek legal advice.

Reprinted with permission from Families USA. Copyright Families USA. ■

Access to Health Insurance Legislation

By Debra Howell, with material from the National Patient Advocate Foundation, npaf.org and The Library of Congress, thomas.loc.gov.

If you have ever been locked out of health insurance, or feared loss of health insurance because of a pre-existing condition, a recent initiative of The National Patient Advocate Foundation (NPAF) may be of interest. NPAF is a non-profit organization dedicated to creating avenues of patient access to healthcare through legislative and policy reform. They have been engaged in a Health Insurance Portability Assurance Initiative to ensure continuous access to health insurance for individuals who may be locked out of the health insurance market due to pre-existing conditions. Since people with hydrocephalus are among this group, we at the Hydrocephalus Association want to keep you informed of the progress.

NPAF held a briefing about this initiative at Dartmouth College on May 3, 2007. The May meeting resulted in the introduction of legislation to address accessible healthcare coverage for people with chronic conditions, often termed “pre-existing conditions,” by insurance companies. Two bills, HR 2833 and HR 2842, to provide protections for people with chronic health conditions were crafted and introduced in the House. The bills are designed to address gaps in existing law.

Introduced by Rep. Joe Courtney (D-CT), HR 2833, “Preexisting Condition Exclusion Patient Protection Act of 2007,” protects patients from pre-existing condition limitations. Under HR 2833, people who change their health plan would have to wait three months rather than the 12 to 18 months required under current law. The ‘look-back’ period to determine whether someone has a pre-existing condition would be shortened to 30 days instead of the current six months. HR 2833 requires health insurance companies to cover people who lose their coverage due to downsizing or their employers dropping coverage. It covers people moving

from individual to individual plan, unlike current law. HR 2833 does not address affordability. Instead, the bill focuses on the first barrier to healthcare coverage: access to an insurance plan.

HR 2833 has 11 co-sponsors and is supported by the House Democratic leadership. At deadline, the bill has been sent to the House Energy and Commerce, Education and Labor and Ways and Means Committees. A similar bill is expected to be introduced in the Senate.

A second House bill, HR 2842, “Children’s Health Protection Act of 2007,” introduced by Representative Allyson Schwartz (D-PA), eliminates pre-existing condition limitation periods for children in the private health insurance market, including group health plans and health insurance coverage in the group and individual markets. HR 2842 has 44 co-sponsors and has been referred for hearings to the same committees as HR 2833.

The Hydrocephalus Association and NPAF ask that you urge your members of Congress to support legislation eliminating barriers to health insurance coverage for individuals with pre-existing conditions.

For more information and updates on the legislation, visit the NPAF website at npaf.org and select “Health Insurance Portability Assurance Initiative” under “Federal” on the top menu bar. ■

The Prenatal Diagnosis Experience: Parents Share the Moments That Lives Changed

By Pip Marks

In the course of revising our prenatal educational booklet, we collected some very personal and moving stories of the emotional upheaval at time of diagnosis. The stories here are from parents who decided to continue their pregnancy. We

understand there are many parents who decide to terminate their pregnancy after finding out their unborn child has hydrocephalus and typically we do not hear back from those parents.

We share a few of those stories here in hopes that other parents will gain insight from these real life stories from the experts in parenting a child with hydrocephalus. Perhaps they will offer a measure of support as you and your wonderful children continue to face the challenge of living with hydrocephalus.

Here are excerpts from some stories we received. We trust many of you will relate to these experiences:

“At 34 weeks in my pregnancy, I went in for an ultrasound to check measurements for a planned C-section. When the ultrasound technician was very quiet during the procedure, I asked in a very casual way if everything was okay, expecting the response, “Yes, everything looks great.” But instead she answered, “I found something in your baby’s brain. Your doctor will talk with you.” My husband and I were taken to a room and waited for my ob-gyn. She walked in and said, “I am so sorry. It doesn’t look like your baby is going to make it.” That moment will forever be embedded in my memory. It was the most horrific, devastating and painful time in my life. I wish I had known to meet with a pediatric neurosurgeon as soon as we found out. I had no idea. I prayed to God: ‘Please, just let my baby live. I will take her anyway she is.’ Amber is now 3 years old and even though she has many disabilities, she is perfect! She has proven so many wrong in so many ways that I do not ever underestimate her!”

“I am the mother of two boys who were diagnosed in utero, one in 1992 and the second in 1997. Both boys have X-linked hydrocephalus. They have severe disabilities; they use wheelchairs, are nonverbal, have apnea, reflux and my oldest has a feeding tube. They both have cerebral palsy. Despite all their challenges they are wonderful boys. While some of the things the first set of doctors told me were true, my sons are so much more than a list of diagnoses. I don’t see how

doctors can look at a newborn or a prenatal ultrasound and predict outcomes on quality of life. My boys have very different personalities, a sense of humor, strong preferences and likes and dislikes. They attend school, go to summer camp and participate in Challenger sports like baseball and swimming. They enjoy other activities in the community. While it can be stressful at times to deal with all the medical and disability issues, they are a joy to our family. You just need to look below the surface to see the unique individuals they are.

"People ask me how I can go on with two children with this degree of disability. But how can I not? I am their mother and they are depending on me to make sure they receive the care they need and help them live life to the fullest. Of course, I sometimes feel overwhelmed or sad that we have to deal with this. Anyone would. It has helped to seek out other parents of children with special needs through Internet groups, school and therapy centers. It helps you feel that you are not alone to hear how other parents deal with medical and disability challenges."

"The doctor pulled my mother and me into a private room to explain that she suspected the baby had hydrocephalus. My nerves were shot at this point but I knew that I had to hold it together for the sake of my mother. After all, this wasn't just my first child, it was her first grandchild. Within a few hours the initial diagnosis was confirmed. Needless to say, I went numb. Of course, the option of terminating the pregnancy was mentioned. We had no idea what the condition entailed but did know that this was our child from the day that we found out I was pregnant and we would do everything in our power to help this baby survive and live a normal life. Dara is now 11 years old. She is a beautiful child inside and out. She is kind, gentle and I believe has the special gift of being insightful, something that I often see in other children with chronic conditions. As with other children with hydrocephalus, Dara has learning disabilities and difficulties with school work, especially comprehension and memory. All the troubles we have gone through don't compare to the joy she brings us." ■

Volunteers Sought to Inspire Advocacy at TEAM Events

By **MaryBeth Godlewski**

The Hydrocephalus Association is looking for volunteers to serve as an 'Advocacy Point Person' (APP) for each TEAM Hydrocephalus Walkathon event. Our immediate hope is to find at least one point person in each area where we will hold a TEAM event. The APP will work in unison with the TEAM event chairs to beef up awareness of hydrocephalus through the TEAM event in both the state legislature and local community. In addition, they will share information and generate support among TEAM participants for the Association's national research advocacy initiatives. Long-term, we'd like to have an APP in every community across America. So even if there isn't a TEAM event you are able to attend, we encourage you to become an APP!

Already serving as the APP in Colorado is Association member Shannon Christian. Shannon worked with Phyllis Rogers, TEAM chair for the Denver, Colorado area event. In her new role, Shannon contacted local, state and federal legislators to secure a state resolution declaring September 'Hydrocephalus Awareness Month' in Colorado to coincide with the TEAM Denver 2007 event.

At the September Denver TEAM event, Shannon collected signatures in support of letters to policy makers along with handing out information about the Association's advocacy efforts.

Please join us in meeting our goal of achieving greater awareness of hydrocephalus within your community and state. For more information about what it takes to be an APP, please contact me at marybeth@hydroassoc.org or 484-270-8523. ■

Other Volunteer Opportunities Available

We are constantly looking for volunteers who can lend their time, energy and creativity to promote hydrocephalus awareness. Four possible ways to contribute are:

1 Create shunt pins. Our pins are made from actual shunt tubing and come with a small card with statistics on hydrocephalus. They are easy to make and we will send you the necessary materials and instructions. Shunt pins are a great tool to promote education and awareness of hydrocephalus for legislators, family and friends.

2 Assist with TEAM: Walk-Run-Wheel-a-thons. We have TEAMS in cities across the United States. TEAM is a one-day event where individuals and families can get together and network with other people with hydrocephalus while raising money for the Association. Gina DeGennaro, HA's Development Director, can be reached at gina@hydroassoc.org for more information.

3 Become an advocate. Speak with your local and state legislators about increasing hydrocephalus awareness, funding and research. If you have any questions regarding advocacy, please email MaryBeth, the National Advocacy Director, at marybeth@hydroassoc.org.

4 Help build 'Boozle Hydro Bears' and introduce them to local hospitals. Our shunted teddy bear named Boozle is a great teaching tool for medical professionals and families, especially those with young children. Boozle's shunt can be taken out and put back in to demonstrate the basics of shunt surgery and test your neurosurgical skills!

Now is the time to become more involved with the hydrocephalus community. Please email Bonnie at bonnie@hydroassoc.org if you would like to become a volunteer.

The Men and Women Behind Boozle Bear

Boozle bears are not made by elves but by special individuals around the country. One day last winter Executive Director, Dory Kranz, and her sister, Sarah Zadoroznyj, envisioned and created the first of these bears at Sarah's home in New Jersey. Since then Sarah has been sewing the bears in her living room and engaging friends and members of her local church in completing the other steps for making the bears.

One special person, JJ Sherrill from Larksville, Pennsylvania, decided to cut, turn and stuff bears for his Eagle Scout project. He chose building the bears to do something nice for children with hydrocephalus and to teach other people what it is like to have hydrocephalus.

JJ sought an Eagle Scout Project related to hydrocephalus in memory of his cousin Mike and to honor his best friend who has hydrocephalus and is doing well. Mike Sherrill, who was in his mid-20s, passed away last year. He had 92 shunt surgeries and was one of the first recipients of an Association scholarship.

Once the Boozle project was selected, Sarah helped JJ recruit 35 friends—including other Boy Scouts, members of JJ's family, Girl Scouts and other nice people from JJ's home town—who all rolled up their sleeves and completed 100 Boozle bears in one day!

Supplies for the 100 prototype bears were paid for by Thrivent Financial for Lutherans, a not-for-profit organization that offers financial services in addition to supplementing money for fundraisers to local chapters. For more information, please visit www.thrivent.com, click on 'Fraternal Programs,' then click on 'Chapter Care Programs,' where you'll find 'Care Abounds in Communities.'

The shunts for Boozle were generously donated by two of the companies who manufacture shunts: Codman, a Johnson & Johnson company, and Medtronic Neurologic Technologies. For this, and all the support they provide to the Association, we are most grateful.

The role Boozle bear will play in edu-



JJ Sherrill and his Scout Master father, JJ Sherrill, Sr., admire a brood of Boozle bears that will educate family members, health-care practitioners and the community about hydrocephalus.

cating caregivers and family members is growing every day. We are looking for volunteers who would like to help Boozle win friends in the community. Contact us if you are interested.

But we also need volunteers to make the bears. Each bear has a number of steps which include: tracing, cutting, machine sewing, embroidering, turning, and stuffing. If any or all of these requirements fall into your skill set, please contact Bonnie at bonnie@hydroassoc.org for more information. The Hydrocephalus Association will pay for and send all materials to you.

We thank Sarah, JJ, and Thrivent Financial for Lutherans for their generous contributions of money, time and talent. ■

How the Story of Boozle Came About

The story, Boozle the Hydro Bear, was written by Rebecca Zadoroznyj as a Girl Scout service project when she was in the 8th grade. Rebecca is the great-granddaughter of Reuel Kaighn, Sr., who first told Boozle and Minchee stories to his children in the 1930's and 40's. Rebecca grew up hearing Boozle and Minchee sto-

ries from her grandfather, Reuel Kaighn, Jr., whom she calls "Captain," as well as her aunts, her mom and her cousins.

Boozle and Minchee stories are meant to be told—made up on the spot—with funny words to make kids laugh and bits of their own experience to keep them interested. These stories celebrate adventures, especially the kind one encounters when embracing someone different—and I mean really different than themselves—as a friend.

To give you an idea of how a story about Boozle goes, here's an excerpt from the Hydro Bear story written by Rebecca:

ONCE UPON A TIME there was a bear named Boozle and a rabbit named Minchee. Now, it is not often that bears and rabbits become friends, what with their different sizes, schedules and lifestyles. However, these two have been best friends since the day they were thought up by Grandpa Kaighn, or, to put it another way, since the day they were born.

One year, on Bring-Your-Friend-to-School Day, Minchee brought Boozle. As often happened Minchee was the only one to bring a friend of another species. At first, some of Minchee's rabbit friends were a bit afraid of Boozle. He was awfully big and did not fit very well in the small desks in the rabbit-sized classroom.

Although, when it was time for recess, things began looking up. Having considerable experience navigating in a rabbit-size world, Boozle lay down in the middle of the playground and became an immediate hit as part of the gungle gum, the common animal word for what you might call a jungle gym.

A few of the rabbits had a crazy idea to go on the swings and then jump off them onto Boozle's fuzzy stomach. It was a very soft landing and it made Boozle, who was a wee bit ticklish, laugh. Only one rabbit wanted to go on the upsy downs, the common animal word for you might call a see-saw. So Boozle used one of his gigantic paws to push down the other end.

If you would like to hear a recording of a Boozle story using a podcast, visit www.zike.com/boozle_minchie_001.mp3. ■

Kid's Corner

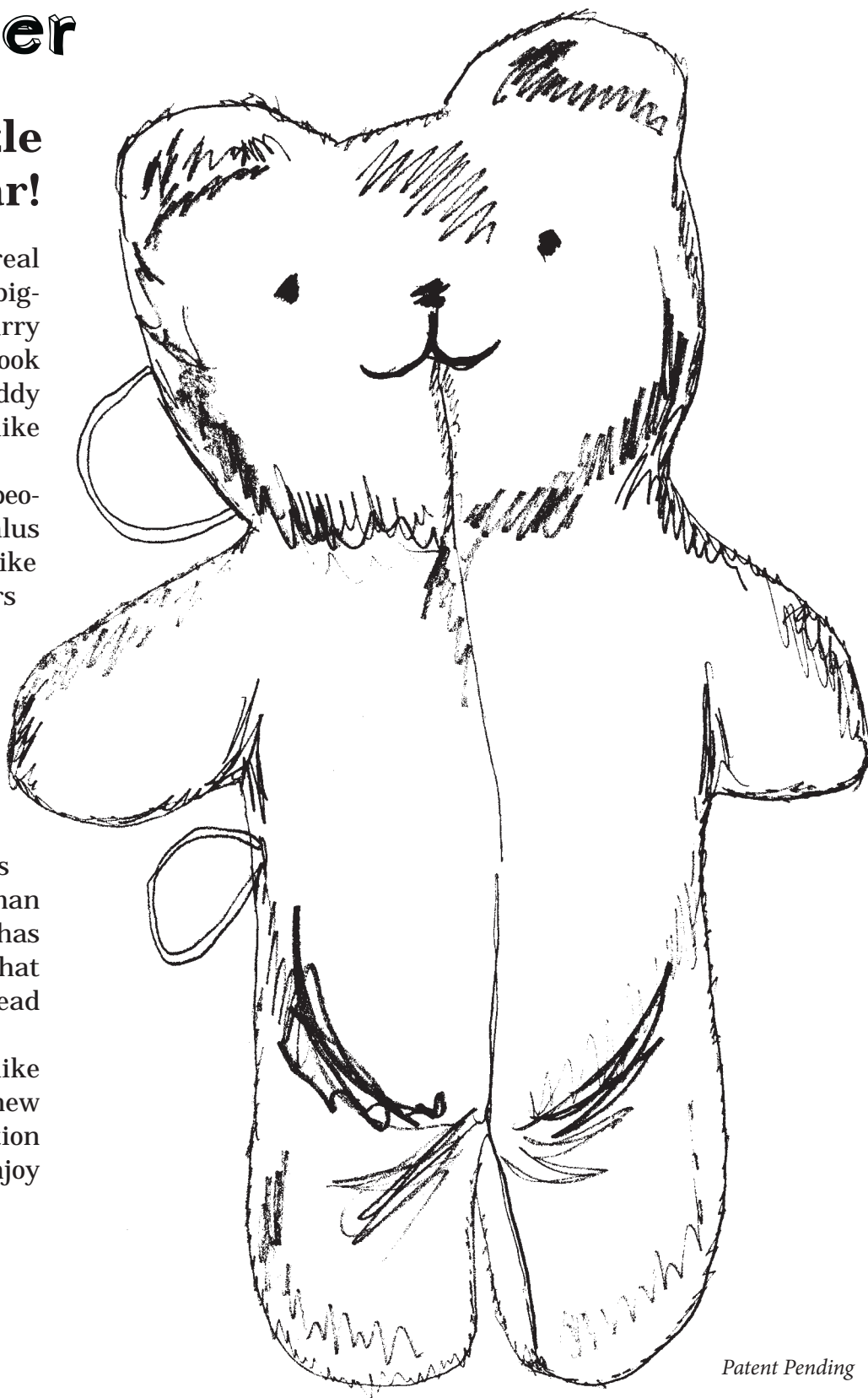
Welcome Boozle the Hydro Bear!

Meet Boozle bear. In real life he is slightly bigger than this picture, furry and has hydrocephalus. Look carefully. Boozle is a teddy bear with a shunt, just like someone you know.

Boozle was created by people at the Hydrocephalus Association to teach kids like you, their friends, members of their family, doctors, nurses, teachers and just about anyone else about what it's like to get a shunt.

Anyone can easily perform "surgery" on Boozle. Thanks to generous shunt manufacturers Codman and Medtronic, Boozle has real shunt components that you can insert from his head to his abdomen.

A lot of people really like Boozle. He is a brand new addition to the Association family. We hope you enjoy coloring him.



Patent Pending

Beat the Blues

By Catherine Lee, PhD, a clinical geropsychologist with the Over 60 Health Clinic in Berkeley, CA.

Depression is a serious medical illness, and not just “feeling down,” which we all experience at times. It is not personal weakness or a normal part of aging. Late life depression may be caused by a number of factors combined, including:

- Psychological factors—issues from childhood; previous history of depression; fears and anxiety.
- Environmental factors—loneliness and isolation; being unmarried or widowed; lack of a support system.
- Physical factors—genetic (depression can run in families); medical conditions that often co-exist with depression; vitamin deficiencies; menopause; chronic pain.
- Personality factors—low self-esteem; dependency.
- Medications—some medications that treat common diseases can cause depression—such as some drugs that treat pain, high blood pressure, anxiety, heart disease, cancer, Parkinson’s disease and arthritis. You should read the medication inserts, or ask someone to read them for you, and talk to your healthcare provider about the risk of depression. Alcohol is a depressant and can affect mood, and the affect increases with age.

Symptoms

Feeling “down” for more than two weeks, with those feelings interfering with daily life, is a sign of depression. Major depression affects your appetite, sleep, work and relationships, and causes a loss of interest in things you once enjoyed. Irritability, confusion, carelessness, reduced energy and fatigue may also be signs of depression.

Estimates of the rate of depression in the community range from 5-15 percent of people over age 65. Rates are much higher for hospitalized and skilled nurs-

ing facility residents. Women are more than twice as likely to have depression as men—many related to hormonal changes. Men are also more likely to go undiagnosed or to seek help.

Untreated depression can lead to suicide—rates among older adults are double that of the general population—older white men are six times more likely to commit suicide than the general population. It can also lead to premature death from other conditions.

Depression is not always easy to diagnose because it is different in everyone, and it is often under-diagnosed in older adults. It often co-exists with other conditions—and can be especially difficult if co-existing with Alzheimer’s disease and other dementias (such as normal pressure hydrocephalus, NPH). Ageism plays a role—physicians may think symptoms are part of the aging process. Doctors often don’t have enough time to talk to their patients about how they are feeling. Older adults, due to stigma, often don’t talk about this problem or seek help.

Treatment

Depression is treatable, and treatment is safe and generally effective for 80 percent of people. Untreated depression can affect other health conditions, shorten life and increase healthcare costs. Treatments include treating the underlying medical condition, counseling, cognitive-behavioral therapy, psychotherapy, medications and ECT (electroconvulsive therapy, which is rarely used). There are a variety of medications and sometimes it might take a few different tries to find the right medication; it also takes several weeks for the medications to start working, so be patient.

Self-Help Tips

Recognize the signs and symptoms of depression, and seek treatment early. If you pretend the problem isn’t there, it is likely to get worse.

- Set goals—focus on staying on a

daily routine and try not to feel overwhelmed by everything you should be doing.

- Do what you enjoy—set aside time, even if you don’t really feel like it.
- Avoid making big decisions until you feel better.
- Avoid alcohol—it won’t make you feel better, and may interact with medications or lead to abuse.
- Exercise and maintain a healthy diet.
- Music, pets, gardening or other hobbies, volunteering and visiting with friends can also help to ward off depression.

For a mental health screening, visit: www.mentalhealthscreening.org or for more information, visit www.nimh.nih.gov.

Reprinted with permission from Great Age, winter 2007, a quarterly newsletter of the Marin County Commission on Aging. ■

Spanish Version of Association Booklet—New Layout to Match English Version

Our Spanish version of “About Hydrocephalus: A Book for Families” is available in a new layout that matches the English version page for page. Titled “Sobre Hidrocefalia: Un Libro para los Padres,” the Spanish edition can now be used as a bridge between caregivers and patients who don’t share a common language by pointing to the page that contains the desired information. If you would like to receive a copy of our booklets or other resources, please email info@hydroassoc.org or call our toll free number 888-598-3789.

HA Fact Sheet Explores Attending College While Living with Hydrocephalus

By Pip Marks

All children have the right to be their own person as they mature, explore the world and establish, to the best of their ability, a life independent of their parents. However, as parents, we will always be concerned for them, hydrocephalus or not. It's important not to inflict these very natural instincts on them and as one mother says, "...if you do freak out (at the thought of) your child going away, do it in private."

Helping our children prepare for independence is an on-going process and chances are most of us won't get it 100 percent right. But we can give our children the support and the tools that will enable them to learn to take responsibility for themselves and then stand back, keep our mouths shut and let them have

a go at it, knowing that they will appreciate us for it some day, but probably not in the near future.

Living well with hydrocephalus is no longer an impossible dream for many young people. While there are still lots of unanswered questions, challenges and, of course, associated conditions that may impact quality of life, it is now reasonable to think that a lot of young people, diagnosed in infancy with hydrocephalus, can live full, productive, happy and satisfying lives—lives that include a college education. Our fact sheet "College and Hydrocephalus," includes tips, guidance and commentary from some of the experts: young people with hydrocephalus who are now attending college and their parents, who are still coping with 'letting go' while supporting and championing their children's new-found

independence. The fact sheet is written primarily for high school students who are getting ready to head off to college and their families.

Whether you stay close to home or travel far away, heading off to college is an exciting and emotionally charged time. For people who have hydrocephalus, there are a few extra challenges and concerns thrown into the mix. These extra challenges may include learning to take charge of your own medical care, whom to tell about your hydrocephalus and how to assert your independence while maintaining necessary support systems for your health and well-being.

If you would like a copy of our fact sheet "College and Hydrocephalus," please email or call our office: info@hydroassoc.org or 888-598-3789. ■

HA Holiday Cards

The Hydrocephalus Association has initiated a program to have holiday 'Cards With a Heart.'™ The purpose of implementing this program is for advocacy as well as fundraising. 'Cards With a Heart' is a leader in raising funds for the nonprofit sector through greeting card sales.

Each card prominently carries our message:



Hydrocephalus is a neurological condition that may occur at any age. The primary characteristic is an excessive accumulation of fluid and an abnormal dilation of the spaces (ventricles) in the brain which may lead to potentially harmful pressures on the tissues of the brain.

Our mission is to provide support, education and advocacy for individuals, families and professionals affected by hydrocephalus.

870 Market Street, Suite 705, San Francisco, CA 94102
Phone: 415-732-7040 or toll-free 888-598-3789
www.hydroassoc.org



Cards may be ordered from Cards with a Heart through einvite.

Go to www.einvite.com/hydro and click on Hydrocephalus Association on the left hand menu to order cards online. Support your Hydrocephalus Association and get our message out by using our new greeting cards for your holiday mailings.

Exceptional Parent Magazine

Exceptional Parent (EP) is an excellent magazine for parents that addresses the full spectrum of special needs, from infancy to geriatrics. Readers include parents, caregivers and healthcare professionals. *EP's* mission is to be the premier information source for parents, educators and healthcare professionals dedicated to caring for children and young adults with special needs. Each year, subscribers receive 11 *EP* monthly issues and an outstanding Resource Guide. Subscriptions are \$39.95 for one year (12 issues) and \$65.95 for two years (24 issues). To learn more go to www.eparent.com.

Planning for Children with Special Needs

MetLife, through a service called MetDESK, provides specialists to help families plan for the future of children with special needs. To learn more, check out www.metlife.com, select 'Individuals' from the top menu and then select 'Planning Services' and 'Planning for Children with Special Needs' from the left-hand menu.

Consumer's Tool Kit for Health Care Advance Planning

The American Bar Association's Commission on Law and Aging has created a tool kit that contains a variety of self-help worksheets, suggestions and resources on health care advance planning. Go to www.abanet.org/aging/ where you can read about and download the tool kit under 'Featured Publications.'

To order a print copy for \$5.00, email the Commission at abaaging@abanet.org or call 202-662-8690.

2007 Resource Guide for Caregivers

MetLife Mature Market Institute and the National Alliance for Caregiving, in cooperation with the National Association of Area Agencies on Aging (n4a), recently released its updated *Resources for Caregivers*. It includes caregiver services and support, including books, Internet sites, organizations, financial and legal resources, disease-specific resources, information about end-of-life care and government resources. For more information, visit www.metlife.com/Applications/Corporate/WPS/CDA/PageGenerator/0,4132,P8894,00.html

New Fact Sheets on Long-Term Care: Medicaid's Spousal Impoverishment Protections and Medicare Coverage of Long-term Care

Georgetown University's Long-Term Care Financing Project has released two new fact sheets. *Medicaid's Spousal Impoverishment Protection* explains the Medicaid eligibility rules regarding income and assets for couples in which one person requires long-term care in a nursing home. *Medicare and Long-Term Care* explains what expenses Medicare will and will not cover. For more information, go to www.ltc.georgetown.edu/

Workplace Giving

Payroll deductions are an easy way to donate to the Association. To contribute through United Way, simply write in the 'Hydrocephalus Association.' For Communities Health Charities (CHC) in California, look up the number in your county CHC directory. For Combined Federal Campaign (CFC), our number is 10066.

Funding a Special Needs Trust with Life Insurance

Funding a special needs trust with enough money to pay for the needs of a child with special needs can be a daunting task for many families. The costs of providing a home and care, as well as a care manager to take the place of the parents when they are no longer around, exceed the resources of most families. A solution for many parents is to fund a special needs trust with a form of life insurance. In these instances, a parent will take out a life insurance policy on his or her life to ensure that once the parent is gone, monies will be available to care for the special needs child. To learn more go to www.specialneedsanswers.com

Adapted Physical Education

For generations children with disabilities received little or no physical education (PE). More recently they have been consigned to special education PE classes. Still, many with severe and profound disabilities were left out by well-meaning PE teachers who possessed little or no training in how best to include them in a class's physical activities.

Today, however, an increasing number of educators are being trained in adapted physical education and are certified by the Adapted Physical Education National Standards. This is resulting in more children with severe and profound disabilities experiencing the exultation of play and the health benefits of physical activity. A recent newsletter issue examines the role of assistive technology in adapted physical education.

To learn more go to www.fctd.info/resources/newsletters/index.php

HYDROCEPHALUS ASSOCIATION 2007 Membership Form

Renewal New

Name: _____ Telephone: _____

Address: _____

_____ Email: _____

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

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

Count me in as a member for 2007. Enclosed is my unrestricted donation of:

\$30 \$50 \$100 \$250 \$500 Other \$ _____

How would you like to receive your quarterly newsletter?

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

Please send my newsletter via email to: _____

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

Charge my: VISA MasterCard Discover Amount charged \$ _____

Card no. _____ - _____ - _____ - _____ Exp. date ____ / ____ VIN # _____

Print name _____

Signature _____

Please remove my name from your mailing list.

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

Please check all that apply:

I am on SSI or disability.

My medical bills have exhausted my finances.

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

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

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

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

The Hydrocephalus Association is a national nonprofit organization providing support, education, resources and advocacy for families and professionals. The Newsletter is published quarterly. Dory Kranz is the editor. Lisa Jervis is the copy editor. Layout is done by Briar Levit. Articles included in the Newsletter are for the reader's information and do not signify endorsement by the Association. We welcome letters and articles from our readers but reserve the right to edit any material submitted for publication. Information and articles from the Newsletter may be reprinted provided a full citation of source is given. © 2007 Hydrocephalus Association

Executive Director: Dory Kranz
Director of Outreach Services: Pip Marks
Outreach and Public Affairs Manager: Suzanne Leigh
Development Director: Gina DeGennaro
National Advocacy Director: MaryBeth Godlewski
Operations Manager: Maggie Mamer
Outreach Coordinator: Karima Roumila
Outreach Assistant: Bonnie Hom

Medical Advisory Board

Rick Abbott, MD • Marvin Bergsneider, MD • James M. Drake, MD •
Michael Egnor, MD • Richard G. Ellenbogen, MD • Ann Marie Flannery, MD •
Bruce A. Kaufman, MD • John R. Kestle, MD • Mark Luciano, MD, PhD •
Joseph R. Madsen, MD • Anthony Marmorou, PhD • James P. (Pat)
McAllister II, PhD • J. Gordon McComb, MD • C. Scott McLanahan, MD •
David G. McLone, MD, PhD • Joseph H. Piatt Jr., MD • Harold L. Rekate, MD •
Mary Smellie-Decker, RN, MSW, PNP • Marion L. Walker, MD • Michael A.
Williams, MD • Jeffrey H. Wisoff, MD • Michael Edwards, MD, Emeritus

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 • (888) 598-3789 Toll-Free
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 Healthcare Decisions
Endoscopic Third Ventriculostomy
Cerebrospinal Fluid Shunt Systems for Management of Hydrocephalus
Nonverbal Learning Disorder Syndrome
How to Be an Assertive Member of the Treatment Team
Second Opinions
College & Hydrocephalus
Understanding Your Child's Education Needs/IEP Resource Packets

HYDROCEPHALUS

▪ ASSOCIATION ▪

SUPPORT EDUCATION ADVOCACY

870 MARKET STREET
SUITE 705
SAN FRANCISCO, CALIFORNIA 94102
