

CONGRATULATIONS TO OUR 2009 SCHOLARSHIP RECIPIENTS!

Bonnie Hom, Youth and Community Coordinator

We are pleased to announce the recipients of the 2009 Hydrocephalus Association Scholarship Awards. This marks the fifteenth year HA has awarded scholarships. HA is extremely proud to honor these future community leaders and their ability to overcome unimaginable obstacles to succeed and prosper in their education. These scholarships were funded by two Gerard Swartz Fudge Memorial Scholarship

Funds, two Morris L. and Rebecca Ziskind Memorial Scholarship Funds, two Anthony Abbene Scholarship Funds, the Justin Scot Alston Memorial Scholarship Fund, and the Mario J. Tocco Hydrocephalus Foundation Scholarship Fund. To read more about our outstanding scholars, please turn to page 4. A complete list of scholarship finalists appears on page 5.



Erin Rae Breedlove
Fayetteville, GA
Justin Scot Alston Memorial Scholarship



Katelyn Dekoski
Bay City, MI
Mario J. Tocco Hydrocephalus Foundation Scholarship



Ryan James Derleth
Running Springs, CA
Gerard Swartz Fudge Memorial Scholarship



Lydia Gonzales
Las Vegas, NV
Gerard Swartz Fudge Memorial Scholarship



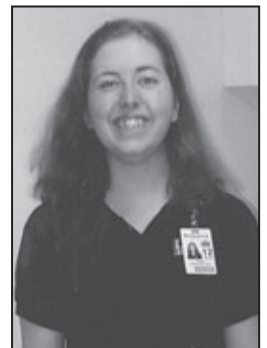
Margaret Hackett
Chicago, IL
Morris L. and Rebecca Ziskind Memorial Scholarship



Justin Mark Salisbury
Willington, CT
Anthony Abbene Scholarship



Maria K. Nevarez
Pittsford, NY
Anthony Abbene Scholarship



Faye Elizabeth Zimmerman
Slidell, LA
Morris L. and Rebecca Ziskind Memorial Scholarship

A FAREWELL LETTER FROM DORY

It is with sadness, pride and hope that I write to tell you that I have decided to leave my position with the Hydrocephalus Association: Sadness that, after 8 years, I will be leaving this work and this community which are both sources of inspiration and meaning for me; pride in what we have accomplished together; and hope that the aspirations that we share for a better future for people affected by hydrocephalus continue to manifest through this worthy organization and community of people.

I believe that it is healthy for non-profits to experience new leadership and it is time for me to move on. A good and natural transition point for the Association occurred after the announcement of the research RFA at the end of June when there were a couple of months before grant applications are due in September.

It has been a privilege to work with you, for this Association, and for the community that we serve. I am grateful for the opportunity this work provided me to grow personally and professionally.



FROM THE EDITOR

Tom Smith, Outreach and Media Liaison

Things are hopping here at the Hydrocephalus Association. We've had changes galore: we have started our annual Awareness WALK season, have entered the world of directly funding research for a cure, and are organizing the 2010 National Conference on Hydrocephalus, among many other developments. Read on and find out all about it!

The most immediate result of this can be seen right here, in this issue of Pathways. Because of the schedule getting so cramped, we were forced to compress our Summer and Fall issues of Pathways into a single newsletter. This is not a pattern we intend to duplicate, and come winter, we'll be back to our regular schedule.

We might almost call this our 'Back to School' issue of Pathways. We cover our annual scholarship recipients and finalists; Ella Arnold gives advice on what to share with college roommates; how parents can ease a child's transition into middle school; the new Campus Community Coordinator program; unveil a new education initiative for NPH; etc. We also give an update on the progress of our next conference and much, much more.

As always, we thank you for your patronage interest and patience. ❖

CHANGE AND PROGRESS GO HAND IN HAND AT HA

Rick Smith, Acting Chief Executive Officer

Ten years ago I gave up my consulting practice to focus most of my professional life on helping non-profits like the Hydrocephalus Association transition to new executive leadership. Twenty organizations later (and after serving as the Interim Executive Director in each), I can honestly say it was a great decision because it gave me the opportunity to help facilitate organizational development during periods of leadership change. First and foremost, when a leader steps down, staff and the board of directors have an opportunity to reflect, plan, and seriously consider their future directions. In other words, executive transition is a real opportunity for organizations to develop and grow in ways previously unimagined. Over the years I have found this to be an extremely rewarding and intellectually challenging task.

Now, after almost eight months at the Hydrocephalus Association, I am pleased to report that HA is making the most of this organizational moment. The staff and board have spent the last four months critically examining our organizational mission, goals and strategies – what I like to call the strategic framework. As a result of this planning work, some important decisions have been made, including an expanded mission: *to eliminate the challenges of hydrocephalus*. Building on a remarkable track record of providing education and support services to thousands of individuals and their families, HA is expanding its five-year agenda to include an aggressive research program with the goal of *driving the research agenda by directly funding \$3 million annually and influencing government granting entities to ensure that hydrocephalus is provided it "fair share" of NIH research support* (which is estimated to be in the neighborhood of \$100 million based on comparisons to conditions with similar prevalence or disease burden). We will start to make good on this new commitment in the fall when we award four to six Mentored Young Investigator Awards.

We have also decided to increase the scope and reach of our education and support program with a new goal of raising our numbers by 50% while maintaining our service quality. To achieve this goal, we are enhancing the value of our website by adding a knowledge base for answering members' and visitors' complex questions, as well as providing regular updates via our website and through popular social media such as Facebook and Twitter. Another important new element of this effort will be the development of nationally supported "Partners Network" of volunteers who can generate awareness and provide support and education to those affected by hydrocephalus in communities throughout the country.

With this strategic review completed, the Board of Directors decided to resume its search for a new chief executive officer. One critical question that emerged during the review was whether or not the new HA leader should be located in the

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CHANGE AND PROGRESS

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Washington, DC, area. After much discussion the Board of Directors decided unanimously to open a second office in the DC area to house the new CEO. Relocation of the Association's CEO will greatly enhance our advocacy and fundraising work, both of which are critically important to our vision and the success of our new research agenda. As for me, I am enthusiastically looking forward to my continued role as Acting CEO in the months ahead. HA has seized the moment and it is an honor to play a helping hand in so much progress. ❖

I want to acknowledge Dory Kranz, HA's former Executive Director and Research Director. After almost a decade of service, Dory has decided to leave the HA staff. In large part, it was Dory's leadership that enabled HA to enjoy years of growth and success, which has set the stage for all the success to come in the future. It has been a pleasure to follow in her footsteps and everyone on the HA Board and staff wishes her well.

Rick Smith



RESEARCH UPDATE: MENTORED YOUNG INVESTIGATOR GRANT APPLICATIONS ARRIVE SEPTEMBER 15TH

Donna Schaffer, Research Associate

Grant applications have arrived in the San Francisco Hydrocephalus Association office in response to a Request for Applications (RFA) for young scientists beginning a career in hydrocephalus research. The awards, for up to \$55,000 per year, are designed to:

- Fund promising research to advance our understanding and improve treatment of hydrocephalus;
- Foster the development of young researchers who will have an enduring focus on hydrocephalus;
- Support accomplished investigators who will serve as mentors to these young scientists.

A Scientific and Medical Review Committee comprised of biomedical re-

searchers and clinicians will employ procedures modeled on the National Institute of Health's (NIH) peer review process in assessing the applications submitted. HA seeks to strategically balance basic, translational and clinical research and to encourage collaboration across scientific disciplines. It is hoped that many of these grants will support preliminary investigation into research questions ultimately funded by larger public and private entities.

Grant awards will be announced in December 2009.

For more information on this first research funding cycle contact: Donna Schaffer at: research@hydroassoc.org or go to: www.hydroassoc.org/research_advocacy/ha-research-grants/rfa-guidelines ❖

TEACHING THE ABCs OF NPH: A New Approach to the NPH Outreach Initiative

Tom Smith, Outreach and Media Liaison

The Hydrocephalus Association is unveiling "Teaching the ABC's of NPH," a new NPH outreach initiative that is part of our effort to spread awareness of hydrocephalus. Awareness is a primary concern for all the members of the Association, but we believe it is perhaps the single most important issue surrounding NPH. There is a staggering rate of mis- or non-diagnosis of NPH. An estimated five to ten percent of persons diagnosed with either Alzheimer's or Parkinson's disease are actually believed to have NPH. As NPH symptoms are easily mistaken for the natural aging process, the number of people who are not diagnosed at all is impossible to know.

The primary goal of this particular initiative is to raise awareness by directly providing information and education about NPH to the staff members of assisted living facilities. Our initial effort is slated to begin by the end of 2009 and to be focused primarily in the San Francisco Bay Area. This will be followed by an assessment period and, subsequent to the assessment's findings, the initiative will be expanded to other regions of the United States.

HA staff will target assisted living facilities in the greater Bay Area and hold meetings to discuss and explain NPH with the staff. We will emphasize recognizing the symptoms of NPH, such as gait disturbance, urinary difficulties and dementia. We will also assist their clients and clients' family members in becoming their own medical advocates.

The ultimate aim of this awareness initiative is to target and support key elements of our ever-aging population, as well as their care providers - private, professional or family - and raise NPH awareness throughout our communities. ❖

Spanish Outreach: Call for Volunteers

In our hopes and efforts to reach out to many individuals and families affected with hydrocephalus, we are asking our members who have the skill of speaking fluent Spanish to become peer supporters.

Please contact Karima Roumila at karima@hydroassoc.org if you are interested in helping others by sharing your Spanish speaking skills.

2009 SCHOLARSHIP RECIPIENTS (Continued from page 1.)

Erin Rae Breedlove is a freshman at Georgia College and State University majoring in Interrelated Special Education. She chose to attend GCSU because of its accessibility, opportunities for community service, and proximity to a hospital. She remarked that she credits hydrocephalus and cerebral palsy as reasons doctors enjoy taking pictures of her brain. Her many passions include working with children and adults with disabilities, disability advocacy and raising awareness, volunteerism, writing poetry and fiction, and being around family and friends. She particularly appreciates her twin sister's unconditional support. She plans to pursue a master's degree in rehabilitation counseling to work with the Georgia State Department of Labor to assist disabled residents achieve independence by addressing crucial needs during post-secondary education, securing gainful employment, and catering to independent living needs.



Katelyn Dekoski, of Bay City, Michigan, is currently attending Delta College in hopes of becoming a Certified –Neuroscience Registered Nurse to work with patients with neurological disorders in a hospital setting. Katelyn explains, "Having hydrocephalus is also the reason I want to go into nursing. Spending much of my...last seven years in a hospital bed...[and] watching the nurses doing their jobs has made me see that I want to help people the way they helped me and my mom." In her free time, Katelyn enjoys reading inspirational stories, writing her blog, creating short stories about hydrocephalus, and knitting hats for cancer patients undergoing chemo. She has also been vocal in the hydrocephalus community by speaking at hydrocephalus support groups and successfully lobbying the Michigan State Legislature to pass a resolution commemorating May 2009 as Dandy-Walker Syndrome and Hydrocephalus Awareness Month



Ryan Derleth, of Running Springs, California, is currently attending the Pathway program through UCLA Extension, which provides academic enhancement and teaches independent living skills. Ryan says, "You have to have the attitude that you can do anything no matter what the disability." With his determination and spirit and through the Pathway program, he is learning to budget, cook and clean, explore career paths, and advocate for himself. He intends to participate in medical internship during the program. His extracurricular activities include visiting museums, playing golf, attending football and basketball games, working on cars, and experiencing various cultural events around Los Angeles County.



Lydia Gonzalez will attend the College of Southern Nevada to become a certified occupational therapy assistant. Diagnosed with Von Hillebrand's Disease at a young age, Lydia is currently involved with a youth program at the Hemophilia Foundation to plan fundraisers to support summer camp for children affected by bleeding disorders. She is also involved in a youth council at a community center designed to educate adolescents about getting along with their peers and making wise educational and health decisions. Lydia has undergone many shunt revisions and experienced medical, academic, and social challenges associated with hydrocephalus, yet she strongly believes that "Nothing has [kept or]...will keep me from being the person I was meant to be, [or] from having the life I was meant to have."



Margaret Hackett will major in animal sciences at the University of Illinois starting this fall. She is particularly interested in the area of working with service, therapy, and companion animals. Due to several medical conditions, Margaret cannot play sports like she used to, although she has mastered Wii sports and frequently attends White Sox games.

Margaret states that one positive impact from having hydrocephalus is learning to take charge of her medical care and take an active role in her health care decisions. She is now more responsible and assertive in her health management and hopes to be a mentor for future high school students with hydrocephalus and other disabilities.



Justin Mark Salisbury is a freshman at East Carolina University in Greenville, North Carolina, where he is working towards two degrees in mathematics and psychology. Justin was very active in high school as a Chair in Student Congress, a varsity athlete in track and field, and a competitor in national math competitions. His dream is to teach math and psychology. He says, "Professors are lifelong students because they are always learning through their research; by becoming a professor, I can pursue questions, discover their answers, and teach my students how to find them...As a researcher in the field of psychology, I want to assess and articulate the nature of my own learning difficulties along with those of other hydrocephalus patients. I want to pave the way for a brighter future...so that our challenges are recognized and understood."



Maria Nevarez, of Pittsford, New York, has been accepted into several colleges and will major in computer science or information technology and minor in music. Maria is a seasoned pianist and has taken lessons since she was seven. Despite dealing with the repercussions of a brain tumor, hydrocephalus, and other complex medical conditions at the age of four months, she has still been able to excel in school and was inducted into the National Honor Society. Maria says that the difficult medical tests and procedures she has endured throughout her life and her ability to handle these tough situations have made her into the person she is today. She says, "I feel that I am mentally older than I actually am because of

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2009 SCHOLARSHIP RECIPIENTS (continued)

the many surgeries [I have had] and medical decisions that I have had to make throughout the years. I also think my medical history has made me a calm and rational thinker." In the future, she wants to share the lessons she has learned from her experiences, bring people together, and improve their lives by starting a hydrocephalus support group in her area.



Faye Zimmerman, of Slidell, Louisiana, will pursue a degree in psychology at Southeastern Louisiana University and wants to open her own practice to counsel disadvantaged youth. She and her old-

er sister (who are "inseparable") were both born with hydrocephalus. Faye says, "I educate my peers about what hydrocephalus is and show them that there is nothing 'wrong' with us; we merely have a few extra parts." In her spare time, Faye distributes toys at Toys for Tots, leads canned food drives, and hosts Relay for Life in her hometown. Faye has also volunteered at the same animal shelter for a decade. She states, "It doesn't matter how great [or] small you are...any living creature enriches someone else's life, and it is my job in this world to contribute to other people's lives." ❖

CONGRATULATIONS TO THE 2009 SCHOLARSHIP FINALISTS!

Adrienne Alexander	Marissa Good	Kristian Mullins
Briana Alston	Hannah Gordon	Teddy Nolley
Matthew Arietta	Kaitlynn Grueber	Austin Osteen
William Bakos	Christopher Guzman	Giovanni Olvera
Sarah Barnhart	Jordan Hinson	Jared Pace
Michael Becker	Sarah Hochberg	Thomas Penman
Emily Beene	Justin Horton	Spencer Peterson
Elizabeth Bertels	Amanda Huelsman	Daniel Powers
Aaron Black	Erin Hyerczyk	Nicholas Richards
Anna Blake	Patrick Juris	Tami Rickert
Brian Casady	Shehani Karunanayake	Nicholas Robinson
Peter Casey	Josephine Kelley	Derek Salazar
Megan Charlebois	Rebecca Kemen	Hannah Salo
Jessica Coffman	Monica Kempfski	Jennifer Sandwell
Krista Cole	Jake Kent	Steven Satterfield
Caitlin Cowen	Justine Keys	Andrew Schneider
Catharine Cox	Kamber Kigin	Douglas Scholidon
Danny Dacanay	Robert Kilian	Andoni Schultz
Amanda Daubner	Greg Kirby	Daniel Shedd
Darryl Dill	Michelle Koehler	Diane Shoemaker
Elizabeth Dillow	Jessica Lasig	Annette Simms
Bradley Dykstra	Caitlin Loving	Isabel Slettebak
Courni Eaton	Jamie Lucin	Megan Stuckey
Christian Eldred	Grace Majors	Isaac Thomason
Hilary Elliot	Jacob Martinez	Christina Tinkler
Kayla Eugenio	Shaylene Michaels	Hannah Walton
Brittany Fasnacht	Paige Mathis	Kimberly Warren
Heather Faulkner	Heather Miller	Kimberly Weaver
Amanda Feld	Rosemary Miller	Mackenzie Williams
Jessica Ford	Lynwood Meyer	Karen Wilson
Samuel French	Nora Morrison	Amanda Witzig
Eleanor Geer	Heather Taylor	
David Gonzalez	Brendon Mullen	

TAKING THE MESSAGE TO CAMPUS

Thara Jinadasa, Development Associate

The Hydrocephalus Association is proud to announce the new "Campus Community Coordinator" initiative, which is the brainchild of HA member Peter Finlayson.

In January 2009, Pete contacted the Association with an idea to harness the potential awareness-raising, fundraising, and advocacy work that exists in college campuses across the country for the purposes of hydrocephalus research. He proposed a Campus Community Coordinator program that would recruit motivated students on selected campuses to create grassroots events to raise awareness of hydrocephalus at their schools.

His goal is to create a self-sustaining program that will eventually reach about 100 campuses nationwide. For the program's inaugural year, Peter has recruited three CCC's, two from the University of California at Berkeley and one from Stanford University.

Peter has already lent his imagination, energy, and dedication to our community. In 2008 he started Sharkfest, a team swim in the icy waters of San Francisco Bay that benefited the Association. In 2009, he transformed that event into a tradition that is now bigger and better than last year.

We here at the Hydrocephalus Association would like to express our gratitude and support to Pete for his innovative ideas. We are very excited about the Campus Community Coordinator program.



PARENTS CAN EASE CHILD'S FEARS OF MOVE TO MIDDLE SCHOOL

Pacesetter, Fall 2008, Vol. 32, Issue 3 (c) [2008]. Used with permission from PACER Center Inc., Minneapolis, MN, (952) 838-9000. www.pacer.org. All rights reserved.

The transition from elementary school to middle school can pose new challenges for teens and added concerns for youth with disabilities. Studies also show that students who drop out of school often struggle making the shift from elementary to middle school or middle school to high school. A parent's support and involvement at this pivotal time, however, can pave the way to a successful school life and help a student maintain a positive view of school.

Following are the typical challenges of moving on to middle school and how parents can help students prepare for them.

NEW BUILDING AND NEW STAFF

Preparation in the following ways can help your child's adjustment to an unfamiliar setting and new teachers.

- Request an Individualized Education Program (IEP) meeting just prior to the start of school. Parents can request that all of their child's regular education teachers be invited to the meeting. They can also write a short introduction to their child and leave a copy with each teacher. The introduction should briefly describe when their child was diagnosed, what the child's needs are, and growth in development from year to year. Parents can also give a brief overview of their child's strengths and needs to the teachers at the meeting. Children may also come to the meeting so they can talk about what works best for them in school. "Not all kids will do that," says Jody Manning, PACER advocate. "If they can't come, bring a recent photo of your child."
- Request a copy of your child's schedule. An unknown schedule can be a source of anxiety for students, Manning says. Parents can lessen that anxiety by taking their child to school and finding the classrooms on the schedule.

- Mail the introduction to teachers who weren't able to attend the IEP meeting. Parents should also provide phone and/or e-mail contacts so teachers can contact them. Two to three weeks after school begins, parents may want to e-mail teachers asking them if they have any concerns about their child or the IEP.

NEW AND LARGER GROUP OF PEERS

Oftentimes, students in middle school are moving to a building that incorporates students from other elementary schools, which means more new faces. To help children meet more students their age, parents can enroll them in summer opportunities such as community education classes, citywide sports teams, or summer camps. Adaptive recreation assistance that supports inclusion in activities may also be offered in a community.

MORE THAN ONE TEACHER A DAY

Greater organizational skills are required when students have multiple teachers and classrooms. Parents can support their child in these ways:

- Provide organizational tools, such as a three-ring binder with pockets for storage.
- Keep an eye on their child's organizational needs for the first few weeks. If a student is having great difficulty, request an IEP meeting to discuss this new need and some possible accommodations. For example, parents can request an extra set of textbooks at home, assistance with a locker, or having a cubby in classrooms where students can leave supplies.
- Help the student develop a checklist that he or she can review each morning to make sure needed materials are ready.

TEENS LIKELY WANT MORE PRIVACY AND INDEPENDENCE

At the middle school age, parents are challenged by finding a balance between encouraging independence and providing

Transition Tips for Schools

Studies show that schools can create an environment that makes transition easier and drop-out rates lower.

Fewer students drop out when schools have:

- Smaller enrollments
- Focused, rigorous, and relevant curriculum
- Better interpersonal relationships among students and adults
- Supportive teachers
- Extra support with teaching teams or small learning communities look this spring.

and enforcing guidelines that teenagers still need.

"Parents should set fair and consistent rules with boundaries," Manning says. "The boundaries help children learn that responsibility comes with new independence."

Other ways to strike the right balance in the relationship with young teens include the following:

- Be involved in their education at school. Parents can do this by volunteering, joining school committees, building relationships with teachers, visiting the school, and attending parent-teacher conferences. One mother graded school spelling sheets at home. "She felt like part of the school community, and her children had pride in her," Manning says. Research shows that when parents are involved in their child's education, children earn higher grades in school and have better behavior.
- Keep the lines of communication open. Talk every day about what happens at school; ask often if there are messages from school. If teens bring concerns home from school, listen and offer help to improve the situation. "If a teen brings bad news home, they've probably already been disciplined," Manning says. "They would benefit from a dis-

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EVERYBODY'S GOT THEIR SOMETHING

Ella Arnold

As you get older and become more independent by going to college and living on your own, you will need to tell your roommate(s) about your hydrocephalus.

During high school I revealed that I had hydrocephalus to my close group of girlfriends and to a couple of guys that I had come to trust. The girls, many of whom I had been there for when they were facing their own personal problems, reacted to my news with indifference, leaving me feeling hurt, rejected, and alone. The boys, on the other hand, showed genuine concern for my health and were interested in what I had to say. Most importantly, when I was done telling them about my hydrocephalus, they told me about their various medical issues in return, which helped me feel like I was not alone.

During my first two years of college, I had to tell my roommates about my hydrocephalus in case I ever had an emergency because I knew that they would most likely be the people around if something happened. I chose a time during the first week of school when I knew my roommates were all home and not busy. It is important to tell your roommates as soon as possible so that if you ever have a problem, they will be prepared.

First I told them that I was born with hydrocephalus and then I explained to them in layman's terms what hydrocephalus is. It is important to keep it simple because if you use too much medical

jargon people may not understand what you are saying.

I explained why I was telling them about my hydrocephalus: because in the event of an emergency, they would be the people I would turn to for help.

Make sure that you tell your roommates where your emergency folder is so that they can be sure to grab it if you should ever need it. Your emergency folder should contain all of your medical information, copies of scans, contact information for your family, surgical reports, and directions to and contact information for the hospital and doctors you would need to be taken to in the event of an emergency.

Also explain the multiple signs and symptoms of a shunt malfunction and infection.

You may also want to tell your roommates the hydrocephalus statistics, because while the chances are good that your roommates have never heard of hydrocephalus, you and I both know that it is more common than people think; about one or two of every 1,000 babies are born with it.

Overall, the most important thing to make sure of is that your roommates understand your condition. Ask if they have questions about what you have told them and assure them that if they have any questions in the future, they should feel comfortable asking you.

Tell them that you are not trying to scare them. Rather, you are following the umbrella policy: if you prepare them for the worst, hopefully nothing will ever happen – and if it does, they will be able to help you through it.

You are your own best advocate so make sure that before you tell your roommates about your hydrocephalus, you yourself know all of the information about your condition. Knowledge is power, and by knowing as much as you can

about hydrocephalus you will exude confidence when the time comes to explain it to your roommates, which will help them feel more secure as well.

It may take some people a few days to comprehend what you have told them and they may not initially react the way

that you want them to, but always give them time to come around. Unlike my best friends in high school, the roommates and friends I have had in college have all been incredibly accepting of me and of my hydrocephalus. I hope

that those of you who are heading off to college in the fall will have roommates who accept you for who you are, despite the challenges you face.

When I was dealing with the aftermath of telling my high school girlfriends about my hydrocephalus, my parents gave me some excellent advice that changed my perspective and helped give me the confidence to continue to tell others about my hydrocephalus. My parents told me that "everybody's got their something." Whether it's hydrocephalus, A.D.D., colorblindness or a sixth toe, most everyone has or will face some kind of medical issue, some more common than others, at some point in their life. Having hydrocephalus is mine.

My experiences telling people about my hydrocephalus, from those who I thought were my closest friends to roommates I barely knew at the time, have run the gamut from incredibly frustrating to wonderfully liberating. It is my hope that through the experiences I have had and the suggestions and advice I have offered here, I can help others to be confident in telling people about their hydrocephalus.

If you want more resources, please email bonnie@hydroassoc.org for a copy of our Transition Guide and College and Hydrocephalus Fact Sheet. ❖

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MOVE TO MIDDLE SCHOOL

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cussion about possible solutions. At the middle school age, it's time to step into a solution mode."

- Review the IEP and school records each year.
- Get to know other parents and form support groups to work on problems and issues of mutual interest. ❖

WHAT SIBLINGS WOULD LIKE PARENTS AND SERVICE PROVIDERS TO KNOW

The Sibling Support Project. All rights reserved.

In the United States, there are over 4.5 million people who have special health, developmental, and mental health concerns. Most of these people have typically-developing brothers and sisters. Brothers and sisters are too important to ignore, if for only these reasons:

- These brothers and sisters will be in the lives of family members with special needs longer than **anyone**. Brothers and sisters will be there after parents are gone and special education services are a distant memory. If they are provided with support and information, they can help their sibs live dignified lives from childhood to their senior years.
- Throughout their lives, brothers and sisters share many of the concerns that parents of children with special needs experience, including isolation, a need for information, guilt, concerns about the future, and caregiving demands. Brothers and sisters also face issues that are uniquely theirs including resentment, peer issues, embarrassment, and pressure to achieve.

Despite the important and life-long roles they will play in the lives of their siblings who have special needs, even the most family-friendly agencies often overlook brothers and sisters. Brothers and sisters, often left in the literal and figurative waiting rooms of service delivery systems, deserve better. True “family-centered” care and services will arrive when siblings are actively included in agencies’ functional definition of “family.”

The Sibling Support Project facilitated a discussion on SibNet, its listserv for adult siblings of people with disabilities, regarding the considerations that siblings want from parents, other family members, and service providers. Below is a discussion of themes discussed by SibNet members and recommendations from the Sibling Support Project:

1. THE RIGHT TO ONE’S OWN LIFE.

Throughout their lives, brothers and sisters may play many different roles in the lives of their siblings who have special

needs. Regardless of the contributions they may make, the basic right of siblings to their *own* lives must always be remembered. Parents and service providers should not make assumptions about responsibilities typically-developing siblings may assume without a frank and open discussion. “Nothing about us without us” – a phrase popular with self-advocates who have disabilities – applies to siblings as well. Self-determination, after all, is for everyone – including brothers and sisters.

2. ACKNOWLEDGING SIBLINGS’ CONCERNS.

Like parents, brothers and sisters will experience a wide array of often ambivalent emotions regarding the impact of their siblings’ special needs. These feelings should be both expected and acknowledged by parents and other family members and service providers. Because most siblings will have the longest-lasting relationship with the family member who has a disability, these concerns will change over time. Parents and providers would be wise to learn more about siblings’ life-long and ever-changing concerns.

3. EXPECTATIONS FOR TYPICALLY-DEVELOPING SIBLINGS.

Families need to set high expectations for all their children. However, some typically-developing brothers and sisters react to their siblings’ disability by setting unrealistically high expectations for themselves – and some feel they must somehow compensate for their siblings’ special needs. Parents can help their typically-developing children by conveying clear expectations and unconditional support.

4. EXPECT TYPICAL BEHAVIOR FROM TYPICALLY-DEVELOPING SIBLINGS.

Although difficult for parents to watch, teasing, name-calling, arguing and other forms of conflict are common among most brothers and sisters – even when one has special needs. While parents may be appalled at siblings’ harshness toward one another, much of this conflict can be a

beneficial part of normal social development. A child with Down syndrome who grows up with siblings with whom he sometimes fights will likely be better prepared to face life in the community as an adult than a child with Down syndrome who grows up as an only child. Regardless of how adaptive or developmentally appropriate it might be, typical sibling conflict is more likely to result in feelings of guilt when one sibling has special health or developmental needs. When conflict arises, the message sent to many brothers and sisters is, “Leave your sibling alone. You are bigger, you are stronger, you should know better. It is your job to compromise.” Typically-developing siblings deserve a life where they, like other children, sometimes misbehave, get angry, and fight with their siblings.

5. EXPECTATIONS FOR THE FAMILY MEMBER WITH SPECIAL NEEDS.

When families have high expectations for their children who have special needs, everyone will benefit. As adults, typically-developing brothers and sisters will likely play important roles in the lives of their siblings who have disabilities. Parents can help siblings now by helping their children who have special needs acquire skills that will allow them to be as independent as possible as adults. To the extent possible, parents should have the same expectations for the child with special needs regarding chores and personal responsibility as they do for their typically-developing children. Not only will similar expectations foster independence, it will also minimize the resentment expressed by siblings when there are two sets of rules – one for them, and another for their sibs who have special needs.

6. THE RIGHT TO A SAFE ENVIRONMENT.

Some siblings live with brothers and sisters who have challenging behaviors. Other siblings assume responsibilities for themselves and their siblings that go beyond their age level and place all parties in vulnerable situations. Siblings deserve to have their own personal safety given as

(continued)

WHAT SIBLINGS WOULD LIKE PARENTS AND SERVICE PROVIDERS TO KNOW *(continued)*

much importance as the family member who has special needs.

7. OPPORTUNITIES TO MEET PEERS.

For most parents, the thought of “going it alone,” raising a child with special needs without the benefit of knowing another parent in a similar situation would be unthinkable. Yet, this routinely happens to brothers and sisters. Sibshops, listservs such as SibNet and SibKids, and similar efforts offer siblings the common-sense support and validation that parents get from Parent-to-Parent programs and similar programs.

Brothers and sisters – like parents – like to know that they are not alone with their unique joys and concerns.

8. OPPORTUNITIES TO OBTAIN INFORMATION.

Throughout their lives, brothers and sisters have an ever-changing need for information about their sibling’s disability, and its treatment and implications. Parents *and* service providers have an obligation to proactively provide siblings with helpful information. Any agency that represents a specific disability or illness and prepares materials for parents and other adults should prepare materials for siblings and young readers as well.

9. SIBS’ CONCERNS ABOUT THE FUTURE.

Early in life, many brothers and sisters worry about what obligations they will have toward their sibling in the days to come. Ways parents can reassure their typically-developing children are to make plans for the future of their children with special needs, involve and listen to their typically-developing children as they make these plans, consider backup plans, and know that siblings’ attitude toward the extent of their involvement as adults may change over time. When brothers and sis-

ters are “brought into the loop” and given the message early that they have their parents’ blessing to pursue their dreams, their future involvement with their sibling will be a choice instead of an obligation. For their own good and for the good of their siblings who have disabilities,

brothers and sisters should be afforded the right to their own lives. This includes having a say in whether and how they will be involved in the lives of their siblings who have disabilities as adults, and the level, type, and duration of involvement.

Throughout their lives, brothers and sisters may play many different roles in the lives of their siblings who have special needs.

10. INCLUDING BOTH SONS AND DAUGHTERS.

Just as daughters are usually the family members who care for aging parents, adult sisters are usually the family members who look after the family member with special needs when parents no longer can. Serious exploration of sharing responsibilities among siblings – including brothers – should be considered.

11. COMMUNICATION.

While good communication between parents and children is always important, it is especially important in families where there is a child who has special needs. An evening course in active listening can help improve communication among all family members, and books, such as *How to Talk So Kids Will Listen and Listen So Kids Will Talk and Siblings Without Rivalry* (both by Adele Faber and Elaine Mazlich) provide helpful tips on communicating with children.

12. ONE-ON-ONE TIME WITH PARENTS.

Children need to know from their parents’ deeds and words that their parents care about them as individuals. When parents carve time out of a busy schedule to

grab a bite at a local burger joint or window shop at the mall with their typically-developing children, it conveys a message that parents “are there” for them as well and provides an excellent opportunity to talk about a wide range of topics.

13. CELEBRATE EVERY CHILD’S ACHIEVEMENTS AND MILESTONES.

Over the years, we’ve met siblings whose parents did not attend their high school graduation – even when their children were valedictorians – because the parents were unable to leave their child with special needs. We’ve also met siblings whose wedding plans were dictated by the needs of their sibling who had a disability. One child’s special needs should not overshadow another’s achievements and milestones. Families who seek respite resources, strive for flexibility, and seek creative solutions can help assure that the accomplishments of all family members are celebrated.

14. PARENTS’ PERSPECTIVE IS MORE IMPORTANT THAN THE ACTUAL DISABILITY.

Parents would be wise to remember that the parents’ interpretation of their child’s disability will be a greater influence on the adaptation of their typically developing sibling than the actual disability itself. When parents seek support, information, and respite for themselves, they model resilience and healthy attitudes and behaviors for their typically-developing children.

15. INCLUDE SIBLINGS IN THE DEFINITION OF “FAMILY.”

Many educational, health care, and social service agencies profess a desire to offer family-centered services but continue to overlook the family members who will have the longest-lasting relationship with the person who has the special needs – the sisters and brothers. When brothers and sisters receive the considerations and services they deserve, agencies can claim to offer “family-centered” – instead of “parent-centered” – services.

(Continued on page 10.)

WHAT SIBLINGS WOULD LIKE PARENTS AND SERVICE PROVIDERS TO KNOW (Continued from page 9.)**16. ACTIVELY REACH OUT TO BROTHERS AND SISTERS.**

Parents and agency personnel should consider inviting (but not requiring) brothers and sisters to attend informational, IEP, IFSP, and transition planning meetings, and clinic visits. Siblings frequently have legitimate questions that can be answered by service providers. Brothers and sisters also have informed opinions and perspectives and can make positive contributions to the child's team.

17. LEARN MORE ABOUT LIFE AS A SIBLING.

Anyone interested in families ought to be interested in siblings and their concerns. Parents and providers can learn more about "life as a sib" by facilitating a Sibshop, hosting a sibling panel, or reading books by and about brothers and sis-

ters. Guidelines for conducting a sibling panel are available from the Sibling Support Project and in the Sibshop curriculum. Visit the Sibling Support Project's website for a bibliography of sibling-related books.

18. CREATE LOCAL PROGRAMS SPECIFICALLY FOR BROTHERS AND SISTERS.

If your community has a Parent-to-Parent Program or similar parent support effort, a fair question to ask is: why isn't there a similar effort for the brothers and sisters? Like their parents, brothers and sisters benefit from talking with others who "get it." Sibshops and other programs for preschool, school-age, teen, and adult siblings are growing in number. The Sibling Support Project, which maintains a database of over 200 Sibshops and other sib-

ling programs, provides training and technical assistance on how to create local programs for siblings.

19. INCLUDE BROTHERS AND SISTERS ON ADVISORY BOARDS AND IN POLICIES REGARDING FAMILIES.

Reserving board seats for siblings will give the board a unique, important perspective and reflect the agency's concern for the well-being of brothers and sisters. Developing policies based on the important roles played by brothers and sisters will help assure that their concerns and contributions are a part of the agency's commitment to families.

20. FUND SERVICES FOR BROTHERS AND SISTERS.

No classmate in an inclusive classroom will have a greater impact on the social development of a child with a disability than brothers and sisters will. They will be their siblings' life-long "typically developing role models." As noted earlier, brothers and sisters will likely be in the lives of their siblings longer than anyone – longer than their parents and certainly longer than any service provider. For most brothers and sisters, their future and the future of their siblings with special needs are inexorably entwined. Despite this, there is little funding to support projects that will help brothers and sisters get the information, skills and support they will need throughout their lives. Governmental agencies would be wise to invest in the family members who will take a personal interest in the well-being of people with disabilities and advocate for them when their parents no longer can. As one sister wrote: "We will become caregivers for our siblings when our parents no longer can. Anyone interested in the welfare of people with disabilities ought to be interested in us." ❖

About the Sibling Support Project

The Sibling Support Project, believing that disabilities, illness, and mental health issues affect the lives of all family members, seeks to increase the peer support and information opportunities for brothers and sisters of people with special needs – and to increase parents' and providers' understanding of sibling issues.

Our mission is accomplished by training local service providers on how to create Sibshops (lively community-based for school-age brothers and sisters); hosting workshops, listservs, and websites for young and adult siblings; and increasing parents' and providers' awareness of siblings' unique, life-long, and ever-changing concerns through workshops, websites, and written materials.

Based in Seattle since 1990, the Sibling Support Project is a national effort dedicated to the interests of over six million brothers and sisters of people with special health, mental health and developmental needs.

For more information about Sibshops, sibling issues, and our workshops, listservs and publications, contact:

Don Meyer
 Sibling Support Project
 A Kinderling Center program
 6512 23rd Ave NW #213
 Seattle, WA 98117
 206-297-6368
 donmeyer@siblingsupport.org
 www.siblingsupport.org

"A THOUSAND WORDS"

Serra Morgan

I was diagnosed with hydrocephalus when I was eight. I'm 22 now, and since my diagnosis I have had 21 shunt revisions, 11 of which occurred in the year that I was supposed to start college. Not knowing quite what I wanted to do and still recovering from surgery, I decided to take it easy and enroll in some art classes, including a photography course. In the class, I learned the black and white wet lab processes, developing my own negatives and making my own prints. I fell in love with it.

From there, I decided to transfer to the Maine College of Art to major in photography and earn my BFA in photography. At the beginning of my senior year, another shunt revision was necessary. Frustrated with how shunts are prone to failure, I focused my thesis project on the experience of living with hydrocephalus. My photographs featured images of me in the hospital, having stitches removed, going to follow-up doctor's visits, and spending days in bed recovering while doing homework and playing video games. My intent was to bring attention to the condition because it is endlessly frustrating to me that hydrocephalus and its survivors get far less publicity and funding than other more prevalent but equally life-altering conditions and disorders.

The photographs that I took of myself had the aesthetic of a personal snapshot while sticking to the compositional quality of fine art photography. I made this conscious decision because I didn't want the work to become antiseptic in a way that the viewer could distance themselves from it and compartmentalize it for anything other than what it was – a diary of my daily struggles. I then edited the work and arranged it on six 24"x36" pieces of mat board in a style much like oversized scrapbook pages. I felt that matting and framing each photograph would again put a certain amount of distance

from the viewer that would detract from the meaning and potency of the work. During the exhibition, I stood nearby to answer any questions that viewers had, but I was astounded by the responses I received.

While my prediction held true that I would not encounter anyone familiar with hydrocephalus, I noticed that many more people were stopping to really pay attention to my exhibit instead of the ones surrounding it. I was approached by the college staff, who told me what they had seen take place in front of my display on a given day. There were many reports of people being moved to tears with compassion, and with the support of the hydrocephalus community, I was able to educate hundreds of people about the daily trials and tribulations that life with hydrocephalus presents.

The most common response to my explanation was usually "But you're okay now, right? You don't need to have more surgery?" Unfortunately I had to respond that yes, people with hydrocephalus very commonly experience



surgeries throughout their lifetime, and there is no definitive answer as to when the last one will be. As living proof of that uncertainty, I was just tested by my local "hydro hero" (my neurosurgeon), and will be having another revision at the beginning of August 2010. ❖



Donors

Thanks to the individuals who supported the Hydrocephalus Association so generously in 2008. Your support keeps our beacon of hydrocephalus education, support, and research shining.

We do our best to recognize everyone who supports us and we make every effort to avoid mistakes. However, if you find any errors or omissions, please contact our office so that we can make the appropriate corrections. We thank you for your understanding.

This issue includes corporate donors for our annual WALK program, as well as corrections to our list of donors included in the Spring 2009 issue of *Pathways*.

Unfortunately, we do not know all the names of those who generously donated to our WALK events or through payroll deduction via CFC or United Way. We would like to thank all of our anonymous donors here.

CORPORATE DONORS

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Donor List Corrections:- To the right are names that were inadvertently left off of our list of generous donors that was published in the Spring 2009 issue of *Pathways*.

DONORS:

Mary May
David, Janie and Aimee Barraclough
Joanne Domsic-Stephan

GIFTS WERE GIVEN IN MEMORY OF:

Bernadette Krizan Janus (Janusiewicz)
Ann Domsic

PARTNERS NETWORK

Sarah Oxford, Regional Program Manager

In order to better support the hydrocephalus community throughout the United States, the Hydrocephalus Association has developed the Partners Network, a group of volunteers who provide support, fundraise, and advocate for the HA in their respective communities. The Partners Network includes our Support Group Leaders, WALK Chairs, and Advocacy Point

Persons who live in 23 states and represent 40 distinct “partner locations.”

What does this mean for you? Having localized groups of HA members means that more of our members – like you! – can get involved in our support network and events. Please check out the WALK calendar and the Support Group list below. ❖

WALK

We need you to stand up and WALK with other members of our community to raise awareness and fundraise! WALKs increase awareness of hydrocephalus and support the Hydrocephalus Association’s programs, which aim to eliminate the challenges of hydrocephalus through education, support, advocacy, and research. Check out our 2009 WALK calendar below. Is there a WALK near you? If so, participate! If not, consider hosting one next year!

HA Support Groups

HA Support Groups can be found all over the country. Our Support Groups create a forum for patients and families to provide mutual support for issues related to hydrocephalus. They also offer further education about the condition and provide an opportunity to meet other people facing similar obstacles. We have Support Groups in the following states:

WALKS currently scheduled for 2009:



September

- 6 Colorado, Denver
- 13 Ohio, Cleveland
- 19 North Carolina, Graham
- 20 Missouri, St. Louis
- 20 Massachusetts, Cambridge
- 26 New York, Long Island
- 26 Utah, Salt Lake City

October

- 3 Illinois, Chicago
- 4 New Jersey (central), Long Branch
- 4 Maryland, Baltimore
- 10 New Jersey (south), Washington Township
- 10 California, Oroville
- 17 New York, Albany
- 17 New Mexico, Albuquerque
- 18 California, Fresno
- 24 Texas, Austin/S. Antonio
- 24 Pennsylvania, Bloomsburg
- 25 California, San Francisco

November

- 1 Pennsylvania, Philadelphia
- 7 Alabama, Birmingham
- 7 Florida, Tampa

HA Support Groups:

Alabama	Iowa	Ohio
Arizona	Maryland	Oregon
California	Massachusetts	Pennsylvania
Colorado	Missouri	Texas
Florida	New Jersey	Utah
Georgia	New Mexico	Washington
Illinois	New York	

VOLUNTEER SPOTLIGHT: JILL GREGERSON

My name is Jill Gregerson. I love volunteering my time with the Hydrocephalus Association, and I have helped out with the annual WALK in San Francisco. While volunteering at this event, I helped with registration, food, and folding t-shirts. I have also enjoyed helping with administrative tasks in the HA office. I am currently generating a spreadsheet with media contacts for each city that will host a WALK, which is another fun way to be involved with the Association.



I acquired hydrocephalus when I was nine and graduated from the University of California, Santa Cruz, in 1992. I have been a member of the Hydrocephalus Association for eleven years.

I spend much of my time taking my dog to the beach. My other hobbies include volunteering with food distribution at my church, and I am learning how to coordinate volunteers on a weekly basis. ❖

RAISING AWARENESS: MANY PATHS, ONE DESTINATION, SUMMER/FALL 2009

Tom Smith, Outreach and Media Liaison

This section is ongoing feature in which we pay tribute to individuals and groups that go the extra mile and create their own opportunities to raise awareness of hydrocephalus. We also want to extend an invitation to all of our members: If you have an idea for an event to raise awareness, we are here for you, ready and willing to support your efforts. Please contact us at:

development@hydroassoc.org.

GRACIE CLASSIC

Dave and Jessica Fanucchi's two-year-old daughter, Gracie, has hydrocephalus, and since her birth, Dave has wanted to do something meaningful to help find a cure. This September, Dave, who is the Director

of Communications and Public Relations of the United States Golf Association, is joining his two passions and has organized the Gracie Classic to honor Gracie and help others like her who live with hydrocephalus. The event will be held at Chico State University, and the proceeds from hole sponsors and the silent auction will go towards hydrocephalus research. We at the Hydrocephalus Association are inspired by Dave's initiative and wish him swinging success!

OROVILLE PARADE

On May 9, 2009, Jodi Lawrence took the opportunity to raise awareness by entering a float in the annual Feather Fiesta Days parade in Oroville, California (see her story in this issue of *Pathways*, page 19). We would like to acknowledge Jodi and

the tremendous energy and dedication she brings to the task of advocating for her grandson, Justin, 6, and all people living with hydrocephalus. She is also the chairperson for the Oroville Awareness WALK coming up on Saturday, October 10, 2009.

CUSTOM CAR SHOW

On May 24, 2009, The Impalas, a car club based in Chico, California, held their 9th Annual Custom Car Show benefiting the Hydrocephalus Association. We would like to thank David and Korisa Labonte, Jodi and David Lawrence, and the Impalas for their generous support and for contributing raising hydrocephalus awareness in new and exciting ways. ❖

TAKING A BITE

Tom Smith, Outreach and Media Liaison

On August 15th, our very own Team HYDRO struck again at the 17th Annual Sharkfest. Sharkfest is a 1.5 mile swim from Alcatraz to San Francisco, a test of endurance and speed in which athletes brave the icy, shark-frequented waters of San Francisco Bay.

This is the second year Peter and Sam Finlayson, joined by friends and well-wishers, have brought awareness to hydrocephalus in this unique and courageous manner. The first year the team had four members; but this year it ballooned to more than twenty swimmers. Along with 800 other swimmers, they gathered

early on a gusty Saturday morning to take a ferry out to the famous prison island, leap into the water, and swim to the shore.

Not only did they raise hydrocephalus awareness, but they proved themselves true athletes by posting exceptional times in several categories as listed below. From all of us on the staff and from our growing and dynamic membership, go Team HYDRO!!! ❖



The team gives a pre-swim cheer



Sharkseye view of Alcatraz



Team HYDRO 2009

1st, 2nd, 3rd, & 4th PLACE, OVERALL/NON-WETSUIT

Mike Sample
Charlie Steffens
Ryan McCarthy
Sage Wright

TOP 5, 20-24 YEARS/MALE/NON-WETSUIT CATEGORY

1st-4th place swimmers in overall/non-wetsuit category (listed above)
Bryan Schnugg

3rd PLACE, 13-14 YEARS/MALE/WETSUIT CATEGORY

Brayden Curry

4th PLACE, OVERALL, MALE/WETSUIT

Steven Wright (also 2nd place in 20-24 year-old/male/wetsuit category)

5th PLACE, 25-29 YEARS/MALE/NON-WETSUIT CATEGORY

Peter Finlayson

NO RAIN ON THIS PARADE

Jodi Lawrence

Feather Fiesta Days, a week-long celebration that wraps up with a parade, is a big event in Oroville, California. Over the years, our children and grandchildren have participated in this parade with their Little League teams, dance teams, and school bands. So this year, I thought, “Why not create a hydrocephalus awareness float?”

I got an application from the Chamber of Commerce, and Bryan and Debbie Hobbs from our hydrocephalus support group secured a sponsor who provided wristbands to pass out during the parade. We just had to make a float and we would be ready.

The best laid plans do not always work out. Our hitch arrived in the form of rain all week long before the parade, so we had nowhere to build the float. But Friday morning, we woke to clear skies, and some of our children and grandchildren came over to eat pizza and put together our float. One of the local feed stores kindly donated bales of straw to be used as seats.

At 8 a.m. on Saturday morning, we got our line number for the parade and put the finishing touches on our float. Several participants with hydrocephalus dropped out at the last moment, so we rounded up the grandchildren again, and they all wore their shirts from last year’s WALK. They took turns either holding the Hydrocephalus Awareness WALK banner or walking in front of the float.

The actual float was very simple: we used a trailer for carrying ATV’s, and my son cut boards the length of the sides of the trailer that I painted and lettered. We had blue and white crepe paper everywhere, and blue and white balloons adorned the edges of the float. We put signs with hydrocephalus information on the sides, high enough for spectators to read from the streets. My daughter-in-law and I walked along each side of the float and handed out wristbands to the crowd. All along

the route we received cheers.

As we walked, we heard comments like “I didn’t know that!” along the entire parade route. We gave out a total of 250 wristbands and could easily have given out several thousand, as the newspaper estimated that 15,000 people attended the parade. When we stopped in front of the judge’s stand the announcer read hydrocephalus statistics from a shunt-pin card, announced our upcoming WALK in October, and thanked us for being there.

On the Monday following the parade I received an email from the Parks & Recreation department stating that they were already receiving inquiries about our upcoming WALK and people were asking for more information.

Two weeks later, Justin, my grandson who lives with hydrocephalus, had a doctor’s appointment. When the nurse called him in, she told him that she had seen him in the parade. She said to me, “That was such an informative float. I didn’t know any of that and people all around me were reading it out loud.” Another person told me that he have a relative with hydrocephalus and wanted to be on the float next year.



When I started thinking about creating a hydrocephalus awareness float in February, it seemed like a good idea. From the end of April until the day before the parade, I was thinking, “What have I gotten myself into?” Ultimately, we had such a wonderful day and such a tremendous response from the community that we are already thinking about doing it next year and making a better float. However, I’m not sure we could make a better one. Our float wasn’t elaborate, or even particularly pretty. But it sure got the message across. ❖



- Kids Corner Answers:**
1. Pitcher
 2. Diamond
 3. Bases
 4. Umpire
 5. Glove
 6. Field
 7. Home Run
 8. Dugout

THE 11TH NATIONAL CONFERENCE ON HYDROCEPHALUS APPROACHES!

Marybeth Godlewski, National Advocacy Director

As previously announced, our 2010 conference will be held at the Intercontinental Hotel in Cleveland, Ohio, from June 17th through 20th, and it will be orchestrated in close collaboration with the Cleveland Clinic.

Our theme for this conference is “FOR YOU,” which is intended to pay homage to the many individuals living with hydrocephalus. Though we come together collectively in the face of this condition, we must not lose sight of the most important single, indivisible element of the community: the individual – **you**. In more basic terms, the goal of this conference is to present a wealth of information to empower HA members in their daily lives.

Our community will have the opportunity to attend many sessions focused on the clinical side of hydrocephalus. One of the scientific highlights of the upcoming conference will be a live video feed of a shunt placement and an ETV surgery in progress at the Cleveland Clinic, which is located nearby. We will also provide as many information sessions as possible focused on the many conditions related to hydrocephalus. As always, childcare facilities will be provided.

We are in the process of organizing sessions covering topics including IEPs for students; best therapies for infants, toddlers, adults, and seniors; legal rights and responsibilities; and how to get social and emotional support for all ages and family members. ❖



KEYNOTE SPEAKER

We have several exciting speakers and events planned for the 2010 National Conference. One of our confirmed keynote speakers is Michael F. Roizen, M.D. Dr. Roizen is a distinguished physician, best-selling author, and expert on aging, diet and “YOU” – the theme of our conference. He has published more than 165 peer-reviewed scientific papers, 100 textbook chapters, 30 editorials, and 4 medical books. In June 2007 he was named Chief Wellness Officer of the Cleveland Clinic and Chair of the Wellness Institute at the Cleveland Clinic, and he has since become Chairman. He lectures all across the country and been a guest on the Oprah Winfrey show 18 times.



Conference Medical Chairs

Mark G. Luciano, M.D., Ph.D., F.A.C.S., Head of Pediatric, Congenital, Neuroendoscopic Surgery of the Cleveland Clinic. Special interests include the treatment of complex hydrocephalus, neuroendoscopy, and the pathology of hydrocephalus. Dr. Luciano resides in the Cleveland area with his wife and four children.

Stephen Dombrowski, Ph.D., Co-Director of Clinical and Experimental Research in the Section of Pediatric and Congenital Neurosurgery. Special interests include neuroscience, hydrodynamics, and hydrocephalus research. Dr. Dombrowski resides in the Cleveland area with his wife and son.

The Art of Hydrocephalus

The “art of hydrocephalus” will also be featured in the 2010 National Conference! Many HA members who have hydrocephalus are artistic individuals who find unique and positive ways of presenting life through art. We invite artists, both world-renowned and from our community, to present their works of art.

Further information on how to get involved will be announced in future issues of *Pathways*. The nearby Cleveland neighborhood University Circle will provide an exciting space to exhibit material for both sides of the brain.

News Notes

CARINGBRIDGE

A link to CaringBridge will soon appear on our website. CaringBridge provides free, personal websites that make it easy to stay connected to family and friends during a healthcare crisis, as well as treatment and recovery. CaringBridge allows patients' families to instantly and easily keep loved ones informed and frees them from the emotional strain and time commitment of updating loved ones in other ways. To learn more about this resource, visit: www.caringbridge.org/.



CMS EXPANDS HOSPITAL COMPARE WEBSITE

The Centers for Medicare & Medicaid Services (CMS) Hospital Compare introduced important new information to their website recently. Their site now reports how frequently patients return to a hospital after being discharged, which is a possible indicator of how well the facility did during the first visit. Visit CMS Hospital Care at: www.hospitalcompare.hhs.gov.

DIRECTORY OF NEUROSURGEONS FOR ADULTS WITH CONGENITAL HYDROCEPHALUS

The HA is compiling a new "Congenital Directory of Neurosurgeons." These dedicated doctors treat young and middle aged adults who were shunted for hydrocephalus at birth, during infancy, or in childhood. As many members of our community know, the transition of medical care for adults with congenital hydrocephalus is a very serious and pressing issue that is a deep and growing concern to our community. We frequently receive calls from young and middle-aged

HA JOINS FORCES WITH NEWFANGLED GIZMOS

FACEBOOK

Realizing that Facebook is soooo 2008, we have nevertheless joined the world of modern technology by creating a fan page for the Hydrocephalus Association. For updates on the world of hydrocephalus (and our organization), join us on Facebook! Just search for "Hydrocephalus Association," open our page, and click "Become a Fan."

TWITTER

Jennifer Bechard, one of our members and the chairman of this year's Detroit WALK, recently took the liberty of entering the Hydrocephalus Association as one of the Twitter's "Top 10 Causes." Thanks to the support of our beloved membership we were came in second place. Check us out and show support by going on to Twitter and querying for "Top Ten Causes."

TALKING TO YOUR DOCTOR

The National Institute for Health (NIH) has published a new website, "Talking to Your Doctor," which is designed to ease communication between a patient and his or her doctor. As anyone dealing with a chronic medical condition can attest, this is a critical issue for long-term care, and the NIH site offers a variety of tips aimed at smoothing out what can otherwise seem to be a rocky road. Visit their new site at: www.nih.gov/clearcommunication/talktoyourdoctor.htm.

HOUSE PASSES RESOLUTION DECLARING SEPTEMBER NATIONAL HYDROCEPHALUS AWARENESS MONTH

With the passage of House Resolution 373, the U.S. House of Representatives has officially designated September 2009 as "National Hydrocephalus Awareness Month." We would like to extend our congratulations to the Pediatric Hydrocephalus Foundation for their success in leading this effort.

MASSACHUSETTS DISABILITY INITIATIVE

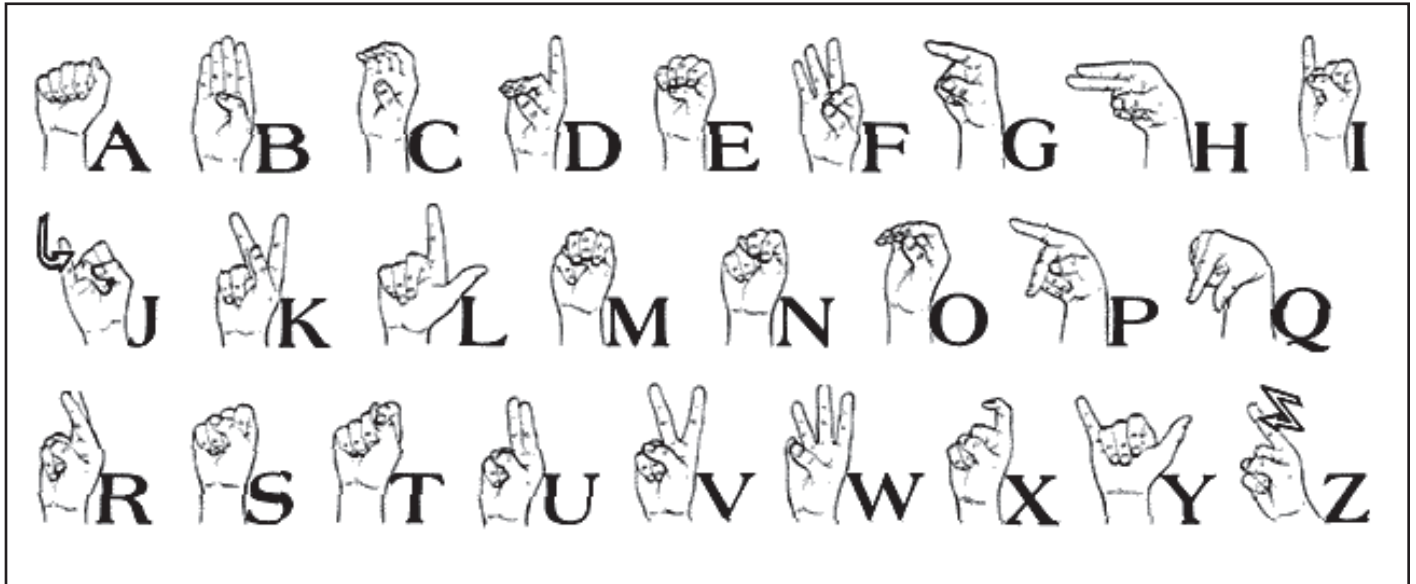
The Massachusetts Disability Employment Initiative has launched a new website, "Talking with Your Doctor and Other Healthcare Professionals," which is geared towards helping youth feel more comfortable talking to their healthcare provider. It is based on the communication model presented in the "Talking with Your Doctor" video, which is also included on the website. For more information, go to: <http://hctransitions.ichp.ufl.edu/gladd/>.

Kid's Corner!

Bonnie Hom, Youth and Community Coordinator

Hey Batter Batter!

Can you decipher these baseball-related words written in American Sign Language? If you get stuck, refer to the American Sign Language chart below. Check your answers on page 15 to see how many you got correct!



Hydrocephalus Association 2009 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 2009. 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:

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The Hydrocephalus Association is a national nonprofit organization providing support, education, resources and advocacy for families and professionals. Pathways is published quarterly. Thomas G. Smith is the editor. Articles included in the Pathways 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 Pathways may be reprinted provided a full citation of source is given.

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HYDROCEPHALUS ASSOCIATION RESOURCES AND FACT SHEETS

The following resources are available free to our members:

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

About Normal Pressure Hydrocephalus (Adult-Onset)

Prenatal Hydrocephalus—A Book for Parents

Hydrocephalus Diagnosed in Young to Middle-Aged Adults

A Teacher's Guide to Hydrocephalus

Health-Care Transition Guide for Teens and Young Adults

Directory of Pediatric Neurosurgeons

Directory of Neurosurgeons for Adults

Fact Sheets

Primary Care Needs of Children with Hydrocephalus

Learning Disabilities in Children with Hydrocephalus

Hospitalization Tips

Headaches and Hydrocephalus

Social Skills Development in Children with Hydrocephalus

Eye Problems Associated with Hydrocephalus

Survival Skills for the Family Unit

Durable Power of Attorney for Health Care Decisions

Endoscopic Third Ventriculostomy

Cerebrospinal Fluid Shunt Systems for Management of Hydrocephalus

Nonverbal Learning Disorder Syndrome

How to Be an Assertive Member of the Treatment Team

Second Opinions

College & Hydrocephalus

Financial Aid and Scholarships

Understanding Your Child's Education Needs/IEP Resource Packets