

# HYDROCEPHALUS

## · ASSOCIATION ·

SUPPORT EDUCATION ADVOCACY

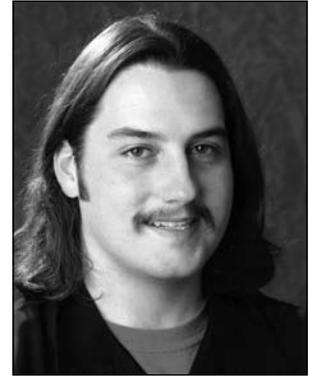
SPRING 2006

VOL. 24, NO. 2

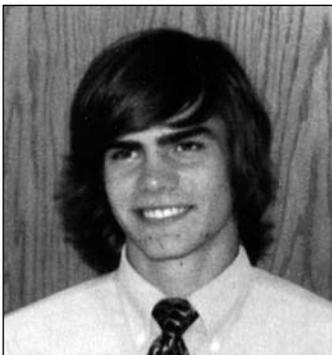
### **Congratulations to Our 2006 Scholarship Recipients!**

We are delighted to be able to award seven scholarships to these outstanding young men and women with hydrocephalus. These scholarships were funded by the Gerard Swartz Fudge Memorial Scholarship Fund, the two Morris L. and Rebecca Ziskind Memorial Scholarship funds, the two Anthony Abbene Scholarship Funds and the Justin Scot Alston Memorial Scholarship Fund. Our congratulations go to the recipients and to all the amazing people who applied for this year's scholarships.

**Please read their stories on page 4. A complete list of scholarship finalists appears on page 5.**



**Austin Hitchin**  
Big Bear City, CA  
*Morris L. & Rebecca Ziskind  
Memorial Scholarship*



**Nathan Myer Auldridge**  
Salem, VA  
*Justin Scot Alston  
Memorial Scholarship*



**Andrew Elkin**  
Punxsatawny, PA  
*Gerard Swartz Fudge  
Memorial Scholarship*



**Kaitlyn Nivins**  
Port Jervis, NY  
*Anthony Abbene Scholarship*



**Joseph Broc**  
Haleiwa, HA  
*Anthony Abbene Scholarship*



**Robin Ennis**  
Denver, CO  
*Gerard Swartz Fudge  
Memorial Scholarship*



**Molly Kate Wilkinson**  
Dewey, AZ  
*Morris L. & Rebecca Ziskind  
Memorial Scholarship*

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## From the Editor

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*By Debra Howell, Advocacy & Adult Services Director*

On Hydrocephalus Advocacy Day, May 30, 2006, 120 hearty souls braved the heat in Washington, D.C. on a mission to ask our elected representatives to devote more federal support to hydrocephalus research and treatment. I was moved by everyone's vibrant courage. Though most of you had never pursued legislative advocacy before, we did amazing work together, meeting with the staff of 48 senators and 51 congressional representatives. We reached almost half of the Senate members and over 11% of the House representatives. Fantastic!

**Latest Update:** At press time, Congressman Mike Thompson of California has agreed to be the lead sponsor for this resolution in the House and we are working toward getting a lead sponsor in the Senate. The resolution wording has been crafted. Congressman Thompson will soon be seeking co-sponsors before the resolution is introduced in the House.

**What You Can Do: Join our Advocacy Alert email list** to receive the latest news and updates about how you can advance our cause. The Association will send you sample letters that you can use to send to legislators. The next alert will be for letters to send to legislators asking them to co-sponsor or support a non-binding "sense of the congress" resolution about hydrocephalus. We hope to introduce this resolution commending the National Institutes of Health (NIH) for their sponsorship of the hydrocephalus workshop in 2005 and directing more federal support to advance hydrocephalus research and treatment.

Look for a new page soon at [www.hydroassoc.org](http://www.hydroassoc.org) with information on how you can be an advocate and share in this amazing work.

If you would like to be on the advocacy email list, want more information or have questions, contact me at (888) 598-3789 or [debra@hydroassoc.org](mailto:debra@hydroassoc.org).

**Together we can make a difference!**

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## Reflecting on Making a Difference: My Experience at the Conference & Advocacy Day

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*By Jill Nehrig, Association Member*

Some of the many difficulties of living with hydrocephalus include feeling a sense of no control, dealing with unanswered questions, and lack of awareness about the condition. Many times you'll walk into the doctor's office full of questions and walk out with just as many, if not more, unanswered questions. As a patient, it is frustrating to realize that the main type of treatment, shunting, was developed over 40 years ago, and yet even today there is no guarantee as to the success of your procedure.

I have always wanted to contribute to getting the word out about hydrocephalus, or in some way help to better understand this condition. On May 30, 2006, I finally felt I was able to help make a difference in the fight to learn more about hydrocephalus. 120 people from 24 different states took the word "hydrocephalus" to the steps of Capitol Hill. This was one of the most empowering moments of my life. I have always felt passionately about hydrocephalus and was finally able to provide information to those who

have the power to give us the tools and resources we need to better understand the condition that affects us all. Getting to meet with my representatives not only meant helping the Association, but also representing the researchers working so hard to learn more about hydrocephalus, those who still live with this condition, and those who have passed away.

I felt this experience was the best therapy I could ever have to help me cope with my hydrocephalus. By taking action, it decreased the feeling of helplessness which so often accompanies hydrocephalus. Visiting Capitol Hill was a chance to take action and filled me with a sense of hope. It is my hope that those of you who went to Washington were able to walk away with the same sense of accomplishment that I did. We did a great thing! We helped lay a foundation for gaining more knowledge and understanding of hydrocephalus. We can only go up from here, and with the determination of the Association and all of us, we will move forward in the exploration of hydrocephalus.

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## A Long, Rewarding Journey to the Conference

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*By Tara Smoot, Association Member*

I set out for the National Conference on Hydrocephalus on May 23, 2006 from Tacoma, Washington. After winding through Spokane, Billings, Denver, St. Louis, and Pittsburgh, my bus arrived three days later on May 26, 2006 in Baltimore, Maryland.

I can't express enough gratitude to all of you who organize the Hydrocephalus Association's biennial conferences. You truly put in a tremendous amount of effort into making arrangements for the workshops. It is a weekend full of educational information that can be put toward a good purpose. All of the fun events we have after each workshop make the conference an even richer experience.

Though some may consider me crazy for traveling over 144 hours on a bus, I believe my trip to and from the conference was a blessing in itself. Despite the many miles of the journey, what matters most are the heartfelt connections each of us make at the conference. In reality we are a distance from one another, but for me, every conference feels like a big family reunion. I consider it a true blessing to be a member of a very loving family that cares so much about the daily challenges of every stage of hydrocephalus.

On my return to Tacoma I saw even more cities and enjoyed the beautiful scenery across the country. We even stopped in Salt Lake City for a meal—and I already know that I will definitely see everyone there in 2008!

## Association Presents Three Lifetime Achievement Awards in Baltimore

By Dory Kranz

It was my honor at the recent conference in Baltimore to present the first-ever Hydrocephalus Association Lifetime Achievement Awards to three people who, by working tirelessly as individuals and together, exemplify the way partnership between medical practice, industry and patient advocacy can make a difference in people's lives—in the lives of all of you who are touched by hydrocephalus. Together they have said, "We can do better," and because of them, we are.

Of the many persons who deserve the award, we were only able to select three. We are keenly aware that others also deserve to be honored; the Association has plans to do this in the future.

In 2006, the award was given to:

**DR. MARION "JACK" WALKER, MD**, a pediatric neurosurgeon who has prolonged the lives of many of the children whom he has treated. However, he has also seen the physical struggles of repeated surgeries, infections and overdrainage along with the developmental and quality-of-life issues that put tremendous stress on families and society. He speaks up again and again to say, "Saving lives is not enough, we must attend to the

quality of those lives that we save." He has trained a new generation of neurosurgeons to believe and actively strive to improve treatment. Jack says, "We can do better," and because of him, we are.

**RALPH KISTLER**, who many people say knows more pediatric neurosurgeons than God, worked for many years for shunt manufacturers, where he used financial resources and his considerable powers of persuasion to support pediatric neurosurgeons in bettering their practice. One milestone for which he is given credit is as an instigator and supporter is having pediatric neurosurgery recognized as a subspecialty of the American Association of Neurological Surgeons and the Congress of Neurological Surgeons, giving them a stronger voice in their professional societies. Ralph built relationships with neurosurgeons at teaching hospitals and influential institutions around the world. He graciously connects us to both his friends in industry and neurosurgery, and helps us advocate that we can do better. And we are.

**EMILY FUDGE**, a mother who simply refused to accept the conventional wisdom about limiting her expectations for her child with hydrocephalus, became an active and vocal advocate. With the con-

stant and essential support of her husband Russell Fudge, Cynthia Solomon and others, she founded and led the Hydrocephalus Association for 20 years. She has built relationships with doctors like Jack Walker and industry representatives like Ralph Kistler. She has modeled how we can work together to demand more—more understanding, more awareness, and more hope. Emily, thank you for saying, "We can do better." Because of you, we are.

The artwork for the award was created by Jay McGrath, an eleventh grade student at Benedictine High School in Cleveland who participated in the Cleveland Clinic eXpressions™ program last fall. McGrath's artwork consists of a painting interpreting the research done by Nick Zingales, a twelfth grader at Benedictine High School who studied blood vessel density and oxygen deprivation in hydrocephalus patients during his 2005 summer internship at Cleveland Clinic.

A picture of these recipients and their awards is included with other conference photos on page 8. Please join us in congratulating these champions of change.

*You are cordially invited...*

*What:* To renew your membership or join the Hydrocephalus Association

*Where:* Please click on the "Membership" button at [www.hydroassoc.org](http://www.hydroassoc.org)  
Or, send a check with the membership form at the back of the newsletter

*When:* Today!

Much to our chagrin, there was a mishap with our membership mailing this spring and many people did not receive their invitation to renew or join as a member.

Please consider this your invitation to join or renew your membership today. Membership is a crucial contributor to our annual revenue. If enough people respond to this request in the newsletter, we will not need to incur the time and expense of another mailing and can direct those funds to important advocacy and support work.

## Congratulations to Our 2006 Scholarship Recipients!

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*Continued from page 1*

*Compiled by Pip Marks*

**Nathan Myer Auldrige** was a senior at James Madison University in Harrisonburg, VA when he was diagnosed with a brain tumor and hydrocephalus in 2005. He is looking forward to returning to school in the fall of 2006. Nathan is a theater major with a minor in film studies. In high school, Nathan was the co-editor-in-chief of his yearbook. He played on the soccer team and had parts in the school plays. Nathan loves hiking, photography, and enjoys nature. Nathan says, "This whole experience has definitely given me a new perspective on life. I have always described myself as a square peg who doesn't particularly want to fit into the round holes of society and I hope to use my creativity to make a contribution to the world in some way."

**Joseph Broc** has been accepted to the Marine Sciences program at Hawaii Pacific University and plans to study marine biology. Joseph has a host of interests: canoeing, boogie boarding, swimming, comedy, singing, and writing poetry. He has traveled to Alaska and Minnesota with his youth group to work on independent living and leadership skills. Joseph also helps to train service dogs that will be placed with individuals who use wheelchairs for mobility. Joseph says, "It takes me a long time to do in-class school work and homework because I have struggled with reading and math. I would help others with hydrocephalus by teaching them how to live with it successfully."

**Andrew Elkin** is attending the University of Pennsylvania, Punxsatawny campus and interning with the Pennsylvania State Police, Bureau of Liquor Control Enforcement. Andrew's

long term goal is to be a State Trooper. Andrew was on his high school track team and participates in weight lifting. He would like to help others with hydrocephalus by "letting them know to never give up and helping them find that there is something out there that each of us can accomplish." Andrews feels he has learned patience and compassion for others through his struggles living with hydrocephalus.

**Robin Ennis** has just finished her senior year at the University of Denver where she received her Bachelor of Science in Human Communication. Robin is planning to pursue her Masters degree in counseling. Robin is visually impaired and would like to help others with hydrocephalus by giving them encouragement to never give up, but to instead pursue their goals and dreams in life. She loves to read (listen to audio books) fiction and non fiction, listen to music, travel, and play video games. For Robin, education is very important because, "It challenges me to new heights. Furthering my education proves that I can achieve whatever I put my mind to. I did not realize how important it was to me until my freshman year in college when I became ill and lost my eyesight. Instead of dropping out and being defeated by my situation, I was determined with strong will to continue on." Robin attended the 2006 Hydrocephalus Association conference in Baltimore.

**Austin Hitchin** will be attending Orange Coast College in Costa Mesa, CA. He loves to play guitar, write music, sing, and act in local theater. Austin will be pursuing a certificate in Neurodiagnostic Technology and eventually plans to become a neurologist. Austin has a deep respect for others who have had brain surgeries: "This respect, curios-

ity and awareness, from having hydrocephalus has helped me guide my path toward my college and career goals." One of Austin's senior year projects was going to local clubs and churches presenting a PowerPoint presentation on hydrocephalus awareness. He also attended the 2006 Hydrocephalus Association conference in Baltimore.

**Kaitlyn Nivins** hails from Port Jervis, NY and will be pursuing a career in health care with the ultimate dream of becoming a doctor. Kaitlyn has had to undergo 40 shunt revisions in the past three years. Despite missing so much high school, she persevered in keeping up her grades and never lost hope. Kaitlyn has been accepted into two colleges and will be attending Mount Saint Mary Dominican College where she will study biology. Kaitlyn also attended the 2006 Hydrocephalus Association conference in Baltimore.

**Molly Kate Wilkinson** from Dewey, AZ will be a freshman this fall at the Yavapai Community College in Prescott, AZ where she will strive to become a Registered Nurse to fulfill her dream of working in the Pediatric Intensive Care Unit at Phoenix Children's Hospital. Molly Kate is currently serving on the Phoenix Children's Hospital Children's Advisory Board. She also was a Children's Miracle Network ambassador representing thousands of children with chronic conditions throughout the United States. Molly Kate has a passion for drawing, laughter, and exploring the wilderness. To date, she has had 52 brain surgeries but believes hydrocephalus has been a blessing in disguise for her as it has allowed her to understand how precious each day is and to not take anything for granted.

## “This Mountain Of Mine”: Scholarship Applicant Champions

By Two Members of the Scholarship Committee

In their popular song, “Speed of Sound”, the band Coldplay sings, “How long do I have to climb up on the side of this mountain of mine?” These lyrics seem to refer to the parts of our lives that can be a struggle, with the all-too familiar steps of putting your life in someone else’s hands, re-building, and fighting back. As many of you know, it gets old and it wears you down. However, some of us have the opportunity to read about, meet, and talk to the extraordinary individuals who apply each year for Hydrocephalus Association scholarships.

One touching aspect of being on the Association scholarship committee is simply our exposure to the applicant pool: champions who open their lives to us in a very personal way. The very real stories inside the applications challenge your strength, hurt your feelings, and amaze you beyond belief. They are laced with conflict and struggle:

*“I’ve had over 40 shunt revisions in three years.”*

*“For me, 2006 started out with five weeks in the hospital, five surgeries including an unsuccessful ETV, and finally the placement of a V/P shunt.”*

*“I did not realize how important education was to me until my freshman year of college when I became ill and lost my eyesight.”*

The scholarship applicants are bold, courageous, and battle-tested. Their stories contain elements of overcoming great obstacles that lift you up and remind us of what great people do in the face of life’s challenges:

*“They told my parents I wouldn’t walk or talk until I was two. I did both by the time I was two.”*

*“I’ve been to the state championship twice with my team.”*

*“I never gave up hope.”*

*“Because I have to work harder, I have become stronger.”*

*“His father fashioned a handle on a bat so Joe could hit the ball and use it with one of his braces to hustle down to first base. The players learned quickly not to underestimate him.”*

*“She is one of my heroes. I witnessed firsthand a rare form of commitment and ‘never say die’ attitude unlike others her age.”*

*“She has become an excellent role model.”*

*“She is an example of what can be accomplished with hard work, grit, and determination.”*

Interestingly, there is one other common thread in this group of applicants. They all have a tight network of support and they have almost always found ways to give back to their community through sustained service.

Being on the Hydrocephalus Association Scholarship Committee has left an indelible impression on all of us; the courage, compassion, integrity, resourcefulness and lack of self-pity that the applicants possess is genuinely inspiring. The process of selecting seven scholarship recipients out of 50 applications is difficult to say the least.

Scholarship applicants: We honor all of you who took the time to apply for the scholarships and truly wish each of you could have received one. You are the future. You stand on top of a mountain, arms raised, a beacon of hope for us all. We are humbled for being allowed a glimpse into your amazing lives. Thank you.

*The Association thanks the Scholarship Committee for their dedication and good work.*

### 2006 SCHOLARSHIP FINALISTS

Congratulations all the 2006 Scholarship finalists! Their hard work and accomplishments continue to impress and inspire us all.

Nichole Abbati  
Amanda Acosta  
Corin Araujo  
Elise Atiee  
Roberta Bader  
Frank Barnes  
Jennifer Bechard  
Annabeth Broyles  
Brittany Fasnacht  
Benjamin Gearren  
Amber Harven  
Marcus Hoefft  
Amanda Huelsman  
Kristin Kennedy  
Lacy Krueger  
Meredith Lynch  
Brittany Mangham  
Paige Mathis  
Ryan McRae  
Nicole Ness  
Christine Pappalardo  
Rachel Parker  
Lauren Reilly  
Amanda Rypel  
Tarron Sarvas  
Elana Schwartz  
Matthew Schwerha  
Justin Spix  
Louise Turner  
Sara Vaden  
Catherine Windyk  
Jamie Wright

## TEAM Hydrocephalus 2006: Now Nationwide!

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By Gina DeGennaro

It's that time again—time to start thinking about TEAM: Walk-Run-Wheel-a-thons! TEAM events are great opportunities to network with other families and promote awareness of hydrocephalus while raising funds for the Hydrocephalus Association. This year there will be 11 TEAM events hosted in ten states, up from last year's tally of seven events in seven states.

At our website, [www.hydroassoc.org/TEAM.htm](http://www.hydroassoc.org/TEAM.htm), there is information about each event, how to register and how to donate. You can also donate to our General TEAM Hydrocephalus Nationwide 2006 Fund at this site, or at <http://www.active.com/donate/hydrocephalus>.

nate/hydrocephalus.

If there is not an event planned in your geographic area, please consider hosting a TEAM fundraising event. We have gathered a list of ideas to get you started and can explain how to host and coordinate an event in your area. Email [gina@hydroassoc.org](mailto:gina@hydroassoc.org).

We would like to thank all of our TEAM leaders for their outstanding support, generous time, complete commitment, and unbelievable determination. Without them, these TEAM events would not be possible. Thank you for all of your hard work in helping us promote awareness of hydrocephalus, raising funds for the Association, and hosting networking events for those affected by hydrocephalus. Go TEAM!

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**California: Angel Island**  
San Francisco, CA  
September 10, 2006

Contact: Hydrocephalus Association  
(415) 732-7040, [pip@hydroassoc.org](mailto:pip@hydroassoc.org)

**Colorado: Northridge Park**  
Highlands Ranch, CO  
September 17, 2006

Contact: Phyllis (303) 346-9566,  
[hydropr2@comcast.net](mailto:hydropr2@comcast.net)

**Florida: Mandarin State Park**  
Jacksonville, FL  
September 23, 2006

Contact: Kimberly (904) 880-8444,  
[kbelzer@comcast.net](mailto:kbelzer@comcast.net)

**Florida: Largo Central Park**  
Greater Tampa Area, FL  
September 3, 2006, 9:00 am

Contact: Paula (727) 415-7339,  
[paula@keyserproductions.com](mailto:paula@keyserproductions.com)

**Georgia: Wills Park Recreation Center**  
Alpharetta, GA  
September 17, 2006, 12:30 pm

Contact: Debbie (404) 325-9874,  
[cran6275@bellsouth.net](mailto:cran6275@bellsouth.net); Linda (770)  
751-0484, [linda.preuss@gmail.com](mailto:linda.preuss@gmail.com)

**Illinois: Yankee Woods Chicago**  
Tinley Park, IL  
October 7, 2006, 10:30 am

Contact: Sherry (708) 560-0460,  
[walkchicago@sbcglobal.net](mailto:walkchicago@sbcglobal.net)

**Kentucky: England Idlewild Park**  
Burlington, KY  
September 17, 2006

Contact: Kim (502) 570-0810,  
[Kimberly.Baker@ky.gov](mailto:Kimberly.Baker@ky.gov)

**Maine: Back Cove Trail and Payson Park**  
Portland, ME  
September 10, 2006, 1:00 pm

Contact: Ralph (805) 683-4291,  
[RKis15960@aol.com](mailto:RKis15960@aol.com)

**New Jersey: TEAM Liberty**  
Liberty State Park  
Jersey City, NJ  
October 22, 2006, 11:00am

Contact: Chris (973) 661-9507,  
[capriccio@aol.com](mailto:capriccio@aol.com)

**Pennsylvania: Norristown Farm Park**  
Norristown, PA  
November 5, 2006, 9:00 am

Contact: Marybeth (610) 664-1355;  
Kelly 610.277.7339; [pahydrowalk@aol.com](mailto:pahydrowalk@aol.com)

**Washington D.C.: Burke Lake**  
Northern Virginia  
September 10, 2006, 10:00 am

Contact: Mimi (703) 406-8021,  
[mkr3@cox.net](mailto:mkr3@cox.net)

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## More Fantastic Fundraisers

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Some of our members are literally going the extra step to raise funds for the Hydrocephalus Association. Please show them your support by donating to or attending their fundraising event. Visit [www.hydroassoc.org](http://www.hydroassoc.org) and click on Events on the left-hand menu.

**Hydrocephalus Golf Outing: Long Island, NY** The Hydrocephalus Association is proud to announce our first golf outing! The event is being run by member Nicole Russo. The golf outing will take place on August 1, 2006 at Eisenhower Park Golf Course in Long Island, NY at 1:30 pm. For information, please contact Nicole with your name and mailing address at [nicolelaurenrusso@gmail.com](mailto:nicolelaurenrusso@gmail.com), or call

her at (516) 448-8982.

**San Francisco Marathon** Association member Jennifer Jimenez Marana will run the half-marathon portion of the San Francisco Marathon on July 30, 2006 to raise funds for the Association. Her son, William, was born premature and diagnosed with hydrocephalus. To support Jennifer and sponsor her run, visit her website: [www.active.com/donate/runforwill](http://www.active.com/donate/runforwill).

**Chicago Marathon** Association member Tomi-Ann Roberts will run her first marathon at the Chicago Marathon in October of 2006. Her mother contracted hydrocephalus after a hospital infection and is now shunted. In honor of her

mother, Tomi-Ann will donate proceeds to the Association. For more information and to donate, please visit [www.active.com/donate/marathonformom](http://www.active.com/donate/marathonformom).

Very Special Kids with Very Special Birthdays

By Pip Marks

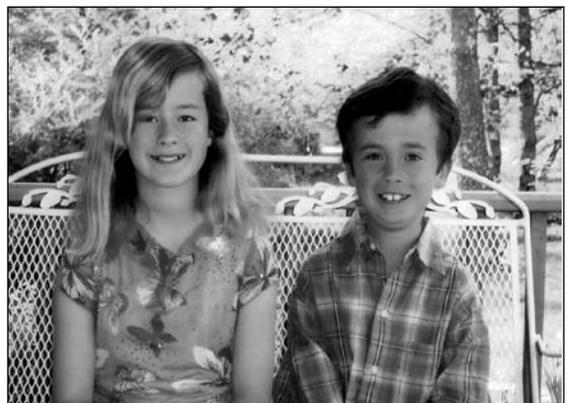
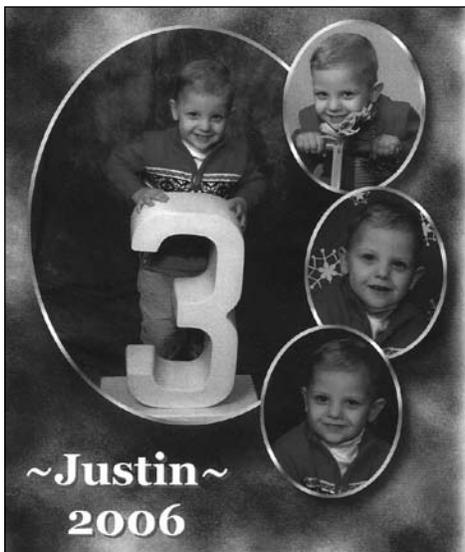


**J**ack Johnson, for the fifth consecutive year, held a fundraising birthday party: he asks for donations to be made to the Association in lieu of gifts. Jack turned double digits this year—and raised \$225! Jack’s younger sister, Grace, has hydrocephalus. His mom, Robin says, “We are so proud of our son for his willingness to give up his birthday presents in exchange for helping others. This is a difficult concept for children to understand and he seems to have grasped it well.” **Happy 10th birthday Jack!** Thank you!



**T**o celebrate Nicole Lemieux Tsicouleas’ first birthday in May, her parents, Stephen and Susan, asked friends, family and business associates to make donations in her special honor to the Hydrocephalus Association. They raised \$7000! Nicole was born prematurely and infection in the brain led to a diagnosis of hydrocephalus. Nicole has three catheters and two complete shunt systems in her little body. Thank you Nicole, Stephen and Susan. **Happy first birthday!**

**J**ustin Walker, born with hydrocephalus and cerebral palsy, turned three in January. His loving grandparents, David and Mary Jo Lawrence, asked family and friends to make donations in honor of Justin’s birthday. They raised over \$600 for the Association. David and Mary Jo wrote in their letter, “The Hydrocephalus Association is the most efficient and compassionately run organizations we have ever dealt with. The Association has been invaluable to us in dealing with Justin’s hydrocephalus.” **Happy birthday Justin!**



**F**or the second year in a row, Sloan Winters has celebrated her birthday by having donations made to the Hydrocephalus Association in lieu of birthday gifts. This year, Sloan turned 11 years old and raised \$300 in honor of her brother, Luke. Sloan wrote, “Please use this money to help study hydrocephalus and to help kids like Luke.” **Happy birthday Sloan!** Thank you!

# Unity+Diversity: Learning from One Another



*The conference attendees were a diverse group; in this photograph, those with hydrocephalus gathered to embrace their differences while showing their unity and pride.*



*From left, Ralph Kistler, Emily Fudge and Dr. Marion “Jack” Walker, MD, received the Hydrocephalus Association’s Lifetime Achievement Awards for their consistent and profound dedication to those with hydrocephalus.*



*Activists in Washington, D.C. held signs displaying their connection to hydrocephalus: the name of the person with hydrocephalus, how they are related, number of surgeries, and home state.*



People with hydrocephalus, their family members and friends—120 strong—gathered before meeting with their legislators' staffs.



*These signs helped put a human face on a serious neurological condition in need of significant medical research.*

## 2006 Conference Presentations, Pictures and T-Shirts Now Available

For those of you who attended this year's conference, *Unity and Diversity: Learning from One Another*, and for those who missed it, we are collecting workshop presentations and posting them online. We can't promise that we will get all of them, but will share with you the ones we do receive.

To view the presentations go to the Hydrocephalus Association's website at [www.hydroassoc.org](http://www.hydroassoc.org), select "Events" from the left-hand menu bar, scroll down to the bottom of the page and click on the link to view conference presentations.

Conference pictures are also available to view and order at [www.pictage.com](http://www.pictage.com). Type "Hydrocephalus" in the "Find Your Event" window and follow the instructions to sign up to be notified when the photos are released. You will then receive an email from Pictage with instructions on how to view and order photos.

You can get conference T-shirts by contacting the Association office by phone: (888) 598-3789 or email [info@hydroassoc.org](mailto:info@hydroassoc.org). T-shirts are only \$10 for one and \$15 for two! They feature our conference logo, "Unity and Diversity" on the front, and conference information on the back.

Be sure to check in during the weeks to come for additional information and presentations. And start planning the 10<sup>th</sup> Annual Hydrocephalus Association National Conference June 20-23, 2008 in Salt Lake City, Utah. There are many wonderful national parks in Utah, including Bryce, Zion, and Canyonlands, so consider planning a family vacation before or after the conference in this beautiful part of the country.

## We Would Like to Thank More of Our Generous Donors

*In the Spring Newsletter, the list of people in whose honor donations were received was inadvertently omitted. Please excuse our oversight.*

*In 2005, donations were made in honor of:*

Matt & Luann Abrams  
Matt & Luann Abrams' wedding  
Candy Agpawa  
Lindsey Ashton Albro  
Chase Alvarado  
Marks Anderson  
Stephanie E. Arnold  
Jacob T. Arnone  
Joshua Ayers  
Nancy A. Bagster-Collins  
John-Henry Baker  
Renee D. Barr  
Joshua Bashant  
Dr. & Mrs. Larry Basirico  
Charlie Battersby  
Jacob Bender  
Holly & David Bergeson  
Thomas Lee Bills  
Carolyn Binder  
Ryan Birko  
Jean Bjork  
Diane Bojarcik  
Justin Bolen  
Sarah-Beth Bowers  
Dr. William Boydston  
Kurt Ryan Brailsford  
Duane & Carol Brekken  
Daniel Breton's fourth birthday  
Kiana Brown  
Betty Jo Bruce  
Katherine Buchanan  
Herb Calhoun  
Zoe Cameron  
Joan Cantoni  
Veronica Card  
Preston Caswell

Christina M. Cavanaugh  
Stephen Cerio, II  
Katie Chadwick  
Aaron Chapple  
Chapple Family  
Lesli Charles Battersby  
Reece Christian  
Finn A. Clancy's first birthday  
Bob Clough  
Codman  
Eleanor Conelley  
Dr. Harold Conn  
Tim Connor  
Jorge Luis Corro  
Jason D. Cote  
Ali Cryan  
Valerie D'Amato  
Jamie Danyko  
Shana Daum  
Zachary Dean  
Hunter Thomas Dellinger  
Brent Dillard  
Kalea Dorow  
Wesley Eason  
Alex Edwards  
Nina Egger  
Jan Elliott  
Stanley Ellis  
Rachel Engelmann  
John-Frederick Escher  
Lauren Ewing  
Ian Chun Farnkopf  
Emily Farrell  
Emily Faulhaber  
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Will Friebel  
Melissa Fruia  
Emily Fudge & all whom she has helped  
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Clayton Willever

### Turn Your Vacations into Donations!

The Hydrocephalus Association is proud to announce a new website, [www.travelforhydrocephalus.com](http://www.travelforhydrocephalus.com) at which you can book your travel at no additional cost to you while financially supporting the Association. The website will be available August 1, 2006.

Every time you book your personal and business travel, whether it is for airline, ho-

tels, cruises, car rentals, even concert tickets at [www.travelforhydrocephalus.com](http://www.travelforhydrocephalus.com), the Association will receive 40% of travel commissions while you get low competitive travel prices comparable to other travel websites.

Remember, starting August 1, 2006 turn your vacations into donations by booking your travel expenses at [www.travelforhydrocephalus.com](http://www.travelforhydrocephalus.com).

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## Board Member Profile: Ralph Kistler

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*Ralph Kistler is the next board member to be profiled in our series. He is the recipient of the Hydrocephalus Association's Lifetime Achievement Award, and his picture can be seen on page 8.*

When I got my first position in the medical device industry in the late 1960s selling Isolette® incubators for premature infants in New England, I had no idea that the next 37 years would be such a terrific ride. From New England to Pennsylvania to Georgia to Florida, and finally to Santa Barbara, California, I worked in many clinical areas. The last half of my career in neurosurgery, however, has been by far the best.

The position I held when I retired, Vice President of Sales for Medtronic PS Medical, was a great one. Not only did I become closely acquainted with pediatric neurosurgeons, the group of special-

ists I shall always believe to be the best people I have ever known, but I also became involved with people all over the world who were looking for better ways to manage hydrocephalus. I was able to assist pediatric neurosurgery positively, which is a great source of pride for me. I continue to act as a consultant to Medtronic, so am able to keep my relationships current and participate in neurosurgical events.

I also became acquainted with a human dynamo named Emily Fudge. With her gentle arm-twisting, I began my relationship with the Hydrocephalus Association, initially with financial support. When I began attending the conferences, I was hooked. Never had I met people who were as courageous, interesting and resilient as those who were affected by hydrocephalus, both individuals and their families. When I retired from

Medtronic in 2002, Emily surprised me by asking if I'd be interested in serving on the Board of Directors. Naturally, I jumped at the chance.

I'm a very lucky guy—I've had a great career, I have a wonderful family and I have amazing friends (although those of you who were in Baltimore saw that Dr. Jack Walker picks on me!). My wife, Dale, and my kids, Greg and Beth, totally support my efforts on the behalf of the Hydrocephalus Association. I only hope that I can continue to be of service in the future, and that I get to live long enough to see *real* advancements in the treatment of hydrocephalus. It is my belief that efforts like our recent visit to over 100 legislators on Capitol Hill and last year's workshop with NIH have the potential to direct more research money to hydrocephalus and move us forward.

I hope those of you in the Northeast can join Dale and me for TEAM Maine on September 10 in Portland!

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## Preparing for Employment: On the Home Front

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*By Sean Roy and Beth Casper*

Young people looking for their first jobs may be overwhelmed by the process and want or need to seek help from others. Individualized Education Program (IEP) teams can help young people with disabilities develop a plan that includes employment goals. Schools can also help youth develop specific career skills by guiding students to courses necessary to enter a particular field, helping students practice interviewing and asking for employment accommodations, or offering work-based learning opportunities.

Work-based learning during the school years leads to better post school employment outcomes (Hughes, Moore, & Bailey, 1999). Volunteer experiences and unpaid internships, in addition to paid employment, can be stepping stones to future employment. Youth and their families need not rely solely on school programs to pursue such opportunities. They can do much on their own to

launch the youth's career search. Recent studies demonstrate the effectiveness of using personal networks as a job search strategy (Timmons, Hamner, & Boes, 2003), and highlight the fact that families make key contributions to successful employment outcomes for individuals with disabilities (26th Institute on Rehabilitation Issues, 2000).

There are creative ways to combine community relationships, a young person's interests, and family or personal networks to help a young person effectively explore work-based learning outside of school settings. Parents may seek opportunities through co-workers, relatives, and neighbors. Moreover, parents often know their children better than professionals do and can help their sons and daughters explore their unique abilities, strengths, and interests—all of which may lead to an appropriate career path.

Many practical strategies for preparing a young adult with disabilities for employment are not difficult. These include such things as assigning chores at home,

encouraging youth to volunteer in their community, or keeping an eye open for employment opportunities. Families can adopt these or other approaches within their own communities or share their ideas with the IEP team. The insights of family members can serve as the basis for strategies and services identified in a student's IEP transition goals. Youth can also learn to be self-advocates in seeking a good job.

*This summary is from PACER Center's publication, Parent Brief, March 2006. The complete publication and references are available at [www.pacer.org/swift](http://www.pacer.org/swift). Used with permission from PACER Center Inc., Minneapolis, MI. All rights reserved.*

*For more information on work-based learning, please explore these resources:*

- National Center on Secondary Education and Transition (NCSET) at:[www.ncset.org](http://www.ncset.org)
- PACER Center at:  
[www.pacer.org/swift](http://www.pacer.org/swift)
- National Collaborative on Workforce and Disability for Youth at:[www.ncwd-youth.info](http://www.ncwd-youth.info)

## Thank You, California NeuroAlliance: Modeling Advocacy in Action

By Daniela Salas

We would not have had such a successful Hydrocephalus Advocacy Day in Washington DC had it not been for many wonderful leaders, organizations and coalitions that advised and inspired us along the way. One of these has been the California NeuroAlliance under the able leadership of Eric Hauth of the American Association of Neurology and Stewart Ferry of the Multiple Sclerosis California Action Network.

California NeuroAlliance is a partnership of patient advocacy non-profit organizations representing millions of California residents affected by neurological conditions, their advocates and physicians. Its mission is to improve quality of life by promoting access to quality health care through education, public awareness and advocacy. The Hydrocephalus Association is a proud member of this coalition along with 13 other organizations.

In March 2006, Association staff participated in California NeuroAlliance's 6th Annual Conference in Sacramento, California. The conference addressed emerging public policies that affect people with neurological disorders.

We spent the first day learning about healthcare issues that affect people living with neurological conditions; then focused on three California State bills that

would impact people with neurological conditions if passed into law. Two of the bills have significance to people affected by hydrocephalus. AB 2281 sets limits on High Deductible Health Plans (HDHP). HDHPs have lower premiums but usually higher annual deductibles (usually over \$1,000 for an individual). The insured person must pay the full deductible amount before the insurance plan pays for any health care service. SB 1312, the Nursing Home Reform Bill, requires

the State Department of Health Services to enforce all state nursing home laws. On the second day, 26 teams, each consisting of two to four people representing different neurological conditions, went to the State Capitol building to lobby legislators to oppose AB 2281 and support SB 1312.

We returned to our work at the Association feeling inspired. Cal NeuroAlliance's conference was a great model for our Hydrocephalus Advocacy Day!

### MAKE YOUR VOICE HEARD!

While at the conference, we had the opportunity to learn about the California NeuroAlliance website and online survey. If you are affected by a neurological condition, we encourage you to go online and complete the survey. The information from this survey is very important to help educate elected representatives in Sacramento, healthcare executives and the public about the critical healthcare needs of people living with neurological conditions. The information can help ensure that their decisions reflect your needs.

Although at this time the focus is on Californians with neurological conditions, the American Academy of Neurology and member organizations of the California NeuroAlliance hope to expand this effort nationally. By including your zip code, they can collect important information from other areas of the country. Your participation will help them build a national version of this important survey and advocacy tool.

Check out Cal NeuroAlliance's website at [www.calneurosurvey.com](http://www.calneurosurvey.com) for more information and access to various surveys, including one for hydrocephalus. If you have not taken the hydrocephalus survey on the Association website, you can take it on the Cal NeuroAlliance website and the hydrocephalus-specific data will go into the Association survey as well. If you have already taken the hydrocephalus survey on the Association website, you can still take the Cal NeuroAlliance survey as duplicate data that goes into the Association survey will not be counted twice.

### First Annual "Tour De Vendage" Bike Ride Announced

San Jose Police Amateur Athletic Foundation (PAAF) announces the First Annual Tour De Vendage bike ride, benefiting the Hydrocephalus Association. It is to be held September 2, 2006, in Livermore, CA. The Tour is a gentle 50-mile bicycle course passing through the rolling hills and wineries of the beautiful Livermore Valley. The ride is suitable for any level of rider. The entry fee is \$40 and all participants receive a commemorative shirt and lunch after the event. For more information contact: Police Amateur Athletic Foundation Sgt. Rich Mongarro, Event Director, at (408) 690-9637 or visit [www.sjpaaf.org](http://www.sjpaaf.org).

### HYDROCEPHALUS ASSOCIATION VOLUNTEERS WANTED!

The Hydrocephalus Association is looking for a few volunteers for the summer. If you are interested in volunteering or interning with the Hydrocephalus Association, please email Daniela Salas at [Daniela@hydroassoc.org](mailto:Daniela@hydroassoc.org).

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## Neuropsicología Pediátrica

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*This article is a translation of "Pediatric Neuropsychology" by Norman J. Cohen PhD published in the Hydrocephalus Association Newsletter in Fall 1999. Please contact our office if you would like to request an English version.*

### Evaluación Neuropsicológica

¿Qué hace un neuropsicólogo? Un neuropsicólogo analiza las diferentes formas de razonamiento presentes en un niño y combina estos resultados con información obtenida de otras fuentes, tales como escuelas, padres y doctores. De este estudio se intenta determinar cuales son las destrezas y dificultades en el razonamiento de un niño.

Durante la evaluación neuropsicológica, el niño pasa por una serie de pruebas diseñadas a determinar como el niño resuelve diferentes tipos de problemas o desafíos. Estas pruebas incluyen ejercicios de memoria, de palabras y además ejercicios visuales (como rompecabezas). Idealmente, estas pruebas también incluyen algún tipo de evaluación general de inteligencia, habilidades de lenguajes al-

canzadas, memoria, atención y concentración.

En total, estas pruebas pueden llevar de cuatro a ocho horas de contacto directo entre el evaluador y el niño. Debido a esta larga duración, generalmente las pruebas se dividen en dos o tres sesiones. Aún cuando muchos niños reciben evaluaciones a través de la escuela, una evaluación neurológica entrega resultados más completos y detallados, midiendo de mejor manera las necesidades de un niño con problemas de aprendizaje.

### Evaluando los Resultados

Una vez que el neuropsicólogo termina la evaluación, las pruebas reciben un puntaje para ver como el niño ha respondido en relación a otros niños de la misma edad. Como resultado, puede ser que el neuropsicólogo sugiera un tratamiento específico para determinados problemas identificados con la capacidad de razonar del niño.

Por ejemplo, algunos niños tienen dificultades con ejercicios que requieren

un planeamiento paso a paso. Estos niños son buenos respondiendo problemas cortos y rápidos. A estos niños probablemente se les enseñara técnicas para reducir la velocidad de razonamiento, en lugar de lanzarse a conclusiones, y también como resolver paso a paso un problema con un plan.

### Conclusión

La evaluación neuropsicológica es exitosa, cuando se obtiene como resultado un plan específico diseñado a mejorar las habilidades del niño para triunfar en la escuela, en la casa y en todas partes donde enfrente tareas que requieran habilidades de razonamiento y tomas de decisiones que enfrentamos diariamente. Una buena evaluación psicológica resulta con un plan que hace que el niño sea más capaz de desarrollar diferentes tareas, para sentirse más feliz, seguro de sí mismo, y para integrarse mejor en la vida familiar y estudiantil.

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## In Memoriam: Jo Kranz

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*By Emily Fudge*

Josephine Shull Kranz, mother of board member Jim Kranz and mother-in-law of Executive Director Dory Kranz, died at her home in Rocky River, Ohio, on April 22, 2006. With the passing of this woman of grace, wit and intelligence, the Association has lost a generous benefactress and dear friend.

Jo was a woman of style, a "classy dame" with a wide circle of friends and a variety of interests. At age 65 she wrote a book called *The Bluenose Master*, the memoirs of sea captain Ernest Hartling, who was skipper of the tall ship *Bluenose II*, a replica of the two-masted ocean fishing and racing vessel depicted on the back of the Canadian 10-cent coin. She

was involved in the Huntington Playhouse in Bay Village, Ohio, and was a classic car fan, serving on the board of the Frederick C. Crawford Auto-Aviation Museum and editing the newsletter of the Classic Car Club of America.

Jo and her family first became involved in the Hydrocephalus Association in the late 1990s, when her husband, Dick, was finally diagnosed with NPH after many frustrating and painful years of declining health. A shunt was inserted and for four days Dick returned to his dynamic and clear-thinking self. Sadly, he then suffered a stroke and died. In his memory Jo began generously providing funding for our budding NPH program, including publication of our booklet *About Normal Pressure Hydrocephalus—A Book for*

*Adults and Their Families* and other projects to help spread the word. She attended our conferences and graciously took time to talk with and counsel other older adults struggling with NPH.

Just as Jo created a strong and meaningful legacy of her husband through her generosity to the Association, her family is creating a legacy to her. At our recent national conference in Baltimore, her daughter Leslie and three of her teenage grandchildren, Merrick, Ally and Erin were on site as spirited and hardworking volunteers. We are deeply saddened by Jo's passing, but our lives will continue to be enriched by future generations of the Kranz family.

## Darling Designs Boutique

Lisa is a work-at-home mom whose child has hydrocephalus. She is the owner of Darling Designs Boutique, which specializes in custom-made creations. They have birthday items for all ages and their designs are one-of-a-kind—you can't find them anywhere else! In honor of her daughter, Lisa occasionally sells items to benefit the Hydrocephalus Association. If you are looking for a unique gift, visit her store online at

[www.darlingdesignsboutique.com](http://www.darlingdesignsboutique.com).

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## DisabilityInfo.gov

DisabilityInfo.gov is a one-stop federal website designed to offer people with disabilities and others access to the information and resources they need to live full and independent lives in their workplaces and communities. Managed by the U.S. Department of Labor's Office of Disability Employment Policy, DisabilityInfo.gov offers a broad range of valuable information for people with disabilities and chronic health conditions, as well as their family members, service providers, employers and others.

DisabilityInfo.gov is organized into categories including benefits, civil rights, community life, education, employment, health, housing, technology and transportation. By selecting a category from the tabs at the top of the homepage, users are directed to information covering state and local resources, news and events, grants and funding, laws and regulations and more.

For information, visit:  
[www.disabilityinfo.gov](http://www.disabilityinfo.gov)  
[www.dol.gov/odep](http://www.dol.gov/odep)

You can also subscribe to receive email alerts at:

<http://service.govdelivery.com/service/user.html?code=USODEP>

## Independent Living Centers

Independent Living Centers (ILC) are typically non-residential, private, non-profit, consumer-controlled, community-based organizations providing services and advocacy by and for persons with all types of disabilities and health conditions. Their goal is to assist individuals with disabilities to achieve their maximum potential within their families and communities.

ILCs serve as a strong advocacy voice on a wide range of national, state and local issues. They work to assure physical and programmatic access to housing, employment, transportation, communities, recreational facilities, health and social services, and more.

The Independent Living USA website lists the nearly 500 ILCs in the United States. This site also offers a wealth of additional information, news, bulletin boards, etc. about and by people with disabilities.

Visit Independent Living USA at:  
[www.ilusa.com](http://www.ilusa.com).

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## Enhancing Everyday Communication for Children with Disabilities

This book, written by Jeff Sigafos, PhD., Michael Arthur-Kelly, PhD., and Nancy Butterfield, M.Ed., is a practical and concise introductory guide with real-world tips and strategies for anyone working to improve communication of children with moderate, severe or multiple disabilities. It includes case studies to illustrate assessment, intervention, and instructional procedures for positive interaction with children who have disabilities.

To order this book, go to:  
[www.brookespublishing.com](http://www.brookespublishing.com).

## Job Accommodation Network

The Job Accommodation Network (JAN) is a free consulting service designed to increase the employability of people with disabilities and chronic health conditions. It provides individualized work-site accommodations solutions; provides technical assistance regarding the Americans with Disabilities Act (ADA) and other disability-related legislation; and educates callers about self-employment options. People with disabilities become educated about their rights under the ADA and the Rehabilitation Act, acquire accommodation options, and learn about other government and placement agencies. JAN is a service of the Office of Disability Employment Policy of the U.S. Department of Labor.

You can reach JAN at:  
(800) 526-7234  
[www.jan.wvu.edu](http://www.jan.wvu.edu).

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## "Karen's Kottage"—Special Angel Dolls

Karen Challender creates handmade custom cloth dolls and can make dolls that have shunts! These can be custom ordered in various skin tones. The dolls stand 21" tall. They take two to three weeks to complete and cost \$65.00 each. For more information, visit her website:

[www.karenskottage.org/SpecialAngel.html](http://www.karenskottage.org/SpecialAngel.html).

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## A Stone in my Shoe By Caroline MacDonald

This is a moving account of the author's problems with hydrocephalus, the discovery of her brain tumor, and her daily struggle to live life as normally as possible. Caroline, now 24, has spent many years in and out of hospital, and in her book reflects on her childhood difficulties, the stigma of being different, and how she found happiness with her partner. To order this book, go to [www.amazon.com](http://www.amazon.com).

# 2006 Membership Form

Name: \_\_\_\_\_ Telephone: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_ Email: \_\_\_\_\_

Name of person with hydrocephalus: \_\_\_\_\_ Birth date \_\_\_\_\_ Age at diagnosis \_\_\_\_\_

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

**Count me in as a member for 2006. Enclosed is my unrestricted donation of:**

\$30  \$50  \$100  Other \$ \_\_\_\_\_

**How would you like to receive your quarterly newsletter?**

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

Please send my newsletter via email to: \_\_\_\_\_

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

Charge my:  VISA  MasterCard  Discover

Amount Charged \$ \_\_\_\_\_

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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. The Newsletter is published quarterly. Debra Howell is the editor. Rachel Fudge and Josie Marks are contributing editors. 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. © 2006 Hydrocephalus Association

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#### HYDROCEPHALUS ASSOCIATION RESOURCES AND FACT SHEETS

##### **The following resources are available free to our members:**

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

##### **Fact Sheets:**

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

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