

IT'S OFFICIAL: 2010 CONFERENCE ANNOUNCEMENT

By Tom Smith, Outreach and Media Liaison

The winter 2009 newsletter contained a teaser article about the location of our next conference. It was a trivia quiz asking such questions as: Where were LifeSavers candies invented? Where was Superman created? (Hint: not Krypton.) Where did Babe Ruth hit his amazing 500th home run? Since publication of the winter newsletter we have received communications from some members, but here is the official announcement of the location.

We are excited to officially announce that the **11th National Conference on Hydrocephalus will be held in Cleveland, Ohio from June 17 through June 20, 2010.** The conference will be held at the beautiful Intercontinental Hotel, a short drive from downtown Cleveland.

The National Conference is a core, defining event for the Hydrocephalus Association. Held every two years, it's a wonderful opportunity to educate ourselves on a subject that is very relevant to us all—hydrocephalus—so we can have a more technical understanding of what the condition is, how it occurs,

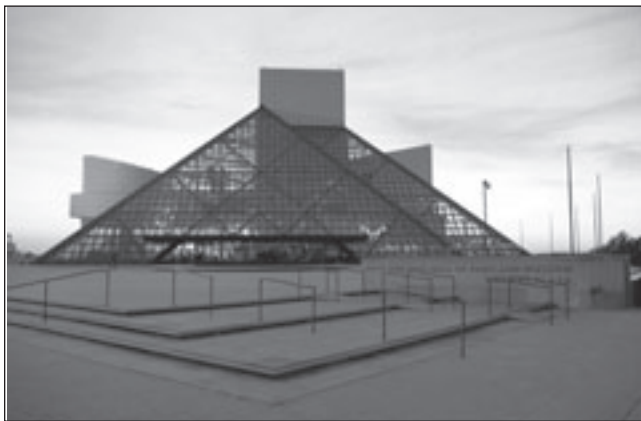


how we can deal with it, and how the medical community has progressed in treating it. Perhaps more importantly, it's an opportunity for our members to interact with each other and our tremendously supportive medical community, to meet others who struggle with the same challenges, and to meet doctors who are committed to their care. Such interaction is one of the founding core values of the Hydrocephalus Association: community.

This decision regarding location was reached after much deliberation. Because the last conference was held in the western half of the United States in Park City, Utah, fairness and balance dictated that the 2010 conference would be held in the eastern half. The finalists were Boston and Cleveland. Ultimately, several factors came into play and swung the vote toward Cleveland. The most important factors were availability of the facilities for our target dates, hotel and parking costs, and the fact that Cleveland is more central and thus more convenient from a driving perspective.

We would like to thank and acknowledge our Boston crew for their efforts and enthusiasm, especially Joe Madsen, M.D., associate professor of neurosurgery, Children's Hospital Boston and Harvard Medical School and member of the Medical Advisory Board; Peter Black, M.D., surgeon-in-chief, Brigham and Women's Hospital; and Greg Tocco, leader of our fantastic Boston, MA affiliate.

We would also like to thank our hosts for the 11th Annual Conference: Mark G. Luciano, M.D., Ph.D., F.A.C.S., head of Congenital and Pediatric Neurosurgery, co-director of
(Continued on page 18.)



Rock and Roll Hall of Fame

FROM THE EDITOR

By Tom Smith, Outreach and Media Liaison

Welcome to the spring 2009 edition of Pathways. We have included in this issue the list of donors from 2008. It is always a privilege to honor these generous people who inspire us to bring passion to our work and give life to the aspirations of our community. To put it in the simplest way, thank you.

Our feature article answers the question that is much on the mind of our membership. The location of the 11th National Conference on Hydrocephalus in 2010 has been agreed upon and we are very excited. I am personally excited to finally be able to answer a question I first

heard on the bus heading to the airport to come home from the 10th National Conference on Hydrocephalus. Watch out Cleveland!!!

We are also highlighting the amazing, the astounding, the admirable HA affiliates and advisors—the wonderful volunteers who are representing us throughout the nation at local levels. They are blazing the trail for our new era of growth, providing support, education and outreach to their individual communities.

As a community we are tremendously blessed to have the support of truly dedicated members of the medical profession. The willingness of these nurses, neurologists and neurosurgeons to give their

time, hard-won expertise, compassion and dedication has made them invaluable in the truest sense of the word. We are starting a series of articles that allow the members of our Medical Advisory Board to share the inspirations that led them to their calling.

We also introduce new board members; discuss the state of research, our latest arena of endeavor, salute the individuals in our community who are pioneering their own ways to raise awareness; and much, much more. ❖

“I stuck my head out the window this morning and spring kissed me bang in the face.” — Langston Hughes

MEET OUR NEWEST BOARD MEMBERS

By Tom Smith, Outreach and Media Liaison

The membership of the Board of Directors rotates every three years on a staggered basis. As a result, we currently have several new members coming on board.

DAVID BROWDY

David is a very thoughtful medical and education professional who has been an active participant in numerous HA activities, including attending four of our conferences. He has a 13-year-old son living with hydrocephalus and brings many skills to bear, offering valuable perspectives on medical research and the expanding roles of the HA.

CRAIG BROWN

Craig is the President and CEO of Keelers Ridge Associations and has been a key executive in global marketing. He also serves on the board of directors of the Partnership for a Drug-Free America and the U.S. Ski and Snowboard Team. Craig has a 23-year-old son living with hydrocephalus, who is currently attending Duke University. Craig is keenly interested in hydrocephalus research.

MATT KURSH

Matt was most recently the CEO of a not-for-profit named Blue Planet Run, whose mission is to raise global awareness of potable water. He has created several start-up software companies and has been an executive at Microsoft. Retired in 2000, Matt has remained very active and brings sage advice on leadership, organization, strategy and marketing to the Hydrocephalus Association.

MARC RANDOLPH

Marc has a long history in direct marketing from the early days of PC-oriented catalogues, which culminated in his founding Netflix, the popular online movie rental company. He brings us his invaluable skills in marketing and experience as an executive in numerous Silicon Valley companies. He is the proud father of three children: Logan, Morgan and Hunter.

MIKE SCHWAB

Mike is the Vice President of Development at Jesuit High School in Portland. He has worked in the development field since graduating from college and brings a wealth of knowledge and experience to the Hydrocephalus Association. Mike has a four year old daughter with hydrocephalus. ❖

IN MEMORY

Our beloved friend and colleague, Mary Smellie-Decker, died on Wednesday April 8, 2009. Mary made an enduring contribution to pediatric neurosurgery. She was especially passionate about the importance of transition treatment for persons with hydrocephalus as they grow from children to adults. She brought the same tenacity to helping children as she did to her battle with cancer. Mary was full of fun, compassion and caring. She touched and enriched thousands of lives. She was devoted to and highly respected by her patients, her colleagues and the nursing profession. We will miss Mary but never forget her.



RESEARCH INITIATIVE LAUNCHES—BON VOYAGE!

By Dory Kranz, Director of Research

The gangplank is up and our shared dream of funding hydrocephalus research is underway. Through generous donors, we have already raised \$100,000 and have given away our first \$30,000 research grant! This kickoff grant was one grateful family's way of breaking a champagne bottle over our bow for good luck on this exciting journey.

Our work will be guided by a Research Initiative Plan that outlines funding philosophies, initial priorities and the grant review process. Finalized at a meeting January 22 and approved by the Board

of Directors on February 9, this plan is based on input over the past year from the Board of Directors, Medical Advisory Board, professional development counsel, and patient advocacy groups with a strong track record of improving lives through research.

We intend to complete our first grant cycle in 2009—raising and giving away at least \$250,000 to worthy research projects. The Hydrocephalus Association will use a two-stage review process modeled on the National Institutes of Health and respected patient advocacy groups that are successfully funding research.

1. Grant submissions will first be reviewed and scored by a Scientific Review Committee focused on scientific merit and likelihood of advancing the field.
2. Taking these scientific review scores into account, a Research Committee will make funding recommendations based on all known hydrocephalus research and the strategic importance and likelihood of changing lives for the better in the near future.

If you want to learn more or provide support to the Hydrocephalus Research Initiative, please contact Dory Kranz at dory@hydroassoc.org or 415-732-7040.



RESEARCH FACT:

Public investment in hydrocephalus research is much lower than conditions with similar public health burden:

| | <u>NIH Spending FY 2006</u> |
|--|-----------------------------|
| Hydrocephalus | \$650,000 |
| Down Syndrome - Similar incidence as congenital hydrocephalus children ¹ | \$19 Million |
| TBI - Similar Hospitalization burden of 40,000/yr in children, 100,000/year adult ² | \$80 Million |
| Autism - Similar prevalence : 164,000 children living with it in 2003 ³ | \$103 Million |
| Brain Tumor - Similar hospitalization burden of 20,000/yr in children, 50,000/year adult ⁴ | \$187 Million |
| Parkinson's - Similar number of adults living with it. 1 per 100 people over 60 ⁵ | \$200 Million |

1. CDC 2006 Surveillance Report; 2. NHDS 2004; 3. Fighting Autism November 2004; 4. National Hospital Discharge Survey (NHDS) 2004; 5. Michael J. Fox Foundation

MARY SMELLIE-DECKER MENTORSHIP AWARD

By Pip Marks,
Director of Support and Education

The Hydrocephalus Association wishes to acknowledge and honor Mary Smellie-Decker, RN, MSN, PNP, for her work as a staff neuroscience nurse, nurse practitioner, and member of the Hydrocephalus Association Medical Advisory Board. As one of the first neuroscience nurse practitioners in the country, her passion for and commitment to

mentoring other nurses in the field of neuroscience has been demonstrated, for she has guided novices and experienced nurses alike.

The HA has developed a scholarship in honor of Mary that will be awarded annually to an American Association Neuroscience Nurse (AANN) member. This scholarship will be applied toward the recipient's travel expenses, hotel accommodations and registration fees as-

sociated with the HA's national conference.

Nominations will be made by AANN members and selection will be in accordance with AANN bylaws. A few key attributes the selection committee will be looking for are excellence in neuroscience (specifically hydrocephalus); dedication to patients; dedication to educating about hydrocephalus; and leadership in the field of neuroscience nursing.



INSPIRATIONS AND EPIPHANIES FROM OUR MEDICAL ADVISORY BOARD MEMBERS

In our upcoming newsletters, we would like to feature short stories from our wonderful, dedicated neurologists and neurosurgeons on our Medical Advisory Board—their personal accounts of what inspired them to take on their profession, the challenges they have faced, and the ways in which they carry their profession forward.

Following is a personal statement by Dr. Harold L. Rekate, Chairman, Pediatric Neurosciences at Barrow Neurologic Institute in Phoenix, Ariz.

In retrospect, I feel that I must have been destined to become a pediatric neurosurgeon and to study hydrocephalus. Few young people who have not had personal experiences with this very small specialty would feel drawn to it. In my own case, I have been certain that I wanted to be a physician since the age of 12. This goal derived from my feelings for my own pediatrician, Dr. Brisco in Annapolis, MD. From that point until my first clinical rotation in medical school at the Medical College of Virginia in Richmond I knew that I wanted to be a pediatrician. Because I had expressed this goal, my first assignment as a third-year medical student was on pediatrics. During those three months, I found that I was not particularly excited about the subjects that I was studying or the disease processes that I was learning to treat. It was a bit deflating.

My next rotation was on surgery. I was amazed at how exciting every aspect of that rotation was. The faculty was replete with dynamic, dedicated faculty, and the residents were great teachers. During that rotation we had four one-week rotations on surgical specialties, including one week on neurosurgery. On my first day on the service I was met by Dr. David Silver, who at the time was a mid-level resident. We spent the next 21 hours together doing neurological exams, going to the emergency room and seeing head-injured patients, and working in the ICU. The first neurosurgical operation I saw lasted 14 hours and demonstrated the intellectual and technical challenges of neurosurgery. At 3 o'clock in the morning, I was disappointed to realize that the day was over. I was hooked. The neurologic examination was elegant, the disease processes were challenging, the surgical procedures were demanding, and the results were often immediate. I had found my calling. My fellow students

were incredulous. I was committing myself to years of every other night call, long hours, and challenging procedures. The most important part of that decision was that my wife, Mary, was so excited for me. She could sense the way I felt and desired only the best for me. We have now been married for 42 years and she still supports me in this way.

In 1970, neurosurgery residencies were very competitive (as they are today). The resident match, which was actually for a general surgical internship, brought us to Cleveland to train at Case Western Reserve University (CWRU). The chairman at the time was Professor Frank E. Nulsen. Dr. Nulsen was instrumental in the development of the first effective valves to treat hydrocephalus. When he came to Case in 1953 as chairman of the newly created neurosurgical section, he began doing shunts and set up a clinic for the multidisciplinary care of children born with hydrocephalus and spina bifida. By the time I moved to Cleveland, this clinic served hundreds of children and young adults who had been cared for in this clinic since birth. Records and X-ray studies were compulsively maintained on all of these patients. Surgical procedures were documented in handwritten log books dating back to the first day of a patient's arrival. The population of Cleveland was very stable, and the majority of those patients were still available for examination and study. It was an extraordinary living laboratory and documented the life history of the treatment of hydrocephalus almost from the invention of the shunt.

As had been done by Case residents who had preceded me, I began to study this population with a view to writing papers and making presentations at meetings. I found much about hydrocephalus and its treatment confusing. There was so much that required study. My first

epiphany regarding hydrocephalus came in 1973 when I was able to attend a meeting of the American Association of Neurological Surgeons (AANS) and listened to a presentation by Professor Fred Epstein in which he described the treatment of hydrocephalus in premature infants by wrapping the head with an elastic bandage. This was the first time that I realized that hydrocephalus wasn't an all-or-none phenomenon. Just because you could see the ventricles were too large did not necessarily mean that the patient needed a shunt. What *was* this thing called hydrocephalus?

With almost two years to go in my residency and in recognition of my interest in following up on the patients who were so important for the program and for Dr. Nulsen specifically, I was asked to remain at Case after residency and to become a pediatric neurosurgeon. I had come full circle from pediatrics to neurosurgery to pediatric neurosurgery. It felt like it was my destiny.

The intellectual environment at Case was quite remarkable. Dr. Nulsen demanded a great deal of the residents and we were constantly anxious because we knew that we were going to be asked question after question until we could not answer or got the wrong answer. You were never able to finish a session with him on a winning note. The anxiety drove me to be more prepared for discussions than I had ever been and probably more than I have ever been since. From him I learned what was important about the examination of a patient and the thought process leading to treatment decisions. While not always pleasant, it was always educational.

Dr. Joseph Foley was the director of the neurology department. Watching him do a neurologic examination was quite an experience. I was amazed at what could be gleaned from careful examination and thorough discussions with patients. This was at a time prior to the invention of CT scans or MRI scans. Many of the faculty members at Case were inspiring to me at that time and my experiences there will stay with me forever.

INSPIRATIONS AND EPIPHANIES *(continued)*

As a resident and a junior faculty member at Case, it is essential that an academic neurosurgeon be a “triple threat.” He or she must establish himself or herself in clinical neurosurgery, teaching, and basic science research. Based on my experiences in medical school, I attempted to concentrate my research on brain tumors and, especially, the immunological aspects of brain tumor treatment. It soon became obvious that keeping up with two rapidly evolving areas of science without a great deal of overlap would be nearly an impossible task. At that time, the engineering school at CWRU was developing exciting relationships with clinical departments of the medical school. Professor Wen Ko of the Electronics Design Center had invented an implantable device to measure intracranial pressure telemetrically. The importance of such a device for hydrocephalus was immediately obvious. This relationship led to a lifelong study of hydrocephalus. Dr. Ko and I and a third player, Dr.

Howard Chizeck of the Department of Systems and Design Engineering, established a program to study hydrocephalus from a biomechanical point of view. It took us two years of meeting for three hours per week to be able to even speak the same language. This work resulted in research that was funded by the National Institutes of Health and NASA. It also developed into a unique approach to the clinical study of hydrocephalus that has guided my thinking ever since. It has taken decades to see the full effect of these thought processes and observations. Unexpected results of treatment and complicated problems of hydrocephalus become understandable when the biophysics are analyzed.

In 2002 I was honored by the AANS/CNS Young Neurosurgeons and was asked to give a talk at their meeting. The title of my talk was “Who are our teachers?” This talk dealt with the issues discussed here. Where did I get my inspiration? I gave credit to the individuals

listed above for being important in my development as well as to a few others who have shaped my thoughts and actions. I then concentrated on those whom I have learned the most from; I have learned the most from my patients. I have had the opportunity to care for a large number of patients from their first day of life into adulthood. I have learned about the effects of intervention on these people decades later. From them I have learned how much of a burden we are capable of shouldering. I have a new definition of courage involving the ability to accept what cannot be changed and the willingness to take risks in the hope for a better life. Each of my patients has benefited from my previous experiences with the patients and families who have come before. The British poet Gerard Manley Hopkins said, “What I do is who I am. It is why I’ve come.” For me this has been a calling as I believe it is for the majority of pediatric neurosurgeons. ❖

ANNOUNCING THE 2008 RESIDENT’S PRIZE WINNER

By Pip Marks,
Director of Support and Education

One way that the Hydrocephalus Association promotes research and leadership in hydrocephalus is through our annual Resident’s Prize. This prize is awarded each year to the most promising hydrocephalus-related research paper presented by a neurosurgical resident at the Pediatric Section meeting of the American Association of Neurological Surgeons/Congress of Neurological Surgeons (AANS/CNS). The HA’s annual Resident’s Prize is funded by Association founders Russell and Emily Fudge. It is designed to encourage young doctors to focus their research efforts on advancing treatment and care of individuals with hydrocephalus.

The HA is pleased to announce Dr. Ellen Air as the winner of our 2008 Resident’s Prize. Dr. Air received the \$500

award for her paper titled “A longitudinal comparison of pre- and postoperative DTI parameters in young hydrocephalic children,” which she presented at the recent Pediatric Section of the AANS/CNS meeting in Spokane, Washington.

Dr. Ellen Air earned her B.A. degree from Northwestern University in 1997. She then matriculated into the M.D./Ph.D. program at the University of Cincinnati, College of Medicine, earning her Ph.D. in 2002. Her thesis work focused on the hypothalamic regulation of food intake and body weight and was supported by a Physician Scientist Training Award from the American Diabetes Association. After completing her M.D. in 2004, she began neurosurgi-



cal training at the University of Cincinnati, where she is currently in her fifth year. She continues active research in several areas of neurosurgery, including new applications for neuromodulatory techniques and the use of advanced imaging techniques for the diagnosis and prognosis of hydrocephalus.

These efforts have resulted in 20 peer-reviewed publications, including a first-authored paper in *Nature Medicine*. She is a member of the Alpha Omega Alpha Honor Medical Society and the Omicron Delta Kappa National Leadership Honor Society, and she was recently recognized by the Ohio State Neurosurgical Society for her presentation on stereotactic biopsy of eloquent brain. ❖

EXAMINING THE COGNITIVE AND EMOTIONAL FUNCTIONING OF CHILDREN BORN WITH HYDROCEPHALUS

Neurosurgeon Dr. David Frim and neuropsychologist Dr. Maureen Lacy are researchers at the University of Chicago Medical Center. They are currently conducting several studies examining the cognitive and emotional functioning of children born with hydrocephalus. The goal of this research is to identify the underlying cognitive difficulties that interfere with everyday functioning at home and at school. Once these difficulties are identified, they hope to develop an effective treatment intervention to improve cognitive skills. They describe their work below.

In our first study, we asked a group of children born with hydrocephalus to complete a series of tests assessing their intellectual and academic skills. We also asked their parents to complete questionnaires regarding their children's behavior at home and at school. The first goal of the study was to determine whether having hydrocephalus at birth impacts later IQ development. Do our children suffer any impairment in their later intellectual development? We found that our children struggled on the intelligence test. On average, they scored 15 points below their peers. Specifically, children without hydrocephalus obtained a Full Scale IQ of 101, a score in the Average range, whereas our children obtained a Full Scale IQ of 85, which is considered to be in the Low Average range of functioning.

Given this finding of lower overall intelligence, which other researchers have also documented, we wanted to see whether our children were struggling in their acquisition of basic school-based tasks: reading, writing and math. Surprisingly, we found our children did not differ at all in their academic skills from a group of healthy children. The children in both groups displayed average academic performances. Unfortunately, upon further inspection we noticed a trend that suggested problems. As the children with hydrocephalus grew older, they began slipping behind in academic areas from their classmates. Specifically, after the age of nine, the children with a history of shunted hydrocephalus began obtaining lower scores on academic tasks than their classmates. We hypothesized that the more independence required of the children in later years resulted in this decline. Essentially, we found that in 5th and 6th grade teachers expected children to do more on their

own in the classroom and thus our group began to fall behind in their scores. Interestingly, other researchers have found this is a critical age for development of white matter tracks in the brain; an area of the brain we know is adversely impacted by having hydrocephalus.

Noting these findings, we wanted to determine if a problem in a specific cognitive task was responsible for this lag in intellectual development and eventual academic problems. Did our children have problems learning, reasoning or paying attention? Did this cause them to fall

behind in higher level classes? Thus, our next goal was to examine how our children performed on a series of tasks assessing skills needed to be successful in the classroom and in life. Specifically, we administered a series of tests that assessed memory, language, visuospatial, processing speed, and executive functioning skills. When we examined the data, we found that our children performed below their peers on many of the tests. The children with hydrocephalus showed the greatest difficulties with tasks requiring executive functioning. Executive skills encompass attentional processes, problem solving, initiation, self-monitoring, and response inhibition skills, with deficits often related to frontal network dysfunction (Garon, Bryson, & Smith, 2008; Filley, 2001). The patients in this study showed more attentional problems and were more prone to distractibility. A closer examination of the data deter-

mined these executive problems may be the reason our children had lower IQ scores. Specifically, poor executive skills may account for some of the limited intellectual development noted in the first study.

When we discovered that children with hydrocephalus had problems on attention tasks in the laboratory, we wanted to see if these problems were significant enough to impact their everyday functioning. Specifically, would their parents notice similar problems at home? We asked each parent to fill out a questionnaire (The Behavior Rating Inventory of Executive Function by Gioia, Isquith, Guy & Kenworthy, 2000) assessing their child's "executive control skills." This questionnaire asks parents to rate their child's ability to start new projects, concentrate, plan, organize, monitor behavior, and

The first goal of the study was to determine whether having hydrocephalus at birth impacts later IQ development.

regulate emotions. Parents of children with hydrocephalus endorsed significant problems with overall executive control, consistent with our data gleaned by the cognitive testing. Specifically, parents reported problems with working memory (i.e., the ability to concentrate and attend to immediate memories) and planning skills (i.e., the ability to develop and execute a plan). As seen with earlier analyses, as children with hydrocephalus grew older, their parents also reported greater difficulties with immediate memory, shifting attention, and initiating projects or ideas.

The second questionnaire parents completed was The Scales of Independent Behavior-Revised (SIB-R); it asks questions about how independent and adaptive a child is at school, home and in the community. Children with a history of hydrocephalus were rated as less independent in all areas: motor control, so-

EXAMINING THE COGNITIVE AND EMOTIONAL FUNCTIONING OF CHILDREN BORN WITH HYDROCEPHALUS

(continued)

cial interaction and communication, personal living and community living. Furthermore, they were viewed as requiring more daily support from their parents compared with their siblings.

When comparing responses on the two questionnaires, we found that parents felt that the more executive inefficiencies their children displayed, especially in working memory and initiation skills, the more problems were noted in overall skill development. Thus, these children had a hard time concentrating and initiating tasks and thus had more life adaptation problems. Furthermore, parents who reported their children had less executive control also reported that these children engage in more maladaptive behaviors.

In summary, in examining the cognitive functioning of this group of patients, we have found that they display slightly lower intellectual functioning (15 points lower), along with memory and executive problems. These executive problems appear to be noted by parents at home and may begin to impact academic performance with advancing age. Combined, these cognitive issues impact adaptive functioning; these children require more support, engage in more maladaptive behaviors, and hinder the development of social skills and skills related to independence.

At this point, pending additional funding, we hope to develop an intervention targeting the executive inefficiencies noted in this population. We hypothesize that remediation of these deficits may improve overall intellect, along with social and adaptive functioning. We hypothesize that the critical age for intervention appears to be around 5th to 6th grade, when a significant spurt in white matter brain development occurs for most children.

ADULT HYDROCEPHALUS

In our clinic, we also began to see adults with a history of shunted hydrocephalus who complained of cognitive problems. Upon examination, we found that these patients—like our child group—displayed

mild cognitive inefficiencies in attention and memory.

Recently we examined the cognitive functioning of a group of adults who were treated with an alternative treatment for hydrocephalus, endoscopic third ventriculostomy (ETV). These adults displayed difficulties on tasks requiring new learning, memory and attention skills. Following this examination, we wanted to determine if patients who had undergone an ETV performed differently from patients treated with a standard shunting procedure. Did one treatment have a better

cognitive outcome? Although we only compared a small group, patients who underwent standard shunting procedures were found to be functioning within the average range on tests of executive functioning, language, and visual memory, with mild inefficiencies seen on tests of processing speed, and verbal memory. Patients who had undergone ETV displayed average verbal memory and language skills with mild inefficiencies seen on tasks assessing mental flexibility and processing speed as well as moderate deficits on a test of visual memory. When the two groups were directly compared, the ETV group performed worse on a task assessing response inhibition, which may reflect impulsivity.

In our final study, we wanted to determine whether patients who experienced Arnold Chiari malformation type 1 also experienced cognitive problems. To date, we have studied eight adult patients who have undergone treatment for this condition and have documented their cognitive profile. This group of Chiari patients had average intellect, but a majority of them demonstrated memory retrieval problems, slowed mental processing, and word-finding difficulties.

SUMMARY

Regardless of age, intervention, or condition, we have found that most patients with a history of hydrocephalus experience some, at least mild, cognitive inefficiencies. Based on these findings, we hope to increase the number of patients enrolled in these studies in order to better

understand the underlying mechanism. At present we are beginning to integrate neuroimaging, especially diffuse tensor imaging, to identify white matter tracks and structural regions associated with these noted cognitive inefficiencies.

Regardless of age, intervention, or condition, we have found that most patients with a history of hydrocephalus experience some, at least mild, cognitive inefficiencies.

With this accomplished, we can develop and track targeted interventions, especially for children whose developmental course may be improved with early interventions.

If you are a patient or a parent interested in participating in our study please call **773-834-3930**. If you are interested in providing funding for our intervention study or have other study ideas, please call Dr. Frim or Dr. Lacy at **773-834-3930** or **773-702-2123**.

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Our HA Partners Network

The Hydrocephalus Association's Regional Support Program was designed to improve the lives of all individuals with hydrocephalus by delivering our core mission services of support and education at the local level while increasing awareness and advocacy nationally. Many of you have read about this new initiative, and we would like you to meet the wonderful, hard-working volunteers who are serving in our Partners Network.. These individuals bring a wealth of passion, experience and hard work to their leadership roles. Without these regional leaders, hundreds of people would still feel isolated and be unaware of community and educational resources to help them live more effectively with hydrocephalus.

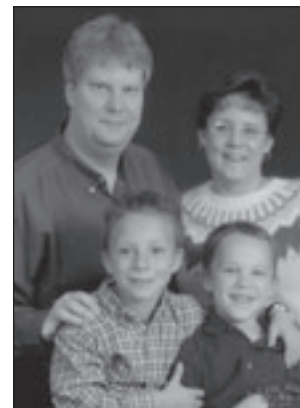
Every one of the estimated one million people living with hydrocephalus in the United States stands to benefit from this regional program, which is designed to unify and amplify the voice of hydrocephalus nationally while delivering support, education and advocacy at the local level. For 2008:

- 46 support group meetings were held in seven states, reaching hundreds of people with one-on-one support and educational materials.
- Seven of the ten partners hosted awareness and fundraising events in 2008. Over 1,500 people came together in seven states, some meeting other people living with hydrocephalus for the first time.
- Pilot Partners (Affiliates and Advisors) were key players in building on the 2005 National Institutes of Health workshop and securing passage of the first concurrent resolution in congress calling for more federal support of hydrocephalus research.
- Five have taken action on state or federal advocacy initiatives, including declaring a hydrocephalus awareness day or month, making hydrocephalus a mandated reportable condition, and increasing federal support of hydrocephalus research.
- More than 25 hydrocephalus stories have appeared in local print media. Two of our Partners have appeared on local television programs to talk about hydrocephalus.

VICKI AND ADAM BELL, UTAH

We are currently Partners with the Hydrocephalus Association representing the states of Utah, Idaho, Wyoming, and Montana. There are actually a few of us. Helen Aoki is a neurosurgery nurse who heads up a family support group for hydrocephalus at Primary Children's Hospital in Salt Lake City. Kelly Varga, who has hydrocephalus, and I chair the annual WALK in Salt Lake City. Then there is me, Vicki Bell. My husband Adam was diagnosed with hydrocephalus in his late 30s. He is my reason, passion, motivation...I could go on for the reasons I do the volunteer work that I do for the Hydrocephalus Association.

Each year we do our WALK reminds me of why I do what I do. Each year we get new families with brand-new infants born with hydrocephalus who show up at our WALK courtesy of the wonderful nurses at Primary Children's. They are in need of support and information from other families who are "veterans" in dealing with this condition. That is what drives me; seeing these people connecting with others and realizing they are not alone.



PAULA AND MARK KEYSER, TAMPA BAY, FL

This year will mark the 5th Anniversary of our Tampa Bay Walk, from which we have collectively raised close to \$50,000 for the Hydrocephalus Association over the past four years. All of the volunteering we do is a lot of work, but I personally believe in good karma and believe that sharing our experience and helping others is our way of giving back.

When our son, Jeremy, was born in 2001, we felt very alone. We had never heard of hydrocephalus before and, suddenly, this was something that we and Jeremy would have to deal with for the rest of his life. We searched the Internet and purchased books to gather the most information and get the most knowledge on this incurable (but treatable) condition. The Hydrocephalus Association graciously sent us a lot of information to help educate us and ease our minds. I don't know what we would have done without their help. We decided, after we were out of the woods, to start a local support group for families who have to deal with hydrocephalus. We had our first picnic in April 2004. At first we met two to three times a year, working towards monthly meetings. In January 2006, we were invited to participate in a focus group to start a regional expansion pilot group program. Being involved with this expansion project has given us the resources we needed to help all of our families locally.

We have been very fortunate that Jeremy has had only three brain surgeries, with his last revision in January 2002. Well, he is in first grade, on grade level with some assistive technology, OT, PT and assistance. He does everything



Our HA Partners Network

that his peers do in his class despite his hydrocephalus and diagnosis of mild cerebral palsy. We truly could not ask for a more loving, brilliant, miracle child. If you have ever met Jeremy, you know just how magical he is; he makes us all very thankful for every single day. We look forward to working together to grow these regional expansion groups; we cannot do it alone, we need the support of the entire hydrocephalus community.

MONICA FERRANTE, NORTHEAST OHIO

When our group became a pilot affiliate of the HA, I was very excited to be given the opportunity to work with such a wonderful group.

My son, Vincent, now 10 years old, was diagnosed with hydrocephalus at 3 weeks of age. He was shunted by 3 months and has been doing very well ever since. My family and I joined our local hydrocephalus support group about 8 years ago. We attend meetings regularly and have become very active in our annual walk/run/family fun day for the Northeast Ohio Hydrocephalus Support Group. The HA community has been a blessing to our family. We have built great relationships with many families affected by hydrocephalus and professionals in the medical community.



JANE AND LARA ANDREN, PHOENIX, AZ

We must, en masse, as a hydrocephalus group, educate ourselves, educate our communities, and seek out good scientists, doctors, and donors to increase awareness, education, and research. By working together we will find a cure!

My daughter, Lara, and I are the co-leaders of the Arizona Partners. Lara was diagnosed with hydrocephalus at age 29 after complaining of a severe, constant, vice-like headache for almost six months. She started having problems with concentration at her work as a microbiologist.



Her assigned neurologist sent her to a neurosurgeon, whose only comments after looking at the MRI were, "no problem, I shave her head, put in a shunt, no problem." Being a registered nurse for more than 30 years, I knew that this man was never going to touch or see my daughter again. I had seen hydrocephalus in infants and young children but not in young adults. I decided at that moment that I wanted to advocate for people with hydrocephalus through education and promoting research.

I feel that we must educate ourselves on this condition that has been around forever that affects people of all ages and ethnicities, with little advancement. Sure the shunts are much better—we don't have to manually pump them—and now endoscopic third ventriculostomies (ETVs) are able to help some, but we still don't have a really good grasp of the dynamics of hydrocephalus.

MAGGIE VARLAND, PHOENIX, AZ

Maggie Varland, originally from Dublin Ireland, has been a resident of Arizona for the better part of her adult life. She holds degrees in nursing as well as a Masters of Business Administration with an emphasis in Health Care Systems. Maggie assumed her current position as program coordinator for Neurosciences at Barrow Neurological Institute (BNI) in December of 2002. Prior to this position, she worked as a surgical nurse in the neurological operating room for approximately 15 years, serving as clinical supervisor during the last 3 of those years. Maggie has been recognized for her accomplishments over the years, including receiving BNI Nurse of the Year in 2002.

Maggie's role at the BNI is multifaceted. Through collaboration with others she serves as program developer, conference facilitator, patient liaison and educator, and clinical coordinator for patients, physicians, and other team members. Maggie was the key initiator of the first normal pressure hydrocephalus support group at Barrow, and continues to play a leading role in the support group meetings by mentoring the Phoenix Affiliate leaders Jane and Lara Andren.

Maggie has been involved with Regional Expansion Program since the beginning of the Pilot Plan in 2006 and has been instrumental in the growth of the program.



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DEBBY BUFFA, ST. LOUIS, MO

In 1987, I began a local support group in St. Louis and have been educating and advocating for families since then. My husband and I have three children—two daughters and a son. Our daughters, ages 27 and



28 both have hydrocephalus and shunts. Our son, age 23, does not. Our girls were diagnosed with aqueductal stenosis at early ages. One daughter has completed college and is employed as an engineer. The other will graduate college in May, successfully overcoming 32 revisions and complications due to her hydrocephalus.

As with most parents, we thought that our daughters were “cured” after they received shunts. We did not realize how important it is to recognize the symptoms of shunt malfunction. After a harrowing experience during our oldest daughter’s first revision, when she was rushed from the ER into surgery, I realized that I needed to learn everything I could about this condition.

During this time frame, I became involved with the Hydrocephalus Association. Their goals of support, education and advocacy aligned with mine. I am a member of the Board of Directors and recently became the St. Louis Affiliate. As an affiliate, now partner, I take support calls, set up periodic meetings, hold an annual one-day conference for families, support the WALK chairs and, basically, do anything else that is needed. The Hydrocephalus Association is a very respected and well-known national organization and I am proud to be the St. Louis Partner.

GREG TOCCO, BOSTON, MA

I have been a long-standing member of the HA and am honored to now be an HA Partner Network leader for the Boston, MA region.

In 1983, I acquired hydrocephalus. Since that time, I have undergone more than 20 surgeries as a direct result of hydrocephalus. In 1995, I reflected on my role in life and future aspirations and The Hydrocephalus Foundation, Inc. was cre-



ated. Dedicated to the patients of hydrocephalus and their families, The Hydrocephalus Foundation assists them as they transition from post-diagnosis to a resumption of their normal lifestyles. Born out of the first-hand knowledge of the ramifications of living with hydrocephalus, I created the Foundation out of love, persistence, and as a way to “give back” the support and resources that I received during a time when hydrocephalus left me in the hospital and rehabilitation facility for an extended period of time.

PHYLLIS ROGERS, COLORADO

When I saw one of the HA newsletters highlighting the fundraising walks held in San Francisco and D.C., I knew I had to jump on board and start my own WALK here in Colorado — to raise money for the organization that provided so much support and education to our family.



My daughter, Jordan, is my motivation and passion behind the work I do for the Association. Born premature in 1992, she was diagnosed with hydrocephalus after an intraventricular hemorrhage at 2 weeks of age, was shunted at 3 months, and developed a shunt infection just 2 days later. She had her first shunt malfunction at age 4 ½, and it became evident that we needed to become more educated about hydrocephalus. We became members of the Hydrocephalus Association, which was the only source of education and support we could find at the time.

From 1996 to 2002, our daughter had seven revisions, but our real wake-up call was in the summer of 2003 when she malfunctioned five times within 3 weeks. We could no longer sit helplessly by while our daughter bravely fought each malfunction, surgery and hospitalization. With Jordan as my co-chair and the support of my family and friends, we held our first Team Colorado WALK in the summer of 2004. Our goal at the time was merely to raise money for the Association. As word got around, though, other families dealing with hydrocephalus came forward to join our efforts. In 2004, we had just three children with hydrocephalus attend our event. Now we have more than 20 children and adults who represent the hydrocephalus community. It brings our entire committee great joy to know that these families and individuals can get together to network, share stories and, more importantly, know that they are not alone.

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Our daughter had three revisions in the past 12 months and I've turned to the HA several times for advice and their invaluable support to our family in some very difficult times; they not only give us emotional support, but also provide us with educational resources we wouldn't have found on our own. I will continue to support the HA and help raise funds and awareness so the HA can continue to support, educate, and advocate for all families living with hydrocephalus.

SHANNON CHRISTIAN, COLORADO

I am an HA Partner Network Leader for Colorado. In my position, I have lobbied successfully for honorary proclamations from Governor Ritter that declare September "Hydrocephalus Awareness Month" (2007-present). In addition, the Colorado General Assembly has recognized the need for increased research and greater awareness of the condition through a resolution and official tributes. Recently, I asked my state senator and state representative to make hydrocephalus a mandated reportable condition in the state of Colorado.

My passion for advocacy stems from my life's purpose, to drastically improve the life of my 4-year-old son, Reece, who was diagnosed with congenital hydrocephalus at 2 months of age. I knew I had found my calling after Reece's brilliant neurosurgeon answered, "We don't know" to most of my questions that related to the predictors of shunt longevity and long-term outcomes. The lack of knowledge and dearth of reasonable treatment options is unacceptable, and that fact energizes me when I feel discouraged about the gap between what is possible now and where we need to go. I educate anyone who will listen, and I advocate vigorously for research and for more reliable and less invasive treatments. My hope of all hopes is to wake up one morning and realize that I no longer ask myself the question, "Is today the day Reece's shunt will fail?" because Reece will be cured.



SHERRY REISING, CHICAGO, IL

After being diagnosed at the age of 22 in 1997, I went through several shunt malfunctions before finally getting the ETV surgery in 2002. During those years, there were many moments I wished I knew someone else that understood what I was going through. So, in 2005 I organized the first Chicago Hydrocephalus WALK. As a result, in March of 2007, we had our first Chicago

Hydrocephalus Support Group meeting. It's my hope that this group will provide opportunities for people of all ages who have been diagnosed with hydrocephalus and parents of children with hydrocephalus to meet, support and encourage each other, and hold educational and informative meetings throughout the year.



SPECIAL THANKS

Dr. Robin Wilson, associate director of the LifeBridge Health Brain & Spine Institute Adult Hydrocephalus Center, recently facilitated Baltimore's first Hydrocephalus support group. She spoke about shunt mechanisms, the different types of shunts available, and what to expect after shunt surgery. This support group is for individuals and families (adults and children) who are impacted by hydrocephalus. It is an excellent opportunity to share experiences with others in a similar situation as well as advance or update your knowledge of hydrocephalus. Speakers will include a variety of experts, such as neurologists, neurosurgeons, neuropsychologists, nurses, and physical and occupational therapists. Meetings will be held quarterly at the LifeBridge Health Brain & Spine Institute's Michel Mirowski Medical Office Building. Additional information can be obtained from:

www.finallyanswers.com



Are you interested in volunteering for our Regional Program? H.A. is always looking for motivated leaders such as yourself. Please contact Sarah Oxford our Regional Program Manager at Sarah@hydroassoc.org for more information!



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Thanks to the individuals who supported the Hydrocephalus Association so generously in 2008. Your support keeps the beacon 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 does not include donors from our Annual WALK program. In the Summer 2009 edition of Pathways we will list all corporate donors and participants.

Sadly, we do not know all the names of the generous persons who made donations via our WALK events or payroll deduction through CFC or United Way. We would like to thank those of you who comprise our anonymous donors.

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Siobhan Reardon
John and Diane Reseska
Shawn Rice
Hayley Roach
Alexis Rocciola
Giancarlo Rodriguez Guerrero II
Emily Rogers
Phillip Rosenthal
Hilary Rossen
Amber Rowen

Antonina Ruriani
Elizabeth Saavedra
Ben Sanchez
Emerson Page Sarre
Benjamin Saylor
Romi Scarlett
Aaron Scarpato
Angie Scherer
Sara Schieder
Dennis Schreibeis and Family
Dr. Robert Schultz
Elane Schwarz
James G. Scimos
Colfax Selby
Alexander Senanou
Eric Carter Shields
Brenna Smith
Joe Neal Smith
Tara Smoot
Noelle Joy Sokolnicki
Jordan Mitchell Spring
Michael Stabile
Agnes M. Stone
Emma Stoner
Jeremy Tam
Maria Tatman
Lucy Tatum Tayler
Abbey Testa
Katherine Mae Thayer
Karson Palmer Thomas
Matthew Thomas
Odekunle Titilayo
Ashlee Tracy
Cheri Trieber
Nicholas Trotto
David Updike
Salvatore Vassallo Jr.
Remington Veillieux
Christine Votraw
Rachel Walden
Sophia Walsh
Sadie Waters
June Webb
Hannah Weil
Dr. Stuart Weiss
Tycen Welle
Chad Whisenant
Abigail Wood
Warren Yalowitz
Quinten Zalesky

GIFTS WERE GIVEN IN MEMORY OF:

Aurora Adler
Walter Aglietti
Sog Baker
Lorraine Belmont
Joseph Beninati
Florence Berger
Ellen von Ende Billeter
Peter Caporino
Joseph Carotenuto
Charles Carrocetto
Mike Collins
James Copeland
Bernice Crespin

Sam 'Skip' Cypert
Sandra DeWald
George Dorsey
Mary Lou Duffy
Laura Dunafin
Elizabeth Falaglia
Mike Farris
Teddy Fattoross
Uncle Fritz
Gerard Fudge
Jack W. Gilbert
Robert Gossen
Virgil Hiveley

Kenneth G. Hughes
Eldred Hulbert
Eleanor Jacobs
Mildred and Toge Johansson
Thomas Kelley
Mr. and Mrs. Richard Kranz
Johnny Dean Ladner
Edythe Magduff
Phyllis Mancuso
Elyse Mandel
Ida Markus

Rudolph Masseria
Ronald and Pat McClain
Christopher Rembert Meister
Francis "Ducky" Mello
Tyler Michael
Sue Middleton
Eloise Miles Moons
Sally Mullen
Sara Mullen
Dave Newsom
Gemma Marie Norkus
Aurora Padron

Tyler Padron
Irene Peckham
Nathan Carl Pedersen
Diana McNair Pennell
Liam Jon Robbins
Sidney Rubenstein
Charles Rubin
William Sinclair
Dr. Marvin Stern
Betty Sykora
Anne Traneis
Earl Van Sickle

2010 CONFERENCE ANNOUNCEMENT (Continued from page 1.)

the Pediatric Neurology Center, and co-director of the Aging Brain Clinic at Cleveland Clinic, and Stephen Dombrowski, Ph.D., co-director of Clinical and Experimental Research in the Section of Pediatric and Congenital Neurosurgery, co-founder and scientific advisory board member for CSF Therapeutics, Inc., co-founder/co-director of the Hydrocephalus Association Affiliate-Northeast Ohio Hydrocephalus Support Group.

- The conference site is adjacent to the Cleveland Clinic, ranked sixth in the nation in neurosurgery and a major center for the treatment of hydrocephalus for all ages, including normal pressure hydrocephalus
- The facilities offered by the hotel, particularly the media available for use, are fantastic and the hotel itself is amazing.
- Convenience. Cleveland is a major hub of transportation. The facilities are located in the heart of the city and are central to dining, hotels and shopping. They also happen to be located in the densest accumulation of art and culture located in one square mile in the country, being just a short walk away from the Botanical Gardens, Cleveland Museum of Art, The Museum of Natural History, and the Cleveland Institute of Music.
- Last, but not least, the hotel is a short jog away from the Rock and Roll Hall of Fame.

The conference is still 14 months away and we will keep you, our members, updated as plans finalize and it all comes together. Registration information will definitely be forthcoming and, rest assured, we will get this information to you at the earliest possible moment.

In the meantime, see you in Cleveland.



The City

Cleveland is a diverse city located where the Cuyahoga (pronounced *kuy-a-HO-ga*) River joins Lake Erie. Founded in 1796, it was finally incorporated as a city in 1836. It owes much of its growth and status as an important American city to the completion of the Ohio and Erie Canal. The city is roughly 82.4 square miles with a population of 478,403 in the city proper (as of 2000) and better than 2 million in the greater metropolitan area. The city's motto is: Progress and prosperity—excellent words to live by.

To find out more about Cleveland, go to:

<http://www.city.cleveland.oh.us/CityofCleveland/Home>

The Facilities

The conference will be held in the conference facilities of the Intercontinental Hotel, Cleveland. The hotel is attached to the Cleveland Clinic. The conference spaces are beautiful and the media facilities are well appointed.

To find out more about the hotel, go to:

<http://www.ichotelsgroup.com/intercontinental/en/gb/locations/overview/cleveland>

CLEVELAND, OHIO

Country: United States

State: Ohio

County: Cuyahoga

Founded: 1796

Incorporated: 1814 (village)
1836 (city)

Mayor: Frank G. Jackson (D)

Area

City: 82.4 sq mi (213.4 km²)

Land: 77.6 sq mi (200.9 km²)

Water: 4.8 sq mi (12.5 km²)

Elevation: 653 ft (199m)

Population (2000)

City: 478,403

Density: 6,166.5/sq m (2,380.9/km²)

Metro: 2,250,871



GOING TO COLLEGE WITH HYDROCEPHALUS

By Ella Arnold

Many people choose to go away to college, which is quite an adjustment because they must get acclimated to a new place with new people and new challenges. For those of us living with hydrocephalus, going away to college is difficult because we must become our own health care advocates by making sure that we get what we need in order to stay healthy.

As a college sophomore living with hydrocephalus, I have experienced firsthand the joys and challenges that go along with going away to college. I have found that there are several things that you can do, from the moment you get accepted to that first week of classes, in order to make this transition a breeze.

Contact your new school's disability resource center and let them know that you have hydrocephalus. The people who work in this office can help you get any accommodations you may need, from extra time on exams to tutoring services and beyond. Some schools even allow students with disabilities to register for classes earlier than everyone else, which is a great advantage to have these days.

Next, you should contact your current neurologist's office in order to get a referral for a neurologist and/or neurosurgeon who practices near your new school. Some people may want to make an appointment with their new doctor before school starts so that they can get acquainted with their new doctor. Also have your current neurosurgeon send copies of your patient history and of all of your scans to your new neurologist's office.

Put together an emergency folder that you can keep in your new room in case you should need it. Make sure that this folder contains contact information for your parents, your school neurologist, your home neurologist, a map and directions to your school neurologist's office and the emergency room, a copy of your durable power of attorney form and anything else that you think you may need in the event of an emergency.

"... perhaps the best advice I can give you... is to become your own advocate."

Telling your new roommate(s) about your hydrocephalus is extremely important because you'll probably be around them more than anyone else while you're away at school. Try to tell them about your condition within a few days of the beginning of school so that they know what to expect and how best to help you should you need their assistance. You may also find it advantageous to tell your resident advisor (RA) about your condition because he or she can help you too. Make sure that your roommate(s) and/or RA know the signs and symptoms of a shunt malfunction and a shunt infection so that they can easily assess your condition if you are unable to do so yourself. Help your roommate(s) understand the seriousness of your condition, and make sure to answer any questions that they may have as honestly as possible. Also, tell your roommate(s) where your emergency folder is so that they can get to it quickly if the need arises. Finally, ask your roommates and/or RA if they would be comfortable with accompanying you to the emergency room in the event of a problem so that they can make sure that your family is contacted and that you get the care you need as soon as possible.

Whether or not to tell your professors about your hydrocephalus is a decision that you will have to make once you start your new classes. Even if you register with your school's disability resource center, your professors will not be aware of your condition, so it is up to you to tell each of them yourself if you so choose.

Once you turn 18 years old, you are considered an adult in the eyes of the law. This consideration also applies to your health care because once you turn 18 you are responsible for making your own medical decisions. This means that you, not your parents, must sign consent

forms before you can have surgery or any other form of medical treatment. However, because there may be circumstances when you are unable to make medical decisions for yourself, now is the time to obtain a durable power of attorney form. This form varies slightly from state to state and is available online. It basically allows you the opportunity to appoint a person (or persons) to make medical decisions on your behalf. All you need to do is fill out the form, get it notarized and make sure that you (as well as all of the people whom you list on the form) have a copy of it at all times.

You should also order a shunt card and/or a medical alert bracelet so that others are aware of your hydrocephalus in case you have an emergency. Shunt cards are available through a company called MedTech and lists on one side your name, the name and phone number of your neurosurgeon, the type of shunt you have and the date it was placed. On the other side of the card are small images of your most current medical scans so that your neurosurgeon can compare your current condition to those on the card. Medical alert bracelets are available online through several different companies and come in tons of colors and styles so that you can choose one that fits your personality or your outfit. The bracelets usually have your name on the front side and the name of your medical condition(s) and contact information on the underside.

But perhaps the best advice I can give you before you go away to college is to become your own advocate. Now that you'll be living on your own, you are in charge of your life, so you are responsible for getting any help you may need. This notion may seem scary at first, but with time it will become empowering because you are finally being allowed to be your own boss.

Yes, going way to college while living with hydrocephalus may seem challenging. But if you take the steps to be prepared, I think you'll find that this journey you are about to embark on will be the ride of your life. ❖

OUR STORY

By Vicki and Adam Bell

It all started at our first WALK for hydrocephalus in Utah back in 2007. We obtained a declaration from Governor Jon Huntsman of Utah declaring Saturday, September 21, 2007 as Hydrocephalus Awareness Day in the state of Utah and presented it to Dr. Jack Walker at our WALK. I remember Dr. Walker saying to me, "Wow, Hydrocephalus Awareness Day. Wouldn't it be great to have an awareness month?" I told him later that day that if it was the last thing I did, he would get his Hydrocephalus Awareness Month. Well, time got away from me because my husband, Adam, had two hydrocephalus-related surgeries during the summer of 2008 just before our WALK, so it never got done.

In October of 2008, Marybeth Godlewski provided me with the wording I needed for a bill to make hydrocephalus a mandatory reportable condition in Utah and to make September Hydrocephalus Awareness Month in Utah. I contacted a local congressman that lives in my city, and because he was already so overloaded he gave me a list of people that I could contact to make my requests happen. The list of senators and congressmen that he sent to me was almost overwhelming because there were so many. How would I know who would be the "right one" to help me out? Well, there was a senator on the list by the name of Greg Bell. He lived just a couple of cities south of me. I figured if he had the same last name as me, he couldn't be all bad. I e-mailed him and told him what I needed and asked if he would be willing to take it on. He e-mailed me back telling me that he would be happy to.

Our legislative session in Utah starts in late January each year, so I knew we had some time, but I really wasn't sure what it was going to take. A couple of days later, Sen. Bell had his assistant call me and she asked me what I wanted to have done. I told her that I wanted the issues of mandatory reporting of hydrocephalus and Hydrocephalus Awareness



Month to go through the House and the Senate. I sent her the wording that Marybeth used in Pennsylvania as well as the declaration we received from our state governor to be used for the Awareness Month portion of the bill.

I didn't hear anything for a couple of months, so I e-mailed Sen. Bell's assistant and asked her what was happening and she referred me to our Utah state Web site. I was amazed when I got to the Web site. I found a resolution, and it was in process, but I did not see the mandatory reportable condition information on there and I became very worried. I e-mailed the assistant again and told her that the mandatory reportable condition aspect was so much more important than the Awareness portion and that we really needed to be sure the reporting language was included. She assured me that it would be part of the Awareness resolution.

Our legislative session began on Monday, January 26th. Later that week, I noticed that the resolution was done, but still, the mandatory reportable condition was not worded anywhere in it and it was on the calendar for a Senate hearing in two days! I was very disappointed, so I e-mailed Sen. Bell and reiterated my concern about it not being done. I received an e-mail back that day telling me that they forwarded my wording for it to the drafter back in October and they did not understand why it was not done. He also told me they would contact the drafter and be sure the wording got on there.

Now, I am not too bright when it comes to government process, so a week later, in speaking with an analyst from the Senate, he told me that a resolution would not make the mandatory reportable condition a law in Utah. Was I bummed!!! I called Marybeth that day on my lunch hour totally disappointed. She assured me that it was okay. At least we got in writing that the state of Utah "encourages" the federal government to make hydrocephalus a mandatory reportable condition, and we could always go back later and make it a bill. I e-mailed Sen.

Bell and his assistant that afternoon asking if it was too late to make that portion a bill. I didn't hear back all afternoon. I told Marybeth that they probably thought I was nuts! Just before I was getting ready to leave work for the day, Sen. Bell e-mailed me and asked me for a phone number where he could reach me.

The next day Sen. Bell called me and was concerned about the idea of making the resolution a bill so late in the game. I told him to do his best, but if he had to let it go through as just a resolution, so be it; we would push it further on the next round. He told me he would do his best and asked me to have somebody from the Hydrocephalus Association contact him. I e-mailed Marybeth and asked her to get in touch with Sen. Bell as soon as possible.

The next morning at the Senate hearing, Sen. Bell told me that he was in contact with Marybeth and the Utah Department of Health and thought that we did not have to pass the resolution for mandatory reporting through legislation. He thought we could do it internally, through the state. I was blown away!

That morning at the hearing, we were third in line on the agenda. I was so nervous. It was a very intimidating thing to be in a room full of people, sitting in front of a desk with about seven senators staring at you and just listening to what you had to say. I was just hoping I had my facts straight in case they asked me questions! Sen. Bell called Adam and me up to the desk to sit with him. He presented the resolutions and actually explained

OUR STORY *(continued)*

hydrocephalus pretty well. I was impressed! He obviously did his homework! After Sen. Bell explained hydrocephalus and why we wanted it to be a mandatory reportable condition and have the awareness month, they all voted. The vote was unanimous; it passed!! Sen. Bell then asked me to speak. The night before, I prepared something to say so I would not forget anything if I got emotional or too nervous. I read a little from my notes and explained the wonderful shunt system that hydrocephalus patients have to endure and that we needed the mandatory reportable condition bill to go through so we could have more accurate numbers to support the need for funding from the National Institutes of Health and help people be recognized by the Social Security Administration. Wow, I actually sounded like I knew what I was doing!

After I was done, they asked if anyone in the room would like to speak on behalf of this bill. A lady in the back of the room stood up. I did not know who she was; there was nobody there that I knew to support us. She got up and introduced herself as the Health Commissioner for

the Utah State Parent Teacher Association (PTA). She went on to say that the Utah PTA had a resolution that supported our resolution, and she urged the senators to pass ours and it was a very good thing! I couldn't believe it!! When we were done and she walked out of the room, I followed her to ask her how she knew about us. She told me that part of her job was to search bills each session and see if there are any that the Utah State PTA supports, and then she goes to the hearings and speaks in support of them. She gave me her information and asked me to keep her informed of anything we do here and she would post it on the Utah PTA Web site.

After we were done speaking and they were going to finalize our resolutions, a senator by the name of Luz Robles interrupted and said some very kind words of support also. This was amazing to me that there were people out of the blue who were offering words of support to help us.

They moved our resolutions to something called a consent calendar. I e-mailed Sen. Bell's assistant and asked here what

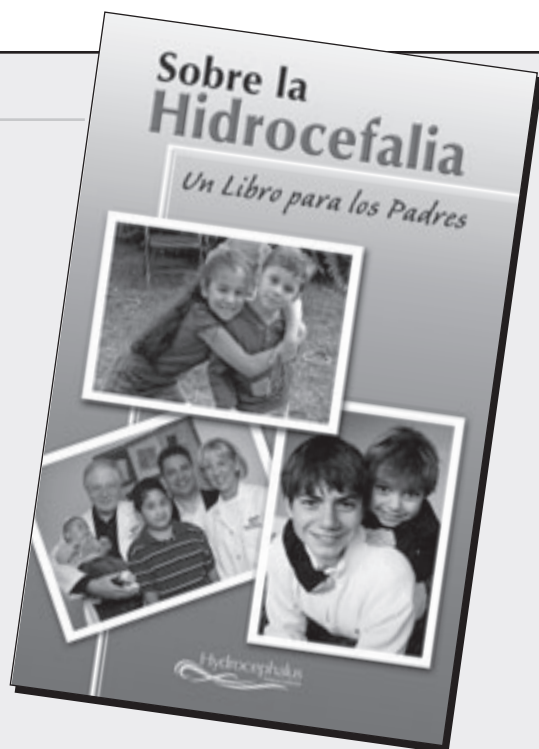
that was. She told me that it was a calendar where they put resolutions that they knew would not be controversial. The resolutions would sit on this calendar for a few days. If nobody asked for our resolutions to be removed for questioning; they would hit the Senate floor. So our resolutions were likely to be through the entire process by the Thursday after the initial hearing.

This process was almost too easy. I just used my right as a United States citizen by putting something out there that is so near and dear to my heart and to the hearts of a lot of other families in our state. It is an amazing thought when you look at it that way. We are lucky in this country to be able to do something like this. I was so nervous to start this process because I was concerned about the time and commitment that it would take, but it was easier than a lot of things I have had to do. If we had somebody to take this on in each state, I believe we could see a lot of improvements in the future of hydrocephalus. ❖

NEW AND IMPROVED/NUEVO Y MEJORADO

By Karima Roumila, Outreach Coordinator

We are so pleased to announce that we have updated the Spanish version of our hydrocephalus booklet for parents and families: **"Sobre la Hidrocefalia: Un Libro para los padres."** The new booklet reflects our new colors and logo and, of course, our community. This booklet is very useful for families and professionals because it explains, in lay terms, what hydrocephalus is and its diagnosis and treatment. We would like to thank everyone who helped make this revision possible for us, especially all the parents who generously shared with us the stories and pictures of their children. ❖



2008 WALK WRAP-UP

At the Hydrocephalus Association we try very hard to include everyone's story in Pathways, particularly those of the WALK chairs and their efforts. This year, we neglected to share the pictures from our St. Louis WALK. We would like to take this space to redress this mistake, and we offer our sincere apologies. Below are pictures from the walk as well as a re-print of their story from our fall 2008 issue.

On September 20th, Stephanie Buffa hosted the 2nd Annual St. Louis Hydrocephalus WALK and Fun Family

Day in Tilles Park. Stephanie's mother, Debbie, founded a support group in St. Louis, which is now an affiliate of the HA. Both Stephanie and her sister, Sara, have hydrocephalus. Stephanie works the night shift, causing her to plan most of this event while the rest of Missouri slept.



Words from event chair Stephanie Buffa:

The walk is over; it was great! We had more than 250 people there and raised over \$25,000! So exciting. Everything ran so smoothly and was just perfect. I couldn't have asked for more. Oh, and the rain held out until after the walk! So exciting! ❖



PREPARING FOR WALK SEASON 2009

By Marybeth Godlewski,
National Advocacy Director

Catch the wave of awareness! Start a Hydrocephalus WALK in your community today! It is never too early to plan a WALK event, and of course it is never too late to plan one either!

Spring is the time of year many members of the Hydrocephalus Association community begin planning a Hydrocephalus WALK for the summer, fall, or winter months. Over the past 16 years, we have built the HA's WALK initiative from one WALK in San Francisco to 25 WALKs all over the country, with a goal of having one in every community nationwide.

Our WALK coordinators are people just like you; they have a connection to hydrocephalus and they want to make a difference in life with hydrocephalus. Last year we introduced our signature




WALKS currently scheduled for 2009:

| | |
|----------|--------------------|
| 8/2/09 | Lavonia, MI |
| 9/6/09 | Denver, CO |
| 9/19/09 | Graham, NC |
| 9/20/09 | St. Louis, MO |
| 9/26/09 | Salt Lake City, UT |
| 10/18/09 | Fresno, CA |
| 10/10/09 | Bloomsburg, PA |

Hydrocephalus WALK event, which has helped us and our WALK coordinators create unified events with ease!

For more information on hosting a WALK in your community, please contact Marybeth@hydrocassoc.org ❖

PHOENIX WALK, RIDE AND ROLL FOR HYDROCEPHALUS AWARENESS

On March 22, 2009, our amazing Phoenix, Ariz. affiliate team, consisting of Maggie Varland and Lara and Jane Andren, threw a successful “walk, ride and roll” awareness event at the Phoenix Zoo. The event represented the hydrocephalus community with dignity as 250 supporters from all ages and races walked together as one. A special thanks to St. Jude’s Hospital, Univision television, the United States Air Force cadets and the Mixed Martial Arts fighters for coming together to make this event such a success!



RAISING AWARENESS: MANY PATHS, ONE DESTINATION

By Tom Smith, Outreach and Media Liaison

One of the core missions of the Hydrocephalus Association is to create awareness; as a result, it’s also part of our mission to support our members in their own efforts to spread awareness. Every year, we hold our Annual WALK for Awareness in cities nationwide. What also happens is that individuals among our membership step up, take the initiative and create their own events. Some run marathons; others create their own walks, sing, dance or host a spaghetti dinner to raise funds/awareness. We would like to take some time to salute some of these individuals and tell you, our members, that if you have an event in mind or you would simply like to find another way to push the bar of awareness, please contact us and we will be happy to support you in any way we can.



SHARKFEST

Last summer, brothers Peter and Sam Finlayson were joined by two friends (fellow members and alumni of the Stanford University water polo team) and created a unique opportunity to raise funds for and awareness of hydrocephalus. They joined up with Sharkfest, an annual endurance event where swimmers brave the icy, sea lion- and shark-infested waters of San Francisco Bay to swim the 1.7 miles from Alcatraz to San Francisco. TEAM HYDRO swims in honor of the brothers’ sister, Kate Finlayson, who lives with hydrocephalus. In 2008 they raised awareness and more than \$10,000.



CAROLING FOR A CURE

During the Christmas season, the Felicia Avenue Players from Livermore, California wassailed their neighbors for the second year in a row. Organized by Madelyn Conner and her family, the caroling raised awareness locally and thanks to an employee gift matching program, they raised \$430—more than twice the amount raised during their inaugural year. Thanks also go out to neighborhood participants, the Modica, Herwig and Weiler families, for their singing and support of Madelyn, the Conner family and everyone with hydrocephalus.



WORLDWIDE PERSPECTIVES: "SAY NO TO STIGMA" HYDROCEPHALUS WALK, LAGOS, NIGERIA.

By Tom Smith, Outreach and Media Liaison and By Karima Roumila, Outreach Coordinator



Last October, I received an e-mail from one of our members and a hydrocephalus advocate, Afolabi, from Nigeria, Africa. It read:

"We are preparing for Spina Bifida and Hydrocephalus WALK-2008, tagged "SAY NO TO STIGMA" of children living with spina bifida and hydrocephalus. This is to draw the public attention toward the plight of numerous challenged children from this part of the world. . ."

Afolabi is the president of the Festus Fajemilo Foundation (FFF) dedicated to raising awareness of spina bifida and hydrocephalus. We first heard from Afolabi when the FFF organized a conference in Nigeria in correspondence and solidarity with our own 10th Annual National Conference, at Park City, Utah.

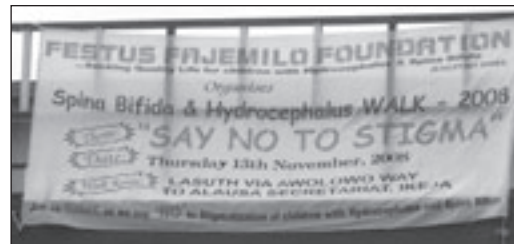
In the same vein, the FFF planned and carried out a walk in Lagos during the month of November. The walk was to do more than raise simple awareness; its goal was to fight against social stigmatization. In many African countries, birth defects

such as spina bifida and congenital hydrocephalus are considered a form of punishment or a curse on families and those living with them. Individuals affected by these conditions commonly find themselves the target of various forms of discrimination.

Other problems faced by Africans with hydrocephalus or spina bifida include a severe lack of information and support and the cost of surgery or a shunt. Despite all the limitations, Afolabi organized presentations to the families and nurses of the walk's participating hospital, and then walked through the streets of Lagos carrying signs and ban-

ners denouncing the stigmatization and bringing awareness to the communities about hydrocephalus and spina bifida.

I am very humbled and proud to report such activities around the world, and even more so to know that our work here at the national level reaches and inspires others all over the world. ❖

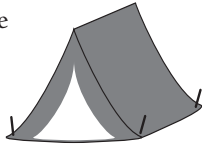


News Notes

ATTENTION CAMPERS!

By Bonnie Hom,
Youth and Community Coordinator

Does your child like camping and playing in the great outdoors? If the answer is “yes” and you would like more information on accessible camps, please contact the National Center on Physical Activity and Disability (NCPAD) at (800) 900-8086 or visit www.ncpad.org.



The NCPAD developed a guide titled “Discover Camp: Considerations for Sending Your Child with a Disability to Camp for the First Time.” Please contact NCPAD for a copy.

CHILD CARE RESOURCE

As any parent of a special needs child can tell you, the process of finding appropriate child care can be very difficult. To help in your search for child care, visit www.care.com. This Web site allows parents to search for caregivers available in and around their town.

CREATING AWARENESS!

“How can I create awareness of hydrocephalus?” is one of the frequently asked questions we hear. It is time we “Catch the Wave of Awareness” and spread the word on hydrocephalus and we can all help.

Now available through the HA, “Hydrocephalus~Catch the Wave of Awareness~” wrist bracelets! These are very popular for kids and adults of all ages to wear in support of a cause that is important to them.

They’re a great way to start a conversation with someone about hydrocephalus. You can distribute them at local schools, churches, clubs, teams, legislators, hospitals, etc. . . . You can use them as party favors, stocking stuffers or

SUGGESTED READING

These suggested readings are available for purchase on www.lapublishing.com or www.amazon.com.

Remind Me Why I’m Here: Sifting through Sudden Loss of Memory and Judgment

By Diana Lund, 2006

Diana Lund was a top-ranked project manager in her mid-thirties when a car accident instantly changed her personality and her life’s direction. Thrust into short-term memory loss and cognitive deficit, knowing herself was like knowing a ghost. Each time she grabbed for the illusion, self-perception collided into reality. Neurologists underestimated her difficulties; they sent her back to work to manage multi-million dollar contracts in a mentally compromised state. Outside of work, her marriage-minded boyfriend kept expecting more than she could give.

This book brings humor, healing, and hope to one woman’s quest to become whole again and to understand the world.

All About Me!

By Roberta DePompei, Ph.D. and Bob Cluett, 1998

This booklet helps elementary school children understand brain injury or any disability by using checklists and answering questions. A Spanish version is also available.

The Memory Doctor: Fun, Simple Techniques to Improve Memory & Boost Your Brain Power

By Doug Mason, Psy.D., LCSW and Spencer Xavier Smith, 2005

Dr. Mason explains how memory works and the different types of memory that we use every day. How we remember things is a process. By helping you understand and pay more attention to the steps of this process, you can improve your memory by using specific techniques.

All About Me! My Life as a Teenager

By Roberta DePompei, Ph.D., 2000

This booklet helps teenagers with any diagnosis describe special needs and become self-advocates. Using short narratives and checklists, sections include friendships and interests, special needs, and assistance needed. It provides detailed information on how to negotiate accommodations and compensatory strategies in school.



ask you local businesses to display them for a donation.

Like the Awareness Pins, they are distributed at cost by us and can be acquired in a variety of incremental amounts (a dozen for instance) by ordering them through the San Francisco office.

Please see our Web site for more information or contact Marybeth Godlewski at marybeth@hydroassoc.org or 484-270-2385.



HYDRO-FACT:

DID YOU KNOW?

Hydrocephalus is the most common reason for brain surgery in children.

The Federal government spends less than \$1 million per year on hydrocephalus related research.

If you already knew this, congratulations.

If not, now you know.

Now, tell a friend.

Kid's Corner!

By Bonnie Hom, Youth and Community Coordinator

Riddles of Fun

Rudolf's nose is red
The sky is blue
Here is a riddle
Made especially for you!

What can do the wave but has no hands?
Has many vessels but cannot sail?
Is full of wrinkles but has no skin?
What am I?

Answer: A brain

Kidding Around

What did Mama Shunt say to the anxious
Baby Shunt?

Answer: Relax; go with the flow.

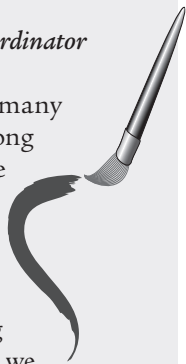
What happens to the kitty at the checkout
register?

Answer: It gets a CAT scan.

CALLING ALL ARTISTS

By Bonnie Hom,
Youth and Community Coordinator

We know there are many talented artists among our members, and we would love to see your work. Send us a drawing, sketch, or painting of what hydrocephalus means to you. Depending on the number of entries we receive, we will select some of the artwork to be printed onto greeting cards. These greeting cards will be available for purchase, and all profits will go toward a financial aid fund for individuals and families who otherwise cannot afford to attend our 2010 conference in Cleveland. Your art will also be considered for exhibition at the conference.



Details for entry

- What:** The Hydrocephalus Association Greeting Cards and Art Exhibition
Who: Open to children with hydrocephalus between the ages of 3 and 17
Why: To encourage youth with hydrocephalus to artistically express their perspectives on hydrocephalus
How: Draw, sketch or paint on paper that is no smaller than 8 inches × 11 inches and no larger than 20 inches × 24 inches
Deadline: All entries must be received by Monday, August 31, 2009.

Mail entries to:

The Hydrocephalus Association
870 Market St., Suite 705
San Francisco, CA 94102
Attn: Art Exhibition

Please note that artwork will not be returned, so please make a photocopy of or take a picture of your artwork before you submit it. Please write your name, age and date on the back so we will know who to give credit to. Do not attach anything (e.g., glue, staples, etc.) to the artwork. By submitting your artwork, you agree to allow the Hydrocephalus Association to use your name and photograph to promote this event. If your artwork is selected, we will mail you a consent form to obtain your permission to reprint and sell your work. We are looking forward to receiving your works of art!

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:

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

The Hydrocephalus Association is a national nonprofit organization providing support, education, resources and advocacy for families and professionals. The Newsletter is published quarterly. Thomas G. Smith is the editor. 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.

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Hydrocephalus Association

servicing individuals, families and professionals since 1983

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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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