Hydrocephalus Association

Pathways

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New Research 2008: A Summary

The following research papers appeared in peer-reviewed medical and scientific journals in 2008. Due to space limitations resulting from the exciting abundance of articles relating to hydrocephalus, we have summarized the conclusions and listed the full citation for your reference. For more information on these and other articles, visit the article search section of our Web site at: **http://www.hydroassoc.org/research_advocacy/search-pubmed** or the U.S. National Library of Medicine's PubMed Web site at : **http://www.ncbi.nlm.nih.gov/sites/entrez**. You may also contact our office.

ADULTS, INCLUDING NORMAL PRESSURE HYDROCEPHALUS (NPH)

Brain metabolism in adult chronic hydrocephalus. *Kondziella D, Sonnewald U, Tullberg M, & Wikkelso C. (2008).* Journal of Neurochemistry. 106*(4), 1515-24; Department of Neurology, Sahlgrenska University Hospital, Göteborg, Sweden*

Delayed hippocampal neuronal death, accumulation of beta-amyloid and disturbed cholinergic neurotransmission may contribute to memory dysfunction. Compromised periventricular blood flow, decreased dopamine levels in the substantia nigra and damaged striatal GABAergic interneurons may reflect basal ganglia symptoms. At least in human hydrocephalus cerebrovascular co-morbidity of the white matter plays an important role as well.

Changes in aqueductal CSF stroke volume and progression of symptoms in patients with unshunted idiopathic normal pressure hydrocephalus. *Scollato A, Tenenbaum R, Bahl G, Celerini M, Salani B, & Di Lorenzo N. (2008). AJNR.* American Journal of Neuroradiology. 29*(1),* 192-7*; Department of Neurosurgery, Geriatric Agency, University of Florence, Florence, Italy*

Patients with a low SV have not necessarily had brain atrophy and can show, in the following months, a progressive increase in SV, which qualifies them as good candidates for VPS. The progressive reduction of the SV in untreated patients with worsening clinical symptoms may be a sign of a progressive cerebral ischemic injury, which renders the NPH irreversible.

Diagnosis, treatment, and analysis of long-term outcomes in idiopathic normal-pressure hydrocephalus. *McGirt MJ, Woodworth G, Coon AL, Thomas G, Williams MA, & Rigamonti D. (2008).* Neurosurgery. 62, *670-7; Department of Neurosurgery and The Adult Hydrocephalus Program, The Johns Hopkins Hospital, Baltimore, Maryland 21287, USA*

INPH can be diagnosed accurately with CSF pressure monitoring and CSF drainage via a spinal catheter. CSF shunting is safe and effective for INPH with a long-term shunt response rate of 75%. Independent predictors of improvement are the presence of gait impairment as the dominant symptom and shorter duration of symptoms.

Features of gait most responsive to tap test in normal pressure hydrocephalus. *Ravdin LD, Katzen HL, Jackson AE, Tsakanikas D, Assuras S, & Relkin NR. (2008).* Clinical Neurology and Neurosurgery. 110*(5), 455-61; Department of Neurology and Neuroscience, New York Presbyterian Hospital, Weill Medical College of Cornell University, Cornell Memory Disorders Program, 428 East 72 Street, Suite 500, New York, NY 10021, USA*

The classic features of gait often used in determining diagnosis of NPH (wide based stride, reduced foot-floor clearance, and small steps) were not helpful in identifying responders to the TT. Walking speed, steps for turning, and tendency towards falling were most likely to improve post-TT. These straightforward measures can readily be adapted into clinical practice to assist in determination of shunt candidacy.

Heritable essential tremor-idiopathic normal pressure hydrocephalus (ETINPH). *Zhang J, Williams MA, & Rigamonti D. (2008).* American Journal of Medical Genetics. Part A. 146A*(4), 433-9; Department of Neurosurgery, University of Mississippi Medical Center, Jackson, Mississippi 39216-4505, USA*

The pedigree reported here is a new autosomal dominant genetic disorder ETINPH. The characterization of the gene that causes ETINPH will certainly enhance the understanding of motor diseases in general.

Improvement after cerebrospinal fluid drainage is related to levels of N-acetyl-aspartate in idiopathic normal pressure hydrocephalus. *Lenfeldt N, Hauksson J, Birgander R, Eklund A, & Malm J. (2008).* Neurosurgery. 62*(1), 135-41, discussion 141-2; Department of Clinical*

(Continued on page 6.)

From the Editor

By Tom Smith, Outreach and Media Liaison

This space has traditionally been called "From the Executive Director." Over the years, our executive director has also acted as the chief editor of the newsletter. Due to the changes in organizational structure that have taken place at the Hydrocephalus Association, the role of editor has been passed on to me. These are some pretty large shoes, and I promise to do my best to fill them.

There are several very encouraging developments on the horizon, many of which we discuss in this issue. The Americans with Disabilities Act Amendment Act has passed into law and went into effect on January 1, 2009. We include in this issue our annual summary of research. Also, you will find a piece entitled "Year in Review," which covers much of the growth within the HA that your support has allowed.

Additionally, we bid adieu to one board president and say hello to a new chairman. During his two-year term, Bob Jacobsen has been a tremendous leader whose efforts and presence will be sorely missed. Stepping up, however, is Mr. Paul Gross, who has already had a tremendous impact on the HA and the hydrocephalus community as a whole. *(See his profile below.)*

This newsletter will not come out until we are in the New Year. Nevertheless, I would like to take the time to wish you all belated Happy Holidays and a happy and prosperous New Year. Now. . . bring, on the challenges of 2009!

Meet Paul Gross, Chairman of our Board of Directors

By Paul Gross, Chairman, Board of Directors

With the progress that Hydrocephalus Association has made on so many fronts over my first 2½ years as a board member, I'm very excited to be stepping into the Chairman's role at this time in the HA's growth. In addition to my experience as a senior executive at Microsoft, I'm the father of two children. My youngest, William, has hydrocephalus as an outcome of his premature birth. He has had five brain surgeries in his scant 3½ years, and I am as eager as the next parent to see treatments and outcomes improve rapidly and a cure found.

When my son was diagnosed with hydrocephalus, my wife and I read just about every book and article on hydrocephalus we could consume. I attended the National Institutes of Health (NIH) workshop on hydrocephalus, which the HA was instrumental in orchestrating back in September 2005. I came away both depressed by the state of hydrocephalus research and energized by the potential set in motion by the HA and the passion of the people who attended the workshop (researchers, neurosurgeons, medical device industry, NIH program directors, parents and advocacy groups). I met Dory Kranz at that workshop and began the dialogue that resulted in my joining the board of directors in June 2006.

I also forged other relationships at the workshop that I knew would be important. I met Dr. John Kestle, who was reputed to be the leader of most of the multicenter clinical trials that had been conducted in hydrocephalus. I connected with Curt Stewart, currently a fellow board member, who founded BrainChild Foundation, which was also a catalyst of the NIH workshop.

In the months that followed the workshop, I sought to understand and eventually influence the hydrocephalus research ecosystem. I engaged a group of executive MBA students at the University of Washington to help me formulate a plan to "move the needles" in hydrocephalus research. As a team, we boiled the hydrocephalus ocean: We interviewed Dory Kranz, Dr. Rich Ellenbogen (then head of the Congress of Neurosurgeons), Curt Stewart, and Dr. John Kestle. In May 2006, the team determined that the most impact we could have with limited resources was to start a clinical research network. As a result, the Hydrocephalus Clinical Research Network (HCRN) was born with Dr. Kestle as its chairman. The network now has four (soon to be five) centers and has accrued more than 1,500 patients into its shared registry.

But the team's strongest recommendation to me was that I get involved with the HA and help determine how to combine all of the fragmented voices of hydrocephalus into one powerful voice to advocate for and fund hydrocephalus research. I took that advice and joined the board. I was gratified to learn about the HA's affiliate program, which has been put into place to create local chapters for support, advocacy and grassroots fundraising around the country. The HA was also beginning to make great strides in advocacy at the federal level, but it was not quite ready to tackle the development steps necessary to raise sufficient funds for research.

Most of my efforts on the board over my initial term have been aimed at strategically advancing the HA's agenda on fundraising and research. I am further motivated by the progress the HA has made with affiliates, in advocacy and in grassroots fundraising. It provides a stable platform for the next phase of the HA's impact on people living with hydrocephalus. Now, with the addition of research funding to our core mission, the HA is poised to make the greatest difference to these people. So it is a great honor and opportunity to lead the board at this time of great potential. There is a lot to accomplish at the board and operational levels of the organization, and I'm excited by the challenge. Please feel free to e-mail me at **paul@hydroassoc.org**.

Staff Profile: Rick Smith

As the Hydrocephalus Association expands, we have sought out and found a consummate professional to act as our Interim Executive Director. Rick Smith has more than 25 years of experience in the field of nonprofit management support and organizational development. His experience includes 15 years as the CEO of the Support Center of San Francisco (now called CompassPoint) and the Support Centers of America, a national nonprofit organization dedicated to increasing the effectiveness of nonprofit organizations through the provision of management and organizational development services. Rick is recognized as a national leader in the field of management and technical assistance for nonprofit organizations and led the development of more than a dozen local nonprofit management support organizations throughout the United States, and he helped establish similar programs overseas. In addition, he has served as an adjunct faculty member at the University of California, Berkeley and Golden Gate University. Since 1997, as an independent consultant, Rick has focused his practice in the areas of organizational assessment and development, strategic planning, and transition management. During this time he has served as the Interim Executive Director for numerous nonprofit organizations around the Bay Area, most recently with Raising a Reader, Center for Medical Technology Policy, and SF Works.

Many Impressive Hydrocephalus Research Papers Presented at the Pediatric Section Meeting

By Dory Kranz, Director of Research

At the Pediatric Section meeting of the American Association of Neurological Surgeons (AANS) and Congress of Neurological Surgeons (CNS) in December, it was heartening to see many research papers on hydrocephalus presented. A number of worthy papers were eligible for the Hydrocephalus Association Resident's Prize. The winner will be announced in our spring newsletter.

> *"A number of worthy papers were eligible for the Hydrocephalus Association Resident's Prize."*

In all, 24 papers focused on hydrocephalus; eight of these were from institutions or researchers from the Hydrocephalus Clinical Research Network (HCRN). This number is evidence of the exciting progress that has occurred during the first year of the first-ever multicenter research network focused on pediatric hydrocephalus research. HCRN, headed by Dr. John Kestle of the Association's Medical Advisory Board, is comprised of four centers in the United States and Canada: Primary Children's Medical Center in Utah, Children's Hospital of Alabama at Birmingham, Texas Children's Hospital in Houston and The Hospital for Sick Children (SickKids) in Toronto, Canada.

Update from the Medical Advisory Board

By Dory Kranz, Director of Research

The Hydrocephalus Association's Medical Advisory Board met in Spokane, WA on December 3, 2008. The main topic of discussion was how the HA can transparently and proactively manage potential conflicts of interest as we embark on funding research. Like many disease-specific patient advocacy groups that fund research, we will initially draw from a small pool of researchers who are qualified to apply for and review grants. A poll of other organizations similar to ours conducted before the meeting revealed that the consensus was to have reviewers recuse themselves from a particular grant if they have any relationship with the researchers or institutions that are applying. The strategy of having a percentage of reviewers who would not apply for grants at all during their reviewing cycle—either because the researchers are fully funded during that cycle or because their research is not specifically focused on hydrocephalus, although they understand enough to review grants for scientific merit—was raised as a possibility. This dialogue is in its early stages and we welcome input.

Medtronic Global Heroes Program

Applications are now being accepted for this unique program that brings runners from around the world who benefit from medical devices to Minnesota to run in Medtronic Twin Cities Marathon events. Application deadline is March 31, 2009.

For more information go to: **http://www.medtronic.com/2009globalheroes/**

2008 Year in Review

By Tom Smith, Outreach and Media Liaison

2008 was a year of growth for the Hydrocephalus Association. It was a year to expand toward new horizons, with new resources and a new mission arm.

One of the most visible changes is currently in your hand (or, for the technically inclined, on your monitor). First published in 1983, the HA newsletter has changed its look a couple of times over the years, starting out as a simple handout and then expanding in 1992. This year, as a strategic move, the newsletter changed its appearance and name. The information is the same and our goal is the same—to provide our community with a broad range of meaningful information—but we changed the newsletter's color palette to reflect our new logo design and named it "Pathways." Parallel to this change was the unveiling of the new Web site, with its greatly expanded functionality.

Of course, the most exciting change is the addition of a new role for the HA—to directly fund research that improves the quality of life for people living with hydrocephalus and ultimately to find a cure. It's a huge task and not something that will happen overnight, but it is a task that we are looking forward to fulfilling. We are already laying the groundwork by creating a new division of the HA, headed by Dory Kranz, to develop and direct this effort. This change is in response to our strategic position, the advice of our Medical Advisory Board, and the urging of you, our community.

As a result of this new role for the HA, our organizational structure has changed. Dory has moved from the position of executive director to the head of the new research division. We welcome Rick Smith, our interim executive director, who will be working with us until we hire a chief executive officer *(See the staff profile on page 3 for more information about Rick Smith.)*

What will not change is our commitment to maintaining what has been our core mission: to provide support, education, and advocacy to people whose lives have been touched by hydrocephalus and to the professionals who help them. So, despite the changes to structure and the addition of research to our mission, our fundamentals remain the same.

What better example of our ongoing commitment to our mission than Boozle Bear! Having passed safety tests, Boozle has been unleashed in all of his cuddly fury. Boozle is the latest addition to our collection of educational tools and has proved to be wildly popular among our young members. Boozle Bear allows children to visualize and take ownership of the processes of installing and having a shunt and also gives kids a way to show off to their peers. Boozle Bear was actually one of the stars of the 10th National Conference on Hydrocephalus in Park City, Utah. He was included in a workshop where kids were able to try their hands at creating their own bears.

The theme of this year's conference was "It's About Life," and it truly lived up to its billing. The setting was beautiful, the sessions were informative and, as always, the people were inspirational. Our keynote speaker, Sherman Alexei was witty and wise, the talent show was a hit, and our associated medical community proved once again how fortunate we are to have such caring and knowledgeable people supporting us. The conference allowed us to participate in perhaps the core value of the HA, which is community.

On the national front, we have made great progress as well. Our annual WALK season is coming to a close and mirrors the new era of growth. Simply put, we had 17 walks across the nation in 2007; in 2008 we had 24.

One of the major approaches in creating growth within the HA is expanding our nationwide network of affiliates. These affiliates involve motivated members of the HA community who have created grassroots support in their local communities. We are proud to have added three new affiliates in 2008: Phoenix, Boston, and St. Louis. These additions bring our affiliate total up to five.

We look forward to the challenges of 2009. With an open heart we welcome you to join us as we grow. ✠

Raising Awareness of NPH

By Tom Smith, Outreach and Media Liaison

Perhaps the most critical task facing our community regarding normal pressure hydrocephalus (NPH) is to raise simple awareness in the medical community and in the public mind. The statistics remain the same; the facts regarding frequency of diagnosis have not changed. A significant percentage of persons diagnosed with Parkinson's disease and/or Alzheimer's disease are cases of misdiagnosed NPH. It is nearly impossible to accurately predict how many of our nations elderly have not been diagnosed or have not seen a doctor because their symptoms have been relegated to "just getting older."

But there are individuals living with NPH, and it is part of our mission to increase the level of awareness of this condition. Therefore, we rejoice when something occurs to spark awareness. On October 22, 2008, Neurology NOW, the official publication of the American Academy of Neurology (AAN), published Michael Smolinsky's article "Hidden Pressure," a simple but excellent four-page article on NPH. The article is human and informative and includes success stories of people living with NPH as well as interviews with leaders in the field of NPH treatment and research, including Hydrocephalus Association Medical Advisory Board members Michael Williams, Ph.D., who is medical director of LifeBridge Brain and Spine Institute and director of the Adult Hydrocephalus Center at Sinai Hospital, and Anthony Marmarou, Ph.D., who is professor of neurosurgery and director of research at the Department of Neurosurgery at Virginia Commonwealth University.

Says Marybeth Godlewski, our National Advocacy Director, "When it comes to NPH, anything that creates awareness is a real accomplishment. Really, you can't go forward or create change without changing awareness at the national level."

The article's publication in Neurology NOW was strategically significant because the journal is typically distributed to neurologist's offices nationwide, and its impact has been felt here at the Hydrocephalus Association. The number of calls we have received from people requesting more information on NPH is up by 20% from this same time last year. Most of the callers specified that they became interested in obtaining more in-depth information after reading the article in their neurologist's or neurosurgeon's office.

> *"... we'd like to see the diagnostic process for Alzheimer's or Parkinson's disease to also include testing that would rule out or establish the presence of NPH."*

Of course, this influx of calls does not mean that every caller is or will be diagnosed with NPH, but the point of raising awareness—within the general public as well as within the medical world—is to reduce the number of people who suffer needlessly as a result of misdiagnosis or a non-diagnosis of NPH.

In the instance of an elderly person visiting a neurologist or neurosurgeon, we'd like to see the diagnostic process for Alzheimer's or Parkinson's disease to also include testing that would rule out or establish the presence of NPH. Additionally, we'd like for older adults and their adult children to be familiar enough with the signs and symptoms of NPH so that they don't mistake a slow, deliberate gait or a continence problem as simply a natural consequence of getting older.

To see Michael Smolinsky's article online, visit the Neurology NOW Web site at **www.neurologynow.com** and click on "Issue Archive" to search for the September/October 2008 issue.

UC Irvine Study Ongoing

By Tom Smith, Outreach and Media Liaison

In an effort to promote medical advancement in the treatment of movement disorders, the Department of Neurology at the University of California, Irvine, headed by Laura S. Paré, M.D., a neurosurgeon and medical director of the General Neurosurgery Ambulatory Care Clinic at UC Irvine Medical Center, is currently conducting a study to determine which combination of tests will enable physicians to predict whether a patient with symptoms of NPH will improve with a shunt.

They are currently screening patients who experience these symptoms:

- gait disturbance
- memory problems
- incontinence.

To find out more about or participate in the study, please contact Dr. Paré at **lpare@uci.edu**.

New Research 2008: A Summary (continued from page 1)

ADULTS, INCLUDING NPH (Continued)

Neuroscience, Center for Biomedical Engineering and Physics, Umeå University, Umeå, Sweden

NAA/Cr ratios were decreased in patients with idiopathic normal pressure hydrocephalus, which is consistent with neuronal dysfunction in the frontal white matter. Improved patients had NAA/Cr ratios close to normal, indicating that enough functional neurons are a prerequisite for the cerebrospinal fluid drainage to have an effect.

Infectious complications of temporary spinal catheter insertion for diagnosis of adult hydrocephalus and idiopathic intracranial hypertension. *Greenberg BM, & Williams MA. (2008).* Neurosurgery. 62*(2), 431-5; discussion 435-6; Department of Neurology, The Johns Hopkins Hospital, Baltimore, Maryland, USA*

Although infection is the most serious complication of spinal catheter insertion for evaluation of hydrocephalus or IIH, the infection rate can be maintained below 2% with use of chlorhexidine topical antiseptic application, single-dose preprocedural antibiotic administration, and clinical surveillance of the patient. The benefit of cerebrospinal fluid drainage via spinal catheter for normal pressure hydrocephalus outweighs the risks associated with the procedure.

Lower incidence of reoperation with longer shunt survival with adult ventriculoperitoneal shunts placed for hemorrhage-related hydrocephalus. *Hoh BL, Lang SS, Ortiz MV, Chi YY, Lewis SB, & Pincus DW. (2008).* Neurosurgery. 63*(1), 70-4; discussion 74-5; Department of Neurological Surgery, University of Florida College of Medicine, Gainesville, Florida 32610, USA*

Adult VPS placed for hemorrhage-related hydrocephalus have a significantly lower incidence of reoperation and significantly longer shunt survival. This result may be related to an incidence of transient shunt dependency in patients with hemorrhage-related hydrocephalus. However, the precise mechanism remains unclear.

Lumbar subcutaneous shunt: a novel technique for therapeutic decision making in normal pressure hydrocephalus (NPH) and benign intracranial hypertension (BIH). *Ushewokunze S, Haja Mydin HN, Prasad R, & Mendelow AD. (2008).* British Journal of Neurosurgery. 22*(5), 678-81; Department of Neurosurgery, Newcastle General Hospital, Regional Neurosciences Centre, Newcastle-upon-Tyne, UK*

The percutaneous introduction of a lumbar subcutaneous shunt (LSS) under local anaesthesia facilitates both a prolonged CSF drainage under aseptic conditions and also elicits an adequate clinical response. We describe the technique of a lumbar subcutaneous shunt and our experience with its use in patients with BIH and NPH.

Mechanism of bladder dysfunction in idiopathic normal pressure hydrocephalus. *Sakakibara R, Kanda T, Sekido T, Uchiyama T, Awa Y, Ito T, Liu Z, Yamamoto T, Yamanishi T, Yuasa T, Shirai K, & Hattori T. (2008).* Neurourology and Urodynamics. 27*(6), 507-10; Neurology Division, Department of Internal Medicine, Sakura Medical Center, Toho University, Sakura, Japan*

While incontinence can result secondarily from gait disturbance or dementia, detrusor overactivity mostly underlies urinary urgency/frequency and incontinence in iNPH.

Normal pressure hydrocephalus: are you missing the signs? *Siedlecki SL. (2008).* Journal of Gerontological Nursing. 34*(2), 27-33; quiz 34-5; Cleveland Clinic, OH 44195, USA*

It is imperative that patients with gait problems, slowness of thought or actions, or urinary incontinence be evaluated and screened for NPH. Geriatric nurses are in the best position to intervene by recognizing the signs of NPH and making early and appropriate referrals.

Normal pressure hydrocephalus: diagnosis and treatment. *Shprecher D, Schwalb J, & Kurlan R. (2008).* Current Neurology and Neuroscience Reports. 8*(5), 371-6; University of Rochester School of Medicine, 1351 Mt. Hope Avenue, Suite 100, Rochester, NY 14620, USA*

There are many tests used to predict possible response to surgery, such as MRI of the brain, formalized neuropsychological and gait testing, large-volume lumbar puncture, and prolonged lumbar drainage, but no one test has been validated to rule out potential response to surgery.

Normal pressure hydrocephalus: long-term outcome after shunt surgery. *Pujari S, Kharkar S, Metellus P, Shuck J, Williams MA, & Rigamonti D. (2008).* Journal of Neurology, Neurosurgery, and Psychiatry. 79*(11), 1282-6; Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA*

Clinical improvement of patients with NPH can be sustained for 5-7 years in some patients with NPH, even if shunt revision surgery is needed multiple times. With earlier diagnosis and treatment of NPH and the increasing lifespan of the ageing population, the need for long-term follow-up after shunt surgery for NPH may be greater than it was in the past. Monitoring, identification and treatment of shunt obstruction is a key management principle.

Objective assessment of gait in normal-pressure hydrocephalus. *Williams MA, Thomas G, de Lateur B, Imteyaz H, Rose JG, Shore WS, Kharkar S, & Rigamonti D. (2008).* American Journal of Physical Medicine & Rehabilitation / Association of Academic Physiatrists. 87*(1), 39-45; Adult Hydrocephalus Program, Department of Neurology, Johns Hopkins Hospital, Baltimore, Maryland 21287, USA*

There are significant, quantifiable changes in gait after CSF drainage that correspond to improvement after shunt surgery for patients with NPH. Use of objective gait assessment may improve the process of identifying these candidates when response to CSF removal is used as a supplemental prognostic test for shunt surgery.

Retrograde jugular flow associated with idiopathic normal pressure hydrocephalus. *Kuriyama N, Tokuda T, Miyamoto J, Takayasu N, Kondo M, & Nakagawa M. (2008).* Annals of Neurology. 64*(2), 217-21.; Department of Neurology and Gerontology, Kyoto Prefectural University of Medicine, Kamigyo-ku, Kyoto, Japan*

Retrograde jugular venous flow may be associated with the development of iNPH; therefore, the analysis of retrograde jugular venous flow could be a useful element in the diagnosis of iNPH.

Sensitivity and predictive value of occupational and physical therapy assessments in the functional evaluation of patients with suspected normal pressure hydrocephalus. *Feick D, Sickmond J, Liu L, Metellus P, Williams M,*

New Research 2008: A Summary *(continued)*

Rigamonti D, & Hill-Briggs F. (2008). Journal of Rehabilitation Medicine : Official Journal of the UEMS European Board of Physical and Rehabilitation Medicine. 40(9), 715-20; Department of Physical Medicine and Rehabilitation, Johns Hopkins School of Medicine, Baltimore, MD 21205, USA

Specific occupational therapy and physical therapy assessments demonstrate sensitivity to change and predictive value with patients with suspected normal pressure hydrocephalus undergoing cerebrospinal fluid drainage.

Surgical management of adult hydrocephalus. *Bergsneider M, Miller C, Vespa PM, & Hu X. (2008).* Neurosurgery. 62, *643-59; discussion 659-60; Division of Neurosurgery, Department of Surgery, University of California-Los Angeles, David Geffen School of Medicine, University of California-Los Angeles Medical Center, Los Angeles, California 90095-6901, USA*

For the condition of normal pressure hydrocephalus, recommendations are offered regarding the evaluation, surgical treatment, and postoperative management of this disorder.

Sylvian aqueduct syndrome with slit ventricles in shunted hydrocephalus due to adult aqueduct stenosis. *Maroulis H, Halmagyi GM, Heard R, & Cook RJ. (2008). Journal of* Neurosurgery. 109*(5), 939-43.; Department of Neurosurgery, Royal North Shore Hospital, Sydney, Australia*

Although it is well known that SAS can be caused by shunt blockage producing a transtentorial pressure gradient, these cases emphasize that an identical clinical pattern can occur with a reverse transtentorial pressure gradient and slit ventricles due to shunt overdrainage. The authors propose a simple management plan for patients with shunted hydrocephalus who develop SAS.

Techniques and complications of external lumbar drainage for normal pressure hydrocephalus. *Governale LS, Fein N, Logsdon J, & Black PM. (2008).*Neurosurgery. 63*(4), 379-84; discussion 384; Department of Neurosurgery, Brigham and Women's Hospital, Boston, Massachusetts 02115, USA*

The rate of serious complications from external lumbar drainage for normal pressure hydrocephalus is low. It is hoped that continued evaluation of the procedure will lead to further reductions in the complication rate.

The pathophysiology of idiopathic normal pressure hydrocephalus: cerebral ischemia or altered venous hemodynamics? *Bateman GA. (2008). AJNR.* American Journal of Neuroradiology. 29*(1), 198-203; Department of Medical Imaging, John Hunter Hospital, Newcastle, Australia*

Ischemia in the deep venous territory is not a prerequisite for NPH. Patients with high-inflow NPH show alterations in superficial venous compliance and a reduction in the blood flow returning via the sagittal sinus. These changes together suggest that an elevation in superficial venous pressure may occur in NPH.

Validation of grading scale for evaluating symptoms of idiopathic normal-pressure hydrocephalus101. *Kubo Y, Kazui H, Yoshida T, Kito Y, Kimura N, Tokunaga H, Ogino A, Miyake H, Ishikawa M, & Takeda M. (2008).* Dementia and Geriatric Cognitive Disorders. 25*(1), 37-45; Psychiatry and Behavioral Science, Osaka University Graduate School of Medicine, Osaka, Japan*

The iNPHGS cognitive domain score significantly correlated with the cognitive test scores, including the Mini-Mental State Examination (MMSE), the gait domain score with the Up and Go Test and Gait Status Scale scores, and the urinary domain score with the International Consultation on Incontinence Questionnaire-Short Form (ICIQ-SF) score. The MMSE, Gait Status Scale and ICIQ-SF scores significantly improved in patients whose iNPHGS scores improved after CSF tapping but not in those whose iNPHGS scores did not improve after CSF tapping.

What do physicians know about normal pressure hydrocephalus and when did they know it? A survey of 284 physicians. *Conn HO, & Lobo FM. (2008).* The Yale Journal of Biology and Medicine. 81*(1), 19-29; Emeritus, Yale University School of Medicine, New Haven, Connecticut, USA*

Two-thirds of them had learned of NPH in medical school, and one-fourth during residency and fellowship. Seven percent had never heard of NPH.The significance of these studies is discussed.

When to consider normal pressure hydrocephalus in the patient with gait disturbance. *Factora R, & Luciano M. (2008).* Geriatrics. 63*(2), 32-7*

Diagnosis is made based on suspicion of NPH symptoms, the additional finding of ventriculomegaly on imaging, and confirmatory testing with a trial of CSF drainage, which can predict improvement with CSF shunting. The differential diagnosis must consider common causes of each of the symptoms and include Alzheimer's disease (AD), Parkinson's disease (PD), vascular dementia, and spinal stenosis. Treatment involves CSF diversion, usually through implantation of a shunt from the ventricles to the peritoneal cavity. After surgery and in the absence of other contributing factors, the benefit of surgical intervention can be durable over years.

BASIC SCIENCE

Cerebrospinal fluid cleaved-tau protein and 9-hydroxyoctadecadienoic acid concentrations in pediatric patients with hydrocephalus. *Cengiz P, Zemlan F, Ellenbogen R, Hawkins D, & Zimmerman JJ. (2008).* Pediatric Critical Care Medicine: A Journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies. 9*(5), 524-9; Department of Pediatrics, Pediatric Critical Care Medicine, University of Washington, Seattle, WA, USA*

Children with hydrocephalus who have clinical signs of increased intracranial pressure and require ventriculoperitoneal shunt placement or revision exhibit markedly elevated cerebrospinal fluid cleaved-tau levels, suggesting evidence of axonal damage. However, this axonal injury does not seem to be associated with significant lipid peroxidation, at least as assessed by quantifying cerebrospinal fluid 9-hydroxyoctadecadienoic acid at a single, concurrent time point. The significant relationship between age and cerebrospinal fluid cleaved-tau levels suggest that brain injury associated with hydrocephalus may be more pronounced in older children.

Cerebrospinal fluid shunt infections in children over a 13-year period: anaerobic cultures and comparison of clinical signs of infection with Propionibacterium acnes and with other bacteria. *Arnell K, Cesarini K,*

(Continued on page 8.)

New Research 2008: A Summary *(continued from page 7)*

BASIC SCIENCE *(continued)*

Lagerqvist-Widh A, Wester T, & Sjölin J. (2008). Journal of Neurosurgery. Pediatrics. 1*(5), 366-72; Department of Pediatric Surgery, Uppsala University Hospital, Uppsala, Sweden*

Addition of anaerobic cultures and prolonged incubation times led to an increase in the detection of shunt infections. Infections caused by propionibacteria often result in mild symptoms that may be overlooked if adequate anaerobic cultures are not obtained.

Chronic hydrocephalus-induced hypoxia: increased expression of VEGFR-2+ and blood vessel density in hippocampus. *Dombrowski SM, Deshpande A, Dingwall C, Leichliter A, Leibson Z, & Luciano MG. (2008).* Neuroscience. 152*(2), 346-59; Department of Neurosurgery, Cleveland Clinic Foundation, Cleveland, OH 44195, USA*

VEGFR-2 may play an adaptive role in angiogenesis after CH-induced hypoxia. Modulation of vascular endothelial growth factor/VEGFR-2(+) may be important in developing treatments for hypoxic conditions including hydrocephalus and other forms of cerebral ischemia.

Comparative evaluation of 5-HIAA (5-hydroxy indoleacetic acid) and HVA (homovanillic acid) in infantile hydrocephalus. *Gopal SC, Pandey A, Das I, Gangopadhyay AN, Upadhyaya VD, Chansuria JP, & Singh TB. (2008).* Child's Nervous System: ChNS: Official Journal of the International Society for Pediatric Neurosurgery. 24*(6), 713-6; Department of Pediatric Surgery, Institute of Medical Sciences, Banaras Hindu University, Varanasi 221005 U.P., India*

Both the neurotransmitter metabolites 5-HIAA and HVA are found to be significantly high in the hydrocephalus, but 5-HIAA is a more sensitive parameter. These markers levels decrease after shunt insertion. Thus, estimation of these metabolites could be valuable markers for its diagnosis and follow-up.

Demonstration of uneven distribution of intracranial pulsatility in hydrocephalus patients.

Eide PK. (2008). Journal of Neurosurgery. 109*(5), 912-7; Department of Neurosurgery, Division of Clinical Neuroscience, Rikshospitalet, Oslo, Norway*

The present observations demonstrate uneven distribution of intracranial pulsatility in patients with hydrocephalus, higher pulse pressure amplitudes within the ventricular CSF (ICP(LV)) than within the brain parenchyma (ICP(PAR)). This may be one mechanism behind ventricular enlargement in hydrocephalus.

Intracranial pressure waves: characterization of a pulsation absorber with notch filter properties using systems analysis: laboratory investigation. *Zou R, Park EH, Kelly EM, Egnor M, Wagshul ME, Madsen JR. (2008).* Journal of Neurosurgery Pediatrics. 2*(1):83-94; Neurosurgery Department, Children's Hospital Boston, Harvard Medical School, Boston, MA 02115, USA*

The authors found that the intracranial system in these animals could be considered to include a pulsation absorber for which the target frequency appears to be close to the cardiac frequency. One possible source for such an absorber mechanism might be the free movement of cerebrospinal fluid, implying that impairment of this motion may have important clinical implications in various neurological conditions such as hydrocephalus.

Multiplicity of cerebrospinal fluid functions: New challenges in health and disease. *Johanson CE, Duncan JA 3rd, Klinge PM, Brinker T, Stopa EG, & Silverberg GD. (2008).* Cerebrospinal Fluid Research. 5, *10; Department of Clinical Neurosciences, Warren Alpert Medical School at Brown University, Providence, RI 02903, USA*

This review integrates eight aspects of cerebrospinal fluid (CSF) circulatory dynamics: formation rate, pressure, flow, volume, turnover rate, composition, recycling and reabsorption. Novel ways to modulate CSF formation emanate from recent analyses of choroid plexus transcription factors (E2F5), ion transporters (NaHCO3 cotransport), transport enzymes (isoforms of carbonic anhydrase), aquaporin 1 regulation, and plasticity of receptors for fluid-regulating neuropeptides.

The impact of microsurgical fenestration of the lamina terminalis on shunt-dependent hydrocephalus and vasospasm after aneurysmal subarachnoid hemorrhage. *Komotar RJ, Hahn DK, Kim GH, Khandji J, Mocco J, Mayer SA, & Connolly ES Jr. (2008).* Neurosurgery. 62*(1), 123-32; discussion 132-4; Department of Neurological Surgery, Columbia University, New York, New York 10032, USA*

In contrast to other retrospective multisurgeon series, the authors' retrospective single-surgeon series suggests that microsurgical fenestration of the lamina terminalis may not reduce the incidence of shunt-dependent hydrocephalus or cerebral vasospasm after aneurysmal subarachnoid hemorrhage.

The importance of the cortical subarachnoid space in understanding hydrocephalus. *Rekate HL, Nadkarni TD, & Wallace D. (2008).* Journal of Neurosurgery. Pediatrics. 2*(1), 1-11; Pediatric Neurosciences, Barrow Neurological Institute, St Joseph's Hospital and Medical Center, Phoenix, AZ 85013, USA*

The important role of the CSAS in the pathophysiology of various forms of hydrocephalus has been largely ignored. Attention to the dynamics of the CSF in this compartment will improve understanding of enigmatic conditions of hydrocephalus and improve selection criteria for treatment paradigms such as ETV. These concepts lead to clearly defined problems that may be solved by the creation of a central database to address these issues.

White matter microstructural abnormalities in children with spina bifida myelomeningocele and hydrocephalus: a diffusion tensor tractography study of the association pathways. *Hasan KM, Eluvathingal TJ, Kramer LA, Ewing-Cobbs L, Dennis M, & Fletcher JM. (2008).* Journal of Magnetic Resonance Imaging: JMRI. 27*(4), 700-9; Department of Diagnostic and Interventional Imaging, The Hospital for Sick Children, University of Toronto, Toronto, Canada*

DTT revealed diffusion tensor characteristics of abnormal development (nonvisualization/poor visualization of tracts, downward arrow FA, upward arrow diffusivities), impairment in myelination (upward arrow transverse diffusivity) as well as abnormalities in intrinsic axonal characteristics and extraaxonal/extracellular space (upward arrow axial diffusivity) in the association pathways of the SBM children. The differences in the diffusion metrics observed in the children with SBM are suggestive of abnor-

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mal white matter development and persistent degeneration with increased age.

ETV

Complications of endoscopic third ventriculostomy in previously shunted patients. *Hader WJ, Walker RL, Myles ST, & Hamilton M. (2008).* Neurosurgery. 63*(1), ONS168-74; discussion ONS174-5; Division of Neurosurgery, Department of Clinical Neurosciences, University of Calgary, Calgary, Canada*

ETV is an effective treatment both in selected patients with newly diagnosed hydrocephalus and in patients with a previous shunting procedure who are presenting with malfunction. Complications of ETV occur more frequently in previously shunted patients than in patients treated for newly diagnosed hydrocephalus, and care must be taken in the selection and treatment of these patients.

Complications of endoscopic third ventriculostomy. *Ersahin Y, & Arslan D. (2008).* Child's Nervous System: ChNS: Official Journal of the International Society for Pediatric Neurosurgery. 24*(8), 943-8; Division of Pediatric Neurosurgery, Ege University Faculty of Medicine, Izmir, Turkey*

ETV should be the first choice in the management of noncommunicating hydrocephalus. Training, experience, and meticulous technique will decrease the complication rate. Patients undergoing ETV should be followed in a similar manner to patients with cerebrospinal fluid shunts.

Endoscopic management of hydrocephalus in pediatric patients: a review of indications, techniques, and outcomes. *Sandberg DI. (2008).* Journal of Child Neurology. 23*(5), 550-60; Division of Neurosurgery, Miami Children's Hospital, Miami, FL 33155, USA*

For selected patients with obstructive hydrocephalus, endoscopic third ventriculostomy and other endoscopic techniques offer substantial advantages over shunting.

Endoscopic third ventriculostomy for obstructive hydrocephalus in children younger than 6 months of age: is it a first-choice method? *Lipina R, Reguli S, Dolezilová V, Kuncíková M, & Podesvová H. (2008).* Child's Nervous System: ChNS: Official Journal of the International Society for Pediatric Neurosurgery. 24*(9), 1021-7; Department of Neurosurgery, University Hospital of Ostrava, 17. listopadu 1790, Ostrava-Poruba, 708 52, Czech Republic*

The authors recommend ETV as the method of choice in children younger than 6 month of age.

Endoscopic third ventriculostomy: the best option in the treatment of persistent hydrocephalus after posterior cranial fossa tumour removal? *Tamburrini G, Pettorini BL, Massimi L, Caldarelli M, & Di Rocco C. (2008).* Child's Nervous System: ChNS: Official Journal of the International Society for Pediatric Neurosurgery. 24*(12), 1405-12; Paediatric Neurosurgery, Institute of Neurosurgery, Catholic University Medical School, Rome, Italy*

Post-operative ETV should be considered the best option to treat persistent hydrocephalus after the removal of posterior fossa tumours.

Reproductive implications of endoscopic third ventriculostomy for the treatment of hydrocephalus. *Bedaiwy MA, Fathalla MM, Shaaban OM, Ragab MH, Elbaba S, Luciano M, El-Nashar SA, & Falcone T. (2008).* European Journal of Obstetrics, Gynecology, and Reproductive Biology. 140*(1), 55-60; Department of Obstetrics and Gynecology, University Hospitals of Cleveland, Case Western Reserve University, Cleveland, OH, USA*

ETV appears to alter reproductive function postoperatively. In patients who establish a pregnancy, abortion rates seem to be higher in the ETV group; however, a prospective study will be required to validate these observations.

Success and complication rates of endoscopic third ventriculostomy for adult hydrocephalus: a series of 108 patients. *Dusick JR, McArthur DL, & Bergsneider M. (2008).* Surgical Neurology. 69*(1), 5-15; Division of Neurosurgery, University of California at Los Angeles David Geffen School of Medicine, UCLA Medical Center, Los Angeles, CA 90095-6901, USA*

Endoscopic third ventriculostomy is an effective treatment option for adult patients with noncommunicating hydrocephalus. Although most procedures resulted in long-term shunt independence, more than half of the eventual failures were delayed, and therefore, appropriate follow-up is required.

OTHER

A unifying hypothesis for hydrocephalus, Chiari malformation, syringomyelia, anencephaly and spina bifida. *Williams H. (2008).* Cerebrospinal Fluid Research. *5, 7; 19 Elibank Road, Eltham, London, SE9 1QQ, UK*

The hypothesis proposed in this essay supports the view that spina bifida is a manifestation of progressive hydrocephalus in the fetus. It is proposed that that mesodermal growth insufficiency influences both neural tube closure and central nervous system pressure, leading to dysraphism.

Antimicrobial suture wound closure for cerebrospinal fluid shunt surgery: a prospective, double-blinded, randomized controlled trial. *Rozzelle CJ, Leonardo J, & Li V. (2008).* Journal of Neurosurgery. Pediatrics. 2*(2), 111-7.; Women and Children's Hospital of Buffalo, Kaleida Health, Department of Neurosurgery, School of Medicine and Biomedical Sciences, University at Buffalo, State University of New York, Buffalo, New York 14222, USA*

These results support the suggestion that the use of AMS for CSF shunt surgery wound closure is safe, effective, and may be associated with a reduced risk of postoperative shunt infection.

Apparent diffusion coefficient and cerebrospinal fluid flow measurements in patients with hydrocephalus. *Anik Y, Demirci A, Anik I, Etus V, & Arslan A. (2008).* Journal of Computer Assisted Tomography. 32*(3), 392-6; Department of Radiology, School of Medicine, Kocaeli University, Umuttepe, Kocaeli, Turkey*

The ADC values increase in hydrocephalus and decrease significantly after treatment. Preoperative ADC value may serve as baseline, and the change in ADC may be an indicator of response to treatment and CSF flow measurements.

Historical trends of neuroendoscopic surgical techniques in the treatment of hydrocephalus. *Enchev Y, & Oi S. (2008).* Neurosurgical Review. 31*(3), 249-62; Division of Pediatric Neurosurgery, Jikei*

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OTHER (continued)

University Hospital, Women's and Children's Medical Center, Tokyo, Japan

The future trends of neuroendoscopic treatment of hydrocephalus such as robotics, image-guided neuroendoscopic surgical techniques, treatment "in utero", application of stem cell therapy, implementation of new technological solutions, and so on are discussed in the light of the approaching end of the century of neuroendoscopy.

How does CSF dynamics change after shunting? *Petrella G, Czosnyka M, Keong N, Pickard JD, & Czosnyka Z. (2008).* Acta Neurologica Scandinavica. 118*(3), 182-8; Academic Neurosurgical Unit, Addenbrookes Hospital, Cambridge, UK*

A functioning shunt has an important impact on CSF circulation and pressure-volume compensation. Infusion studies can demonstrate the return of disturbed CSF dynamics to normal values even if clinical or radiological changes are not dramatic.

Intracranial pressure and ventricular expansion in hydrocephalus: have we been asking the wrong question? *Levine DN. (2008).* Journal of the Neurological Sciences. 269*(1-2), 1-11; New York University School of Medicine, USA*

If the brain is relatively incompressible, transmission is efficient and high intracranial pressure is required to maintain the mini-gradient between the ventricles and the subarachnoid space, resulting in tension hydrocephalus. If the brain is more compressible, the parenchyma attenuates any increase of intraventricular pressure, reducing transmission to the outer surface. The theory explains why tests measuring CSF resistance have limited diagnostic usefulness in hydrocephalus.

Medical, social, and economic factors associated with health-related quality of life in Canadian children with hydrocephalus. *Kulkarni AV, Cochrane DD, McNeely PD, & Shams I. (2008).* The Journal of Pediatrics. 153*(5), 689-95; Division of Child Health and Evaluative Sciences, The Hospital for Sick Children, University of Toronto, Toronto, Ontario, Canada*

Despite a national universal health care system, socioeconomic disparities remain important as determinants of HRQL. Given the absence of a parallel private health care system in Canada, this suggests that the impact of socioeconomic factors is related to issues other than access to care.

Shunt-related headaches: the slit ventricle syndromes. *Rekate HL. (2008).* Child's Nervous System: ChNS: Official Journal of the International Society for Pediatric Neurosurgery. 24*(4), 423-30; Pediatric Neurosciences, Barrow Neurological Institute, St. Joseph's Hospital and Medical Center, Phoenix, AZ, USA*

Following the analysis of attempts to remove shunts, there are three possible outcomes. In about a quarter of patients, the shunt can be removed without having to be replaced. This is most common in patients treated in infancy for post-hemorrhagic hydrocephalus or patients shunted early after or before brain tumor surgery. Another half of patients have increased intracranial pressure and enlarged ventricles. In these patients, there is an 80% success rate for endoscopic third ventriculostomy. Finally, the most severe form of the slit ventricle syndrome involves intracranial hypertension without ventriculomegaly, which is managed optimally by shunt strategies that emphasize drainage of the cortical subarachnoid space such as lumbo-peritoneal shunts or shunts that include cisterna magna catheters.

The venous hypothesis of hydrocephalus. *Williams H. (2008).* Medical Hypotheses. 70*(4), 743-7*

When venous pressure is only slightly elevated CSF will accumulate and the manifestations of ischaemia may be less apparent, although ischaemia will be a feature of all instances of pathologically raised CNS pressure.

PEDIATRIC PATIENTS

Age-related differences in executive function among children with spina bifida/hydrocephalus based on parent behavior ratings. *Tarazi RA, Andrew Zabel T, & Mark Mahone E. (2008).* The Clinical Neuropsychologist. 22*(4), 585-602; Department of Neuropsychology, Kennedy Krieger Institute, Baltimore, MD, USA*

Children with MMH may continue to require targeted interventions and modifications to address executive dysfunction into young adulthood in order to promote functional independence.

Cerebrosp inal fluid eosinophilia in children with ventricular shunts. *Fulkerson DH, & Boaz JC. (2008).* Journal of Neurosurgery. Pediatrics. 1*(4), 288-95; Department of Neurosurgery, Division of Pediatric Neurosurgery, James Whitcomb Riley Hospital for Children, Indiana University School of Medicine, Indianapolis, Indiana 46202, USA*

Cerebrospinal fluid eosinophilia is a relatively common finding in children with shunts. Patients with CSF eosinophilia had an increased risk of shunt malfunction in the present series. Eosinophilia is associated with infection, CSF extravasation, and blood in the CSF. Patients with P. acnes-induced shunt infections have higher eosinophil percentages than are found in infections associated with other common organisms. Therefore, in patients with eosinophilia, extended anaerobic culture studies should be performed with particular attention paid to searching for this pathogen.

Clinical diagnosis of ventriculoperitoneal shunt failure among children with hydrocephalus. *Piatt JH Jr, & Garton HJ. (2008).* Pediatric Emergency Care. 24*(4), 201-10; Section of Neurosurgery, St Christopher's Hospital for Children, Philadelphia, PA 19134-1095, USA*

Analysis of symptoms and signs of ventriculoperitoneal shunt complications can inform clinical judgment in the assessment of children with hydrocephalus.

Comparing children's and parents' perspectives of health outcome in paediatric hydrocephalus. *Kulkarni AV, Cochrane DD, McNeely PD, & Shams I. (2008).* Developmental Medicine and Child Neurology. 50*(8), 587-92; Division of Child Health and Evaluative Sciences, Hospital for Sick Children, University of Toronto, Toronto, Canada.*

Agreement was higher for assessments of physical health, but lower for assessments of cognitive health and social-emotional health.

Endoscopic cyst fenestration in the tr eatment of multiloculated hydrocephalus in children. *El-Ghandour NM. (2008).* Journal of Neurosurgery. Pediatrics. 1*(3), 217-22; Department of Neurosurgery, Cairo University, Cairo, Egypt*

An endoscopic cyst fenestration (ECF) procedure is recommended in the treatment of multiloculated hydrocephalus because it is effective, simple, minimally invasive,

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and associated with low morbidity and mortality rates.

Epileptic encephalopathy with continuous spikes and waves during sleep in children with shunted hydrocephalus: a study of nine cases.
Caraballo RH, Bongiorni L, Cersósimo R, Semprino M, Espeche A, & Fejerman N. (2008). Epilepsia. *49(9), 1520-7; Hospital de Pediatría Prof Dr Juan P Garrahan, Buenos Aires, Argentina*
In children with early-onset hydrocephalus, particularly with behavioral and language disturbances and/or motor deterioration, CSWS should be considered. Periodic EEG recordings during sleep should be done in these children. The early identification of this particular electroclinical picture is crucial to start adequate treatment to avoid progressive cognitive deterioration.

Hospital care for children with hydrocephalus in the United States: utilization, charges, comorbidities, and deaths. *Simon TD, Riva-Cambrin J, Srivastava R, Bratton SL, Dean JM, & Kestle JR. (2008).* Journal of Neurosurgery. Pediatrics. 1*(2), 131-7; Department of Pediatrics, Division of Inpatient Medicine, University of Utah, Salt Lake City, Utah 84113, USA*
Children with hydrocephalus have a chronic illness and use a disproportionate share of hospital days and healthcare dollars in the US. Since 1997 they have increased in age and in number of comorbid conditions. For important changes in morbidity and mortality rates to be made, focused research efforts and funding are necessary.

Intellectual functioning in children with early shunted posthemorrhagic hydrocephalus. *Lacy M, Pyykkonen BA, Hunter SJ, Do T, Oliveira M, Austria E, Mottlow D, Larson E, & Frim D. (2008).* Pediatric Neurosurgery. *44(5), 376-81; Department of Psychiatry, University of Chicago, Chicago, IL 60637, USA*
Intellectual functioning in this selected group of children with hydrocephalus is normally distributed, yet significantly below that of nonaffected peers. Previously reported discrepancies between verbal IQ and performance IQ were not evident in this study. This finding may be accounted for by the selectivity of our study population, implying a differential effect of etiology and treatment on intellectual function outcome in hydrocephalic children.

Learning, memory and executive functions in children with hydrocephalus. *Lindquist B, Persson EK, Uvebrant P, & Carlsson G. (2008).* Acta Paediatrica *(Oslo, Norway : 1992). 97(5), 596-601; Department of Habilitation, Halmstad County Hospital, Halmstad, Sweden*
Despite an IQ of > or = 70, children with hydrocephalus had significantly impaired learning, memory and executive functions. When major brain lesions resulting in learning disability had been excluded, the hydrocephalus, rather than the underlying aetiology, was most important for the development of cognitive functions.

Sustained attention in children with two etiologies of early hydrocephalus. *Swartwout MD, Cirino PT, Hampson AW, Fletcher JM, Brandt ME, & Dennis M. (2008).* Neuropsychology. 22*(6), 765-75; Department of Psychology, University of Houston, Houston, TX 77204-5355, USA*
Hydrocephalus does not account for the attention profile of children with spina bifida meningomyelocele (SBM), which also reflects the distinctive brain dysmorphologies associated with this condition.

The Dandy-Walker variant: a case series of 24 pediatric patients and evaluation of associated anomalies, incidence of hydrocephalus, and developmental outcomes. *Sasaki-Adams D, Elbabaa SK, Jewells V, Carter L, Campbell JW, & Ritter AM. (2008).* Journal of Neurosurgery. Pediatrics. 2*(3), 194-9; Division of Neurosurgery, Department of General Surgery, University of North Carolina School of Medicine, Chapel Hill, NC 27599, USA*
The DWV was associated with both extra- and intracranial anomalies. Associated radiographic abnormalities including ventriculomegaly were observed. Hydrocephalus requiring cerebrospinal fluid diversion may be indicated. Isolated DWV was associated with a good developmental outcome.

Toward reducing shunt placement rates in patients with myelomeningocele. *Chakraborty A, Crimmins D, Hayward R, & Thompson D. (2008).* Journal of Neurosurgery. Pediatrics. 1*(5), 361-5; Department of Neurosurgery, Great Ormond Street Hospital for Sick Children, London, UK*
Applying more stringent guidelines for shunt placement, permitting moderate ventricular dilation, and accepting some mild increase in ventricular size after myelomeningocele closure has resulted in a reduced rate of shunt placement compared with previous series. The rate is comparable to that reported following in utero closure of myelomeningocele.

Ventricular shunt tap as a predictor of proximal shunt malfunction in children: a prospective study. *Rocque BG, Lapsiwala S, & Iskandar BJ. (2008).* Journal of Neurosurgery. Pediatrics. 1*(6), 439-43; Department of Neurological Surgery, University of Wisconsin-Madison, Madison, Wisconsin 53792-8660, USA*
Poor flow of CSF on shunt tap is highly predictive of obstruction of the proximal catheter. Because not all patients with good flow on shunt tap underwent surgical shunt exploration, the specificity of this test cannot be determined. Nonetheless, a shunt tap that reveals good flow with a normal opening pressure can be misleading, and management of such cases should be based on clinical judgment.

Ventriculosubgaleal shunts in the management of infective hydrocephalus. *Kariyattil R, Mariswamappa K, & Panikar D. (2008).* Child's Nervous System: ChNS: Official Journal of the International Society for Pediatric Neurosurgery. 24*(9), 1033-5.; Department of Neurosurgery, Amrita Institute of Medical Sciences, Amrita Lane, Elamakkara, Cochin, 682026, India.*
VSG shunts are a simple and efficient way of managing infective hydrocephalus.

SHUNTS

Antibiotic-impregnated shunt catheters for the treatment of infantile hydrocephalus. *Sciubba DM, Noggle JC, Carson BS, & Jallo GI. (2008).* Pediatric Neurosurgery. 44*(2), 91-6; Department of Pediatric Neurological Surgery, Johns Hopkins University, Baltimore, MD 21287, USA*
AIS systems can safely be used to treat hydrocephalus in pediatric patients <1 year old, even for those with a history of prematurity. One possible therapeutic application for such premature patients may be the incorporation of antibiotic impregnation into VADs or ventriculosubgaleal components to treat infants with hydrocephalus prior to definitive CSF shunt placement.

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SHUNTS *(continued)*

Clinical and economic consequences of antibiotic-impregnated cerebrospinal fluid shunt catheters. *Eymann R, Chehab S, Strowitzki M, Steudel WI, & Kiefer M. (2008).* Journal of Neurosurgery. Pediatrics. 1*(6), 444-50; Department of Neurosurgery, Saarland University Medical School, Saarland, Germany*

From clinical and economic perspectives, AISCs are seemingly a valuable addition in hydrocephalus therapy.

Have we made progress in preventing shunt failure? A critical analysis. *Stein SC, & Guo W. (2008).* Journal of Neurosurgery. Pediatrics. 1*(1), 40-7; Department of Neurosurgery, University of Pennsylvania School of Medicine, Philadelphia, Pennsylvania 19106, USA*

Progress in preventing shunt failures has not been made over the last several decades. Any improvements made in shunt materials or insertion techniques have been overshadowed by biological and other factors.

Intra-abdominal pressure: the neglected variable in selecting the ventriculoperitoneal shunt for treating hydrocephalus. *Sahuquillo J, Arikan F, Poca MA, Noguer M, & Martinez-Ricarte F. (2008).* Neurosurgery. 62*(1), 143-9; discussion 149-50; Department of Neurosurgery, Neurotraumatology, Vall d'Hebron University Hospital, Autonomous University of Barcelona, Barcelona, Spain*

In the study, the authors determined that IAP had a strong positive linear relationship with BMI. This correlation was independent of sex. An IAP of 0 mmHg can, therefore, only be assumed for patients with a normal BMI who are recumbent. In obese or overweight patients, neurosurgeons should take IAP into account when selecting both the most adequate differential pressure valve to be implanted and in which distal cavity to place the distal catheter to avoid shunt underdrainage induced by high IAP.

Magnetic field interactions in adjustable hydrocephalus shunts. *Lavinio A, Harding S, Van Der Boogaard F, Czosnyka M, Smielewski P, Richards HK, Pickard JD, & Czosnyka ZH. (2008).* Journal of Neurosurgery. Pediatrics. 2*(3), 222-8; United Kingdom Shunt Evaluation Laboratory, University of Cambridge, Cambridge, UK*

All valves, with the exception of the Polaris and ProGAV models, are prone to unintentional reprogramming when exposed to heterogeneous magnetic fields stronger than 40 mT. All tested valves can be considered safe for 3-T MR imaging. All valves generated a distortion of the MR image, especially the GE sequences.

Management of hydrocephalus in infants by using shunts with adjustable valves. *Weinzierl MR, Rohde V, Gilsbach JM, & Korinth M. (2008).* Journal of Neurosurgery. Pediatrics. 2*(1), 14-8; Department of Neurosurgery, University Hospital RWTH, Aachen, Germany*

The adjustable differential-pressure valve used in this study was not effective in preventing slitlike ventricles in the majority of patients. Despite the small number of patients, this study provides a rationale for examining whether new shunt designs (gravitational shunt valves) are superior to conventional shunt systems in managing challenging hydrocephalus problems.

Management of neonatal hydrocephalus: feasibility of use and safety of two programmable (Sophy and Polaris) valves. *Martínez-Lage JF, Almagro MJ, Del Rincón IS, Pérez-Espejo MA, Piqueras C, Alfaro R, & Ros de San Pedro J. (2008).* Child's Nervous System: ChNS: Official Journal of the International Society for Pediatric Neurosurgery. 24*(5), 549-56; Regional Service of Neurosurgery, Virgen de la Arrixaca University Hospital, El Palmar, 30120 Murcia, Spain*

The authors have concluded that: (1) Both programmable valves (Sophy and Polaris) can be safely used for treatment of neonatal hydrocephalus, introducing some technical modifications. (2) Both valves are comparable to other shunts with regard to indications, performance, and safety. (3) The possibility of modifying their working pressure seems to constitute their main advantage. Prevention of late overdrainage syndromes with these valves needs a longer follow-up.

Rethinking the indications for the ventriculoperitoneal shunt tap. *Miller JP, Fulop SC, Dashti SR, Robinson S, & Cohen AR. (2008).* Journal of Neurosurgery. Pediatrics. 1*(6), 435-8; Department of Neurological Surgery, University Hospitals of Cleveland, Cleveland, Ohio 44106, USA*

The authors have shown that it is possible to evaluate the majority of ventricular shunt malfunctions without tapping the device. Because it is possible to diagnose shunt obstruction correctly by other means, the shunt tap may not be obligatory as a routine test of the device's patency.

The Miethke dual switch valve: experience in 169 adult patients with different kinds of hydrocephalus: an open field study. *Hertel F, Züchner M, Decker C, Schill S, Bosniak I, & Bettag M. (2008).* Minimally Invasive Neurosurgery: MIN. 51*(3), 147-53.; Department of Neurosurgery, SHG-Klinik, Idar-Oberstein, Germany.*

Among the currently available shunt systems, this series is one with the lowest complication rates due to overdrainage and valve obstructions. In patients with NPH, where low opening pressures are essential, the DSV seems to bear an advantage because of a high drainage rate and, in spite of this, a low rate of overdrainage. Even in patients with relatively high CSF protein content, the authors did not observe any valve obstruction.

Ventriculoperitoneal shunting after aneurysmal subarachnoid hemorrhage: analysis of the indications, complications, and outcome with a focus on patients with borderline ventriculomegaly. *Little AS, Zabramski JM, Peterson M, Goslar PW, Wait SD, Albuquerque FC, McDougall CG, & Spetzler RF. (2008).* Neurosurgery. 62*(3), 618-27; discussion 618-27; Division of Neurological Surgery, Barrow Neurological Institute, Phoenix, Arizona 85013, USA*

Although the authors currently use a proactive shunting paradigm for posthemorrhagic hydrocephalus, this report demonstrates that a conservative approach to patients with borderline ventricle size (i.e., RBCI of 1.0-1.4) and normal intracranial pressure should be evaluated in a prospective randomized trial.

2009 Scholarship Applications Available

By Bonnie Hom, Youth and Community Coordinator

We are very pleased to offer eight scholarships to young adults with hydrocephalus in 2009. The scholarships are $500 each and will be awarded in June. If you would like to apply, please call our office (888-598-3789) or e-mail Bonnie at **bonnie@hydroassoc.org** to request an application. Depending on your preference, we will mail or e-mail you the application with instructions.

ELIGIBILITY REQUIREMENTS

- Applicants must be between 17 and 30 years old and have hydrocephalus.
- Scholarship funds must be used for an educational purpose, such as a four-year or junior college, a high school postgraduate year to prepare for college, a technical or trade school, an accredited employment-training program, or a postgraduate program.
- The scholarship funds may be used for tuition, books, housing or an expense directly related to the educational experience.
- The deadline for completed applications and recommendation forms is **April 1, 2009.** Applications received by our office after this date will not be considered, nor will applications that are incomplete (e.g., missing the recommendation form).

SCHOLARSHIPS OFFERED

Gerard Swartz Fudge Memorial Scholarship

This fund was established in 1994 by the Fudge family. Their son, Gerard, had hydrocephalus and died in 1992 at the age of 22 in the midst of his college experience. Two scholarships are awarded each year from this fund.

Morris L. and Rebecca Ziskind Memorial Scholarship

This fund was established in 2001 by Rebecca Ziskind and her family in memory of her husband, Dr. Morris Ziskind, who had normal pressure hydrocephalus. After Rebecca Ziskind's death in 2005, their three surviving children and their spouses—Carrie and Dee Norton, Jerome and Rosemary Ziskind, and Janet and Charles Tarino—graciously funded one more scholarship in loving memory of their parents. Two scholarships are now awarded from this fund.

Anthony Abbene Scholarship

This fund was established in 2002 by Anthony Abbene's extended family. Anthony is a teenager with hydrocephalus. This fund awards two scholarships in honor of Anthony to help others with hydrocephalus with their education.

Justin Scot Alston Memorial Scholarship

Gloria M. Alston established this scholarship in loving memory of her son, Justin Scot Alston, who died in 2004. Justin received a Hydrocephalus Association scholarship in 2002 and will be remembered for his tremendous upbeat attitude and for all that he accomplished during his short life.

Mario J. Tocco Hydrocephalus Foundation Scholarship

This scholarship was endowed in 2007 by Greg Tocco, executive director of the Hydrocephalus Foundation, Inc. of Saugus, Massachusetts, and his family in honor and memory of Greg's grandfather, Mario J. Tocco.

Shunt Pin Cards Now Available in Spanish

By Karima Roumila, Outreach Coordinator

We are pleased to announce that our shunt pin cards are now available in Spanish. They are great for advocacy and awareness. They contain key statistics about hydrocephalus. The pins are made with actual shunt tubing and are made by our wonderful volunteers throughout the country. So call us and raise awareness! Give some cards to your family, friends and government representatives. To order call: 1-888-598-3789.

Taking Steps to Improve Life

More 2008 WALK News

By MaryBeth Godlewski, National Advocacy Director

As the Hydrocephalus Association's national WALK coordinator, I personally extend my gratitude for the opportunity to work with a team of courageous, dedicated, heartwarming, talented, tenacious women and men who turned lemons into lemonade this WALK season! Thank you for allowing me to assist you in your mission and journey to create change for those living with hydrocephalus. On behalf of the HA, the board of directors and the hydrocephalus community, THANK YOU! I look forward to working with you all in 2009.

Sacramento Area, CA

On September 27th, Jodi Lawrence hosted the 2nd Annual Oroville WALK at Riverbend Park. It was attended by more than 100 people and raised $8,200. Participants enjoyed live music, face painting and wonderful barbeque.

Jodie and David Lawrence, the organizers of the Oroville WALK, aren't sitting still during their golden years. They are raising their grandson, Justin, who was born with hydrocephalus. Jodie and David have had custody of Justin since he was 3 months old. He is now 7. Jodie not only has hosted WALK events for the past two years, she also runs a support group.

To kick off the 2008 WALK, Justin's school (grades kindergarten through third—a total of 600 students) held a WALK on the school track the day before the official event. The entire school participated in the WALK and collected pledges. Some of the children brought their piggy banks and gave the entire contents of them. These wonderful kids raised $4,300 of the $8,200 raised. These donations are extremely significant because Oroville County was devastated by wildfires only weeks prior to the WALK. Nevertheless, this community reached into their hearts and pockets.

Jodie Lawrence said "We are so touched and so grateful to all the wonderful people that participated in our event in any way. We feel truly blessed by them."

Louisville, KY

On September 27th, Elizabeth Gladden hosted the 2nd Annual Louisville Hydrocephalus WALK at Otter Creek Park. Twenty-seven dedicated walkers raised over $3,000 and enjoyed a delectable hot dog feast after their workout.

Elizabeth, a retired mother with little extra time, has organized the past two WALKs in Kentucky. Elizabeth's daughter, Emily, was diagnosed with hydrocephalus at birth. Now 26, Emily is doing well after many surgeries. Emily and her husband, Jim, have just adopted a baby girl. Now Elizabeth plans to spend every spare minute with her new granddaughter and her one-year-old grandson.

Colonie, NY

The 1st Annual Colonie Hydrocephalus WALK was held at the Colonie Town Park on October 12th. It was a beautiful 68-degree day in upstate New York, and the leaves were still a glorious array of reds and golds. It was the perfect backdrop for the WALK. Attendance totaled 32 fabulous people, who together raised over $6,000! Andrea Barno, the chair of this event, was overwhelmed by the effort and support shown by all who participated. The day included more than the walk. There were games, music, face painting and refreshments. It was a great day to hang out and get to know one another! Andrea, mother of 8-month-old Jacob, who was born with hydrocephalus, is looking forward to and has already started planning next year's Hydrocephalus WALK!

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Milwaukee, WI

The Wisconsin Hydrocephalus WALK was held at the Milwaukee County Zoo on October 11th. More than 300 people attended, and the event raised $85,000!

The Honorary Chairperson was Wisconsin State Rep. Leah Vukmir (R), who was a pediatric nurse before becoming a legislator. The special guest was Dr. Bermans J. Iskandar of the Department of Neurological Surgery University of Wisconsin Hospital & Clinics. The WALK program emcee was Margo Fieseler, a nationally known speaker and author who used to be a special education teacher and worked with children with hydrocephalus.

There were several memorable moments during the short program held before the WALK. Joseph Batterman, a 6-year-old with hydrocephalus, and his 3 year-old sister, Grace, sang the National Anthem. Rep. Vukmir announced that she will work to make October Hydrocephalus Awareness Month in the state of Wisconsin. Dr. Iskandar spoke of the day that there will be a cure for hydrocephalus and that the status quo is not good enough!

Red Hot Dixie (a local Dixieland band) played fun music for everyone at the starting line and for the post-WALK celebration. Event coordinators Angela Batterman, Diane Weichert, and Gloria Frane received a lot of wonderful feedback from the event. The speakers were inspiring, the weather was gorgeous (mid-70s and sunny), and the zoo atmosphere and Dixieland music were fun for everyone who attended!

The event coordinators are excited to announce that Wisconsin's 2nd Annual Hydrocephalus WALK will be October 10, 2009 at the Milwaukee County Zoo.

Washington D.C.

On October 12th, Mimi Kramer-Roberts, with the help of her family and other dedicated hydrocephalus family members, hosted the 7th annual Washington D.C. WALK. The five-mile WALK was held at Burke Lake in Virginia and was followed by the annual picnic. The weather couldn't have been better and the camaraderie was great! A warm thank you to the following people for shopping, setting up, registering, cooking, speaking, demonstrating, sewing, photographing, cleaning up, and recycling: Heather and Larry Blackwell, Gail Buckmaster, Pat Callahan, Bryson Chapple, Justine Chester, Patrick Gemmill, Martha Goughnour, Jeff and Christina Kramer, Marilyn McNulty, Lisa Novgrod and her Target crew, Matt and Carolgene Reardon, and Christina and Brad Saull.

The WALK event was generously sponsored by NOVA (Network of Volunteer Associates) and LifeBridge Health. At this time, the event raised $12,752, with donations still coming!

Photos from the WALK can be viewed at:
http://share.shutterfly.com/action/welcome?sid=8IbNGrhy3cvLg.

Baltimore, MD

The 2nd Annual Baltimore Hydrocephalus WALK was held October 19th at Lake Elkhorn in Columbia, Maryland. The event was chaired by Terri Smith, whose daughter Devin has hydrocephalus. It was a beautiful day with clear skies for the WALK, which had 12 participants with hydrocephalus. It was a wonderful experience for the "VIPs" to meet others with hydrocephalus, many for the first time. More than 86 people participated in the walk and together, along with their family members and friends, they raised over $9,000. A physician assistant from LifeBridge Health spoke at the event and brought a sample of a shunt for everyone to see and touch. This was a unique experience, especially for the kids. In addition, the children were able to enjoy face painting, crafts and balloons. A picnic lunch and raffle concluded the day. A young boy with hydrocephalus expressed his excitement at the end of the event so beautifully when he smiled, gave a hug to thank Terri, and said he was excited because the day was his special day—a day just for him! Many thanks to everyone who attended and contributed to the Baltimore Hydrocephalus WALK!

Albuquerque, NM

The 3rd Annual Albuquerque Hydrocephalus WALK was held October 18th at the Village of Los Ranchos De Albuquerque. The WALK was chaired by three enthusiastic people: Kathy Carrilo, mother of four, whose youngest daughter Amy (age 5), was born with congenital hydrocephalus; Margaret Wood, mother of Patrick (age 12) and Abby (age 8), who was diagnosed with hydrocephalus at 3

Taking Steps to Improve Life

Albuquerque, NM *(continued)*

weeks of age; and Mark Medley, an adult with congenital hydrocephalus.

The WALK was a great success with more than 100 participants. The event raised more than $7,000. Kathy, Margaret and Mark are very grateful to everyone who participated, volunteered and sponsored this year's WALK. Kathy said "If not for them, we could not have had such a blessed walk, so thank you very much New Mexico for all of your support this year and we look forward to seeing you again next year for a bigger and better WALK for hydrocephalus!"

Austin-San Antonio, TX

The 2nd Annual Austin-San Antonio Hydrocephalus WALK was a big success! Approximately 300 participants and volunteers attended the WALK held on October 25th at Landa Park in New Braunfels, Texas.

"We came, we learned, we walked, we played, we laughed, we cried and we raised around $20,000! But more important than the money, we raised awareness for those who live with hydrocephalus. That is PRICELESS!" said WALK Chair Sheri Burdine, who was diagnosed with hydrocephalus at age 11.

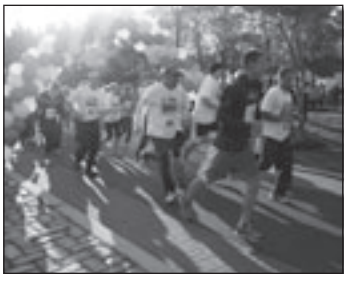
"The event's Honorary Chair was American Beauty Queen of Hearts USA Mrs. Kay Scott, whose young daughter died from complications of hydrocephalus. Participants learned about the Hydrocephalus Association from Keynote Speaker Dr. Patricia Aronin of Austin's Central Texas Neurosurgery for Children. We also had a very special guest share the day with us: 'The Chicken' (Keith Burdine). He really got things going! Fun was had by all"

Birmingham, AL

On October 26th the first (hopefully of many) Hydrocephalus WALK was held in Alabama. The WALK was hosted by a team of dedicated and ambitious co-chairs. Becca Cardin is a single mother attending University of Alabama Law School. Her son Noah, age 8, was diagnosed with hydrocephalus at 30 weeks' gestation and has had more than 40 hydrocephalus-related surgeries. Rhonda Fort is the mother of two. Her daughter, Jackie (age 2), was diagnosed with hydrocephalus in utero. Amanda Smith was born with hydrocephalus. She had her first shunt placed this year at age 25. Misty McGrew is a mother of five. Her 8-month-old son, Nash, was diagnosed with hydrocephalus at 10 weeks. Deborah Norris is an Air Force Reserve wife and mother of four. Her youngest daughter, Adora, (age 3) was born with hydrocephalus.

More than 200 people attended the WALK, which was held at Veterans Park in Hoover, Alabama. The event has raised $20,898 to date. Special guests in attendance included Dr. John "Jay" Wellons, III, a pediatric neurosurgeon at Children's Hospital in Birmingham and part of the Hydrocephalus Clinical Research Network team. Hoover's Mayor, the Honorable Tony Petelos, presented an award to the top fundraising team, "Nash's Gang." A highlight of the day was when WALK Honorary Chairperson Sen. Vivian Davis Figures (D) presented the WALK event co-chairs with a proclamation from Gov. Bob Riley, declaring November as "Hydrocephalus Awareness Month" within the state of Alabama. Music was graciously provided by the Cuttin' Loose Band.

Philadelphia, PA



On November 1st, the 4th Annual Philadelphia Hydrocephalus WALK was held on Philadelphia's beautiful Boathouse Row. The event was attended by more than 1,000 participants and raised over $50,000. I had the pleasure of co-chairing the event

Taking Steps to Improve Life

with Kelly Rambo, mother of Nicholas, age 18, who acquired hydrocephalus when he was 16 months old from a brain tumor, and Erica Stivaletti, a long-time friend and supporter of the hydrocephalus community. My inspirations for co-chairing the event are my daughters Emma and Aydin. Emma acquired hydrocephalus from Chiari decompression surgery at age 5 months. NBC-10 news reporter Deanna Durante was once again the honorary chairperson and emcee.

The WALK was kicked-off by the sounds of the Philadelphia Irish Society's pipes and drums! And for the third year, the Philly skyline glowed blue as buildings were lit in honor of November being Pennsylvania's Hydrocephalus Awareness Month!

San Francisco, CA

The 15th Annual San Francisco Hydrocephalus WALK was held November 9th on the east beach of Crissy Field. It was a beautiful "un-foggy" day, with the Golden Gate Bridge as the backdrop. The event was supported and attended by veteran and new participants. It was inspiring to see the families and individuals who have attended this event for all (or close to) 15 years and motivating to meet first-time participants! The WALK was attended by more than 200 participants and raised more than $35,000!

Special thanks to our team of organizers and volunteers. Mary Jane Kelly was a WALK co-chair and her son Will Kelly was the face of the HA's national WALKs. Kathryn Surso-

Dr. Jay Wellons Takes Steps to Improve Life

By John C. Wellons, III, M.D.
Associate Professor of Surgery and Pediatrics Section of Pediatric Neurosurgery University of Alabama Children's Hospital of Alabama, Birmingham

The Birmingham chapter of The Hydrocephalus Association had its first annual Hydrocephalus WALK on Sunday October 26, 2008. In early August, I was asked by Becca Cardin, Mandy Smith, and Debbie Norris to be the honorary co-chair of the event. I was absolutely thrilled, especially after my experience at the Hydrocephalus Association's 10th National Conference on Hydrocephalus in Park City, Utah earlier this year. I knew what a meaningful organization the Hydrocephalus Association was and was truly pleased to be asked to be a part of the local chapter's efforts.

We put together a request for participation and support that went out to a number of physicians in the area. There were sponsor levels for industry. Becca, her son Noah, and I were even interviewed about the upcoming walk on the Fox News early morning television show. The interview was received extremely well, particularly by my colleagues at the hospital, and it drummed up a great deal of interest.

The day of the event could not have been more beautiful here in Birmingham in the fall. The weather was approximately 75 degrees, the sky was blue, and the venue at Veterans Park in Hoover, Alabama was fantastic. A number of sponsors showed up with tables and information for families. There was a huge amount of food and a small carnival was set up for the children. The carnival included a strong man event in which a heavy mallet was used to hit a platform and a weight shot up in an effort to hit a bell. One of the parents and I had a contest to see who could hit the bell the most times. I lost.

The walk itself went very well. The camaraderie and fellowship was fantastic. I saw a number of my patients and families. It was fantastic to see everyone doing so well, and the discourse was very similar to the national meeting, with fun give and take between neurosurgeon and patients. My 3-year-old son, Jack, went and had a fantastic time, and my older sister, Eve, was visiting and was amazed to see her "little brother" seeming to know what he was doing. At the end of the day, the local mayor and local congresswoman spoke and made further donations to the cause. A band played, the organizers spoke, I spoke, and then, coincidentally, was paged away to perform a shunt revision in the operating room later that afternoon. I am very grateful to the national and local chapters of the Hydrocephalus Association for allowing me to be a part of this group, and I look forward to the second annual walk next year.

Taking Steps to Improve Life

San Francisco, CA *(continued)*

Rodriguez, mother of Brendan, who was diagnosed with hydrocephalus when he was a week old, became active in organizing our event for the first time this year. She was a huge help and we hope she will consider taking the lead in 2009! Bonnie Hom and Thara Jinadasa, staff members of the HA, were instrumental in coordinating the food, registration, and all the day's volunteers. Additional thanks to Angeline Ong, Ella Arnold, Claudia Bermudez, Brian Lambson, Jill Gregerson, Patrick Kwok, Mindy Vu, Tommy Lau, Juliana Jung, Joaquin Jang, Nicole Walker, the band Brasshopper and the helpful hands of everyone who volunteered. The day was a great success!

Cambridge, MA

The 1st Annual Cambridge Hydrocephalus WALK was held on November 9th at the Fresh Pond Reservoir. The WALK was chaired by Jennifer Miles, a mother of three sons, Thomas (age 12), Luc (age 6), and Sam (age 10), who was diagnosed with hydrocephalus as a result of intraventricular hemorrhage at birth.

The walk was a great success. It was attended by more than 275 people and raised $17,965 and still counting! Jennifer reports: "This year we were reminded how quickly 'life can change' for Sam and for all of us. We hope that our small efforts here in Cambridge can help raise awareness and money so more research can go into finding a cure for hydrocephalus or at least finding better ways to manage it."

Lenoir, NC

On November 15th, Elizabeth Norris, an 18-year-old high school student, organized the 1st Lenoir, North Carolina Hydrocephalus WALK. Elizabeth was diagnosed with hydrocephalus at four weeks old. She decided to plan a Hydrocephalus WALK as part of her graduation project. She had only three months to make all of the arrangements and work out all of the details. Days before the event, which was supposed to take place on the high school football field, Elizabeth's high school won the play-offs, making the field unavailable on the day the WALK was planned! The WALK was ultimately held at St. Stephens Lutheran Church, a backup location arranged by Elizabeth. Approximately 80 people attended the WALK, which managed to raise $6,772. "I am very proud of my accomplishment of planning this walk, but also that I raised awareness to my community," stated Elizabeth.

ADA Amendments Act of 2008 Passes Congress

By Marybeth Godlewski, National Advocacy Director

Information presented in this article is compiled from the National Rehabilitation Association article "U.S. Senate Passes S. 3406, the ADA Amendments Act of 2008" and information from the Committee on Education and Labor Web site.

The Hydrocephalus Association is one of more then 220 national organizations that supported the ADA Amendments Act (ADAAA) of 2008, which went into effect on January 1, 2009. The U.S. House of Representatives passed the bill on June 25, 2008 by a vote of 402–17. The bill then passed unanimously in the Senate on September 11, 2008, and outgoing President George W. Bush signed the bill into law on September 25. The ADAAA is "... intended to nullify those cases... and clarify Congress' intent in writing the original ADA in 1990," said bill co-sponsor, Sen. Tom Harkin (D-Iowa). Other sponsors of the bill included Sen. Orrin Hatch (R-Utah), Rep. Jim Sensenbrenner (R-Wisc.) and House Majority Leader Steny Hoyer (D-Md.), which makes this a truly bipartisan issue.

BACKGROUND ON THE ADA

The Americans with Disabilities Act (ADA) of 1990 was intended to "provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." Just as other civil rights laws prohibit entities from basing decisions on characteristics such as race or sex, Congress wanted the ADA to stop employers from making decisions based on disability.

Unfortunately, four U.S. Supreme Court decisions have narrowed the definition of disability so much that people with serious conditions such as epilepsy, muscular dystrophy, cancer, diabetes, and cerebral palsy have been determined to not meet the definition of disability under the ADA.

The result: In 2004, plaintiffs lost 97% of ADA employment discrimination claims that went to trial, often because of the interpretation of the definition of disability. Individuals who have not been hired or who have been fired because an employer mistakenly believes they cannot perform the job or because the employer does not want "people like that" in the workplace have been denied protection from employment discrimination due to these court decisions. This result was not the intent of the ADA.

ADAAA'S POTENTIAL

The ADAAA is an attempt to overturn several Supreme Court decisions that left people with disabilities unprotected from discrimination. It clarifies that the ADA is intended to provide broad coverage to protect individuals who face discrimination on the basis of disability. Additionally, the ADAAA specifically prohibits "mitigating measures consideration," meaning that the determination of disability should be made without considering improvements to "limited life activity" by use of mitigating measures such as hearing aids, prosthetic devices, medications, and corrective lenses other than ordinary eyeglasses and contact lenses.

Sen. Harkin is quoted in Congress Daily as saying: "This bill is about restoring the ADA to where we intended it to be 18 years ago and to give clear instructions to the Court." He has called the court decisions "an absolute absurdity" and said the decisions forced people to choose between taking medications that enabled them to work and maintaining the protection of the ADA.

"People who were denied coverage under the ADA will now be covered, and we'll get rid of that Catch-22 situation that confronts so many people," said Sen. Harkin.

The ADAAA classifies any condition that limits a major life activity as a disability regardless of whether it is treatable with medication or technology. It updates the definition of a major life activity to include conditions that limit bodily functions, such as those of the immune system, circulatory system, or the brain.

What Should Employers Do Now?

The following recommendations are listed on the Americans with Disabilities Act Amendments Act Information Center section of the Business and Legal Reports (BLR) Web site in response to The ADA Amendments Act of 2008.

1. Revise policies related to the ADA, discrimination, and complaint procedures.
2. Establish procedures for responding to requests for reasonable accommodations and how to document the interactive process.
3. Revise medical certification forms.
4. Make sure job descriptions spell out essential job functions.
5. Train supervisors and managers on the new law and how to handle requests for accommodation.
6. Consider diversity training for all employees that includes disability.
7. Be prepared for detailed regulations in 2009.

The BLR is a company that provides human resource, safety, and environmental professionals with compliance and training information. More information can be found at their Web site, **http://www.blr.com/information-ada/**.

The Seven Wonders of the World of Disabilities

Summarized and compiled by Thara Jinadasa, Development Associate

The November 2008 issue of Exceptional Parent Magazine featured an article titled, "The Seven Wonders of the World of Disabilities" by Jan Carter Hollingsworth and Laura Apel. Here are some highlights:

WONDER 1.
LANDMARK LEGISLATION
Landmark legislation encompasses the Americans with Disabilities Act and Individuals with Disabilities Education Act. Both Acts have deeply impacted the quality of life for individuals with disabilities, guaranteeing equal rights in the form of education, employment and more.

WONDER 2.
ENHANCED COMMUNICATION
Without the ability to communicate we lose our evolutionary gift to connect with others. This is why the second wonder on the list is the enhanced communication systems of Braille and Sign Language. The original Braille system was devised by a man named Charles Barbier for the purposes of reading during the night for military maneuvers during the Napoleonic Wars. Louis Braille adopted and modified the system in 1821 into what it is today, a six-dot coding system to enable the blind to read and communicate. Sign Language is a universal form of communication, signaling a way to express ourselves with our bodies.

WONDER 3.
THE WHEELCHAIR
Mobility allows one to feel not only empowered, but also independent. For those who receive the opportunity to be mobile in circumstances that would mean otherwise, mobility enables on to be more confident, and can bring joy into one's life.

WONDER 4.
THE SPECIAL OLYMPICS
It is a dire mistake and travesty to humanity to view people with disabilities as people without the capacity to achieve great things. The event that best exemplifies what great measures individuals with disabilities are capable of achieving is the Special Olympics.

WONDER 5.
PRINCIPLES OF
DR. WOLFENSBERGER
Dr. Wolfensberger's principles of normalization and social role of valorization aim to limit the number of barriers an individual with disabilities will face in attempting to fulfill a social role. His idea of social role valorization aims to, "Fight, debunk, and counteract societal pigeonholes." The effects these two principles have on professionals aiding individuals with disabilities and the individuals themselves are tremendous. No one deserves to be denied the chance to reach their full potential.

WONDER 6.
HUMAN GENOME PROJECT
One of the biggest advancements in science was the completion of the human genome project. Because of the possible implications of discovering a cure for genetic disorders, the human genome project creates scientific hope for the future for those with disabilities.

WONDER 7.
MEDICAL BREAKTHROUGHS
Medical breakthroughs such as the Guthrie Test and the Polio vaccine create hope for what we are capable of accomplishing and what we hope to continue to accomplish. These two medical breakthroughs give us reason to believe that cures to impossible diseases do exist. These two breakthroughs in particular eliminate disabilities altogether or limit the impact a disability might have on one's life.

✧

On a personal note, I believe there is an eighth wonder—the members of our communities and the individuals around the world living with hydrocephalus. It is not yet recognized by the government as a disability but, as I have discovered, those surviving with the obstacles created by this condition very much share in the challenges others with disabilities face. From my brief encounters with individuals living with hydrocephalus I quickly become awed and inspired by the lifetime of challenges they face, tackle, and overcome. Working at the Hydrocephalus Association has allowed me to reawaken an appreciation for the strength and perseverance of the human spirit. I dedicate this eighth wonder to those friends I have met, and those friends I have yet to meet, who live with hydrocephalus. You are wonderful! ✠

Adapted with the expressed consent and approval of Exceptional Parent, a monthly magazine for parents and families of children with disabilities and special health care needs. For more information, call (877) 372-7368. Offices at 416 Main Street, Johnstown, PA 15901.

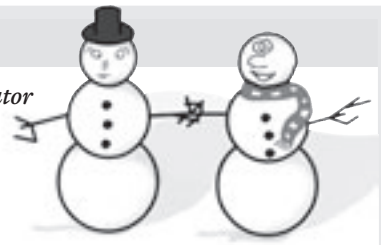
Teen Survey

The University of Illinois at Chicago is looking for parents and caregivers of children ages 12 to 18 with special needs to complete a Web-based survey on the lifestyle and environment of adolescents with disabilities. This survey can be accessed at: **http://www.healthforyouth.org/** Enter the access code: **ECP3**

For more information, or if you experience any difficulty accessing the survey, please contact Brienne Davis (bdavis7@uic.edu), Department of Disability and Human Development, University of Illinois at Chicago, 1640 W. Roosevelt Road, Suite 713, Chicago, Il 60608. You may also reach Ms. Davis by telephone at 312-355-4054.

Kid's Corner!

By Bonnie Hom, Youth and Community Coordinator



Winter Wonderland

Unscramble the winter-themed words below.

1. zbizldra _____
2. fsfameur _____
3. ceierflap _____
4. lodc _____
5. hreate _____
6. hat otohclceo _____
7. ilgoo _____
8. leds _____
9. oswn _____
10. awnomns _____
11. kis _____
12. itdoasroecn _____
13. etmitn _____
14. soblalnw _____
15. dlhyasio _____
16. srcfa _____
17. ovehls _____
18. naklowesf _____
19. iutql _____
20. cektja _____

Ode to a Pediatric Neurosurgeon

By Debbie Buffa

Never sleeping,
Family. . .Who?
Cries of children
Parents, too—
Breaking hearts
Brilliant smiles
Holding hands,
Sitting just awhile.
Eyes that tear
Hearts that ache
Wish you could fix
All who come to you this day.
Bone tired, never enough sleep,
Hugs from parents
And their children, keep
You forging on
Day by day
Praying you are helping
In some small way.
When in truth, all be told
You are a hero
Strong and bold
To the parents
And their children, too.
YOU,
Pediatric Neurosurgeon
Are OUR hero
By all that you do.

Winter Wonderland Answers:

1. blizzard
2. earmuffs
3. fireplace
4. cold
5. heater
6. hot chocolate
7. igloo
8. sled
9. snow
10. snowman
11. ski
12. decorations
13. mitten
14. snowball
15. holidays
16. scarf
17. shovel
18. snowflake
19. quilt
20. jacket

News Notes

Able Play

A company called Able Play provides a useful service for parents of children with special needs. The company's Web site gives an evaluation of toys based on their appropriateness for the developmental needs of their child. A star-based system rates a toy's suitability for children with physical, sensory, communicative and/or cognitive disabilities, and product reviews are provided. For more information, visit **www.ableplay.org**

Math Skills Books for Students with Hydrocephalus

By Ella Arnold, HA Volunteer

Many students with hydrocephalus have problems with math. Here are some books that can help students improve their math skills.

Learning Outside The Lines: Two Ivy League Students with Learning Disabilities and ADHD Give You the Tools
by Jonathan Mooney, David Cole and Edward M. Hallowell (Amazon.com, $10.17)

Winning at Math: Your Guide to Learning Mathematics Through Successful Study Skills
by Paul D. Nolting (Amazon.com, $14.98)

Strategy Instruction for Students with Learning Disabilities
by Robert Reid and Torri Ortiz Lienemann
(Amazon.com, $50.00)

Barron's SAT Strategies for Students with Learning Disabilities
by Dr. Toni Welkes
(Amazon, $9.59)

A Double Dose of Music Medicine!

By Marybeth Godlewski, National Advocacy Director

I recently learned of an organization that offers a very special gift to children and teens who are chronically or terminally ill or living with a disability. The Songs of Love Foundation is a nonprofit 501(c)(3) organization devoted to writing and recording personalized songs for children and teens who are not only in need of a "pick me up" but who truly deserve such a gift and greatly appreciate it. This concept gives a whole new meaning to "music therapy." The smiles these songs put on the faces of the children and teens who receive them are priceless, as are these recordings. Each applicant receives a CD of a personalized song, free of charge, with an original melody and lyrics based on profiles submitted to the foundation by hospitals and families. Each "song of love" is one of a kind and never duplicated!

Since their inception in 1996, the Songs of Love Foundation has worked with more than 700 children's hospitals and health care facilities in the United States, Canada, and Europe. They have reached over 17,000 children with their personalized songs.

Songs can be written in any language and style. The foundation accepts requests from all countries for children up to the age of 21. Songs are completed and sent out within 4 to 6 weeks. Songs can be rushed for special circumstances.

Parents can check the "no publicity" box on the profile sheet should they wish to keep the child's song confidential. The foundation strictly adheres to any requests to restrict publicity. Only one song per child can be requested, unless substantial time has gone by and the child either experiences a relapse or develops a new life-threatening condition. For more information, visit the Songs of Love Web site at **www.songsoflove.org**.

Where in the World is the 2010 Hydrocephalus Association Conference?

By Marybeth Godlewski, National Advocacy Director

See if you can answer these questions to determine the location of next year's conference.

1. What city's international airport is the location of NASA's Glenn Research Center, which is performing the qualification testing of the Orion vehicle that will be used in future missions to the moon and Mars?
2. In what city did thousands of spectators witness the demonstration of the first street lighting in the United States on April 29, 1879?
3. In what city were Life Savers candy invented?
4. In what city was the Superman character created?
5. In what city did John Lambert make the first gasoline-powered automobile in 1891?
6. In what city did Babe Ruth hit his 500th home run?
7. What city offers the nation's largest concentration of cultural arts and educational institutions within one square mile?
8. Which city's zoo includes an indoor two-acre, two-story rain forest?
9. In what city are crime-fighter Eliot Ness' ashes spread?
10. Which city was the birth place of Paul Newman, four-time Olympic medalist Jesse Owens, Oscar-winner Halle Barry, Arsenio Hall, and Don King?

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
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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. 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.

Hydrocephalus Association
serving 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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