This is the text of the proposed resolution, H. Con. Res. 465. For an update on the status of the resolution and suggestions for ways that you can help with our advocacy effort, see “From the Editor,” on page 2, where executive director Dory Kranz brings you the latest scoop.

Concurrent Resolution expressing the sense of the Congress regarding the need for additional research into the chronic neurological condition hydrocephalus, and for other purposes.

Whereas, Hydrocephalus is a serious neurological condition, characterized by the abnormal buildup of cerebrospinal fluids in the ventricles of the brain; and

Whereas, There is no known cure for hydrocephalus; and

Whereas, Hydrocephalus affects an estimated one million Americans; and

Whereas, Over 1 or 2 in every 1000 babies are born with hydrocephalus: and

Whereas, Over 375,000 older Americans have hydrocephalus, which often goes undetected or is misdiagnosed as dementia, Alzheimer’s disease, or Parkinson’s disease; and

Whereas with appropriate diagnosis and treatment, people with hydrocephalus are able to live full and productive lives; and

Whereas the standard treatment for hydrocephalus was developed in 1952, and carries multiple risks including shunt failure, infection, and overdrainage; and

Whereas there are fewer than 10 centers in the United States specializing in the treatment of adults with normal pressure hydrocephalus; and

Whereas each year, the people of the United States spend in excess of $1 billion to treat hydrocephalus; and

Whereas a September 2005 conference sponsored by 7 institutes of the National Institutes of Health—“Hydrocephalus: Myths, New Facts, Clear Directions”—resulted in efforts to initiate new, collaborative research and treatment efforts; and

Whereas the Hydrocephalus Association is one of the Nation’s oldest and largest patient and research advocacy and support networks for individuals suffering from hydrocephalus: Now, therefore, be it Resolved by the House of Representatives (the Senate concurring), that it is the sense of the Congress that—

(1) the Director of the National Institutes of Health should be commended for working with leading scientists and researchers to organize the first-ever National Institutes of Health conference on hydrocephalus;

(2) the Director of the National Institutes of Health should continue the current collaboration with respect to hydrocephalus among the National Institute of Neurological Disorders and Stroke; the Office of Rare Diseases; the National Institute on Aging; the National Institute of Child Health and Human Development; the National Eye Institute; the National Institute of Bio-medical Imaging and Bioengineering and the National Human Genome Research Institute;

(3) funding should be increased for research into the epidemiology, pathophysiology, disease burden, and improved treatment of hydrocephalus; and

(4) public awareness and professional education regarding hydrocephalus should increase through partnerships between the Federal Government and patient advocacy organizations, such as the Hydrocephalus Association.
Advocacy

From the Editor

I am very pleased to turn my column over to our executive director, Dory Kranz, for a perspective on research and advocacy. —Debra Howell

As I write this column, the country has just voted for a change in leadership in both houses of Congress. Our friends in the House of Representatives who have supported our resolution calling for more federal support of hydrocephalus research, H. Con. Res. 465, have their hands full with the change in power; it is unlikely that this resolution will come to a vote in the 109th Congress. Although we succeeded in securing 27 cosponsors in 2006—and we are grateful to the many Association members who contacted congressional representatives to generate this support—we do not expect to have enough cosponsors to bring this resolution to a vote in the lame duck session at the end of the 109th Congress.

The lead sponsor, Representative Mike Thompson, has agreed to introduce the resolution again in the 110th Congress. We need the help of everyone reading this newsletter, and everyone whose help you can enlist, to gather enough cosponsors to bring this important resolution to a successful vote in 2007. This resolution is a critical step in our long-range plans to significantly increase funding for hydrocephalus research from the National Institutes of Health, the Centers for Disease Control, the Agency for Healthcare Research and Quality, the National Science Foundation and other federal agencies.

Research is our only hope to improve treatment or find a cure for hydrocephalus.

Your voices, your visits, your letters to your representatives will demonstrate that there is widespread demand for government support of hydrocephalus research—in every city, every state and every congressional district across our nation. The House of Representatives has 435 members. Twenty-five cosponsors is little more than 5 percent. We can, and we must, do better.

We have worked hard together to create this unprecedented opportunity. Won't you please join our initiative now to raise awareness of hydrocephalus among our nation's leaders and direct more federal support of hydrocephalus research? Visit our website, www.hydroassoc.org, and click on the “Advocacy” button on the left-hand menu. There you'll find sample letters, suggested talking points for legislative visits and a brochure about the need for research, which you can leave with or send to your legislators. You can also sign up to receive advocacy alerts so we can email you when the resolution is reintroduced and keep you updated on our progress. Cosponsorship does not automatically carry over from one legislative session to the next, so even if your representative signed on in 2006, ask him or her to step up and cosponsor our resolution again when it is reintroduced in 2007.

With your help, I am confident that we can achieve this important milestone.
2005 Pudenz Award Goes to James P. McAllister II, PhD

By Emily Fudge

James P. (Pat) McAllister II, PhD, a member of the Hydrocephalus Association’s Medical Advisory Board, has been named the 2005 recipient of the Robert H. Pudenz Award for Excellence in Cerebrospinal Fluid Physiology. This award, presented annually since 1989 by Medtronic NT, is named in honor of Robert H. Pudenz, who was a recognized pioneer in the field of pediatric neurosurgery, research in cerebrospinal fluid physiology and cerebrospinal fluid shunt technology for the treatment of hydrocephalus.

Dr. McAllister was honored in October at a ceremony in Detroit, where he is a professor and the director of neurosurgical research at Wayne State University School of Medicine. In attendance at the ceremony were Dory Kranz, executive director of the Hydrocephalus Association; Association Board of Directors member Ralph Kistler; Marion L. (Jack) Walker, MD, a longtime member of the Association’s Medical Advisory Board; and representatives from Medtronic NT, including Tommy Johns (vice president and general manager), Leanne Lintula (product manager), Ken Wagner (director of marketing), Chris Cerritos (sales representative) and Michael Pollay, MD (medical director). A $7,500 cash grant will be given to Wayne State University’s department of neurosurgery to fund basic research on hydrocephalus and cerebrospinal fluid physiology; the award also includes a $1,000 cash grant to the Hydrocephalus Association in honor of Dr. McAllister.

Dr. McAllister has spent almost his entire career involved in the field of experimental and clinical hydrocephalus research. I met him in 1985, when he attended his first meeting of pediatric neurosurgeons and I was hosting the Hydrocephalus Association’s exhibit table. Neither of us was getting a lot of attention, and in Dr. McAllister’s words, “we bonded together in our loneliness and our search for financial support”: mine for patient educational materials and his for research funding.

His distinguished career has been guided by the principle of active participation, which he learned during his early, and sometimes frustrating, days in research. And nowhere has this philosophy been more evident than in his involvement in last year’s NIH-sponsored hydrocephalus research conference in Baltimore, where he passionately took on a leadership role. Dr. McAllister likes to say that he’s not the smartest scientist in hydrocephalus research, but he has desire on his side. We can’t comment on the IQ part, but we do know that few have devoted as much blood, sweat and tears to furthering our understanding of hydrocephalus as he has.

On behalf of the Board of Directors and the Medical Advisory Board of the Hydrocephalus Association, we salute Dr. McAllister—a brilliant, passionate and committed scientist. In accepting the Pudenz award, he promised, “I will not slow down—not stop participating—for the rest of my life.” How very fortunate for our community.

Mark Your Calendars!

10th National Conference on Hydrocephalus: “It’s About Life!”

Medical Chairs: John R. Kestle, MD, and Marion L. (Jack) Walker M.D. of Primary Children’s Medical Center

Where: The Canyons Resort in Park City, Utah (fly into Salt Lake City)
For more about this family-friendly resort, go to www.thecanyons.com

When: June 19–22, 2008 (Thursday afternoon through Sunday afternoon)

Why: Because hydrocephalus isn’t just about shunts, it’s about life!

We hope to see you there.
2007 Scholarships

By Pip Marks

We are very pleased to offer eight scholarships to young adults with hydrocephalus in 2007. 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 email us at info@hydroassoc.org and we will mail you the application with instructions.

Eligibility requirements:
• Applicants must be between the ages of 17 and 30 years old and have hydrocephalus.
• Scholarship funds must be used for an educational purpose: a four-year or junior college, a high school post-graduate year to prepare for college, technical or trade school, an accredited employment-training program or a post-graduate program.
• The scholarship funds may be used for tuition, books, housing or an expense directly related to the education experience.
• The deadline for completed applications and recommendation forms is April 1, 2007. Applications received at our office after this date will not be considered, nor will applications that are incomplete, e.g., missing the recommendation form.

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 NPH. 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, so that 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 and 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: New this year, this scholarship has been endowed by Greg Tocco, executive director of the Hydrocephalus Foundation, Inc. of Saugus, Massachusetts, and his family in honor and in memory of Greg’s grandfather Mario J. Tocco. One yearly scholarship will be presented from this fund beginning in 2007.

Medical Advisory Board Meets

By Dory Kranz

The Association’s Medical Advisory Board (MAB) met on November 30, 2006, in Denver, Colorado. Here are a few highlights of the meeting.

Building on an issue raised at the 2005 MAB meeting, Dr. Hal Rekate invited attendees of the American Association/Congress of Neurological Surgeons Pediatric Section (Peds Section) Meeting to join our MAB and wrestle with challenges finding and or traveling to reach a qualified pediatric neurosurgeon.

Mike Williams, MD, spearheaded the effort to add a code specifically for NPH within the International Classification of Diseases (ICD-9). Many MAB members wrote letters of support and we anticipate a favorable ruling.

This is a small taste of what was covered. We are so grateful for the valuable input and essential support that we receive from our dedicated and capable MAB members.

Rick Abbot, MD, president of the Peds Section, announced that they will undertake a study on the shrinking pool of pediatric neurosurgeons. The Association may contact members about challenges finding and or traveling to reach a qualified pediatric neurosurgeon.

For the last year, the Association has been distributing the newsletter via email to save on printing and mailing costs. This issue is being mailed to everyone in order to get your feedback on how email delivery is working, so please let us know.

To see which delivery option you’re signed up for, check the mailing label on this newsletter: If an email address appears above your name, we have been emailing your newsletters. If you have not received them, please contact us to confirm or correct your email address. You may also request paper delivery if you prefer. If no email address appears above your name, we have been sending you paper copies. If you are willing to switch to electronic delivery, please contact us with a current email address.
I came to the Hydrocephalus Association in March 1998 in a desperate search for answers. My daughter, Tess, had just been born with a diagnosis of hydrocephalus, and I was trying my best to become an instant expert so that I could understand what was ahead. My quick search of the Internet provided a link to the Association, and I was pleased to find that their office was just a few blocks away from mine.

There I found not only excellent literature and answers for my questions, but also a tremendously supportive staff. My family have been active members of the Hydrocephalus Association ever since. When Tess received her first shunt at four months, we knew what to expect. And later, when we looked for help with her first IEP, the Association was there for us again. We’ve attended the Hydrocephalus Association conferences to get the latest information, and we’ve made many friends there. To use the apt analogy of Sherman Alexie, we’ve found “our tribe.”

I was excited when I had the opportunity to join the Hydrocephalus Association Board in April of this year. For me, this represents an opportunity to give back to an organization that has given my family so much. I’m particularly pleased to be a part of the Association’s efforts for expansion and advocacy. I know that, working together, we can find better answers for hydrocephalus—and I’m looking forward to making that happen.

By Debra Howell

There are several new publications and resources available for caregivers and older adults. Perhaps one or more of these will interest you.

Nurturing Nuggets for Dementia Caregivers
By Susan E. Lanza
This little pocket book is easy to read and has many tips to help caregivers, including those affected by NPH, remember to take care of themselves as well as their loved ones. Each page has ideas, informational tidbits and inspirational messages. It’s available through Buttonberry Books at www.nurturingnuggets.com, Amazon or your local bookstore.

New Web Tool on Care Options for Families
The Alzheimer’s Association has developed a new Web tool to help individuals and family caregivers find care options ranging from home and community-based care to assisted-living and nursing-home facilities. The tool allows users to input personalized information, special needs, abilities and preferences, and receive a customized summary report with recommendations and specific questions to ask potential care providers. For more information, visit www.alz.org/carefinder/index.asp.

Aging Parents and Common Sense: A Directory of Resources for You and Your Parents
AXA Financial, with assistance from the National Alliance for Caregiving, has developed a resource directory of organizations and services that are helpful to family caregivers and older adults. Each listing includes a brief description and contact/website information. For more information, visit www.axa-equitable.com/pdf/Aging_Parents.pdf.

The Emotional Survival Guide for Caregivers: Looking After Yourself and Your Family While Helping an Aging Parent
By Barry J. Jacobs
Dr. Jacobs draws from years of practice as a clinician and his experience with the debilitating impacts of serious illness on his own family. His focus is on the emotional survival of the family, and how important it is to find a balance between taking care of a sick or aging love one and taking care of each other. You can order this book at bookstores or from Amazon.
Our Chicago Marathon Runners

Congratulations and very special thanks to Hydrocephalus Association member Tomi Ann Roberts and Board of Directors member Mark Geiger, who both ran the Chicago Marathon on October 22, 2006, raising funds for the Association. Together they raised close to $7,000.

Tomi Ann ran in honor of her mother, Asta, who has hydrocephalus, and says, “It was my first marathon, and I did better than I could have wished. The experience was a thrill—all 26.2 miles! I exceeded my collection goal for the Hydrocephalus Association. I could not have done it without the support of all of you who donated so generously. You were like the wind, pushing me along to the finish line. Together we did it!”

Mark, who has hydrocephalus and ran the Maui Marathon a few years ago with fellow Board member Emily Clark Farrell, had this to say about the Chicago race: “The marathon was great. Thanks very much for everyone’s support. It was a dream. I beat my last time by 15 minutes.”

Kudos to both Tomi Ann and Mark. Any one else out there ready to go the distance for the Association?

Birthday Benefits

Hydrocephalus Association

Association members Siobhan and Erin Reardon, pictured (right) with their friends from school and soccer, recently celebrated their 8th birthdays by raising $500. Siobhan’s donations were directed to the Hydrocephalus Association and Erin’s went to Little Hearts Inc., a nonprofit advocacy group for children with congenital heart defects. Many thanks, Erin and Siobhan, and happy 8th birthday.

A very special birthday boy

Danny Breton, Jr., who has hydrocephalus, celebrated his fifth birthday in September—and he decided to raise donations for the Hydrocephalus Association in lieu of birthday gifts. He raised close to $1,000! We are truly grateful for this generous gift. Happy birthday, Danny!

Tour De Vendage Bike Ride

Tour De Vendage Bike Ride, Livermore, California

The San Jose Police Amateur Athletic Foundation held their first annual Tour De Vendage bike ride, benefiting the Hydrocephalus Association. The event took place on October 14, 2006, in Livermore, California. Hydrocephalus Association Board member Paul Gross, who traveled from Seattle to take part in the event, joined riders who came from all over the Bay Area. Our thanks to Rich and Tish Mongarro for putting on the ride, raising awareness and more than $2,000 in support of the Association.
TEAM Hydrocephalus Nationwide

An Outstanding Success

Our dream is coming true—a TEAM Hydrocephalus in every state by 2010. Thousands of you are making this a reality and we are truly grateful to each team participant, their sponsors, our corporate sponsors, and of course the amazing Team Queens and Kings who so expertly make these events happen.

There were 13 TEAM events around the U.S. between August and November in 2006, including one in Kentucky organized by Jennifer Grossman and one on Long Island organized by Janine Melomo and Joe Coreno. Together, these 13 TEAMS, comprising almost 1,500 people, raised $250,000. Way to go!

There are too many wonderful people to individually thank in this newsletter. You know who you are; please accept our heartfelt thanks for your amazing hard work and support.

TEAM Hydrocephalus—having fun while raising funds. Won’t you join us in 2007?

To learn more, contact Gina at Gina@hydroassoc.org.

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TEAM Atlanta
Co-Chairs: Debbie Crandall and Linda Preuss

TEAM Illinois
Chair: Sherry Reising

TEAM Colorado
Chair: Phyllis Rogers
Team

TEAM New Jersey  Chair: Chris Riccio

TEAM Washington, DC  Chair: Mimi Kramer Roberts

TEAM Pennsylvania  Co-Chairs: Kelly Rambo and MaryBeth Godlewski

TEAM Maine  Co-Chairs: Ralph and Dale Kistler
TEAM San Francisco  Co-Chairs: Emily Fudge and Pip Marks

TEAM Florida—Jacksonville  Co-Chairs: Kimberly Belzer and Ginger Wheatley

TEAM New Mexico  Chair: Kathy Carrillo

TEAM Florida—Largo  Chair: Paula Keyser
New Research 2006: A Summary

By Dory Kranz, Pip Marks and Debra Howell

We are happy to report that there appears to be an increased interest and focus on hydrocephalus research in recent years. The following summaries are just a small sample of research papers appearing in the clinical literature in 2006. Due to space limitations, we have collapsed the abstracts. For more information on these articles, see our Winter 2006 Newsletter article on how to search and order articles through PubMed, or contact our office.

Basic Neuroscience or Bench Research

Cerebrospinal Fluid Proteins

Accelerated progression of kaolin-induced hydrocephalus in aquaporin-4-deficient mice. J Cereb Blood Flow Metab. 2006 Mar 22: Bloch O, Auguste KI, Manley GT, Verkman AS. At the Cardiovascular Research Institute in San Francisco, researchers studied the role of water-transporting protein aquaporin-4 (AQP4) in mice with obstructive hydrocephalus. Results indicate a significant role for AQP4-mediated transparenchymal CSF absorption in hydrocephalus and provide a rational basis for evaluation of AQP4 induction as a nonsurgical therapy for hydrocephalus.

Aquaporin 4 changes in rat brain with severe hydrocephalus. Eur J Neurosci. 2006 Jun;23(11):2929-36: Mao X, Enno TL, Del Bigio MR. Researchers at the University of Manitoba in Canada hypothesized that increased expression of aquaporins, which are water-permeable channel proteins, would occur in hydrocephalic brains to facilitate water shifts. Results in Sprague-Dawley rats rendered hydrocephalic by injection of kaolin into cistern magna suggest that brain AQP4 up-regulation might be a compensatory response to maintain water homeostasis in hydrocephalus.

Intraventricular administration of hepatocyte growth factor treats mouse communicating hydrocephalus induced by transforming growth factor beta1. Neurobiol Dis. 2006 Mar;21(3):576-86: Tada T, Zhan H, Tanaka Y, Hongo K, Matsumoto K, Nakamura T. At Shinshu University School of Medicine in Japan, researchers examined the effect of exogenous hepatocyte growth factor (HGF) in C57BL/6 mice with induced communicating hydrocephalus. HGF treatment resulted in a reduction of ventriculomegaly, improved spatial memory, improvement of normalized CSF flow, and reduction of collagen fibers in the meninges and normalization of their structures compared to the hydrocephalic mice at baseline. These results indicate that exogenous HGF may be of utility in the treatment of hydrocephalus in humans.

Shunt Infection and Obstruction

Evaluation of polymer and self-assembled monolayer-coated silicone surfaces to reduce neural cell growth. Biomaterials. 2006 Mar;27(8):1519-26: Patel KR, Tang H, Grever WE, Simon Ng KY, Xiang J, Keep RF, Cao T, McAllister JP 2nd. In order to address the problem of cell obstruction in catheters, researchers at Wayne State University in Detroit studied silicone surfaces coated with biopolymers (heparin and hyaluronan) and self-assembled monolayers (SAMs) (octadecyltriethoxysilane-OTS and fluoroalkylsilane-FAS) to investigate the effect of these coatings on astrocyte and choroid plexus cell growth in vitro. Compared to unmodified silicone, FAS surfaces significantly reduced (p<0.05) astrocyte proliferation. Silicone shunts coated with SAMs may be suitable for future clinical applications to improve the treatment of hydrocephalus.

Effect of surface modification of silicone on Staphylococcus epidermidis adhesion and colonization. J Biomed Mater Res A. 2006 Oct 27; Tang H, Cao T, Wang A, Liang X, Salley SO, McAllister JP 2nd, Simon Ng KY. Researchers at Wayne State University in Detroit studied the effect of the surface modification of silicone on Staphylococcus epidermidis adhesion and colonization. Results indicate that the nature of the surface functional group and surface roughness determine the extent of bacterial adhesion and colonization. However, the degree of hydrophobicity of the surface did not appear to play a determining role in bacterial adhesion and colonization.

Effect of cast molded rifampicin/silicone on Staphylococcus epidermidis biofilm formation. J Biomed Mater Res A. 2006 Mar 1;76(3):580-8: Liang X, Wang A, Cao T, Tang H, McAllister JP 2nd, Salley SO, Simon Ng KY. Researchers at Wayne State University in Detroit investigated the effect of the antibiotic rifampicin on the colonization and growth of S. epidermidis 35984 on the surface of silicone. Sparser biofilm structures were observed on rifampicin-loaded surfaces after incubation for the same duration. Deformation of bacteria and different bacterial colony structures on the surfaces of silicone and rifampicin-loaded silicone were observed.

Recanalization of obstructed cerebrospinal fluid ventricular catheters using ultrasonic cavitation. Neurosurgery. 2006 Oct;59(4 Suppl 2):ONS403-ONS412: Ginsberg HJ, Drake JM, Peterson TM, Cobbold RS. Researchers at the University of Toronto and other institutes describe the development of a device that uses ultrasonic...
cavitation to unblock ventricular catheters. In collaboration with Cybersonics, Inc. (Erie, PA), a system was designed, built and tested that produces low-frequency ultrasound (20-28 kHz). In the sheep choroid plexus model, at least 90% of the occluded holes were unblocked in a few minutes, restoring normal flow. There was no adverse effect of the device within shunt catheters inserted into live animal brains. Four patients have undergone treatment with the device during open CSF shunt surgery without adverse effect, and the device seems effective at unblocking and freeing the occluded catheters. Ultrasonic cavitation produced at the end of a fine wire that is introduced percutaneously into a CSF shunt promises to be a useful technique for minimally invasive proximal ventricular CSF shunt catheter revision.

Injury and Recovery


Using an experimental model of chronic obstructive hydrocephalus developed in their laboratory, researchers at Cleveland Clinic Foundation in Ohio investigated the relationship between the duration and severity of hydrocephalus and cardiac output (CO), cerebral blood flow (CBF), myocardial tissue perfusion (MTP), and peripheral blood flow (PBF). Results suggest that chronic hydrocephalus may have more of an influence on CO and CBF in the chronic stage than in the early condition, which was dominated by surgical effect. The cause of this late deterioration of cardiac function in hydrocephalus is uncertain, but may reflect cardiac regulation secondary to physiologic response or brain injury.


The aims of this study by researchers at the University of Michigan Medical School in Ann Arbor were 1) to establish an adult rat model of intraventricular hemorrhage (IVH) and post-hemorrhagic ventricular dilatation, and 2) to examine the role of alterations in cerebrospinal fluid (CSF) drainage and parenchymal injury in that dilatation. The authors found that it is possible that initial ventricular distension (due to the hematoma and the impaired CSF drainage) in combination with periventricular white matter damage results in structural changes that prevent total recoil once the hematoma has resolved and CSF drainage is normalized, leading to long-term hydrocephalus.

Genetic Studies


To discover candidate genes in the pathogenesis of congenital hydrocephalus, researchers at Wayne State University utilized gene arrays to analyze transcripts from the midbrain region of 5-day-old H-Tx rats with congenital obstructive hydrocephalus. A relatively few number of transcripts were found to be altered in the development of hydrocephalus in this model. This is the first experiment of its kind to identify changes in gene expression in a congenital model of rodent hydrocephalus that are occurring locally in the area surrounding the cerebral aqueduct. Studies are now needed to examine these candidate genes and their cognate proteins to delineate their role in hydrocephalus.

Expression of the human PAC1 receptor leads to dose-dependent hydrocephalus-related abnormalities in mice. J Clin Invest. 2006 Jul;116(7):1924-34: Lang B, Song B, Davidson W, MacKenzie A, Smith N, McCaig CD, Harmar AJ, Shen S. Researchers at Grampian University Hospitals in the U.K. looked at the relationship of hydrocephalus with G protein-coupled receptors (GPCRs). The data demonstrate that altered neuronal proliferation/apoptosis and disrupted ependymal cilia are the main factors contributing to hydrocephalus in PAC1-overexpressing mice. This is the first report to our knowledge demonstrating that misregulation of GPCRs can be involved in hydrocephalus-related neurodevelopmental disorders.


Researchers at Brown Medical School in Rhode Island investigated the role of atrial natriuretic peptide (ANP) in reducing cerebrospinal fluid (CSF) formation rate, and thus, intracranial pressure. In adult rats (Sprague-Dawley), authors found that ANP neuroendocrine-like regulation at CSF transport interfaces and blood-brain barrier impacts brain fluid homeostasis.

Modeling


Based on a recently developed model of communicating hydrocephalus which suggests that ventricular dilation may be related to the redistribution of pulsations in the cranium from the subarachnoid spaces (SASs) into the ventricles,
researchers at Stony Brook University in New York have developed a method for analyzing flow pulsatility in the brain by using the ratio of aqueductal to cerebral subarachnoid stroke volume and the phase of cerebrospinal fluid (CSF) flow, which is obtained at multiple locations throughout the cranium, relative to the phase of arterial flow. Findings: Under normal conditions, pulsatile ventricular CSF flow is a small fraction of the net pulsatile CSF flow in the cranium. A thorough review of the literature supports the view that modified intracranial compliance can lead to redistribution of pulsations and increased intraventricular pulsations. The phase of CSF flow may also reflect the local and global compliance of the brain.


Researchers at the University of Oxford in the U.K. formulate in general terms the equations for axisymmetric and fully 3D models of a hydrocephalic brain. Results of a fully 3D simulations are described for two horn-like lateral ventricles, and one case with two lateral ventricles and a third ventricle.

Clinical Studies

Pediatric

Care and management of the child with shunted hydrocephalus. Pediatric Nurs. 2006 May-Jun;32(3): 222-5: Chiapery M.

Dr. Chiapery at the Strong Memorial Hospital in Rochester, NY, reviews the physiology of cerebrospinal fluid formation and flow, the causes of hydrocephalus in the pediatric patient, symptoms of increased intracranial pressure, recent advances in shunt technology, the medical and surgical management of hydrocephalus, and potential complications of ventricular shunting devices. Nursing care in the post-operative period and for the child with shunt malfunction is discussed, as well as the long-term management needs and anticipatory guidance issues as related to a child with a ventricular shunting device.


Dr. Dalen and his colleagues at the Department of Medical Psychology at the University of Bergen in Norway ran a population-based controlled study to investigate non-verbal learning disabilities (NLD) in children with hydrocephalus. Children with myelomeningocele (spina bifida), intracranial tumors or IQ of less than 70 were excluded. They found there is a higher frequency of NLD in the child hydrocephalus group, and the model of the elements and the dynamics of the NLD syndrome may be useful when analyzing neuropsychological test results obtained with traditional and comprehensive test batteries.


Dr. Duhaime, a pediatric neurosurgeon at the Children’s Hospital at Dartmouth in Lebanon, NH, reviews the history, causes, presentation, management and outcome from shunt infections in children. She writes about the pitfalls in diagnosis and management and outlines prevention strategies and research questions still remaining in this area.


A study by Dr. Andersson and his colleagues at the Department of Ophthalmology at Goteburg University in Sweden detects and quantifies visual and visual-perceptual dysfunction in 75 children who have been treated for hydrocephalus. Visual function deficits were identified in 83% of the children with hydrocephalus. In this study, children with hydrocephalus associated with myelomeningocele (spina bifida) were least commonly affected. Visual disorders were most frequent in those with epilepsy, cerebral palsy and/or cognitive disability.


Dr. Kim and his coworkers at the Department of Emergency Medicine at Loma Linda University Medical Center and Children’s Hospital in Loma Linda, CA, evaluated the medical records of children with cerebrospinal fluid shunts who presented to a pediatric emergency department to determine if any signs and/or symptoms were predictive of shunt malfunction. They found that lethargy and shunt site swelling were predictive of shunt malfunction. Other signs and symptoms studied did not reach statistical significance; however, one must maintain a high index of suspicion when evaluating children with an intracranial shunt, because the presentation of malfunction is widely varied. A missed diagnosis can result in permanent neurological sequelae or even death.


Drs. Simpkins, Clark and Daughtery of Lakeland, FL, discuss ventriculoperitoneal (VP) shunt infections and how they can be detrimental to the pediatric patient with hydrocephalus and his or her family. Their article reviews current treatment modalities when a ventriculoperitoneal shunt infection has occurred and the differences between the causes of late and early shunt infections. Most
importantly, they discuss the signs and symptoms that the families of the child undergoing a VP shunt must know during the postoperative period, and the tools they can use to help combat and prevent VP shunt infections.

**Adult, Including NPH**

Normal pressure hydrocephalus: diagnosis and new approaches to treatment. Clin Geriatr Med. 2006 Aug;22(3):645-57: Factora R, Luciano M. Drs. Factora and Luciano of Cleveland Clinic in Ohio note that impairment of gait, dementia and urinary incontinence are common problems occurring in the elderly. Although many times these problems are mutually exclusive, with treatments chosen to address each disease entity separately, Drs. Factora and Luciano suggest that when these symptoms appear over time in the same patient, these symptoms raise the possibility of NPH.


CSF drainage ameliorates the motor deficit in normal pressure hydrocephalus: evidence from the analysis of grasping movements. J Neurol. 2006 May;253(5):640-7. Epub 2006 Feb 7: Nowak DA, Gumprecht H, Topka H. NPH can cause deficits in hand and arm movements. Dr. Nowak and colleagues found that CSF removal improved the ability of eight study subjects to lift and grasp an object, suggesting that the measurement of grasping forces may provide an additional test to quantify the clinical response to CSF removal in NPH.

Ventriculoperitoneal shunting of idiopathic normal pressure hydrocephalus increases midbrain size: a potential mechanism for gait improvement. Neurosurgery. 2006 Oct;59(4):847-50; discussion 850-1: Mocco J, Tomey MI, Komotar RJ, Mack WJ, Frucht SJ, Goodman RR, McKhann GM 2nd. Building on their recent work which demonstrates that the maximal midbrain anteroposterior (AP) diameter is significantly smaller in patients with iNPH than in healthy age-matched controls, Dr. Mocco and colleagues at Columbia University in New York, NY, undertook a study to determine the effect of VP shunting on midbrain dimensions in 12 iNPH patients. Both the mean AP diameter and left-to-right diameter increased from pre- to postoperative imaging. The approximate cross-sectional area determined as the product of AP and left-to-right diameters also increased. This study provides supportive evidence that midbrain cytoarchitecture may play a role in the pathophysiology and post-VP shunt gait improvement of iNPH patients.

Demographic factors influence cognitive recovery after shunt for normal-pressure hydrocephalus. Neurologist. 2006 Jan;12(1):39-42: Chang S, Agarwal S, Williams MA, Rigamonti D, Hillis AE. Dr. Chang and colleagues at Johns Hopkins University in Baltimore, MD, set out to identify demographic factors associated with cognitive improvement after shunt insertion to improve assessment of prognosis for cognitive gains with treatment. Cognitive testing was administered before and after VP shunting in 36 patients with NPH who previously had improvement of any clinical symptom—gait, urinary incontinence or cognition—after a diagnostic trial of continuous CSF drainage. The authors found that one third of patients met their definition of good cognitive improvement. Demographic factors included age, sex, and ethnicity. Improvement by at least 25% on at least half of the cognitive tests administered. There was a significant negative linear relationship between age and probability of good cognitive improvement. The degree of cognitive improvement was found to be greater in women than men. Age was found to be a better predictor of improvement on memory tests, while sex was a better predictor of improvement on non-memory tests, after shunt insertion.

Biomarkers in chronic adult hydrocephalus. Cerebrospinal Fluid Res. 2006 Oct 4;3:11: Tarnaris A, Watkins LD, Kitchen ND. The area of biological markers that might be helpful in the selection of surgical patients has been overlooked in iNPH compared too other neurodegenerative disorders and dementias. Dr. Tarnaris and colleagues from the National Hospital for Neurology and Neurosurgery in London reviewed research from the last 25 years regarding the identification of serum and CSF biomarkers for chronic hydrocephalus, discussed the potential for each one, and discussed the limitations for use, as well as future directions and possibilities in this field. They concluded that tumor-necrosis factor, tau protein, lactate, sulphate and neurofilament triple protein are the most promising CSF markers for chronic hydrocephalus. At present, however, none of these meet the criteria required to justify a change in clinical practice.

Normal pressure hydrocephalus. Clin Geriatr Med 2006 Nov;22(4):935-51, viii: Wilson RK, Williams MA. This article by Drs. Wilson and Williams at the Johns Hopkins Hospital Adult Hydrocephalus Program in Baltimore, MD, helps geriatricians identify patients who might have NPH, and care for these patients after shunt placement. The authors discuss diagnosis, treatment and recently published guidelines for the diagnosis and management of idiopathic NPH by an international, independent study group.
General Studies

Pediatric and Adult


In an effort to identify critical gaps in the prevailing knowledge of hydrocephalus, Dr. Bergsneider from the University of California at Los Angeles and colleagues formulated 10 key questions. Rigorous answers to these questions should lead to more effective and reliable treatments.


The purpose of this study by Dr. Winston and colleagues from University of Colorado Health Sciences Center and Children’s Hospital in Denver was to review the clinical features of a group of patients in whom ventricular enlargement was not a manifestation of prolonged CSF shunt failure. Twelve patients with prolonged symptoms consistent with CSF shunt failure and stable normal ventricular size were demonstrated at the time of surgery to have obstruction of their CSF shunts. The authors conclude that ventricular enlargement is a common but not sine qua non indicator of CSF shunt failure. Shunt obstruction may occur with stable normal ventricular size. Delaying the diagnosis in such a case can have potentially serious adverse consequences.


Dr. Smith and colleagues from Massachusetts General Hospital in Boston investigated whether the arrival of new interns and residents at teaching hospitals each July might cause an annual transient increase in poor patient outcomes and inefficient care. Data were analyzed for 4,323 craniotomies for tumor resection and 22,072 shunt operations performed in pediatric patients between 1988 and 2000 in U.S. nonfederal hospitals. Data for patients treated in July and August were compared with similar data for patients in other months. The researchers found that although moderate increases in some adverse end points could not be excluded, there was no evidence that brain tumor or shunt surgery performed during the remainder of the year. The data suggest an advantage to having surgery in September and June on some outcomes related to shunt surgery, but the “July effect” was small.


Drs. Power, George and Fuchs from Duke University Medical Center in Durham, NC, suggest that chronic constipation may result in abnormally elevated intra-abdominal pressure and may be an underrecognized cause of distal VP shunt failure. The authors describe the cases of two children who presented with clinical and imaging evidence of VP shunt failure and who were also severely constipated. Treatment of their constipation resulted in both clinical and imaging-documented resolution of their shunt failure.


Dr. Kestle and colleagues from the University of Utah in Salt Lake City present a multicenter pilot study undertaken to evaluate current strategies in the treatment of shunt infection. Seventy patients from 10 centers were followed...
up for one year after their CSF shunt infection. Reinfection occurred in 18 patients (26%). The treatment time with antibiotic therapy varied from four to 47 days, with a mean of 17.4 days for those who later experienced a reinfection compared with 16.2 days for those who did not. The researchers found that reinfection after treatment of a CSF shunt infection is alarmingly common. According to the data available, the incidence of reinfection does not appear to be related to the duration of antibiotic therapy.


Dr. Brown and colleagues from Frenchay Hospital, Bristol, U.K., describe their experience with a protocol that they developed in 1986 for the conservative management of patients with infected but functioning shunts by treating with administration of a combination of intraventricular and systemic antibiotics. An observational study of 122 patients treated for CSF shunt infection between 1986 and 2003 was undertaken. The researchers found the success rate of conservative management of patients with CSF shunt infections caused by coagulase-negative staphylococci is comparable with those in the published literature for patients treated conventionally. This form of management avoids surgical intervention with its attendant risks, and is safe.


Drs. Agrawal and Durity from University of British Columbia in Vancouver, Canada, describe a child with a ventriculoperitoneal shunt in place for five years who presented with “postural” seizures (seizures while sitting upright, which resolved on recumbency). At the time of revision of the shunt, no evidence of malfunction was found and the valve was changed to one with a higher opening pressure. Following this, she became asymptomatic and seizure free. This case illustrates the fact that following shunting, intracranial hypotension may also predispose to seizures, and should be kept in mind while managing these patients.


In this report, Dr. Clarke and colleagues from the Mayo Clinic in Rochester, MN, present two unique cases of very low pressure hydrocephalus in which the patients experienced rapid deterioration requiring negative-pressure cerebrospinal fluid drainage to achieve the best possible neurological function; outcomes in both patients ultimately were poor. The constellation of findings suggests that this may be a distinct clinical entity.

Shunts

Is it possible to optimize treatment of patients with idiopathic normal pressure hydrocephalus by implanting an adjustable Medos Hakim valve in combination with a Miethke shunt assistant? Acta Neurochir Suppl. 2006;96:381-5: Meier U, Lemcke J.

Drs. Meier and Lemcke from Unfallklinikum Berlin, Germany, have observed that implantation of a low-pressure valve in patients with NPH normally comes at the cost of a distinctly higher rate of overdrainage. They found that by combining an adjustable differential pressure valve with a gravity unit currently represents the optimal treatment variant for patients with NPH. In their view, the gravity valve should also be adjustable.


Dr. Kiefer and his colleagues at the Saarland University Medical School in Homburg-Saar, Germany, studied the outcome predictors for better selection for treatment of normal pressure hydrocephalus (NPH) patients. A total of 125 patients were evaluated and provided with a gravitational shunt. They found the well-known paradigm of a worse prognosis with NPH is not the result of the hydrocephalus etiology itself, but the consequence of a typical accumulation of negative outcome predictors as a consequence of the misinterpretation of normal aging and delayed adequate treatment.

The programmable adult Codman Hakim valve is useful even in very small children with hydrocephalus: a 7-year retrospective study with special focus on cost/benefit analysis. Eur J Pediatr Surg. 2006 Feb;16(1):1-7: Arnell K, Eriksson E, Olsen L.

Drs. Arnell, Eriksson and Olsen at Children’s Hospital in Uppsala, Sweden, present a seven-year retrospective study of 122 children with hydrocephalus who were shunted with the adult Codman Hakim programmable valve. Their study had a special focus on the costs and benefits. The most common reason shunts were changed to programmable valves was due to overdrainage. The study concluded the programmable valve was easy to handle; only one size was required, and the adjustment made it possible to achieve an optimal intraventricular pressure with a lower total cost, reduced hospital stay and an increased quality of life for the children.


Drs. Browd, Ragel, Gottfried and Kestle of Primary Children’s Medical Center in Salt Lake City, UT, write a two-part review on the failure of CFS shunts. It discusses the common findings in patients
Research

In vitro hydrodynamic properties of the Miethke proGAV hydrocephalus shunt. Cerebrospinal Fluid Res. 2006 Jun 29;3:9: Allin DM, Czosnyka ZH, Czosnyka M, Richards HK, Pickard JD. Dr. Allin and his colleagues at Addenbrooke's Hospital in Cambridge, England, evaluated the ProGav Miethke adjustable shunt valve in their shunt evaluation lab in the U.K. They found this adjustable, low-resistance valve is able to limit posture-related overdrainage. Unlike other adjustable valves, the ProGav cannot be accidentally readjusted by an external magnetic field such as a 3T MR scanner.

Gravitational valves: relevant differences with different technical solutions to counteract hydrostatic pressure. Acta Neurochir Suppl. 2006;96:343-7: Kiefer M, Meier U, Eymann R. Dr. Kiefer and his colleagues at the Saarland University Medical School in Homburg-Saar, Germany, studied the two different technical principles of gravitational Aesculap-Miethke valves (G-valves): counterbalancer and switcher G-valves. The authors found the outcome of their study to be better with the usage of the GAV (counter balancer) than with the DSV (switcher). They recommend the Aesculap-Miethke-GAV valve with a low opening pressure in a posture-independent valve for patients with NPH.

The Strata programmable valve for shunt-dependent hydrocephalus: the pediatric experience at a single institution. Childs Nerv Syst. 2006 Oct 7: Ahn ES, Bookland M, Carson BS, Weingart JD, Jallo GI. Drs. Ahn, Bookland, Carson, Weingart and Jallo at the University School of Medicine, Baltimore, MD, studied the efficacy of the adjustable Medtronic PS Medical Strata valve used in shunt-dependent children. They found the one-year shunt survival rate of 67.2% is comparable to the rate previously reported from a multi-center trial. Their data indicated adjustments can be used to treat symptoms of CFS over- or underdrainage that may obviate the need for surgery.

ETV vs. Shunts

Long-term outcome and neurologic development after endoscopic third ventriculostomy versus shunting during infancy. Childs Nerv Syst. 2006 Oct 5: Takahashi Y. Researchers from Tomakomai Neurosurgical Hospital in Hokkaido, Japan, evaluated the clinical course and long-term outcome of infants with obstructive hydrocephalus who were less than nine months old, comparing those initially treated by neuroendoscopic third ventriculostomy (ETV) and ventriculoperitoneal shunting. Conclusions: In infants with obstructive hydrocephalus in whom the cerebral cortex is intact, adequate development can be achieved with ETV alone, although catch-up tends to be slow. In infants in whom cerebral development is inadequate or in whom the cerebrum has already been affected by hydrocephalus, sufficient improvement of development cannot be achieved with ETV alone, even if the intracranial pressure is controlled. It seems that early shunting is more useful for achieving cerebral recovery in this patient group.

Outcome prediction of third ventriculostomy: a proposed hydrocephalus grading system. Minim Invasive Neurosurg. 2006 Aug;49(4):238-43: Kehler U, Regelberger J, Gliemrth J, Westphal M. Researchers from Asklepios Clinic in Hamburg, Germany, propose a simple, easily applicable grading system that is designed to predict the outcome of third ventriculostomy. The hydrocephalus is graded on three criteria with grade 5, the most severe subtype, showing a markedly downward bulged floor of the third ventricle and direct detection of the CSF pathway obstruction (i.e., aque ductal stenosis) with progressive clinical deterioration. The success rate in grade 3 reached 40%; in grade 4, 58%; and in grade 5, 95%.

Late rapid deterioration after endoscopic third ventriculostomy: additional cases and review of the literature. J Neurosurg. 2006 Aug;105(2):118-26: Drake J, Chumas P, Kestle J, Pierre-Kahn A, Vinchon M, Brown J, Pollack IF, Arai H. Researchers at University of Toronto in Canada found 16 cases of late rapid deterioration as a complication of ETV combining their own data, other case reports and canvassing pediatric neurosurgeons in North America, Europe, Australia and Asia. Conclusions: Late rapid deterioration is a rare but lethal complication of ETV. The mechanism is unclear, but deterioration can occur long after the ETV becomes occluded. Patients and caregivers should be counseled regarding this potential complication. An indwelling ventricular access device is an option for patients undergoing ETV.

Is there an indication for ETV in young infants in aetiologies other than isolated aqueduct stenosis? Childs Nerv Syst. 2006 Sep 19: O’Brien DF, Seghedoni A, Collins DR, Hayhurst C, Mallucci CL. A retrospective analysis and literature review by researchers from the Royal Liverpool Children’s Hospital in England compare outcome results of ETV for different aetiologies of obstructive hydrocephalus in those less than one year of age. Conclusions: The definitive initial neurosurgical management of suprasellar arachnoid cysts causing significant
Elderly Can Take Steps to Prevent Falls

By Jose Loera, MD, University of Texas

A lthough many seniors may fear catching a cold at the grocery store or being involved in a fender bender, one of the biggest preventable dangers to people over age 65 exists within their own homes—accidental falls. More than one-quarter of seniors experience at least one fall per year. Commonly, both the number of falls and severity of injuries increase with age.

Injuries from falls account for a large percentage of hospital admissions in seniors and can potentially cause severe trauma, such as hip or other bone fractures and head injuries. Three of the most common causes of falls in the elderly living independently are: accidents; poor balance or weakness when walking, resulting from arthritis, side effects of medications, alcohol, pain and/or seizures; declining hearing and vision.

As one ages, the body may experience a loss of muscle mass and slowing nerve responses. These changes may make it difficult for a person to avoid a fall, because the ability to detect and react to potential obstacles is diminished.

Common Hazards
Accidents generally involve something in the environment. Most occur from a change in stability while walking, or changes associated with aging. Poor posture, poor vision, and hearing and memory problems all tend to impair a senior’s ability to avoid falls. Some avoidable hazards include doorway thresholds, uneven carpeting or flooring, and poor lighting—especially from the bedroom to the bathroom—along with clutter in hallways and stairways. Lack of stability-enhancing devices like railings or grab bars in bathrooms, or not using prescribed canes or walkers, also create problems.

Tips for Prevention
Specific exercises can be learned to strengthen a person’s muscles and improve balance. These exercises can be tailored around the patient’s living environment, level of strength and balance deficits. For example, older people can reduce the potential for falls by learning to lift their feet higher when they step, learning more effective ways of sitting and rising from chairs or from bed, and learning ways to improve balance. Behavioral changes, such as sleeping with a night-light so that the room is adequately illuminated or wearing rubber-soled shoes to prevent slipping, can help create a safer environment.

If you have fallen, or if you are experiencing walking difficulties and are afraid you might fall, have your family doctor refer you for a falls assessment.

Checklist Available
To download a home fall-safety checklist in order to evaluate fall risks within the home of your loved one, visit www.poststat.net/RightAtHome/pub.59/issue.375/article.570 and scroll to the bottom of the page.

José Loera, MD, is with the University of Texas Medical Branch in Galveston, Texas. This article is reprinted from the Caring Right at Home newsletter (www.caringnews.com) with permission from its publisher, Right at Home (www.rightathome.net).

Database Registry News

The Hydrocephalus Association database registry continues to provide useful information to researchers. Data from 1,249 of the surveys was used for a presentation, “Headaches and Hydrocephalus,” given by Dr. Hal Rekate at the pediatric section meeting in Denver, Colorado. Over one-quarter of those surveyed said they, or their children, suffered from “frequent, chronic headaches.” Dr. Rekate plans to further analyze this data for a paper on the subject.

If you have not yet filled out a survey, please go to www.hydrocephalusdatabase.org and enter your information so it will be available for future research projects.
Gift ideas for kids

Miaja Rociolla is a member of the Hydrocephalus Association and has a daughter, Lexi, who was born with hydrocephalus. Miaja is raising funds for the Association through sales of the Doctor’s Suitcase, a children's doctor kit, on her website. For every Doctor’s Suitcase sold, she will donate $5. The kit is imported from Germany and costs $24.50. It comes complete with a prescription pad, a pencil, a tongue depressor, a wooden syringe, wooden pills, a tube of ointment, a wooden spoon, four band-aids and an elastic bandage—all packaged in a charming tin suitcase with a wooden handle. It is appropriate for ages three and up. You can order the doctor kit directly from Miaja’s website, www.bellalunatoys.com/imaginativeplay/items/doctorsuitcase.htm, or call toll free at 888-502-3552.

Books and DVDs

Brookes Publishing offers great books and DVDs that can be ordered online at www.brookespublishing.com/books.

The First IEP: Parent Perspectives, by Deborah Chen, PhD, and Annie Cox, MA.
This DVD is perfect for guiding parents and training new and future practitioners about the IEP process. It is an encouraging and unintimidating resource that answers common questions and concerns. Learn from parents who have been there, watch parent/professional collaboration at work and see a successful IEP in action.

Brothers and Sisters: A Special Part of Exceptional Families, by Peggy Gallagher, PhD, Thomas Powell, EdD, and Cheryl Rhodes, MS.
A brother or a sister is usually the first close friend and playmate a child has—and when that child has a disability, the sibling relationship takes on a new meaning and importance. This is a classic resource to deepen your understanding of sibling relationships. Readers will get specific ideas, ready-to-use strategies and personal anecdotes from siblings. Brothers and Sisters combines lots of inspiring stories, facts and wisdom with practical advice.

Websites

Through the Looking Glass is a nationally recognized organization that has pioneered research, training and services for families in which a child, parent or grandparent has a disability or medical issue. Their mission is to empower, create, demonstrate and encourage non-pathological and empowering resources and model early intervention services that integrate expertise derived from personal disability experience and disability culture.

They provide direct services, information and referrals. Check out their website at www.lookingglass.org.

The National Accessible Travelers Database
Project ACTION (Accessible Community Transportation in Our Nation) has developed an online database, searchable by city and state or zip code, to help people with disabilities or disabling chronic health conditions locate accessible transportation, including vans, taxis, buses, volunteers driving cars and other services. For additional information on contacts and resources on accessible transit in your area, visit Easter Seals Project ACTION: http://projectaction.easterseals.com. Click on Free Resources, then the National Accessible Travelers Database.

Kid’s Corner!

Riddles o’ Fun

I begin in the ventricle in the center of the brain, snaking my way to the heart or stomach like a train.

Thinner than a drinking straw, extra fluid is what I withdraw.

Sometimes I get a terrible infection—then it is necessary to get a doctor’s inspection.

What am I?

Words in a Word

How many words can you make out of the letters in “brain”?

Hint: “Brain” counts as one word.

Answer: 14 words

Answer: A Shunt
HYDROCEPHALUS ASSOCIATION

2007 Membership Form

Name: ____________________________  Telephone: ____________________________

Address: ________________________________________________________________

__________________________________________________________  Email: ________

Name of person with hydrocephalus: ____________________________  Birth date ________  Age at diagnosis ________

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

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

☐ $30  ☐ $50  ☐ $100  ☐ Other $______

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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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