

HYDROCEPHALUS

▪ ASSOCIATION ▪

SUPPORT EDUCATION ADVOCACY

WINTER 2006

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Baltimore, Here We Come!

Unity and Diversity: Learning from One Another

9th National Conference on Hydrocephalus for Individuals, Families and Professionals

May 26–29, 2006
Hyatt Regency Baltimore

THE GOAL OF THE Hydrocephalus Association's biennial national conference is to give individuals, families and professionals the tools and connections they need to address the medical, educational and social challenges of hydrocephalus. Highlights of the conference scheduled for May 26–29, 2006, include a plenary session on the National Institutes of Health–sponsored workshop "Hydrocephalus: Myths, New Facts, Clear Directions" held in September 2005, a keynote speech by a long-standing congressional staffer about how to build on this workshop to increase national support for hydrocephalus research and an intergenerational forum where we learn from one another about similarities across the age spectrum. We will have plenty of interactive sessions and time for Q&A with medical professionals. The conference will be followed by a trip to Capitol Hill. We will join our voices to raise visibility in Congress through visits with legislators, where we will tell our stories, publicly thank the NIH for supporting hydrocephalus in 2005 and ask for more federal attention to this important condition.

* We are blessed with a top-notch team of medical and scientific advisors

who represent neurology, neurosurgery and neuroscience and cover the spectrum of hydrocephalus treatment from babies to older adults. We are delighted to have Dr. Michael A. (Mike) Williams as our Medical Chair. Mike is a neurologist who co-directs the Adult Hydrocephalus Program at Johns Hopkins Hospital in Baltimore. In addition to his expertise in diagnosing and treating adult hydrocephalus, Mike is also the head of the Ethics Committee for the American Association of Neurologists. You will see his influence in some of the tough issues he has encouraged us to tackle this year. Mike is being ably assisted by Dr. Marion (Jack) Walker, Chief of Pediatric Neurosurgery at Utah Children's Hospital in Salt Lake City, and JP (Pat) McAllister III, a neuroscience researcher at Wayne State University in Detroit who has focused on hydrocephalus research for over 20 years. It was my privilege to work with Mike, Jack and Pat as the medical chairs for the NIH-sponsored workshop in September 2005. I am confident that they will lead us through a meaningful and enjoyable learning experience.

* The conference begins at 1 pm on Friday, May 26, with interactive sessions where you can meet other people from around the country who are in similar situations. Friday afternoon we will have hands-on anatomy and physiology labs where you can brush up on your brain anatomy with the help of neuroscientists. The medical and scientific sessions begin Saturday morning. The conference continues through Monday, May 29, at 3 pm. For those who plan to join us in Washington, DC, for Advocacy Day on Tuesday, May 30, we will use Monday afternoon to practice in small groups for our legislative visits.

* You are encouraged to make reservations at the Hyatt at your earliest convenience. The phone number for Hyatt reservations is 410-528-1234 or 800-233-1234. Be sure to ask for the special Hydrocephalus Association Conference rate of \$139 per night for a single room and \$149 per night for a double. **This rate is only guaranteed if you book before May 1, 2006.** Remember, you can always cancel your reservation a week before the conference, but this reduced rate isn't available forever.

* A limited amount of financial aid is available to members of the Hydrocephalus Association to cover conference registration fees. Financial aid is awarded based on need. Please call our office to request a financial aid application form. The completed financial aid form must be submitted to our office no later than March 26, 2006. Financial aid awards will be decided by April 1, 2006. Recipients will be notified by mail.

* All registered participants are invited to an opening reception on Friday night courtesy of Medtronic Neurologic Technologies. This will be an opportunity to enjoy dessert and coffee with your fellow conference attendees—many of whom you will have met during the interactive sessions on Friday afternoon.

* **Everybody gets to dance!** Codman, a Johnson and Johnson Company, has generously offered to underwrite the cost of the Saturday-night dinner dance, so everyone who is registered for the conference is invited, at no cost, to this wonderful networking soirée.

Keep your eyes out for the conference brochure and sign up early. This is one conference you won't want to miss! ■

From the Editor

By Dory Kranz

IN WINTER we move through the darkest time of the year with short days and long nights. It is a time to reflect on the year past and gather our thoughts for what we want in the year to come.

I am first and foremost grateful for our outreach directors, Pip Marks and Debra Howell, who have worked tirelessly to maintain our commitment to core services this year. Primarily through Pip and Debra, we provided information and **support to over 1,000 people each month**, including first-time inquiries from 7,500 individuals and families, and thousands of calls and emails from longtime friends and supporters. It is with delight that I welcome Daniela Salas to our outreach staff to help us respond to the ever-increasing demand for support and to spearhead a formal outreach initiative geared to the Latino community.

Pip worked with members across the country hosting **TEAM events in seven states** where participants were stunned by the power of meeting

others in a similar situation for the first time. These fundraising events also provide critical income for our core services—a total of more than \$120,000 in 2005. Well done, TEAM! Our goal is to add another seven states in 2006.

We **exhibited at six medical meetings** in 2005. Traveling around the country for these three-to-four-day meetings takes a considerable investment of time and money. We feel it is important because our presence serves to keep hydrocephalus visible in the medical community and helps us strengthen our network of friends and advisors among neurosurgeons, neurologists and neuroscience nurses. We also use the opportunity to educate ourselves about new research in diagnosis and treatment of hydrocephalus so we are prepared for support calls and able to plan meaningful workshops for our conference.

We **published four newsletters** to keep in touch with you, the community that we are here to serve. I hope this gives you a glimpse into the tremendous amount of work done by

our small staff. We said good-bye to Daniel midway through the year and for a while there were just three of us in the office. The occasional thank-you card we receive is always greatly appreciated and helps us know which of these services has value to you and should continue to receive our time and attention.

You will read in this newsletter about initiatives that were planned in 2005 and will come to light in 2006, including our **9th National Conference** described in the cover article and our **Latino Outreach Program**, which is introduced on page 3.

Through generous donors, we have expanded the number of **educational scholarships** we can award to young adults going beyond high school from five in 2005 to seven in 2006. See page 5 for more info.

It is a pleasure and privilege to look back on this year that we have spent together. Your stories of courage in the face of hardship inspire us and help us keep life in perspective. As always, your comments and suggestions are welcome as we move forward into 2006. ■

Medical Advisory Board Meets in Chicago

THE ASSOCIATION was privileged to have 13 esteemed members of our Medical Advisory Board meet with us for a day and a half in Chicago, on October 29–30, 2005. Much of the meeting was devoted to the Association's role in building on the NIH-sponsored workshop on hydrocephalus and facilitating the writing of the manuscript to set out national research priorities for hydrocephalus.

The issue of finding appropriate medical care for adults who have been living with hydrocephalus since infancy and childhood also received considerable time and attention. There was consensus among the pediatric and adult neurosurgeons present that this is an issue that deserves attention from the American Association of Neurological Surgeons and the Congress of Neurological Surgeons. Hydroceph-

alus is not the only condition facing challenges of transitioning medical care, since improved medical intervention is allowing more and more people with the condition to live into adulthood. Some other conditions that share this challenge are congenital heart disease and epilepsy. Members of our Board and Medical Advisory Board are working together to raise the issue and devise solutions at the national level. ■

Spanish Outreach Program Is Under Way



By Daniela Salas

GREETINGS! It has been a great pleasure to join the Hydrocephalus Association team and become part of this amazing network of people. I am looking forward to meeting and working with you.

I started my career in nonprofits

working at the international headquarters of Lions Clubs (Oak Brook, Illinois) and subsequently worked for Rotary International (Evanston, Illinois). I bring experience in grant administration, project management and grant writing. I am fluent in Spanish and Portuguese and I have 18 years of international living and travel, mostly throughout Latin America.

As the Latino Outreach Coordinator, I will be designing and implementing the Latino outreach plan. In the next months, we will be developing new educational and informational resources in Spanish, meeting with community leaders and conducting several focus groups and surveys. Our website will be updated with addition-

al Spanish pages, and you will also be able to read sections of the newsletter in Spanish (including this one!). In addition, it is a pleasure to announce that we are now able to answer inquiries and requests in Spanish.

In order to develop a successful and effective Latino outreach plan, we will need your assistance. If you have a Hispanic background or are simply interested in participating in our preliminary studies, I invite you to participate in a short survey below.

I look forward to hearing from you and thank you for your support. Please feel free to contact me at (888) 598-3789 or daniela@hydroassoc.org. My best. ■



By Daniela Salas

CORDIALES SALUDOS! Con gran gusto he pasado a formar parte de la Asociación de Hidrocefalia y a unirme a este maravilloso grupo de personas. Con gran ansias espero conocerle y trabajar con usted.

Comencé mi carrera en esta area, trabajando para la organización internacional del Club de Leones (Oak Brook, Illinois). Posteriormente, trabajé para la organización Rotary Internacional (Evanston, Illinois). Tengo experiencia trabajando en administración de subvenciones, proyectos humanitarios y con solicitudes de subvenciones. He vivido y viajado a través del mundo por más de 18 años, especialmente América Latina. Hablo Español y Portugués.

Como Coordinadora del Programa de Extensión Latino, estaré diseñando y llevando a cabo el plan de Extensión para Latinos. Durante los próximos meses, estaremos produciendo nuevos recursos educacionales e informativos en Español, realizaremos varios grupos de estudio y encuestas. Tam-

bién nuestra página del internet contendrá más información en Español y este periódico incluirá artículos en Español. Es un placer anunciar que además estamos recibiendo preguntas y solicitudes en Español.

Para poder diseñar un plan de extensión para Latinos que sea efectivo y exitoso, necesitaremos de su ayuda. Si es o tiene antepasado Hispano, o simplemente esta interesado (a) en participar en nuestro estudios preliminares, por favor entre en contacto conmigo. Si tiene fotos de su familia o de sí mismo que quisiera compartir con nosotros, por favor envíelas a nuestra dirección.

Espero que entre en contacto conmigo y desde ya, le agradezco su apoyo. Por favor, no dude en contactarme al teléfono (888) 598-3789 o Daniela@hydroassoc.org.

Para su mayor conveniencia, puede enviar sus respuesta por correo, fax o email. Esta encuesta es voluntaria.

► ¿Qué tipo de ayuda y servicios está actualmente recibiendo en relación a la Hidrocefalia?

► Cómo ha recibido información de los programas relacionados a la Hidrocefalia? (Por ejemplo, por correo, radio, centro medico, etc.)

► ¿Está recibiendo todos los servicios necesarios en relación a la Hidrocefalia? Si es que no, por favor explique.

► ¿Cómo prefiere recibir nuestros materials informativos y educativos? (Por ejemplo, email, fax, correo, etc.)

► En general, ¿dónde busca información relacionada a su salud o a la de su familia?

► ¿Estaría interesado (a) en ingresar en un directorio para gente con Hidrocefalia de habla Español?

Nacionalidad: _____

Tipo de Hidrocefalia: _____

Edad: _____

Sexo: _____

Ciudad, Estado y Correo Postal: _____

Conrad Johanson Recognized for Dedication to CSF Research

CONRAD E. JOHANSON, PHD, director of neurosurgery research at Rhode Island Hospital and professor of clinical neurosciences and physiology at Brown Medical School, has received the 2004 Robert H. Pudenz Award for Excellence in Research in Cerebrospinal Fluid (CSF) Physiology and Hydrocephalus. He is the first nonphysician to receive the award solo for his outstanding contributions to the field.

In addition to the award, Johanson received \$5,000 for future research in CSF and hydrocephalus from Medtronic, Inc., who sponsors the award. Medtronic also sent a \$1,000 donation to the Hydrocephalus Association in honor of Conrad Johanson and Robert H. Pudenz, for whom the award is named. Dr. Pudenz is an internationally recognized pioneer in pediatric neurosurgery who is known for his contributions to CSF, hydrocephalus



From left: Ken Wagner of Medtronic, Conrad Johanson, and Austin Noll of Medtronic.

and shunt technology.

Dr. Johanson has been funded by the National Institutes of Health (NIH) for nearly 25 years. A pioneer researcher of choroid plexus function, he has elucidated various principles of CSF secretion and volume distribution. He investigates the effects of cerebral ischemia, a condition in which blood flow is restricted to parts of the brain, hydrocephalus and Alzheimer's disease on the compromised dynamics of CSF. Through his research, he

and colleagues are looking for nonsurgical ways to minimize CSF build-up in the brain, which can cause problems with cognition, urinary incontinence and gait. He also analyzes the physiology and pathology of the cerebral capillaries, which regulate the brain extracellular fluid.

We send our warm congratulations to Dr. Johanson for this well-deserved award and our gratitude to Medtronic for their generosity in sponsoring the award. ■

Resident's Prize Winner Announced



ONE WAY the Hydrocephalus Association encourages young doctors to focus their research on bettering the treatment and care of individuals with hydrocephalus is through our annual Resident's Prize. In 2005, Dr. Jeffrey Greenfield received the \$500 award for his paper "Intraoperative Assessment of Third Ventriculostomy

Success." Dr. Greenfield has been invited to present a synopsis of this paper at the AANS meeting in San Francisco in April 2006.

Many excellent young doctors vied for this award and we are delighted by the rich range of research in hydrocephalus that is being conducted. The Resident's Award was initiated and funded for many years by Cynthia Solomon, a founder and longtime board member of the Association, in honor and memory of Henry Werdegar. Current board members Emily and Russell Fudge have generously offered to fund this award for the next five years.

Jeffrey P. Greenfield received a BA in neuroscience from Amherst College, graduating magna cum laude in 1994. He then received his PhD in neuroscience in 1999 under the guidance of

Nobel Laureate Paul Greengard, PhD, and his MD in 2002, from Cornell University Medical College. That same year he began his neurosurgical residency at the New York Hospital Cornell Medical Center, where is currently a fourth-year resident.

This year he received a Sharma Foundation fellowship to do research in the Ansary Center for Stem Cell Therapeutics at Cornell Medical College under the guidance of Howard Hughes member Shahin Rafii, MD. His research is examining the role that hematopoietic stem cells play in developing the vasculature of both pediatric and adult brain tumors. His clinical interest is in endoscopic neurosurgery with a focus on pediatrics and oncology, and he hopes his basic science and clinical interests converge in an academic career in pediatric and adult neurosurgical oncology.

Our warm congratulations to Dr. Greenfield! ■

Scholarship Applications Now Available

WE ARE EXCITED to announce that our scholarship program for young adults with hydrocephalus has been expanded to support seven scholarships in the range of \$500 each. The scholarship applications for 2006 are now available in English and in Spanish. Please call or email us with your address and we will mail you the application with instructions.

Anyone with hydrocephalus between the ages of 17 and 30 may apply for a scholarship. Scholarship funds must be used for an educational purpose, including, but not limited to, a four-year college, technical or trade school, an accredited employment training program or a postgraduate program. The funds may be used for tuition, books, housing or an expense directly related to the educational experience.

The deadline for submission of both

the application and the recommendation form is Monday, April 3, 2006. Applications received by our office after this date will not be considered, nor will applications that are incomplete (i.e., missing the recommendation form). Scholarships will be awarded in June.

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. & 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, the three surviving children and their spouses, Carrie and Dee Norton, Jerome and Rosemary Ziskind and Janet and Charles Tarino, have graciously funded one more scholarship in loving memory of their parents.

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 has established this new scholarship in loving memory of her son Justin Scot Alston, who died in 2004. Justin was awarded 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. ■

Se Encuentran Disponibles Las Solicitudes De Becas

ES UN PLACER ANUNCIAR que nuestro programa de becas para adultos jóvenes con hidrocefalia ha sido ampliado a siete becas de \$500 cada una. Las Solicitudes de Becas para el año 2006 se encuentran disponibles en Inglés y Español. Por favor, llámenos o envíenos un email con su dirección y nosotros le enviaremos una solicitud con las instrucciones.

Cualquier persona con hidrocefalia, que tenga entre 17 y 30 años, puede solicitar una beca. Los fondos de la beca deberán ser utilizado para fines educacionales incluyendo (pero no limitado), un grado universitario, estudios técnicos, programas acreditados de entrenamiento laboral o programas de post-grado. Los fondos pueden ser utilizados para matrícula, libros, alojamiento o gastos directamente relacionados con la práctica educacional.

La fecha límite para enviar su solici-

tud junto con el formulario de recomendación es el 3 de Abril del 2006. Las solicitudes que sean recibidas después de esta fecha en nuestra oficina, no serán consideradas, ni tampoco las solicitudes que esten incompletas (por ejemplo, que no tengan adjunto el formulario de recomendación). Las becas seran otorgadas en Junio del 2006.

Beca en Memoria de Gerard Swartz Fudge

Estos fondos fueron establecidos en 1994 por la familia Fudge. Gerard, su hijo, tenía hidrocefalia y falleció en 1992 a la edad de 22 años en medio de su vida universitaria. Dos becas de este fondo son otorgadas cada año.

Beca en Memoria de Morris L. & Rebecca Ziskind

Este fondo fue establecido en 2001 por Rebcca Zisking y familia en memoria de su esposo, Dr. Morris Ziskind, quien tenía NPH. Posteriormente al falleci-

miento de Rebecca Ziskind en 2005, sus tres hijos junto con sus esposos (as): Carrie y Dee Norton, Jerome y Rosemary Ziskind y Janet y Charles Tarino, amablemente otorgaron una beca más en memoria de sus padres.

Beca Anthony Abbene

Este fondo fue establecido en 2002 por la familia de Anthony Abbene. Anthony es un adolescente con hidrocefalia. Este fondo otorga dos becas, en honor a Anthony y para ayudar a otras personas con hidrocefalia en su educación.

Beca en Memoria de Justin Scot Alston

La madre de Justin, Gloria M. Alston, ha establecido esta nueva beca en memoria de Justin Scot Alston, quién falleció en el año 2004. Justin recibió una beca de la Asociación de Hidrocefalia en el año 2002 y siempre será recordado por su actitud positiva y por todos los logros alcanzados en su vida. ■

New Research 2005: A Summary

By Marvin Sussman, Board Member, and Debra Howell

WE ARE PLEASED that there appears to be an increased interest and focus on research in hydrocephalus. The following summaries are a small sample of the research papers that have appeared in the clinical literature during 2005. In the interest of space, we have collapsed the abstract to the findings only. For more information on any of these articles, see our instructions on p. 11 about how to search and order articles through PubMed.

Basic Neuroscience or Bench Research

Pressure gradients in the brain in an experimental model of hydrocephalus: *Journal of Neurosurgery* 2005 Jun;102(6):1069-75: Penn, Lee, Linninger, Miesel, Lu, Stylos
Dr. Richard Penn and colleagues at the University of Chicago found that precise monitoring of pressure before and during the development of kaolin-induced hydrocephalus did not detect pressure gradients between the ventricle, brain, and subarachnoid space.

Hydrocephalus shunts and waves of intracranial pressure: *Medical and Biological Engineering and Computing* 2005 Jan;43(1):71-7: Czosnyka, Cieslicki, Czosnyka, Pickard
Dr. Czosnyka and coworkers at Addenbrooke's Hospital in the UK found that shunt operating pressure may be influenced by intracranial pressure (ICP) waveform dynamics, demonstrated by the value mean operating pressure decreasing when simulated amplitude of heart pulsations was increased.

Computational modeling of the mechanical behavior of the cerebrospinal fluid system: *Journal Biomechanical Engineering* 2005 Apr;127(2):264-9: Kurtcuoglu, Poulidakos, Ventikos
Dr. Kurtcuoglu and coworkers at the Swiss Federal Institute of Technology in Zurich propose that computational fluid

dynamics (CFD) can be used to analyze pressure propagation between the third and lateral ventricles. This is illustrated by the pressure amplitude in the lateral ventricles increasing with aqueductal stenosis and no phase difference between the third ventricle walls and pressure in the lateral ventricles observed due to aqueductal stenosis.

Pulsatile cerebrospinal fluid dynamics in the human brain: *IEEE Transactions on Bio-Medical Engineering* 2005 52:557-65 Linninger, Tsakiris, Zhu, Xenos, Roycewicz, Danziger, Penn
Dr. Linninger and colleagues at the University of Illinois at Chicago present a model of fluid-structure interactions that predicts flows and pressures throughout the brain's ventricular pathways consistent with both animal intracranial pressure (ICP) measurements and human CINE phase-contrast magnetic resonance imaging data.

A viscoelastic model of the brain parenchyma with pulsatile ventricular pressure: *Applied Mathematics and Computation* 2005, 165:687-98. Sivaloganathan, Stastna, Tenti, Drake
Dr. Sivaloganathan and fellow researchers solve the boundary value problems corresponding to the case of adult hydrocephalus, obtain solutions for displacement and stresses and show how the mechanical parameters that appear in the constitutive equation for the viscoelastic solid can be calculated from data obtained from dynamic load experiments.

Evaluation of polymer and self-assembled monolayer coated silicone surfaces to reduce neural cell growth: *Biomaterials Epub* 2005 Sept. 19; 2006 Mar; 27(8):1519-26. Patel, Tang, Grever, Ng, Keep, Cao, McAllister
Dr. Patel and colleagues at Wayne State University, Detroit, MI, and another institution found that silicone shunts coated with self-assembled monolayers (SAMs) may be suitable for future clinical applications to improve the treatment of hydrocephalus.

Clinical Studies: Pediatric

Potentially useful outcome measures for clinical research in pediatric neurosurgery: *Journal of Neurosurgery*; 2005 Sep;103(3 Suppl):207-12. Klimo, Kestle
Drs. Klimo and Kestle at the University of Utah illustrate several guidelines for the determination of appropriate outcome measures by using examples from their experience and describe several outcome measures that can be used in pediatric neurosurgery. These include general outcome measures such as the Pediatric Evaluation of Disability Inventory and the Functional Independence Measure for Children as well as disease-specific measures for hydrocephalus (Hydrocephalus Outcome Questionnaire) and other conditions.

Idiom comprehension deficits in relation to corpus callosum agenesis and hypoplasia in children with spina bifida meningocele: *Brain Lang.* 2005 Jun;93(3):349-68. Huber-Okraimec, Blaser, Dennis
Dr. Huber-Okraimec and colleagues at the Hospital for Sick Children in Toronto found that, compared to age peers, children with SBM understood decomposable idioms (which are processed more like literal language) but not non-decomposable idioms (which require contextual analyses for acquisition). The impairment was related to congenital agenesis of the corpus callosum, which suggests that the consequences of impaired interhemispheric communication, whether congenital or acquired in adulthood, are borne more by configurational than by compositional language.

Use of rapid-sequence magnetic resonance imaging for evaluation of hydrocephalus in children. *Journal of Neurosurgery*; 2005 Aug;103(2 Suppl):124-30. Ashley, McKinstry, Leonard, Smyth, Lee, Park
Dr. Ashley and colleagues at St. Louis Children's Hospital in Missouri found that rapid-sequence MR imaging yields reliable visualization of the ventricular catheter and offers superior anatomical detail while limiting radiation exposure. The authors' protocol is rapid and each image is acquired separately; therefore, motion artifact is reduced

and the need for sedation is eliminated. They recommend the use of rsMR imaging for nonemergent evaluation of pediatric hydrocephalus.

Cerebrospinal fluid shunt infections in children: *Pediatric Neurosurgery*; 41(3):131-6: Turgut, Alabaz, Erbey, Kocabas, Erman, Alhan, Aksaray

Dr. Turgut and colleagues at Cukurova University in Turkey found that the management protocol consisting of removal of the infected shunt, application of ventricular taps or reservoir placement, intraventricular antibiotic treatment, and placement of a new shunt when cerebrospinal fluid sterility was achieved is effective for the treatment of cerebrospinal fluid shunt infections.

Hydrocephalus in children with posterior fossa tumors: role of endoscopic third ventriculostomy: *Journal of Neurosurgery* 2005 Jul;103(1 Suppl):40-2: Fritsch, Doerner, Kienke, Mehdorn

Dr. Fritsch and coworkers at Universitätsklinikum Schleswig-Holstein in Germany found that for children with posterior fossa tumors, ETV is not normally indicated before or after tumor removal but may be suitable for patients with fourth ventricle outflow obstruction and persisting or progressive hydrocephalus following tumor removal.

A multicenter prospective cohort study of the Strata valve for the management of hydrocephalus in pediatric patients: *Journal of Neurosurgery* 2005 Mar;102(2 Suppl):141-5: Collective Name: Strata Investigators (Kestle, Walker)

In a prospective multicenter cohort study of children implanted with an adjustable Strata valve, Drs. Kestle and Walker and the Strata Investigators at various institutions found that one-year shunt survival with use in shunt insertion or revision was similar to other valves, with 63% of patients having symptom relief or improvement after adjustment.

Epilepsy in shunted posthemorrhagic infantile hydrocephalus owing to pre- or perinatal intra- or periventricular hemorrhage: *Journal of Child Neurology* 2005 Mar;20(3):219-25: Battaglia, Pasca,

Cesarini, Tartaglione, Acquafondata, Rando, Veredice, Ricci, Guzzetta

Dr. Battaglia and coworkers at Catholic University in Rome found that cerebellar atrophy, in addition to epilepsy and other brain injuries, accounted for cognitive development disorders in shunted post hemorrhagic hydrocephalus patients due to pre- or perinatal intra- or periventricular hemorrhage.

Effect of antibiotic-impregnated shunt catheters in decreasing the incidence of shunt infection in the treatment of hydrocephalus: *Journal of Neurosurgery*; 2005 Aug;103(2 Suppl):131-6. Sciubba, Stuart, McGirt, Woodworth, Samdani, Carson, Jallo

Dr. Sciubba and coworkers at Johns Hopkins School of Medicine in Baltimore found that an Antibiotic Impregnated Shunt (AIS) catheter significantly reduced incidence of CSF shunt infection in children with hydrocephalus during the early postoperative period (< 6 months).

The gravity-assisted Paedi-Gav valve in the treatment of pediatric hydrocephalus: *Pediatric Neurosurgery* 2005 Jan-Feb;41(1):8-14: Meling, Egge, Due-Tonnessen

Using the Paedi-Gav gravity-assisted valve, Dr. Meling and coworkers at the University of Oslo in Norway found that with a 53% shunt-survival rate, overall results are comparable to those reported for primary shunt insertions with conventional valves in children with hydrocephalus.

CSF shunt removal in children with hydrocephalus: *Acta Neurochirurgica (Wien)* 2005 May;147(5):503-7: Iannelli, Rea, Di Rocco

Dr. Iannelli and coworkers at the University of Pisa in Italy performed a study which suggests that the highest incidence of shunt independence is reached in children affected by non tumoral hydrocephalus operated on in early infancy, possibly due to the delay in maturation of the CSF absorption mechanisms followed by a late normalization.

Looking at hydrocephalus: where are we now, where are we going?: *Child's Nervous System* 2005 Jul;21(7):524-7: Walker

In this address from the ISPN meeting

in Buenos Aires, Dr. Walker, President of the ISPN at the time, takes a look at the successes in pediatric neurosurgery over the past 40 years and explores the challenges that mean we have not been as successful with hydrocephalus as we have with other disorders.

Quality of life and psychomotor development after surgical treatment of hydrocephalus: *European Journal of Pediatric Surgery* 2005 15:2-5: Topczewska-Lach, Lenkiewicz, Olanski, Zaborska

Dr. Topczewska and colleagues at the Medical University of AM, Bialystok, Poland, analyzed the long-term outcomes of shunted children with hydrocephalus, noting that the children's rehabilitation and integration into society is essential.

Neurodevelopmental outcome in children with posthemorrhagic hydrocephalus: *Pediatric Neurology* 2005 33:26-32. Futagi, Suzuki, Toribe, Nakano, Morimoto

Dr. Futagi and colleagues at the Division of Pediatric Neurology, Osaka Medical Center and Research Institute for Maternal and Child Health, Izumi, Osaka, Japan, found that the outcomes in children with posthemorrhagic hydrocephalus were far more affected by the existence or extent of parenchymal hemorrhage than by the hydrocephalic process, which was suggested to be effectively controlled by surgical, medical or no intervention.

Clinical Studies: Adult, including NPH

Guidelines for the diagnosis and management of idiopathic normal pressure hydrocephalus: *Neurosurgery* 2005 Sep;57(3 Suppl): Marmarou, Bergsneider, Relkin, Klinge, Black

In this 52-page supplement, Dr. Marmarou and colleagues at various institutions in the U.S. and Germany reviewed currently available information on idiopathic normal pressure hydrocephalus (INPH) and established evidenced-based guidelines for diagnosis and treatment.

Diagnosis, treatment, and analysis of long-term outcomes in idiopathic normal-pressure hydrocephalus: *Neurosurgery* 2005

Continued on page 10

TEAM PENNSYLVANIA



TEAM PA takes off.



TEAM organizers with the Neff family.

Sunday, November 6, 2005, marked the 1st annual PA TEAM Hydrocephalus Run-Walk-Roll-A-Thon. Organized by Kelly Rambo and Marybeth Godlewski, the event was in memory of Dr. Samuel Neff, and in honor of Nicholas Rambo and Emma Godlewski. The Walk, held at the Norristown Farm Park on an absolutely gorgeous day, was an overwhelming success with over 100 participants. Many non-walkers and runners came out to show their support to the Hydrocephalus Association. The event raised over \$15,000. Thank you, Kelly and Marybeth, for all your great effort and support.

THANKS FOR RUNNING ROAD RACE



On Thanksgiving Day, more than 80 runners and walkers braved the white-out conditions of an early snowstorm to run the 8th annual Thanks for Running! Road Race in Fitchburg, Massachusetts. The race has donated over \$23,000 to the Hydrocephalus Association over the past six years. The race organizers, the Maynard and Ginnity families, plan to continue this fundraiser for the Association in coming years. Thanks for Running! has become an annual event for many people, and includes long-sleeved t-shirts, great food and a raffle with many prizes. Our special thanks to the Maynard and Ginnity families for organizing this great event.

What A Gift!

By Mark Geiger, Board Member

I'VE BEEN CARRYING this story inside for almost a year. It still affects me. I recently received a message from a stranger with all the discretion of Tony Soprano, including the accent: "It's *in* you to tell this story...you should tell it." Let's just say it was an offer I couldn't refuse. I'll do my best, Ray.

At my company's holiday luncheon last year, we had a guest speaker, a pediatric neurosurgeon, present a customer's perspective on the medical products this facility manufactures and why they are so important, specifically those for hydrocephalus. There is no better way for line-manufacturing personnel, and people all the way up the ladder, to see the impact the products they build by hand have on the world.

The 230 or so employees attending the luncheon had finished eating when Dr. Mike gave his presentation about the condition, its origin, prog-

nosis, treatment and how the scientific field has a very long way to go to understand and conquer this chronic, lifelong condition. It was very powerful in a way that made you wish you were paying more attention during geometry and trig, and that if you had you might contribute an important piece to solve this enigmatic puzzle.

Throughout this festive holiday luncheon, the MC would call raffle ticket numbers and the winners would leap up to get their pick of some wrapped gifts on the front table. Winning is a big deal because the organizers don't skimp—a \$100 gift card to Best Buy is not uncommon, and there are no rubber chickens.

Dr. Mike finished his talk by highlighting a patient of his, a beautiful 9-year-old girl named Noel with long brown hair, deep brown eyes and a smile that melted you. She had a way about her unlike a child of 9, or 19, for that matter. A wisdom of sorts that perhaps comes from surviving a multitude of cranial surgeries, nights hooked up in hospitals and mustering up positive energy for your parents when theirs finally runs out. Noel's

mother stood up with her and imparted some very poignant words to the audience about their experience and their gratitude for the work put into designing and building this medical device that was doing so well in her child, implanted at a time when hope seemed scarce for her and her family. Her teary words of encouragement received a standing ovation.

Toward the end of the holiday program, Noel's raffle ticket number got called. She lit up like any child would staring at a table full of gifts wrapped with colorful paper and bows, and walked up to the front of the room to select hers. Noel's selection was unknown to everyone, even her. She turned, facing the 230 cheering people, and paused for a moment looking at her wrapped prize, then looked lovingly at Dr. Mike. Noel then raised her gift, took seven steps toward the surgeon who had skillfully changed her life when others before could not, and said, "I want you to have this gift, Dr. Mike." The cheering ceased, marked by the vacuous sound of air being rapidly inhaled by the audience and then a total silence at the realization of what

was occurring. Dr. Mike didn't understand and turned to me with a puzzled look, so I said, "I think she wants to give you *her* gift!"

What child anywhere would do that? Noel. This child. This angel. This tiny source of brilliant light knocked us all off our chairs with a gesture so uncommon and out of character for children her age. She had the presence of mind, or something clicked to create awareness in a fraction of a second in front of a room filled with strangers, to realize that she now was holding something to offer the man who had given her a life back.

I've never witnessed a teammate hit a walk-off home run or catch a touchdown pass in overtime, but now I know what it feels like. Being there was my best gift that year...maybe any year. Thank you, Noel. ■

SPECIAL BIRTHDAYS



Hannah Bowers (left) wanted to have her birthday party in honor of her 2-year-old sister Sarah-Beth (right), who has hydrocephalus. The sisters live in South Carolina. Hannah raised \$200 in donations for the Association. Thank you, Hannah, for your wonderful contribution and for being such an amazing big sister to Sarah-Beth!



Daniel Breton turned 4 years old in September. The young Connecticut resident has hydrocephalus. His family threw him a big party and raised \$600 for the Association in lieu of birthday gifts for Daniel. Happy belated birthday, Daniel! Thank you for your wonderful gift to the Association.

Continued from page 7

Oct;57(4):699-705: McGirt, Woodworth, Coon, Thomas, Williams, Rigamonti

Dr. McGirt and colleagues at Johns Hopkins Hospital in Baltimore found that 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.

Baseline neuropsychological profile and cognitive response to cerebrospinal fluid shunting for idiopathic normal pressure hydrocephalus: *Dementia and Geriatric Cognitive Disorders 2005;20(2-3):163-8: Thomas, McGirt, Woodworth, Heidler, Rigamonti, Hillis, Williams*

Dr. Thomas and coworkers at the Adult Hydrocephalus Program at Johns Hopkins Hospital in Baltimore found that shunting INPH patients on the basis of CSF pressure monitoring and drainage response shows a significant rate of cognitive improvement. Baseline neurocognitive test scores may distinguish patients likely to respond to shunt surgery from those who will not.

Diagnosis and management of idiopathic normal-pressure hydrocephalus: a prospective study in 151 patients. *Journal of Neurosurgery 2005 Jun;102(6):987-97: Marmarou, Young, Aygok, Sawauchi, Tsuji, Yamamoto, Dunbar*

Dr. Marmarou and coworkers at Virginia Commonwealth University Medical Center in Richmond found that gait improvement immediately following external lumbar drainage (ELD) is the best prognostic indicator of a positive shunt outcome, with an accuracy of prediction of more than 90%. Bolus resistance testing is useful as a prognostic tool in predicting successful ELD outcome with an overall accuracy of 72%.

The syndrome of hydrocephalus in young and middle-aged adults (SHYMA): *Neurological Research 2005 Jul;27(5):540-7: Cowan, McGirt, Woodworth, Rigamonti, Williams*
Drs. Williams and Rigamonti and co-

workers at Johns Hopkins University found that shunting is effective in resolving symptomatology in hydrocephalus in young and middle-aged adults (SHYMA), with symptomatic improvement being observed in 93% of patients.

Normal pressure "herniation": *Neurocritical Care 2005;2(2):172-5: Pratt, Mayer.*

Drs. Pratt and Mayer at Columbia-Presbyterian Medical Center in New York suggest that NPH can result in delayed brainstem herniation after ventricular hemorrhage. CSF siphoning in such patients can reverse the syndrome.

Good outcome in patients with normal-pressure hydrocephalus and factors indicating poor prognosis: *Journal of Neurosurgery 2005 Sep;103(3):455-63: Poca, Mataro, Matarin, Arikian, Junque, Sahuquillo*

Dr. Poca and coworkers at the Autonomous University of Barcelona assert that NPH patients with traditionally accepted markers of poor prognosis can improve after shunt surgery, so these markers should not be considered to be an absolute criterion for ruling out shunt surgery.

Clinical relevance of hydrocephalus in bacterial meningitis in adults: *Surgical Neurology 2005 Jul;64(1):61-5; discussion 66: Wang KW, Chang WN, Chang HW, Wang HC, Lu CH*

Dr. Wang and coworkers at Chang Gung Memorial Hospital found that because of fulminated clinical courses and high mortality in adults with bacterial meningitis, surgical intervention may be suitable only for those who are neurologically stable and have progressive hydrocephalus, with adequate treatment of neurological complications and aggressive antimicrobial therapy being essential in improving therapeutic outcomes.

The role of lumbar shunts in the management of slit ventricles: does the slit-ventricle syndrome exist? *Journal of Neurosurgery; 2005 Aug;103(2 Suppl):119-23: Sood, Barrett, Powell, Ham*

Dr. Sood and fellow researchers at Children's Hospital of Michigan in Detroit found that conversion to an LP shunt is a safe and effective procedure in patients prone to rapid decompensation

and recurrent shunt malfunctions from small, slitlike ventricles. They found the term "SVS" confusing and felt it should be abandoned.

Gravitational shunts in longstanding overt ventriculomegaly in adults: *Neurosurgery 2005 Jul;57(1): 109-19; discussion 109-19: Kiefer, Eymann, Strowitzki, Steudel*
Dr. Kiefer and colleagues found that unlike conventional differential pressure shunts, gravitational shunts can be used in the treatment of high-risk patients with longstanding overt ventriculomegaly in adults.

General Studies: Pediatric & Adult

The value of C-reactive protein in the management of shunt infections: *Journal of Neurosurgery; 2005 Sep;103(3 Suppl):223-30: Schuhmann, Ostrowski, Draper, Chu, Ham, Sood, McAllister.*

Dr. Schuhmann and colleagues at Children's Hospital of Michigan in Detroit found that S-CRP level (the level of c-reactive protein in the blood) should be included in the first-line workup of patients with suspected shunt/CSF infection to avoid performing a shunt tap if S-CRP levels are less than 7 mg/L. A larger multicenter trial is necessary to confirm these promising diagnostic results.

Short-term dexamethasone treatment for symptomatic slit ventricle syndrome: *Child's Nervous System 2005 21:981-84: Fattal-Valevski, Beni-Adani, Constantini*

Dr. Fattal-Valevski and colleagues at Dana Children's Hospital, Tel Aviv University, Tel Aviv, Israel, found that dexamethasone appears to be a useful treatment providing temporary relief in acutely increased intracranial pressure caused by slit ventricle syndrome.

Indications for neuroendoscopic aqueductoplasty without stenting for obstructive hydrocephalus due to aqueductal stenosis: *Minimally Invasive Neurosurgery 2005 Jun;48(3):136-41: Miki, Nakajima, Wada, Haraoka*

Dr. Miki and coworkers at Tokyo Medical University found that neuroendoscopic aqueductoplasty (EAP) without stenting can be considered the

How to Use PubMed

ALTHOUGH we would like to send copies of the articles listed here to anyone who is interested, copyright laws prohibit us from doing this. We can, however, share with you how we order articles from medical journals through an online service developed by the National Library of Medicine (NLM) at the National Institutes of Health called PubMed.

To get you familiar with searching on PubMed, here are a few tips:

- Go to the PubMed search page: www.ncbi.nlm.nih.gov/entrez/query.fcgi
- Enter key words. PubMed assumes consecutive search terms are connected with Boolean logic AND unless you specify otherwise.
 - Simply entering “hydrocephalus” will return all the articles that reference hydrocephalus and may be overwhelming to sort through.
 - If you know a particular publication date [dp], author [au] or

language [la], you can designate those with the codes in square brackets:

“Hydrocephalus shunt Kestle [au] 2005 [dp] English [la]”

The search string above will return articles published about hydrocephalus and shunts by Kestle in English in 2005.

- Review articles tend to summarize results from many related research studies and are a good way for laypeople to gain an understanding of trends without reading every article. Click on the “Review” tab after any search to see just the review articles that fit the criteria.
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best surgical procedure for restoring physiological circulation of CSF in patients with obstructive hydrocephalus caused by aqueductal stenosis if EAP candidates are selected very carefully using the following indications: 1) obstructive triventricular hydrocephalus with increased intracranial pressure, 2) translucent membranous stenosis or aqueduct obstruction, and 3) prestenotic dilatation of the aqueduct.

Hydrocephalus due to superior sagittal sinus thrombosis: *Acta Neurochirurgica (Wien) 2005 Apr;147(4):427–30; discussion 430: Weidauer, Marquardt, Seifert, Zanella*
Dr. Weidauer and coworkers at Johann Wolfgang Goethe-University in Germa-

ny note that although hydrocephalus associated with cerebral sinus thrombosis is rare, it is clinically important since it entails disastrous sequels if unrecognized, and hydrocephalus is treated in the usual fashion with ventricular drainage.

Distal ventriculoperitoneal shunt failure caused by silicone allergy. Case report: *Journal of Neurosurgery 2005 Mar;102(3):536–39: Hussain, Wang, James, Carson, Avellino*
Dr. Hussain and coworkers at Johns Hopkins in Baltimore found that replacing the original silicone-based shunt system with a polyurethane-based system alone is sufficient in the treatment of a silicone shunt allergy. ■

Self-Determination: What is it? Why is it beneficial?

Adapted by Pip Marks from Michigan Dept. of Education "Focus on Results" document written by Sharon Field, EdD.

INDIVIDUALS who are self-determined have combinations of skills, knowledge and beliefs that allow them to engage in goal-directed, self-regulated, autonomous behavior. The slogan "nothing about me without me" captures the essence of the meaning of self-determination. Self-determination requires an understanding of one's strengths and limitations and a belief in oneself as capable and effective. When individuals act on the basis of these skills and attitudes, they will have a greater ability to take control of their own lives.

All individuals need skills related to self-determination in order to succeed. However, these skills are especially important to individuals with disabilities because they will often face more barriers to self-determination than other individuals do in our society. People with special needs often have to deal with many people who exert control or influence over major decisions that affect the quality of their lives. Decisions such as where to live, what classes to take, what kind of work to do, how to spend leisure time—all are personal choices that *all* people have a right to make for themselves.

There has been much research and data to support the use of self-determination. Students with learning disabilities who had higher self-determination scores in their last year of high school were more likely to:

- Have expressed a preference to live outside the family home
- Have a savings or checking account

- Be gainfully employed one year following high school

Additional data suggests that self-determination relates to academic success and better mental health:

- Scores on self-determination assessment are positively correlated with grade-point average for post-secondary students with learning disabilities.
- Children who help choose school activities show enhanced motivation to perform tasks related to those activities and are more likely to achieve their goals.
- High self-determination scores are associated with a significant decrease in depressive features of children who are at risk for depression.

There are five basic steps to learn self determination:

1. Know yourself and your environment.
2. Value yourself.
3. Plan.
4. Act.
5. Experience outcomes and learn.

These steps can be taught through the use of a variety of methods and materials. There are several curriculum strategies that are available to help students develop more skills related to each step. Some of the strategies focus specifically on the individualized education program (IEP) process, while others are more general in nature.

When teaching self-determination, adults need to provide support for the learning process. For example, in school teachers provide instruction and then allow students to apply their learning. At that point, teachers provide feedback, guidance and coaching to ensure that the student learns from his or her experience. One excellent opportunity for a student to act in a self-determined manner is to participate in his or her own IEP process. Research has shown that when students receive instruction to help them prepare for their own IEP meetings, they make three times as many comments in their meetings as students who do not receive instruction. One teacher said, "If I get meaningful involvement from the student at the IEP meeting, the rest of the year seems to flow from there."

Of course, the IEP process is only one place for students to apply self determination skills. The same support, in everyday situations, should be offered to help children learn knowledge, skills and beliefs related to self-determination. School, community and home environments provide many additional opportunities for students to practice being self-determined. For example:

- Explore a variety of options for employment or leisure activities and, with support, learn to identify likes, dislikes, strengths and weaknesses regarding these options.
- Allow your child to participate in family decisions about activities and vacation plans.
- Encourage your child to make choices about which classes they will take.

The adults in a child's life play an important role in supporting the development and expression of self-determination. Parents can help their child increase their ability to be more self-determined by:

- ▶ **Modeling self-determination:** Talk to your child about the choices you as an adult make: why you make the choices you do, how you put your choices into action and what you learn from your own efforts towards self-determination. Help your child learn to advocate for him- or herself by modeling self-advocacy.
- ▶ **Encourage exploration and reflection:** By exploring a variety of options, and reflecting on personal reactions to those options, your child will learn what he or she likes and doesn't like and develop a greater understanding of his or her personal strengths and limitations.
- ▶ **Listening attentively:** One of the most empowering experiences is being listened to and understood. Encourage your child to talk about his or her hopes, dreams, preferences and experiences.
- ▶ **Encourage others to actively listen to your child:** Encourage all people who play a role in your child's life to show respect for his or her opinions.

Self-determination can have a positive impact on the lives of individuals with disabilities. People with special needs who are self-determined are more likely to engage in goal-directed autonomous behavior that can lead to successful outcomes. By modeling self-determination, encouraging exploration and reflection, actively listening and encouraging others to listen, adults help children develop the self-determination skills.

For self-determined instructional websites and downloads, visit www.uncc.edu/sdsp, www.self-determination.com, www.ncset.org/topics/sdpse. ■

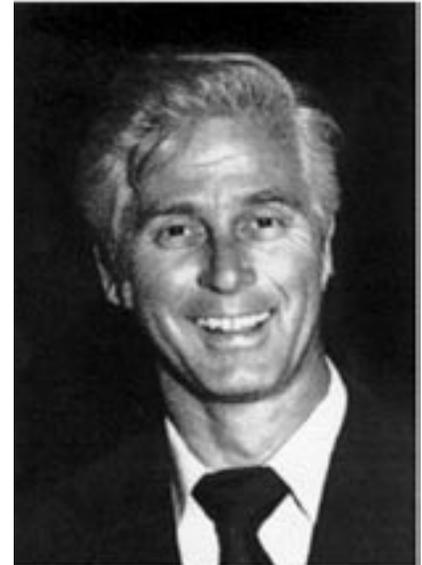
Rudi Schulte 1932–2005

A TRUE PIONEER and great friend of the Hydrocephalus Association has passed away. Rudi Schulte passed on December 20 after a long battle with pancreatic cancer. Born February 8, 1932, in Althundem/Sauerland, Germany, Rudi planned for an American home from childhood. He realized his dream in 1954, reaching America on the *Mauritania*, with his pregnant wife and year-and-a-half-old son.

Having achieved the distinction of being the youngest master watch maker in Germany by the age of 21, Rudi used those skills in Los Angeles. However, his ambition, creativity and skill in working with tiny objects soon found him working on the prototype space suit pressure sensors used by Chuck Yeager in his pioneering supersonic flights. This in turn led Rudi to work with a neighbor, Ted Heyer, who was working with a famous neurosurgeon, Dr. Robert Pudenz, on developing a shunt for hydrocephalus. His watch making skills, his mind for inventing and his gift to work with doctors led to a number of products, many of which are still used today, including the first tri-leaflet heart valve, the prototype of which is on view at the Smithsonian Institute.

Rudi took up residence in Santa Barbara, and formed the Heyer-Schulte Corp., founded on the 1961 patent of the hydrocephalus shunt. The company grew, with myriad other silicone implant devices. In 1974, it was sold to the American Hospital Supply Co.

At this time, Rudi went into ranching, acquiring several large ranches,



chief among which is the historic Dos Pueblos Ranch, and began producing avocados, cherimoyas, macadamia nuts, Christmas trees and lavender oil.

Rudi went on to establish the Pudenz-Schulte Medical Company, which continues making and marketing his products under the ownership of Medtronic, Inc. His legacy continues through the Rudi Schulte Research Institute and the Rudi Schulte Family Foundation, which contribute financially to worthy causes, including the Hydrocephalus Association. His final wish, in fact, was that donations be sent to HA in lieu of flowers at his funeral.

One of the true pioneers in the search for solutions to hydrocephalus has passed on. We can only hope that those who follow in his footsteps have the same ingenuity, dedication and spirit. His legacy is an inspiration to all. ■

Hydrocephalus Association Art Contest

IN AN EFFORT to encourage young people with hydrocephalus to artistically express their imagination and views, the Hydrocephalus Association is holding an art contest for young people with hydrocephalus, ages 5–17. Through their eyes we see their hydrocephalus story. The works created are unique and express the young artists' life experiences.

Each artwork will be judged on originality, artistic merit and expression of the theme. The judges will select three grand winners and 12 merit award winners. The grand winners will be announced at the Hydrocephalus Association Conference. Artworks will be displayed on an exhibit during the Association Conference.

How to participate:

The contest is open to children with hydrocephalus between the ages of 5 and 17. Participants can use a variety of mediums to draw, sketch or paint their interpretation of "My Hydrocephalus Story." The deadline for submitting artworks is April 15, 2006.

All entries must be mailed to:
Hydrocephalus Association
870 Market Street, Suite 705
San Francisco, CA 94102

Guidelines, Rules & Conditions:

Please make sure that the artwork meets all the guidelines and deadlines before submitting it. Entries not meeting the rules and conditions listed below will be disqualified.

- a) The HA artwork contest is open to people who are between the ages of 5 and 17 years.
 - b) The artworks must be an expression of the theme "My Hydrocephalus Story."
 - c) Artwork must be no smaller than 8 inches by 11 inches and no larger than 20 inches by 24 inches.
 - d) Only one entry per person, and each entry must be the work of only one person. All artwork must be the person's original creation. Duplications are not accepted.
 - e) All media are accepted. We recommend sealing art pieces if drawn in charcoal, pastel or chalk to prevent smearing.
 - f) Please do not laminate, mat or frame artwork.
 - g) Three-dimensional entries will not be accepted. Nothing may be glued, stapled or attached to the artwork in any way.
 - h) If possible, artist can sign the lower right corner of artwork. The artist name and age should be written on the back of the poster.
- i) Artwork should be done on a flexible material, so it can be rolled for shipping in a mailing tube. Please do not fold artwork.
 - j) The Hydrocephalus Association is not responsible for entries damaged, destroyed or lost during the judging process.
 - k) Entries cannot be acknowledged or returned; they become the property of the Hydrocephalus Association upon receipt. Images cannot be used without written permission from Hydrocephalus Association.
 - l) In consideration of the opportunity to enter the contest, participants agree to allow the Hydrocephalus Association to use their names and photographs for promotional and publicity purposes.
 - m) By entering, participants agree to be bound by these rules and the decisions of the judges and the Hydrocephalus Association. The Hydrocephalus Association may cancel the contest without notice at any time. The contest is void where prohibited, taxed or restricted by law. ■

Send in Your Hydrocephalus Story

WE SEND A BIG THANK-YOU to the many Association members who have shared what it is like living with hydrocephalus by sending in their "My Hydrocephalus Story" sheet. We hope your stories will move and encourage members of Congress to put language supportive of hydrocephalus research in appropriation requests.

If you haven't sent in your story, it's not too late! Send in the "My Hydrocephalus Story" sheet in this newsletter. (An example story sheet is in the Winter 2006 newsletter also.) Together we will make an impact in Washington, D.C., for all people with hydrocephalus and their families.

2006 Membership Form

Name: _____ Telephone: _____

Address: _____

_____ Email: _____

Name of person with hydrocephalus: _____ Birth date _____ Age at diagnosis _____

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

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

\$30 \$50 \$100 Other \$ _____

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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.

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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

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