

I'M ILL, BUT WHO REALLY NEEDS TO KNOW?

By Lisa Belkin, *New York Times* Reporter

*This article originally appeared in the February 21, 2008 edition of **The New York Times**. It is reprinted here with permission from the publisher. We would also like to thank the National Health Council for introducing Richard Cohen and his powerful book to us at their recent annual meeting through a video montage of "Today" show segments with the people whose stories are highlighted.*

One of the first decisions you make in the emotional hours after a scary diagnosis is whether to tell others. Most of us share the news with our loved ones, but what of the circles beyond, particularly those at work? Your boss?

At first, Richard M. Cohen, whose multiple sclerosis was diagnosed at 25, did not tell. Mr. Cohen — whose latest book, "Strong at the Broken Places," recounts the stories of five patients with chronic illnesses — was starting what would become a hard-charging career as a television news producer when he learned of his condition. He feared he would be considered unfit. He kept his secret for years despite failing vision and shaky balance.

Marlene Kahan, in turn, disclosed her condition right away. Four years ago, when she learned she had Parkinson's disease, she had been the executive director of the American Society of Magazine Editors for more than a decade. With that longevity came security, she hoped.

Ms. Kahan was also afraid that the mix of symptoms and side effects from the treatments would leave her at "less than 100 percent," she said, making it seem as if she was either slacking or even sicker than she was. "I didn't want people to wonder and jump to other conclusions," she said.

Gayle Backstrom, whose fibromyalgia, a chronic pain condition, was diagnosed decades ago, understands both paths. Still she advises to keep your condition to yourself for as long as possible, because that is safer.

The Americans with Disabilities Act prohibits an employer from dismissing or failing to hire a chronically-ill employee on the basis of that disability "if they are able to do the job with reasonable accommodation," she said. But in many cases, "reasonable" and "able" and even "job" all become open to interpretation, said Ms. Backstrom, the author of "I'd Rather Be Working" (Amacom, 2002).

An excellent resource for workers facing this choice, she said, is the Job Accommodation Network, a service of the federal Department of Labor. Most questions on its site, she said, come from workers, not management, and "they are looking for suggestions on how to adjust their work without bringing it to the attention of their bosses," she said. They buy themselves custom footstools and wrist-rests, and sneak off to restrooms to take medications. To hide their condition on the worst days, they call in sick, giving a reason other than their chronic illness.

Mr. Cohen did that for nearly 10 years. In "Blindsided: Lifting a Life Above Illness," he recalled an interview for a job as a producer on the "CBS Evening News with Walter Cronkite." He asked a friend, Robert MacNeil, whether he should mention his multiple sclerosis. Recalling Mr. MacNeil's answer, he wrote: "Say nothing. Your silence is an honorable dishonesty."

Mr. Cohen got the job and was able to keep his secret with scrupulous attention to logistics, quietly using public transportation to conceal that he could not see well enough to drive. Years later, the executive who first hired him agreed that he had been wise to stay mum. "I am not proud to say this," Mr. Cohen quoted the man as saying, "but I don't think I would have hired you if I had known."

Celeste Lee also chose to keep the details of her life from her employers for years. An autoimmune disease she developed in high school, 25 years ago, led to kidney failure. A transplant was initially successful, but eventually her body rejected the organ. That left her dependent on regular dialysis.

At first, she managed it on her own with a saline bag and an IV needle. She then worked as an administrator at a Boston law firm, and because the process took 15 minutes behind her closed office door, "it was something they didn't really need to know," she said of her employers and co-workers.

The timing was sometimes tricky, but life went on. She got her master's degree, was promoted, married and had a son.

But after she moved to take a job at Duke University, the simpler form of treatment began to prove insufficient. She had to switch to hemodialysis, which required that she be hooked to a machine that cleaned her blood for three hours, three days a week.

(continued on page 2)

FROM THE EXECUTIVE DIRECTOR

As I write this, the fruit trees are just beginning to bloom in San Francisco. I am reminded of how fleeting some of the most beautiful things in life are. Perhaps this fleeting quality is part of what makes them so beautiful. Familiarity never has a chance to breed contempt or indifference.

One thing to which we are never indifferent is our donors! In this issue we recognize each cherished individual donor who gives so that our work can be fruitful. Every time we receive a donation—large or small—it gives me the same feeling as seeing a fruit tree in bloom in the spring: Gratitude for the beauty of the gift and hope for what is before us in the next year. Whether you have given for the first time or grace us with your donations year after year, we are full of gratitude. We quite literally could not do our work without your generosity. Please check out the growing list of donors beginning on page 11. A list of those who were honored and memorialized by these donations follows.

One of the many exciting ways that our work is bearing fruit is through our Expansion pilot program to align with and develop local affiliates. I had the pleasure of

speaking to one of our Expansion Advisory Groups, the Children's Hydrocephalus Support Group in Seattle, and was warmed to my toes by the interest and enthusiasm for our national advocacy work. Pip Marks and MaryBeth Godlewski were equally delighted with their experience visiting affiliates in northeast Ohio and Tampa Bay, FL. To read more about the progress of this program that has the dual objectives of amplifying a unified voice for hydrocephalus nationally and providing quality support at the local level, please see page 25.

A couple of articles address impacts of chronic illness on meaningful work. On the cover, New York Times reporter, Lisa Belkin, reviews Richard Cohen's powerful book "Strong in the Broken Places". And, on page 3, one of our members, Gianfranco Ciampi, shares his personal experience of challenge and hope in "Finding Myself with the Help of Others".

This issue debuts a new look and the name "Pathways" for our newsletter. The look builds on our swirly logo and compliments the design of our Web site, which has been so well received. The name "Pathways" has

many meanings: Hydrocephalus affects the cerebrospinal fluid pathways; the Association aims to serve as an integrator of communication pathways among all stakeholders in hydrocephalus; we support individuals to navigate informed pathways in a challenging medical system; and the Association is pioneering pathways for change at the national level. On this pathway that is living with, investigating, treating and advocating for people affected by hydrocephalus, we walk together arm-in-arm. Together we will meet whatever challenges await us.

We hope that as you see this newsletter each quarter, you are reminded of all of the ways that our pathways intersect and we create new pathways on our journey together. Please use this as your vehicle. Let us hear from you with stories that will teach and inspire others. Either fax (415-732-7044) or e-mail your ideas to info@hydroassoc.org with "Pathways" in the subject line.

I hope your spring is full of all good things and I look forward to seeing many of you at our conference in Park City, Utah in June.

All the best,
Dory

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Shortly after, she was offered her "dream job" as chief of staff to the chief executive of the Duke University Health System. The high-paced work would require 12- to 15-hour days. For the first time, she wondered whether her illness would hold her back.

She raised the issue in her interview. "At first they were uncomfortable because they thought that if they didn't hire me I would accuse them of discrimination," she said. "But I said: 'No, we have to talk about this. It needs to be on the table.'"

She got the job. Now she is on the dialysis machine at the outpatient dialysis clinic at Duke by 7 a.m. on Tuesdays, Thursdays and Saturdays. On workdays she is at her desk by 10 a.m., respectable by most standards, but hours later than her arrival on nondialysis days. She also arrives feeling "hung over" from the six-pound weight loss post-treatment, she said, another reason why she felt she had to be upfront. "On Tuesdays and Thursdays, everyone knows that I can't always be accountable for my personality," she said.

Mr. Cohen eventually also revealed all once he had proved himself. He then went on to squint his way through the Solidarity protests in Poland and the violence in Beirut, once staring down Palestine Liberation Organization guards because he could not see the guns pointed at his head. Eventually he left breaking news for the slower pace of documentary television.

Now even writing books is increasingly difficult because of his worsening condition. He wrote most of "Strong at the Broken Places" with his left hand, because his right side doesn't function well. The patients profiled in his book live nationwide, so he spent a lot of time in airports. "Picture it," he said. "I am legally blind, I have trouble with mobility, I was constantly lost and under pressure to get from point A to point B. More than once I dropped everything I was carrying, because I do that, and I had tears in my eyes. I thought, 'I can't do this.'"

Yet he commutes daily to his office on the Upper West Side from Westchester, where

he lives with his wife, Meredith Vieira, a host of "Today," and their three children.

"Barbara Walters is always asking me, 'Why do you do that?'" he said of his wife's former colleague on "The View." "Because I can. You do it until you can't do it anymore."

That is Ms. Lee's mantra, too. In recent weeks her doctors have confirmed that she faces a new challenge: nephrogenic systemic fibrosis. It is essentially a thickening of the tissue or subcutaneous skin that can affect muscle and organ functions.

"At some point I have to consider whether I will have to bow out of this position," she said. "But I want that to be my decision, and I won't make it until I have to."

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FINDING MYSELF WITH THE HELP OF OTHERS

By Gianfranco Ciampi

Being on the outside looking in is how I have felt for most of my life. I was born with hydrocephalus, and now, at age 32, I am still struggling with some day-to-day activities. It has always been difficult for me to tackle everyday tasks that most people take for granted. Things as simple as running as well as other more complicated tasks—such as finding meaningful employment—have been ongoing challenges for me. But thankfully, I have found some help through government programs and services that all people with disabilities should learn more about.

While in elementary school, I was classified as “disabled” and put into special education classes. Because the hydrocephalus affected my physical well-being, I was also placed in special gym classes. I felt like I was always on the sidelines, always missing out on something. But through hard work, I was mainstreamed into all major subjects by my freshman year of high school.

As I got older, I started to have more complications because of my hydrocephalus, and they began to interfere with my daily activities. It took me twice as long as most people to complete my college degree. I had to stop for periodic shunt revisions, which took me out of school for weeks at a time. Still, I graduated with a bachelor’s degree in psychology with a minor in education. I was on the road to becoming a teacher...or so I thought. When I entered the workforce, I was only able to get a job as a teacher’s aide, but it was a first step and a full-time position, so I accepted it. Unfortunately, because of continuous complications, I had to take periodic leaves of absence, creating instability for my students. After seven years of being a teacher’s aide, it was obvious that my health condition was preventing me from doing my job effectively and, more importantly, from moving on to becoming a teacher. I left my position thinking I should look at other options that might provide a more flexible work schedule or other workplace programs that would help improve my success in my career field.

Even though I am still having a difficult time finding the right career for me, I strongly believe that working and being active will keep me strong physically, mentally and emotionally. It has not been an easy process, and

I have spent a lot of time searching for job opportunities and submitting my resume to various organizations. At some point, I decided to stop looking for a career and to focus on just getting a job. That is when I came across some helpful resources online.

I began with DisabilityInfo.gov, an online resource for disability-related information. The site offers links to disability programs, services, benefits and so much more. It’s a great starting point. Now the site even offers links to state and community resources, which is how I found out about New York’s Office of Vocational and Educational Services for Individuals with Disabilities (VESID). VESID provides vocational rehabilitation and independent living services to people with disabilities in New York. VESID assigned me to a social worker and connected me with Careers, a local service provider that helps people with disabilities find jobs. Careers then set me up with some job interviews, and I was able to find a full-time job that I started right away.

I was also offered a chance to participate in a video for the U.S. Department of Labor celebrating DisabilityInfo.gov’s fifth anniversary. I attended the premier of the video in Washington, D.C. and met Secretary of Labor Elaine L. Chao. It was an exciting event, and the best part was being able to meet so many people who represent so many different organizations with programs across the country that help people with disabilities. There are hundreds of programs out there to help us succeed in employment and fully participate in our communities. We just have to take the time to uncover them.

Another way to find out what programs are available to you is through your congressional representative. These offices are a wealth of knowledge on what programs and services exist in your state. In contacting your local congressional office, it’s also important that you take the time to educate

your representative and his or her staff about hydrocephalus. The Hydrocephalus Association can help you with that. In May 2006, I participated in the Hydrocephalus Association’s Advocacy Day in Washington, D.C., which followed their annual conference. This was an enlightening experience. As people with disabilities, we try to advance ourselves and achieve independence and excellence; Advocacy Day was a day in which we asked elected government representatives to help us do just that. We had the chance to visit Capitol Hill and talk directly with our state representatives and their staff, and we were given an opportunity to talk firsthand with the people who influence legislation and public policy. Most importantly, we were able to educate them about hydrocephalus and how it affects and impacts the people in their districts. We were advocating not only for ourselves, but also representing the thousands of people with hydrocephalus and their families who could not be there.

Even though my new job doesn’t take advantage of some of my best abilities, it does help me with that first step of getting back into the employment arena. Now I am going to work on taking the next step: to move forward in a position that will help me develop my abilities and pursue my career.

Having hydrocephalus has been difficult for me. I have had to work harder than the average person, and have always been self-conscious about myself and doubtful of my abilities. Because of these difficulties, I have struggled mentally and emotionally, but I am working hard to move forward and become fully independent. Part of this process has included reaching out for help. I encourage you to do the same. There are programs out there to help. Take advantage of these programs and services available to you. Let hydrocephalus be part of your ability, not your disability. ■

Web resources

DisabilityInfo.gov	http://www.disabilityinfo.gov
Department of Labor’s Office of Disability Employment Policy Programs	http://www.dol.gov/odep
One-Stop Career Center Service Locator	http://www.servicelocator.org
Job Accommodation Network	http://www.jan.wvu.edu/

CT SCANS AND THE RISK OF RADIATION EXPOSURE

By Pip Marks, Director of Support and Education

Due to the growing use of computed tomography (CT) scans in recent years in the United States, there is a rising concern that these types of exams may cause a small but significant risk of exposure to radiation. The Hydrocephalus Association receives calls from concerned members about the number of CT scans to which they or their children are exposed. To help us address these concerns, the VHL Family Alliance, an advocacy group for von Hippel-Lindau (a genetic condition causing the abnormal growth of blood vessels), has kindly given us permission to reprint an article from their February 2008 newsletter addressing this concern. At the end of the article, two members of our Medical Advisory Board, Dr. Joseph Piatt and Dr. Michael Williams, have given their expert opinions on the relevance of this article to people with hydrocephalus.

CT AND RADIATION

In the November 29, 2007, issue of the *New England Journal of Medicine*, Drs. Brenner and Hall of the Center for Radiological Research, Columbia University Medical Center, New York, discuss the implications of the rising use of Computed Tomography (CT) scanning in the United States. "The widespread use of CT represents probably the single most important advance in diagnostic radiology." Nonetheless, CT does involve radiation, so it should be used with caution.

They point in particular to the sharp rise in the use of CT for diagnosing children, and for full-body scanning of asymptomatic adults. These two applications in particular are causes for concern. Some doctors are suggesting using full-body CT instead of an annual office exam, which the authors feel, is an unwarranted risk.

"The situation is even clearer for children, who are at greater risk than adults from a given dose of radiation, both because they are inherently more radiosensitive and because they have more remaining years of life during which a radiation-induced cancer could develop."

According to this article, for a 30-year-old person, the lifetime risk of developing a cancer as a result of a single CT scan is estimated to be 0.02% (two hundredths of one per-

cent). Risks are higher for children, lower for older people.

In 1996 it was estimated that approximately 0.4% (less than half of one percent) of all cancers in the United States occurred as a result of CT use. With the increased use of CT scanning we see today and factoring in estimates of future use heavily influenced by new programs to do full-body scans yearly, they estimate that in the future, as much as 2% of all cancer in the U.S. may be attributable to CT.

The press, of course, has focused on this 2%, misquoting the article widely as having declared that 2% of all cancers are now caused by CT. That is NOT what this article is saying. The authors are trying to limit the unnecessary use of CT. At the same time, they applaud the use of CT as a diagnostic tool for good medical reasons, including the preventive scanning of individuals at risk, as recommended in the VHLFA screening protocol.

The authors point out that many doctors were unaware, or at least not thoughtful about the fact that CT involves radiation exposure. Problems also arise "when CT scans are requested in the practice of defensive medicine, or when a CT scan, justified in itself, is repeated as the patient passes through the medical system, often simply because of a lack of communication. Tellingly, a straw poll of pediatric radiologists suggested that perhaps one-third of CT studies could be replaced by alternative approaches or not performed at all."

"From an individual standpoint, when a CT scan is justified by medical need, the associated risk is small relative to the diagnostic information obtained. However, if it is true that as many as one-third of all CT scans are not justified by medical need, and it appears to be likely, perhaps 20 million adults and, crucially, more than one million children per year in the United States are being irradiated unnecessarily."

The bottom line is that the guidelines in the *VHL Handbook* are still on target. For children, we recommend screening methods that avoid radiation. Once you have a diagnosed problem that requires careful following, MRI would generally be preferred unless CT is deemed medically necessary.

REFERENCES:

Brenner D and Hall E, Computed Tomography: An Increasing Source of Radiation Exposure, *New England Journal of Medicine* 2007; 357:2277-84. PMID: 18046031.

Dr. Cohan's talk from the Boston meeting is reported in the September newsletter. The full DVD and handout are available at <http://vhl.impactlearning.org> We would like to thank the Cancer Research Fund/VHL Alliance, www.vhl.org for their permission to reprint their article. ❖

We solicited feedback from two members of our Medical Advisory Board about the relevance of this article to people with hydrocephalus. Dr. Michael Williams is a neurologist who focuses on treatment of adults and Dr. Joseph Piatt a neurosurgeon who focuses on children.

From **Dr. Michael Williams**, Medical director LifeBridge Health Brain and Spine Institute, Baltimore, MD

"The use of CT and MRI scans is a necessary part of caring for patients with hydrocephalus. While MRI scans offer the benefit of avoiding radiation, not all patients can have MRI scans; some are claustrophobic, and some have pacemakers or other devices that prevent them from being in the MRI, and some will have adjustable shunts that will need to be readjusted after exposure to the magnetic field of the MRI. Additionally, MRI scans take longer to perform than CT scans. If a patient has symptoms or findings that might indicate a problem with the hydrocephalus or the shunt, then I would advise that the immediate benefits of a CT scan far outweigh the tiny long-term risk associated with the radiation exposure."

Dr. Joseph Piatt, Chief, Section of Neurosurgery, St. Christopher's Hospital for Children, Philadelphia

"This article is addressed to a group of patients and their families who have something in common in with the readers of the Hydrocephalus Association newsletter: a chronic neurological condition that requires imaging surveillance and occasional unplanned imaging for symptoms. So for readers of the VHL newsletter, as for your readers, if the specialist recommends a CT scan, and if there is no other practical way to get the same imaging information, the immediate value of that information in the present greatly outweighs the future risk of radiation-induced cancer."

REMEMBERING DR. JUDAH FOLKMAN

By Dory Kranz, Executive Director

The field of hydrocephalus research and the world of medical research as a whole lost a giant when Dr. Judah Folkman died suddenly in late January. Best known for his work revolutionizing cancer treatment by preventing angiogenesis (blood-vessel proliferation) to starve tumors, the director of vascular biology at Children's Hospital Boston and professor of pediatric surgery at Harvard Medical School died just as he was beginning to turn his genius to a molecular treatment for hydrocephalus.

Befitting his ever-active mind and lifestyle, Folkman died of an apparent heart attack in the Denver airport en route to a scientific conference at age 74. Despite his age, Dr. Folkman remained active as a professor and researcher. He took heed of his father's advice to be a rabbi-like doctor and honed skills as a world-class researcher and a compassionate clinician.

As a researcher, Folkman's energy, creativity, and dedication led him to change the way cancer is treated today. His hunch that cancer tumors rely on the formation of new blood vessels for nourishment and growth, led to at least seven FDA-approved anticancer

drugs that weaken tumors by blocking their blood supply.

Not only did Folkman's work on angiogenesis benefit cancer patients, but the same principles are now leading to novel treatments for reviving dying heart tissue, restoring circulation to tissues crippled by diabetes, and improving vision in patients with macular degeneration. His theories may yet impact the treatment of other conditions, including hydrocephalus.

After hearing about the dynamic interplay of blood flow and cerebrospinal fluid in a Grand Rounds presentation by Dr. Joseph Madsen (also of Children's Hospital Boston, and of the Hydrocephalus Association Medical Advisory Board), Folkman asked a detailed question about the molecular control of vascular permeability in the brain. He postulated that some of the same strategies that have been useful in eye diseases, which involve treatment with very-low-dose medicines that block formation of new blood vessels, might be appropriate for hydrocephalus in some cases. "It was amazing," Madsen recalls. "In two minutes he outlined two years' work."

The two discussed details in the foyer, and within two weeks, the two began working

together to test out a hypothesis. Early results looked promising, and when I had the pleasure of interviewing Folkman at a BrainChild Foundation collaborative research meeting in Boston in February of 2007, the charming doctor was enthusiastic about the prospects of a molecular treatment for hydrocephalus within his lifetime.

Scientists at the BrainChild meeting had great interest in hearing Folkman speak about the potential relevance of his life's work to hydrocephalus. His laboratory, in collaboration with Dr. Madsen, has already obtained exciting preliminary data showing that vascular endothelial growth factor (VEGF) is increased in the cerebrospinal fluid of adults with hydrocephalus. These new findings suggest that the hydrocephalic brain may try to recover lost or impaired blood vessels by producing new ones. Inspired by these promising new results, Dr. Madsen, Dr. James P. (Pat) McAllister, and others, are planning additional experiments in an effort to continue this exciting research in the absence of the venerable Dr. Folkman.

For all those who stood to benefit from his continued research, we are sad to have lost this great mind and heart. Dr. Judah Folkman will be greatly missed. ❖

A LEGACY OF SPREADING THE WORD ABOUT NPH

By Dory Kranz, Executive Director

A well-loved member of our hydrocephalus community, Robert G. (Bob) Fowler, died recently, and we have lost a generous peer counselor and a key spokesperson for better diagnosis and treatment. Because he was almost like a missionary in his zealous public speaking to raise awareness for normal pressure hydrocephalus (NPH), I often referred to him as "Reverend Fowler." I didn't know until reading his obituary that he was an ordained deacon and an active and faithful member of the Baptist church.

After ten years of misdiagnosis, which led him to write his own obituary in despair, Bob was finally diagnosed with and treated for NPH in 2000 at the age of 70. Hydrocephalus became his passion and he grew into a spokesperson not only for NPH, but also for Codman, the Johnson & Johnson

subsidiary that manufactured the shunt that Bob said "gave him a new lease on life." Bob's efforts led Johnson & Johnson to make a commercial about NPH, starring him. The commercial ran on national TV for more than a year, helping people all over the country recognize the symptoms and seek diagnosis. Through collaboration between the Hydrocephalus Association, Codman, and Communication Partners (a public relations firm in New York), Bob's story was a cornerstone of a national media campaign. Between 2004 and 2006, we were able to place over 25 stories about NPH in the national and local press. Some highlights that featured Bob include CBS News' "60 Minutes," The American Society on Aging's Aging Today, CNN, and the "Today" show (twice).

In addition to doing as much as any one person could to raise public awareness of NPH, Bob was also a peer counselor for the HA. In that role, he was always willing to

reach out, share his personal perspective on NPH, and listen to an individual struggling to make sense of an unpronounceable diagnosis. His inspiring and hopeful story spread hope and inspiration to others.

A graduate of the University of Oklahoma School of Engineering, Bob spent virtually his entire working career in the oil and gas industry. Bob was an avid hunter and golfer and a loving family man. He is survived by his wife of 52 years, Bonita, his two children, Becky and Bob, Jr., and many other relatives including the light of his life, his granddaughter Emma Elizabeth.

We are grateful for the contribution Bob made to raising awareness of NPH through the media and reducing personal suffering one conversation at a time. He will be dearly and sorely missed by many in our community. ❖

DEPRESSION IN ADOLESCENTS AND YOUNG ADULTS WITH HYDROCEPHALUS

By Bonnie Hom

This article is a synopsis of a paper I wrote for a Masters in Public Health course in December 2007. I recognize that there are varying experiences and different levels of depression. This paper does not constitute medical advice, which should be sought from qualified medical advisers.

Individuals with hydrocephalus are more at risk for developing depression than the general population. In one study of 1,459 individuals who had been treated for hydrocephalus, an astounding 71% of adults who received a shunt before the age of 18 months reported that they were or had been depressed. Knowing the risk factors for depression can help decrease the likelihood of it occurring. Use of the ecological model can help identify risk factors and possible interventions.

THE ECOLOGICAL MODEL

The ecological model is a useful tool for describing the association between depression and adolescents and young adults with hydrocephalus because it emphasizes the interaction between various levels of a health issue. A key concept of the ecological model is that multiple factors influence individual behavior and, reciprocally, individual behavior shapes the social environment. These influencing factors may be intrapersonal, interpersonal, community-based, institutional, and related to public policy.

INTRAPERSONAL FACTORS

CHRONIC ILLNESS

Chronic illness such as hydrocephalus is a stressor of long duration. It can lead to deterioration of social support systems and a lowered sense of perceived control. It can also have a negative impact on social maturation. Interference of personal development includes lowered self-worth and feelings of discouragement due to having a disease or condition, demanding treatment, and altered peer and group relationships.

EXTERNAL LOCUS OF CONTROL

Increased risk of depression is associated with external locus of control, in which individuals believe that things are out of their control such that their behavior is mainly controlled by their environment or by chance

or luck. Chronically ill males are more depressed than healthy males and have a more external locus of control. Their coping styles and available social support networks that provide emotional support impact the outcome of depression.

FEMALE GENDER

The authors of one study found that a significantly greater proportion of females with chronic conditions reported having emotional problems, feeling in a bad mood, feeling sad, believing nothing amused them, expressing depressive symptomatology (frequent crying, sleeping problems, and lack of appetite), and having personal problems needing professional help as compared with healthy peers. Having a chronic condition such as hydrocephalus and being female increase the likelihood of developing depression.

HEADACHES

Headaches are associated with and can contribute to the development of depression. Headaches are approximately twice as common in depressed adolescents compared with non-depressed adolescents. Obstruction of the shunt in children, teens, and young adults with hydrocephalus commonly presents itself with symptoms similar to migraines (progressive lethargy, irritability, headaches and vomiting); if left untreated, children can progress into stupor and coma. Such functionally impairing headaches and migraines, may actually determine risk for depression. Frequent, debilitating headaches, invasive brain surgery and lengthy hospital stays can be extremely stressful and lead to impaired personal development and poor self-perceived health, which may in turn lead to depression for adolescents and young adults with hydrocephalus.

INTERPERSONAL FACTORS

PARENTAL DEPENDENCE

To enter adulthood in a fully functional state, the adolescent has to master certain tasks, including the development of a positive self-image, effective separation from parents and achievement of a capability to function independently, and the development of a realistic vocational goal. In one study of hydrocephalus patients, those who scored the lowest in intelligence tests were the most

“babied” by parents’ overprotective attitudes. Low intelligence is more easily understood by the parents who overcompensate for this handicap by overprotecting the child. These children then remain dependent on their parents, which incites greater overprotection. This codependency between children with hydrocephalus who score the lowest on the intelligence test and their parents may lead to poor peer relationships for the children because they opt to be with the parent rather than with kids their own ages. This codependency may lead to poor peer relationships for the children and may hinder their psychosocial development.

POOR PEER RELATIONSHIPS

Adolescents and young adults with hydrocephalus tend to have a home-based lifestyle. They have a firm attachment to their parents and participate in few activities outside of the home. They have difficulty in forming friendships with peers and participating in special hobbies, and many remain single. Although many of these individuals do well as long as they receive motivation from an external source (such as family members or school authorities), they are at risk for failing once they have to function on their own.

COMMUNITY FACTOR

STIGMATIZATION OF DISABILITY

Ignorance, fear and past exclusion from society have led to negative images of people with disabilities. Many adolescents seek acceptance and belonging in social settings, but those with hydrocephalus may be perceived to be undesirable, incompetent or fragile and thus feel isolated and alienated. Stigmatized difference has the potential for marginalization, discrimination and prejudice, which largely affects identity development in youths with hydrocephalus. Disability stigmatization leads to poor self-image, which may in turn develop into depression.

INSTITUTIONAL FACTOR

UNEMPLOYMENT

Unemployment is not only a risk factor for depression in itself, but it can lead to other risk factors, such as poor self-image, poor peer relationships, parental dependence and further stigmatization of disability. One study indicated that it is not justifiable to

DEPRESSION IN ADOLESCENTS AND YOUNG ADULTS WITH HYDROCEPHALUS *(continued)*

make these assumptions about young adults with hydrocephalus regarding employment: 1) Only individuals with academic qualifications can find work; 2) Those who are working are employed in average jobs that are not “sheltered work”; 3) Individuals in sheltered employment are mentally limited and this must be the reason for their inability to work; 4) All young adults who are unemployed have no academic or vocational training. Interestingly, most of the unemployed in the study seemed to have the capability to work but were perceived as incompetent, perhaps due to disability stigmatization.

POLICY FACTOR

INDIVIDUALS WITH DISABILITIES EDUCATION ACT

Factors such as poor success at school, and lack of vocational education, are also significant predictors for depression. The Individuals with Disabilities Education Act (IDEA), enacted by Congress in 1975, is a federal law that ensures free, appropriate public education to eligible children and youth with disabilities. However, according to the latest regulations, hydrocephalus is not considered a disability under IDEA. It is vital for adolescents to receive proper services under IDEA at the beginning of the educational track so that they can develop the necessary skills for academic success, broaden their career options and have the potential to lead full, productive lives. Parents who feel their child with hydrocephalus would benefit from IDEA services and accommodations must make the case for some other disability that is covered under this law.

PRIMARY PREVENTION INTERVENTIONS

THE SOCIAL COGNITIVE/LEARNING THEORY

The social cognitive theory at the interpersonal level offers important insight into how behavior can be modified through health promotion interventions. A self-management program led by adults with hydrocephalus is designed to teach young adults healthier lifestyle habits that would help them manage chronic pain caused by headaches. Topics include fatigue and sleep management, use of medications, and dealing with emotions of fear, anger and depres-

sion. Self-efficacy is promoted through self-selected goals and observational learning is achieved by group-problem solving and assisting one another in reaching the goals.

DIFFUSION OF INNOVATIONS THEORY

The diffusion of innovations theory addresses how new ideas, products and social practices spread from one community to another. This theory can be applied to the hydrocephalus community by having neurosurgeons screen for headaches among youth with hydrocephalus. An emphasis would be placed on research done on the association between headaches and depression as well as a list of questions to screen for headaches. The relative advantage of screening for headaches is that studies have shown that youth with headaches are more prone to depression. This innovation would diffuse from professionals (such as neurologists, pediatricians, and primary care physicians) in medical institutions to professionals in educational institutions (such as school nurses, counselors, and teachers).

LIBERATION EDUCATION

Paulo Freire, the father of liberation education, emphasizes education as liberation—social action to promote freedom within oppressive environments and gaining control of one’s own life. Students with hydrocephalus, particularly those with learning disabilities or nonverbal learning disorders, need better accommodations under the IDEA and Individualized Education Program (IEP). By allowing students with hydrocephalus to be in classrooms where they have control over the method of teaching and educational needs and receive individual attention via IDEA, they will be empowered to learn and attain the skills needed to secure a job and to be independent, which makes them less at risk for depression.

CONCLUSION

For adolescents and young adults with hydrocephalus, risk factors for depression addressed in this article are interrelated and indicate that interventions aimed at reducing the likelihood of depression for this population should target all levels of the ecological model.

WHAT YOU CAN DO

Contact legislators to make amendments to the Individuals with Disabilities Act (IDEA) to include hydrocephalus. Contact Marybeth Godlewski, National Advocacy Director, at Marybeth@hydroassoc.org for more information.

Be more assertive in getting and maintaining an IEP. We have IEP fact sheets and other educational resources that serve as guidelines. Please send an e-mail to info@hydroassoc.org for a copy.

Make an appointment with a neuropsychologist to get a baseline of neurological findings. This baseline can help you understand how hydrocephalus might affect you cognitively and socially.

Consider consulting with a family counselor if you suspect depression.

Visit Gabriel’s Life at www.gabrielslife.org, a resource for networking and blogging in the hydrocephalus community.

Connect with other teens and young adults with hydrocephalus. Join us at our upcoming conference on June 19-22, 2008 at Park City, Utah to meet them in person! Conference registration is available online at www.hydroassoc.org.

Contact me at bonnie@hydroassoc.org if you have ideas or suggestions to add to this piece and/or if you would like the full version of this paper. ❖

HA Medical Advisory Board Member Wins Matson Award

Congratulations to Dr. Marion L. “Jack” Walker on being selected to give the Matson Lecture at the annual meeting of the American Association of Neurological Surgeons. This prestigious award is named for Dr. Donald Matson who was instrumental in the founding of the AANS and served as its President from 1944-1946. In his lecture, Dr. Walker shared history of the AANS as a professional society and the inspiration and challenges of establishing a Pediatric Section of the AANS and a board certified neurosurgical sub-specialty.

IDENTIFICATION: TO LABEL OR NOT TO LABEL

By Marissa Huth

Reprinted from *Connecting*, with permission from *Raising Special Kids*.

Many parents view the moment they learn the name of their child's disability or special health condition as a life-changing event.

Giving a name to a set of troubling symptoms, or having an explanation for puzzling and unusual behavior can serve to define the circumstances for family members, and provide a "thing" at which they can target their feelings. Relief, guilt, fear, and anger are normal reactions. The expression of these feelings are highly varied and grounded in the unique perspectives and life experiences of each person.

Some parents experience feelings of relief and renewed determination.

Knowing what they are facing, and planning how to take the next steps provides a goal and a focus for their efforts. If the parents previously felt something was wrong, and were seeking information, finding the answer might provide reassurance and have a stabilizing effect.

Other parents react with grief and fear stemming from a profound sense of loss. They may feel their vision for their child's or family's future is suddenly taken away. The experience can be a shock — "like the rug was yanked from under my feet" or "our world turned upside down" are oftenheard descriptions. If there is any question about a child's diagnosis or evaluation results, seeking a second opinion is prudent. Some parents and professionals believe certain diagnoses, such as Attention Deficit Disorder, are used inappropriately in response to behavior management problems. Determining whether a child has a disability due to a biological cause, or is reacting to not having needs met in an appropriate environment can be crucial. Clinical Social Worker and parent of a child with a disability. "Parents need to trust their own judgment and their gut. Utilizing what they know as a parent and an expert on their child is an essential part of the process of finding appropriate treatment. It's necessary to receive a competent diagnosis in order to determine proper services." Faced with new and possibly dis-

turbing information, some parents reject what they perceive as a "label" for their child and the frightening prospects they associate with it. "I'd love to chuck the stinkin' labels," commented a mother in a blog for families of children with autism. Adding to parents' confusion are anecdotes that abound in the media, on Internet groups, or shared by word-of-mouth about the wrong diagnoses resulting in delayed or inappropriate services for children. "The reality is that for your child to get the services he or she needs, our health and education systems require these labels in order to provide appropriate care," Siegel continued. "Sometimes the more diagnoses the child has, the more services are available."

DENIAL

Parents sometimes react to a label with denial, explained Kristina Blackledge, M.S., a family counselor. "Denial may be a useful coping mechanism and has helped people manage through that period of adjustment. If denial persists too long, it could interfere with accessing proper supports that can lead to positive outcomes." Stigma, defined as a mark of shame or discredit, can influence a parent's feelings about the disability. Parents may reject needed treatment and services for the child based on their fears about the reactions of family members and the community. These fears are not without some justification. Some parents of children with disabilities have seen changes in their personal relationships when a diagnosis is revealed. Others find they need to insist on setting high expectations for their children with educators and other professionals following the disclosure of a diagnosis.

GUILT

To some degree, many cultures view individuals as a reflection of the family. If there is a negative connotation associated with disability, parents may feel it is in some way their fault. Is the child's situation a result of something the parent did or somehow deserved? Kelly Morris MAPC, LAC specializes in counseling for marriage and family issues and has worked with many families of children with disabilities. She noted "Parents sometimes think 'It's as though I've been labeled — my family has been labeled. What

does this define me as?' Some see their child's health needs as a reflection on them."

FEAR

Unanswered questions may lead to increased anxiety and fear of the unknown for parents of a child with a new diagnosis. Parents face the uncertainty of not knowing about prescribed treatment or therapy, how treatment will be paid for, and how their child will respond. Questions about the child's and family's future life are difficult. Morris explained, "The number one issue I think families face is a feeling of powerlessness. They want to do something, but they don't know what. They may react by thinking 'If I accept this label, that makes it so.'"

Many parents express concern that information entered in their child's health and education records may affect future opportunities. Privacy laws, including The Family Educational Rights and Privacy Act (FERPA), and HIPAA (Health Insurance Portability and Accountability Act) provide safeguards against releasing or sharing information contained in these records without permission.

Sometimes parents feel they must treat their child with a disability "just like everybody else" to help them learn how to be successful. It may help to consider that we treat people differently — whether that is due to differences in ability, personality, personal preferences or just circumstances. Helping a child learn to cope with a disability starts with acceptance of the disability, and acceptance that disability is a normal part of the human condition.

Siegel noted, "Sometimes parents need to get the labels in order to fully advocate for their children. It is important to remember that a child isn't just a diagnosis. Kids are resilient and often exceed expectations. Never settle or stop raising the bar for your child." ❖

Please see commentary by
Joyce Millard Hoie,
Executive Director of
Raising Special Kids,
on the next page.

FURTHER ADVICE ON IDENTIFICATION FROM THE DIRECTOR OF RAISING SPECIAL KIDS

“WHAT’S IN A NAME? THAT WHICH WE CALL A ROSE, BY ANY OTHER NAME WOULD SMELL AS SWEET.”

Shakespeare’s words ring true. A child by any other label, diagnosis, or identification is still a child. A formal medical diagnosis carries with it a range of assumptions, fears, and expectations. While a diagnosis has certain practical value in making available various forms of treatment, medication, therapy and educational programs, it specifically focuses on describing a problem. A formal diagnosis has very limited value in raising a happy, healthy child who will develop his own unique and special capabilities.

In the years since I experienced hearing the news that our son had a significant and life-long disability, I learned it is the creative, intuitive, loving care and attention which brings forth the best in a child, and this process enriches our lives as well as those of our children. If I could return to the day I first heard the distressing news, I would tell myself some of the following things:

Don’t project the current situation into the future. Dire scenarios born of panic and desperation are negative influences that rob you of needed energy and inspiration. Realize that childhood is a precious time and passes much too soon. It may take time to learn to operate on your child’s timetable.

Listen to your parent’s intuition. You will learn things about your child no one else can know with the same degree of depth and understanding. This practical wisdom is a necessary and valuable tool for parenting your child.

Early intervention is essential. I subscribed to the “chaos theory” of parenting (my family would interpret this differently!), but it means sensitive dependence on initial conditions, or the “butterfly effect”, the idea that something as small as the movement of a butterfly’s wings can affect global weather patterns. Early consistent, purposeful, therapeutic interventions provided by parents as well as clinicians, may yield enormous benefits. Small and seemingly inconsequential efforts to train, reinforce, and encourage your child can result in amazing things.

Advocate for your child as a key member of the decision-making team. Learn to work well with professionals. Inform, educate, and listen to the experts with whom you consult. Occasionally someone may need to be “fired”, but the many conscientious professionals who forged partnerships with us helped to provide the optimum interventions for our son. They deserve and receive my deepest respect and appreciation.

Visualize where you need to be in two years. Your goals and objectives will become clearer to you. When I took time to objectively evaluate the situation, we found new goals and new ways to measure performance and progress.

Find ways to encourage your child’s independence. As essential as you are in the life of your child, it reinforces respect and responsibility when you build feelings of confidence and competence in your child.

Parenting a child with a disability is never easy; it’s demanding, exhausting, and the outcome is uncertain. The art of parenting requires the best from us, no matter what we choose to call it.

Reprinted with permission from Joyce Millard Hoie, Executive Director of Raising Special Kids.

STAFF MEMBER PROFILE: BONNIE HOM, OUTREACH ASSISTANT

By Bonnie Hom

After graduating from UC Berkeley with a degree in molecular cell biology, I wanted a job where I would wake up in the morning and be happy to go to work. I found that position at the Hydrocephalus Association. Here I am, reflecting upon my nearly two years at the Association and feel fortunate to be a part of such a passionate and spirited community. As the Outreach Assistant, I provide support and education and am involved in other areas such as the Life Enhancement Project, the scholarship program, and the coordination of local and national volunteers.

In addition to working at HA, I am pursuing a Masters in Public Health with a community health education focus. I also volunteer as co-chair of the pharmacy committee at Clinica Martin-Baro, a student-run, free primary care clinic in San Francisco’s Mission District. I like to keep my plate full!

My passion is to advocate for underserved and underrepresented communities. My commitment to academics and professional and volunteer work has taught me to be vigilant of opportunities to bridge theory and practice. The world we live in is far from ideal, but we need to make the best of limited resources while advocating for more. I strongly believe that we at the HA provide support, education and advocacy daily; but just as importantly, we provide hope. Now that’s something worth waking up for! ❖



2008 SCHOLARSHIP UPDATE

By Bonnie Hom, Outreach Assistant

Thank you to all of those who applied for a 2008 Hydrocephalus Association Scholarship. All the applicants deserve recognition for their accomplishments. This year we are pleased to offer 11 scholarships. We have received 80 completed applications, which we have forwarded to the Scholarship Committee. The Committee will make their final decision by early May. The 11 scholarship recipients and the rest of the applicants will be notified by regular mail mid-May.

The number of scholarship application requests increased noticeably from last year due in part to our new Web site at www.hydroassoc.org. We even received several applications from abroad, including Kenya and Sri Lanka! We strongly encourage all students with hydrocephalus who fit the scholarship criteria to apply during the 2009 scholarship cycle. Please contact me at bonnie@hydroassoc.org with questions regarding scholarships. ❖

Conference Spots Still Available!



Having just returned from a site visit to the beautiful Canyons Resort in Park City, Utah, we are brimming with anticipation for our community gathering June 19-22.

Brush up on your artistic expression because we'll have a time to share with each other at a talent show during the dinner portion of Saturday's dinner dance. Don't worry. We'll still have a DJ to get everyone dancing together after dessert!

Don't delay! Sign up before the price goes up on May 23rd, and join us for three days of learning, networking and celebrating together.

Registration is available online through a link on our Web site, where you will also find information on accommodations at the Canyons Resort, kid's camp, airline discounts for conference attendees and discounted transportation from the Salt Lake City airport to Park City through All Resort Express.

- Go to www.hydroassoc.org.
- Click on "2008 CONFERENCE REGISTRATION" under the welcome headline.
- Click on the "Online Conference Registration" link in the middle of the page.

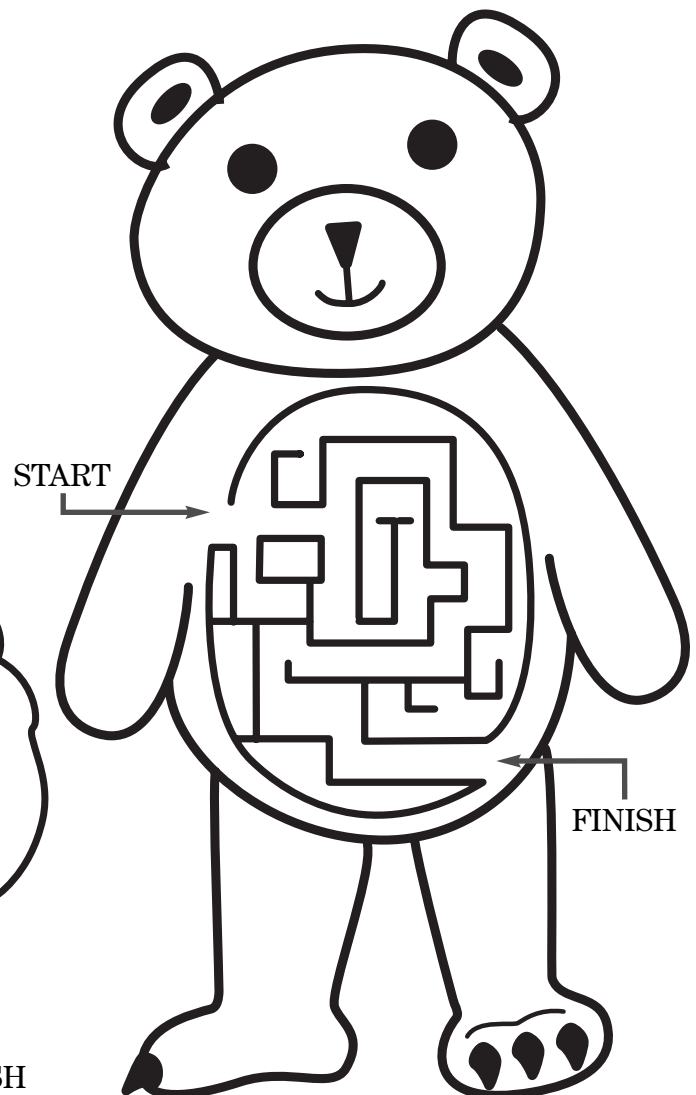
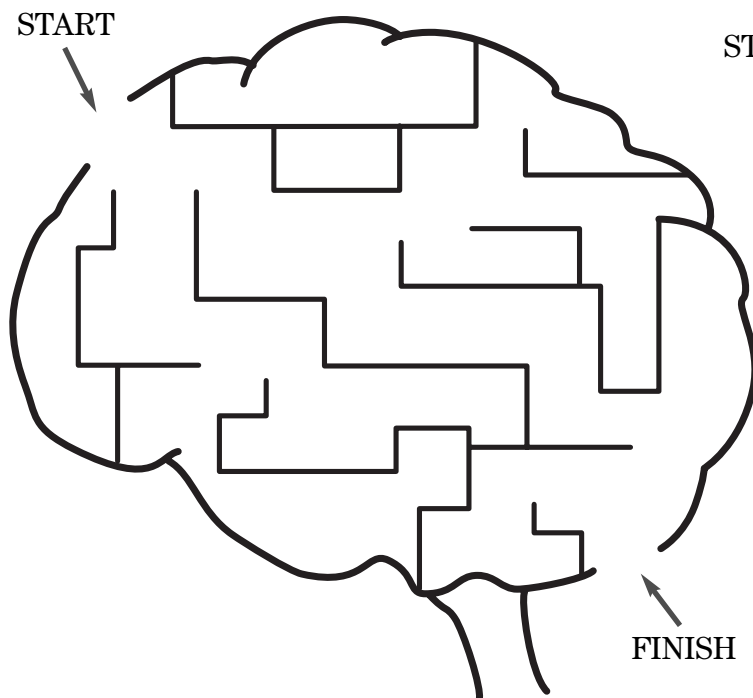
You can also request a paper copy of the registration form through the office.

Kid's Corner!

By Bonnie Hom, Special thanks to Jacqueline Lui!

Test your skills from START to FINISH with these two hand-drawn mazes. Try the brain maze first; it's easier than the bear maze.

Enjoy!



Donors

Thank you to the individuals who supported the Hydrocephalus Association so generously in 2007. Your support is the cornerstone of our community.

We do our best to recognize everyone who supports us and we make every effort to avoid mistakes. However, if you find any errors or omissions, please contact our office so we can make corrections. Thank you for your understanding.

Corporate and Foundation Grant Donors and Event Sponsors will be listed and thanked in our Summer issue.

We do not know all the names of everyone who made a donation via a TEAM event, or a payroll deduction through CFC or United Way, so we thank those of you who were anonymous donors.

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Ian Farnkopf	Robyn Johnson	Saxon Maxe	Theresa Rose	Julia Wiener
Dr Michael Fine	Mary Stewart Jones	Jackson May	Phillip Rosenthal	Maria Wiggins
Samuel Fine	Nile Jones	Caitlin Maynard	Shelby Kaitlyn Sampson	Justin Wilder
Josh Fineman	Rebecca Grace Jones	Catherine McDermott	Ben Sanchez	Luke Winters
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LEGISLATIVE EFFORTS: INCREASING ATTENTION ON HYDROCEPHALUS ISSUES

By MaryBeth Godlewski, National Advocacy Director

Below is a brief recap of the status of HA's major federal efforts in 2008.

The Hydrocephalus Association continues to ramp up our advocacy work with Congress and federal agencies on behalf of all those whose lives are touched in some way by hydrocephalus. Although we continue to see positive results, much more remains to be done to achieve the needed level of federal support and commitment dedicated to hydrocephalus research and awareness.

When dealing with Congress, we must be persistent and patient. 8,000 to 9,000 different pieces of legislation are introduced during an average two-year session of Congress, of which less than 5% are ever enacted into law. Although many of these bills do not have true national significance, the sheer volume of legislation and the range of issues that Congress must consider serve as a reminder of how hard we all must work to gain congressional interest in a new issue—especially an issue such as hydrocephalus that, despite its prevalence, does not carry the level of public awareness of many other disorders.

To this end we have retained a government relations consultant, Deborah Outlaw. Deborah has extensive experience in various federal health policy arenas. She worked on Capitol Hill as a legislative counsel for a U.S. senator, served in various federal agencies, and was an attorney in the Executive Office of the President. Since 1994, she has worked in the private sector, helping health organizations gain support for their federal legislative and regulatory efforts. HA members will be able to meet Deborah at the June conference.

CONGRESSIONAL SUPPORT EXPRESSED FOR INCREASED HYDROCEPHALUS RESEARCH AND ENHANCED PUBLIC AWARENESS

HA is happy to report that the Senate recently passed a resolution: S. Con. Res. 63, (introduced by Sen. Clinton [D-NY], and cosponsored by Sen. Specter [R-PA]), to encourage additional hydrocephalus research by the National Institutes of Health (NIH) as well as greater public awareness and education through building partnerships between the federal government and patient

groups. S. Con. Res. 63 is intended to serve as the Senate's counterpart to an earlier House bill sponsored by Rep. Thompson (D-CA), which passed in 2007.

This particular type of bill (a "Concurrent Resolution") does not have the force of law. At the same time, it represents direct and positive action by Congress specifically focused on our mission, in that it conveys strong support from Congress as a body for increased attention on hydrocephalus. It helps reinforce HA's other advocacy efforts and serves as a benchmark by which Congress can gauge progress.

INCREASING NIH FUNDING FOR HYDROCEPHALUS

HA is actively working to gain congressional support for including comprehensive language in the Labor, Health and Human Services (LHHS) Appropriation bill funding the NIH for the next fiscal year (October 2008 through September 2009). Sen. Specter and Rep. Rosa DeLauro (D-CT) have both once again agreed to submit and support our fiscal year 2009 language. We are on Capitol Hill meeting with key offices, both to shore up our friends and to continue educating new members of Congress about HA issues.

To support NIH in its desire to fund more hydrocephalus research, we are also urging Congress to adopt a robust funding level for NIH. The NIH budget is considered inadequate by many in the scientific community, and existing funding commitments have been reduced somewhere between 18% and 22%. This reduction makes it even harder to get new projects funded. So, while our primary efforts are always geared towards the specific research needs of the hydrocephalus community, we also support increased funding for NIH Institutes of direct concern to HA.

We need your help to make any of this happen. Get ready to start writing your members of Congress; the appropriation season is upon us! We will begin our "Call to Action" e-mail alerts and hope you will respond when you receive them!

HYDROCEPHALUS NOTED IN TESTIMONY TO CAPITOL HILL

As part of our efforts to include hydrocephalus in policy discussions across different venues, HA has joined the 'Friends of NICHD', a respected and proactive health coalition that supports funding for all areas of children's health research. Engaging in select activities with the Friends helps HA highlight many of the special hydrocephalus research needs in child development.

One early positive outcome from our alliance with the Friends is that we were able to include in recent testimony submitted to Congress a special mention of the challenges faced by children with hydrocephalus and to point out the need for more collaborative research:

"Hydrocephalus: More research needs to be done into the many complex issues surrounding hydrocephalus for the 200,000 children under 18 now living with this condition, ranging from obvious medical concerns due to repeated brain surgeries, to less well understood challenges involving learning disabilities of children with hydrocephalus, motor and sensory impairment, and socialization challenges. NICHD has a significant role to play in working with other Institutes regarding the unique issues of hydrocephalus in children."

HA INVITED TO PARTICIPATE IN NINDS MEETING ON RESEARCH NEEDS

HA has been invited to participate in a May 16 meeting with senior staff from the National Institute of Neurological Disorders and Stroke (NINDS) to discuss prioritization of research needs, gaps in funding, the peer review process for obtaining support from NIH, and similar issues. We will report back after the meeting, and are looking forward to the opportunities presented in this all-day forum of dialogue and interaction.

HA EXPLORES OPPORTUNITIES IN THE U.S. DEPARTMENT OF VETERAN'S AFFAIRS FOR HYDROCEPHALUS RESEARCH

HA continues to explore the connection between hydrocephalus and the veteran population. We attended a briefing in March on veteran's health issues with senior Veteran's Affairs officials and research staff, and plan to continue to press forward to encourage research and collaboration, where appropriate, with other federal agencies.

(Continued on page 23.)

HA JOINS CALIFORNIA NEUROALLIANCE AT THE CALIFORNIA STATE CAPITOL!

By *Karima Roumila, Outreach Coordinator*

Hydrocephalus was well represented at a recent conference addressing emerging public policies that affect people with neurological disorders. Board member Emily Farrell joined staff members Marybeth and me at the eighth annual California NeuroAlliance Conference held in Sacramento, Calif. March 11-12, 2008.

Attendees representing about nine different neurological conditions participated in advocacy training and heard from a wide array of speakers on issues, such as the impact of proposed California budget cuts on individuals with neurological conditions and Senate Bill 1198—"Health Care Coverage: Durable Medical Equipment"—introduced by Sen. Sheila Kuehl, D-Santa Monica. The bill prohibits insurance companies from imposing a separate benefit cap specific to DME in their policies that is lower than the benefit cap that broadly applies to other basic medical services.

The potential impact of the across-the-board 10% cut in all state services will be significant for low-income individuals with neurological conditions. Approximately 13% of

patients represented by CNA rely on Medi-Cal for their health services. If approved, cuts would mean 10% reduction in reimbursement to health care providers under Medi-Cal and the elimination of ten state supplied "optional" benefits not mandated under the federal Medicaid program. Six of these ten optional benefits would have an impact on individuals with neurological conditions: adult dental, adult optometry (one of the ways that hydrocephalus is diagnosed in adults), adult optician and optical laboratory services, adult psychology, adult speech therapy, and incontinence creams and washes.

Participants, which included professionals, advocates, and families and patients dealing with the complexities of neurological conditions, were grouped into teams and embarked on State Capitol visits. Each team met with several legislators and urged them to oppose the cuts, citing personal accounts of the impact the cuts would have on low-income individuals with neurological conditions. Overall, ten legislators heard the specific impact budget cuts would have on people with hydrocephalus through our stories.

The California NeuroAlliance Conference provided a platform to share information and advocate for better access to health care for our members. It also provided an opportunity to hear from key decision-makers and state department directors firsthand. We hope and urge our California members to get involved and contact their local representatives and let them hear from you about these important issues. ❖

The Story of NeuroAlliances: The California NeuroAlliance (CNA) began about eight years ago under the leadership of the American Association of Neurology. CNA (<http://www.calneurosurgery.com/>) was the first advocacy partnership to represent millions of state residents affected by neurological conditions, their advocates and their physicians. Building on the success of this alliance dedicated to improving the quality of life by promoting access to quality health care through education, public awareness and advocacy, similar alliances have formed in Florida (the Florida NeuroAlliance) and Washington (The Washington State NeuroAlliance [WSNA]). Groups in Pennsylvania are also considering forming such a coalition.

THE NEWLY-FORMED FLORIDA NEUROALLIANCE VISITS THE FLORIDA LEGISLATURE

By *Marvin Sussman, PhD, HA Board of Directors*

The Florida NeuroAlliance is a recently-formed Florida-based coalition of organizations and individuals concerned about neurological issues. A number of its members visited the Florida Capitol in Tallahassee on March 25, 2008. They met with senators, representatives and legislative aides to introduce the NeuroAlliance and inform them of its mission to:

- be proactive in promoting public policies that assure access to quality health care and support services;
- support cutting-edge research, leading to better treatments and cures for neurological conditions;
- protect the rights of people with neurological conditions; and
- promote full participation of people with neurological conditions in their respective communities.

The formation of this NeuroAlliance was a collaborative effort involving the Florida Society of Neurology and representatives of patient and family support groups. It is a diverse, coalition of patients, health and advocacy organizations, advocates, medical and support service providers, and researchers dedicated to the improvement of the quality of life for Floridians living with neurological conditions.

Participants in this initial lobbying effort included two neurologists (one from Gainesville and one from Jacksonville); a medical researcher from the University of Florida (Gainesville); representatives from the Epilepsy Foundation, the American Association Neuroscience Nurses Northeast Chapter, the National Multiple Sclerosis Society, the ALS Foundation, and the Hydrocephalus Association's Tampa Bay, Fl. affiliate; and several patients with neurolog-

ical conditions. HA board member and Florida resident, Marvin Sussman (with help from Paula Keyser, President of our Tampa Bay affiliate), has been active in the Florida NeuroAlliance since its inception. He participated in the visit to the Florida Capitol and represented our Association there. Florida has a higher proportion of people over the age of 55 years than most states; therefore, age-related issues such as normal pressure hydrocephalus are a concern to the state.

Senate President Ken Pruitt commended the NeuroAlliance for its initiative and assured that the information provided would be passed on to those areas of Florida government that need to know. Meetings were also held with the legislative assistants to the Chair of Health Policy Committee and the Speaker of the House, a senator with a strong interest in issues of the handicapped, and a Florida house representative (Chair,

(continued on page 23)

THIRD GLOBAL PATIENTS CONGRESS OF THE INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

By *Karima Roumila, Outreach Coordinator*

Recently, the third Global Patients Congress of the International Alliance of Patients' Organizations (IAPO) was held in London, United Kingdom. The meeting highlighted the progress being made worldwide to address the role of the patient as an essential partner in the design and delivery of health care.

Over 180 delegates from around the world, representing patients and other stakeholders in health such as the European Commission, The World Health Organization (WHO), and global health professionals' associations attended the Congress. The meeting's focus was on access to health care, patient safety, patient information and patient involvement. The speakers emphasized the progress made since the 2006 Congress and how more and more patients are working together with health care providers to make patient-centered health care a reality. Patient groups increasingly achieve recognition for the contribution they

make to the design and delivery of health care.

Sir Liam Donaldson, Chief Medical Officer, England and Chair of the WHO World Alliance for Patients Safety, in his keynote presentation, addressed the growing recognition given to patients as experts or teachers, helping to ensure that consumers receive the care they need in an appropriate and safe way. He also stressed the notion that the patient should be seen as our conscience for safe care, a catalyst for change, a witness of the quality of care, a compass, giving direction to our efforts and as teachers in how we learn from unsafe care.

IAPO calls on all stakeholders in health care to include patients in a meaningful and sustainable way in all levels of their work and at all points of decision-making, and to build on existing models of involvement in collaboration with patients around the world.

(For more information go to www.patientsorganizations.org) ❖

GABRIEL'S LIFE — THE VALUE OF WRITING MY BLOG

By *MaryBeth Godlewski, National Advocacy Director*

Twelve years ago, when my daughter, Emma, was diagnosed with hydrocephalus, blogging was not yet popular. This meant the parent-to-parent support I so desperately desired and needed to properly learn how to advocate for my child was not easy to find. Today, you can find blogs on the Web for just about everything—even hydrocephalus.

Thanks to Leilani Schweitzer, who envisioned and created the site GabrielsLife.org in memory of her son Gabriel, we have a great new hydrocephalus community blog. This site was created as a way for individuals and families to share their stories and connect with others, learning and growing through their experiences with hydrocephalus.

Last week, I finally “blogged” Emma's story. This wasn't easy for me, but offered great value in the writing and hopefully will provide value for others to read and learn from.

Please visit GabrielsLife.org through the link on the HA home page at www.hydroassoc.org and experience the joy of success stories, the frustration from set backs, but most of all, the love and pride so many have shared. If you feel that your story is so different from all the other stories that you just cannot relate, please post your story anyway. It is the only way that the collection of stories will be a true reflection of the range of experience that people have with hydrocephalus. ❖

FLORIDA NEUROALLIANCE (continued from page 22)

Committee on Health Quality), who plans to run for the U.S. Congress in November. Between appointments, the group split up and dropped off information on the Florida

NeuroAlliance at various senator's and representative's offices.

The Florida NeuroAlliance plans to hold a Legislative Day annually, probably in

LEGISLATIVE EFFORTS

(continued from page 21)

EDUCATION ISSUES

We continue to look into some of the education issues impacting children with hydrocephalus. We have reached out to CCD, the Consortium for Citizens with Disabilities, a 25-year-old coalition of providers, consumers, and other advocates. We contacted the co-chairs of their Education Task Force, and were invited to attend an education task force meeting on April 8, 2008. We continue to think this group could be a good alliance for HA to address issues of concern to our members relative to: 1) education and 2) ADA-related discrimination.

STATE ADVOCACY UPDATE

In our first quarter of 2008, five HA active advocacy members secured legislation within their state declaring a “Hydrocephalus Awareness Month” (HAM). This number adds to the three that were passed in 2007, which we expect to receive again this year. Our goal is to have 15 by the end of 2008!

2008

Florida - Bill Vincent
Washington State - Melissa Lovick
Maryland - Eric Cole
New Jersey - Michael Illions
Missouri - Robin Holloway

2007

Pennsylvania - Ashley Manthey
Colorado - Shannon Christen
California - Dory Kranz

Recently, members of our affiliate support group in Cleveland, Ohio have begun to engage their state and federal legislators, hoping to add Ohio to our list. Please consider joining us and add your state's name to our 2008 list.

For more information on this action and other advocacy initiatives, contact Marybeth Godlewski at marybeth@hydroassoc.org or 484-270-8523. ❖

March, and we plan to make sure hydrocephalus continues to be well represented. ❖

NEW FOR 2008...



2008 is the year of change in many ways for the HA—new Web site, new newsletter and a new, more easily recognizable name for our national awareness and fundraising events: **Hydrocephalus WALK**.

Building on the success events previously held under the name TEAM, we aspire to have a signature Hydrocephalus WALK event in every state. We are making great progress toward our goal, with 20 events in 2007 and 30+ in the works for 2008! The purpose of having signature events in every state is to:

- create the level of recognition achieved by other national organizations, such as those raising awareness for breast cancer, autism, multiple sclerosis, and diabetes;
- brand our new HA logo and look;
- generate greater community and media awareness of hydrocephalus and the efforts of the HA;
- increase funding that can support our core mission of providing support, education and advocacy to all people whose lives are touched by hydrocephalus—including advocating for more federal support of hydrocephalus research.

One of our motivations behind the name change was to alleviate confusion between groups of people who joined an event as a team versus those who worked on the event as a whole. Our vision for signature WALK events includes pursuing opportunities for national and regional corporate sponsors to join community sponsors in supporting our events, creating one national t-shirt to be distributed at every WALK, and promoting celebrity appearances at events. (Do you know any celebrities willing to help?) We are working on all of these ideas and more for this year. If you are interested in participating or have contact with anyone who can help us achieve any of the above, please contact MaryBeth Godlewski at Marybeth@Hydroasso.org or 484-270-8523.

“AN EVENT IN A BOX” refers to our new way of supporting volunteers who host our signature WALK events for ‘08. WALK event chairs will receive everything they need to host a WALK event in a box: signs, t-shirts, letters, tri-fold brochures and more! We hope by creating a signature event and streamlining everything into a step-by-step process, complete with all needed information and material, we will alleviate some of the stress of chairing a walk and encourage more people to try it. If you have interest in chairing, attending or supporting a WALK event, please contact MaryBeth Godlewski at Marybeth@hydroassoc.org or 484-270-8523

All awareness and fundraising events are successful in growing awareness, connecting community members and raising funds. We encourage and support all type of events. ❖

INTRODUCING AND ANNOUNCING “HYDROCEPHALUS WALK ‘08” EVENTS AND CHAIRS... SO FAR!

First let me give a big, belated thank you to Stacy Buckner for her hard work on the Chicago, IL. 2007 TEAM event. Stacy’s name was accidentally omitted for our TEAM thank you in the winter newsletter article.

Pell City, AL	Mandy Smith
Birmingham, AL	Becca Cardin
San Francisco, CA	Emily Clark Farrell MaryBeth Godlewski
Sacramento Valley, CA	Jodi Lawrence
Denver, CO	Phyllis Rogers
Washington, D.C.	Mimi Kramer-Roberts
Tampa Bay, FL	Paula Keyser Jill Barrett
Chicago, IL	Sherry Reising Stacy Buckner
Louisville, KY	Elizabeth Gladden
Baltimore, MD	Terri Smith
Detroit, MI	Denise Bechard Jennifer Bechard
International Falls, MN	Sherry Veillieux
Graham, NC	April Brantley
Edison, NJ	Kim Illions Michael Illions
Albuquerque, NM	Kathy Carrillo Marnie Wood
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Dallas-Fort Worth, TX	Lindsey Thompson
Houston, TX	Stacy Miller
Salt Lake City, UT	Kelly Varga Vicki Bell
Milwaukee, WI	Angela Batterman Diane Weichert Gloria Frane

OUR AFFILIATES AND ADVISORS ROCK!

By Pip Marks, Director of Support and Education

The regional expansion pilot plan is thriving and blossoming. We are very proud and excited to announce that, due to the success of our pilot affiliates in Cleveland, Ohio and Tampa Bay, Fl., three new regional affiliates are joining our team: Boston, Mass.; Phoenix, Ariz.; and St. Louis, Miss. The affiliate leaders and the members of the Advisory committee are true pioneers in this evolving regional expansion. These key players are providing support at a local level, connecting individuals and families, creating opportunities for others to come together to empower one another, and advocating for more awareness and much-needed funding. The leaders of the affiliate program are committed to working very hard, volunteering countless hours and earning well-deserved respect from thousands in our hydrocephalus community.

On February 2, 2008, the Hydrocephalus Association Advisory Group participated in a meeting to provide input on the Regional Support and Expansion Initiative and pilot expansion project. The key objectives for the meeting were to evaluate and enhance the existing program; clarify roles and responsibilities; clarify the process for becoming an advisor and an affiliate; and make recommendations for growing the program. The vision for the Affiliate Initiative has expanded to be more inclusive. We agreed that we wanted to welcome more people who want to work with us, including individuals who can lead and organize fundraising walks and active state and national advocates.

We came to a general consensus on guidelines for new affiliates and emphasized inclusiveness and how we can ensure broad involvement. We had a “meeting of the minds” and will move forward with a much more flexible set of ideas that will help the HA and its affiliates. We were able to accomplish a lot in a very small amount of time.

We continue to reach our goals for the expansion program. Our affiliates are reaching more people where they live, thus coordinating localized communication to increase awareness of the condition of hydrocephalus and the services and resources of the Hydrocephalus Association. They are strengthening bonds with local medical professionals and drawing on local medical sup-

port, thus strengthening existing ties and creating new relationships with medical professionals and institutions. Both affiliates offer educational and inspirational speakers at their support group meetings and are seeing growth in numbers of attendees at their meetings, thus providing educational and networking opportunities at the local level.

The affiliates are holding walk events in their areas and have seen increase in support and commitment and fundraising. Our affiliates are sharing resources and have their own Web pages on the HA’s Web site, thus providing centralized support for educational resources and non-profit administration to allow local entities to focus on outreach and education. We have in place a quality assurance questionnaire and have established a metric/success indicator to measure growth of support and outreach. The affiliates are using the HA’s online database to track support calls and requests for information, thus leveraging existing database and technology tools and providing a consistent technology platform across groups to facilitate information sharing and access. Finally, with the National Institutes of Health Resolution, Congressional Resolution, Labor-Health and Human Services Appropriations report language, and the general moving of research forward, we are coordinating and amplifying the voice of the hydrocephalus community, advocating for more federal support of hydrocephalus research and awareness.

I had the honor and pleasure of visiting with Paula Keyser, the affiliate lead in Tampa Bay, Fl. and Monica Ferrante, the affiliate lead in Cleveland, Ohio. It was a joy to meet their families, and especially to meet their sweet sons—with and without hydrocephalus—who are the inspiration in the work these women do for the HA and their local community affected by hydrocephalus. I was very fortunate to be able to attend their support group meetings and meet many of you. We had the opportunity to work with each other for a day so I could familiarize them with the HA’s database and the resources available for them to share with their local members.

Paula Keyser, our affiliate in Tampa Bay, Fl., sums up her experience with the HA by saying, “Being an affiliate of the Hydrocephalus Association has broadened our horizons and expanded the knowledge and resources for our families. It is a wonderful feeling to be able to help others by being close to them geographically and to meet in person so that they don’t feel so alone. The foundation we are building as a local group will be a wonderful network should we have to struggle with revisions and complications from this condition in the future. The structure that the Hydrocephalus Association has built as a foundation will support a nationwide growth of local Hydrocephalus networking resources and I am privileged to be a part of this effort.”



News Notes

DISABILITY SAVINGS ACCOUNTS

On March 11, 2008, legislation was introduced into Congress by Sens. Dodd (D-CT), Casey (D-PA), and Hatch (R-UT) that would allow for the creation of disability savings accounts and financial security accounts by family members of individuals with disabilities. These bills would serve to amend the Internal Revenue Code of 1986.

The Disability Savings Act of 2008, S.2741 would provide for the creation of disability savings accounts that are exempt from taxation under \$250,000. The purpose of this bill is to encourage individuals with disabilities and their families to save private funds to support and assist them in maintaining their health, independence, and quality of life. It would also serve to provide secure funding for disability-related expenses to supplement benefits that are already provided through private insurance and Medicaid.

If you would like to view the full text of these bills, please visit the Web site at <http://www.govtrack.us/congress/billtext.xpd?bill=s110-2741>.

SSI AND SSDI – WHAT IS THE DIFFERENCE?

Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) are two important programs administered by the Social Security Administration; however they offer very different benefits and have different rules for determining who qualifies for them. To read a complete overview of the key differences between them please go to <http://www.specialneedsanswers.com> and click on news.

By Line

Giving through Payroll Deductions

You can give to the Hydrocephalus Association through workplace campaigns such as the United Way and the Combined Federal Campaign. Here's how:

United Way—Write in Hydrocephalus Association.

Combined Federal Campaign (CFC)—Use code 10066.

Other workplace campaigns—Ask if you can write in Hydrocephalus Association. (If you cannot, let us know so we can apply for future years.)

Designating your contribution as directed above will help us strengthen our work on behalf of all people dealing with hydrocephalus.

NURSING CARE OF THE PEDIATRIC NEUROSURGERY PATIENT

This new book serves as a detailed reference for all nurses caring for children with neurosurgical problems. Explanations of pathophysiology, anatomy, and radiodiagnostic testing and treatment options will help them to understand the rationale behind the nursing care. Presenting symptoms and findings on neurological examination and history will enable nurses to identify normal signs. Each chapter includes information on patient and family education and will give helpful guidelines. Although there

has been a need within the pediatric neurosurgery community for this type of information for years, there is no other reference available that provides this type of specific information. The contents of this important book include hydrocephalus, Chiari malformation, spina bifida, syringomyelia, craniosynostosis, traumatic brain injury, and surgical management of epilepsy.

This book can be ordered by e-mailing orders-ny@springer.com or calling 1-800-SPRINGER.

GABRIEL'S LIFE WEB SITE



The purpose of this Web site is to serve as a source of information, create hope and inspiration, and help build a community through the shared voices and stories of people living with hydrocephalus.

Hydrocephalus impacts the lives of countless people, and there is no cure. However, through collaboration, knowledge-sharing, and interaction, we can bring our collective knowledge and experiences together to improve and save more lives.

Whether you are a parent, pediatrician, grandchild, or someone who has been touched in any way by hydrocephalus, this is an opportunity to reach out to others in your community. MaryBeth Godlewski, Director of Advocacy, recently created a blog on this site and has written about her invaluable experience in this newsletter on page 23.

Please visit <http://www.gabrielslife.org>

DOCUMENTARY BACK ON TRACK

After an unavoidable delay of many months due to the Writer's Guild Strike, we are pleased that the documentary "Learning to Drown" is back in motion. As a member of the Guild, writer/director Sherman Alexie was forbidden to work on the documentary during the strike. We are all breathing a collective sigh of relief now that we can once again move forward with this exciting creative endeavor that we hope will draw attention, raise awareness, open hearts, inspire donations and intrigue scientists around the world.

As a treat for those attending our national conference "It's about Life" in Park City, Utah, Sherman will share a sneak preview of "Learning to Drown" after his creative keynote on June 21st. Hope to see you there!

THANKS TO OUR SHUNT INDUSTRY FRIENDS

There are thousands and thousands of shunt awareness pins now being worn all over the country and our little hydrocephalus bear, Boozle, has been shunted and adopted by hundreds of members. Where does all this shunt tubing come from? Our dear friends and loyal supporters from Codman, Medtronic, and Integra who graciously and generously donate hundreds of feet of shunt tubing whenever there is a need for it. We are sincerely grateful for their continued support.

Hydrocephalus Association 2008 MEMBERSHIP FORM

RENEWAL NEW

Name: _____ Telephone: _____

Address: _____

_____ Email: _____

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

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

Count me in as a member for 2008. Enclosed is my unrestricted donation of:

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

How would you like to receive your quarterly newsletter?

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

Please send my newsletter via email to: _____

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

Charge my: VISA MasterCard Discover Amount Charged \$ _____

Card No. _____ - _____ - _____ - _____ Exp. Date ____ / ____ VIN # _____

Print Name _____

Signature _____

Please remove my name from your mailing list.

I cannot afford a donation at this time but I would like to be counted as a member.

Please check all that apply:

I am on SSI or Disability. My medical bills have exhausted my finances. My income is below \$30,000 per year.

Please return this form with check, money order or completed credit card information to:

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

The Hydrocephalus Association is a national nonprofit organization providing support, education, resources and advocacy for families and professionals. The Newsletter is published quarterly. Dory Kranz is the editor. Articles included in the Newsletter are for the reader's information and do not signify endorsement by the Association. We welcome letters and articles from our readers but reserve the right to edit any material submitted for publication. Information and articles from the Newsletter may be reprinted provided a full citation of source is given.

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Hydrocephalus Association

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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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