

# GUARDIAN NEWS

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*"You have to let the world know what your problems are.."*

*-Dr. Fred J. Epstein*



## ABOUT DR. RICK ABBOTT



Dr. Rick Abbott is a pediatric neurosurgeon in the Department of Neurosurgery at The Children's Hospital at Montefiore (CHAM). Dr. Abbott was previously associated with NYU Medical Center and Beth Israel Medical Center and has been involved in the treatment of Hydrocephalus for many years.

He has worked extensively with Endoscopy since 1991 and participated in the early development of the equipment currently used by neurosurgeons. He has performed over 200 Endoscopic Third Ventriculostomies, a procedure that has become the treatment of choice for many forms of Hydrocephalus.

This procedure eliminates the need for a permanent shunt, thus minimizing the long-term complications that could arise in the future. In addition Dr. Abbott works along side a skilled team of

pediatric surgeons who use the endoscope to directly visualize the placement of shunt catheters into the abdomen for selected cases. This method is extremely useful when scarring is present in the abdomen. Dr. Abbott also uses the computer assisted guidance systems coupled to the endoscope to place catheters into small fluid spaces within the brain and to surgically communicate cysts with normal fluid pathways.

Dr. Abbott recognizes the emotional impact that the diagnosis of Hydrocephalus can have on both the child and their family and is committed to CHAM's philosophy of family-centered care. He knows that a parent's foremost desire is to understand their child's condition and to develop a care plan to successfully manage the disease. He and members of his comprehensive team strive to be



available to families who wish to discuss their child's condition and are dedicated to providing the support needed for them to regain their equilibrium.

## MAKE YOUR DONATIONS COUNT (GIFTS WITH A PURPOSE !!!)

If you would like to make a donation in honor of an anniversary, birth, birthday, marriage or a Memorial Donation, we would be happy to send a card to the recipient announcing your generous donation.

If you would also like to announce that occasion and list it in our seasonal newsletter, please indicate that on your check.



## SAFE SURGERY STOPS SHUNT INFECTIONS

Patients with Hydrocephalus can be spared the devastating effects of infection after being fitted with drainage shunts, a study of more than 100 patients has shown. In operations to 126 patients, covering 176 shunts over seven and a half years, only one shunt infections was recorded—and that seemed to originate from appendicitis progressing to peritonitis seven months after the operation.

This impressive record was attained by adopting a culture of zero tolerance to infection during the operations, with all staff strictly following detailed and rigorous preventive procedures based on asepsis,

antisepsis, prophylactic antibiotic treatment, and—specifically—avoiding haematomas. The operations took place in one dedicated neurosurgery theatre with neurologically trained staff, where entry or exit during the procedure was permitted only in real emergency. All staff were fully gowned and masked, and the protocols went to great lengths to avoid infection from the surroundings, instruments, and implants. All operations were either performed by or closely supervised by the same senior neurosurgeon, and lapses in protocol were not tolerated.

The 126 patients were treated at the neurosurgical

department of one UK hospital trust; 33 of them had revisions to implants fitted at other centers.

Reported mortality from shunt infections varies from 1.5-22% and infections occur in about 5% of procedures, though rates as low as 0.3% have been reported. Infection is to be avoided at all costs as survivors can have severely impaired mental and neurological functions, but others studies of how to do so have been inconclusive.

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## HELPFUL WEBSITES FOR TEENS W/ DISABILITIES

(CLICK TO NAVIGATE)

**Www.followmezone.com** (FollowMe™ is a helpful website that allows a person to upload medical information onto a secure electronic location and it is accessible from any computer with internet access, so the information can travel with you from different locations and times)

**Www.raisingpecialkids.org** ( Includes “My Dreams/My Plan/My Future”, a self-determination tool for high school and beyond.)

**http://hctransitions.ichp.edu** (About health-care transition for youth with special health-care needs)

**Www.brookspublishing.com** (Excellent publications on employment and transition for youth with special needs)

**Www.dralegal.org** (Disability Rights Advocates. Site on health care, insurance and public health benefits.)

**Www.tea.state.tx.us/special.ed** (User friendly for all IDEA regulations)

**Www.ssa.mainstream-mag.com/health.html** (On managing your own health care.)

**Http://disabilityresources.org/KIDS.html** (The DRM WebWatcher just for kids—sites for, by and about kids and teens with disabilities and chronic illnesses.)

**Www.diasbilityinfo.gov** (Supported by the federal government, contains many topics of interest to people with disabilities; extensive links and a children and youth section.)



# WHAT IS CHIARI MALFORMATION?

Chiari malformations (CMs) are structural defects in the cerebellum, the part of the brain that controls balance. When the indented bony space at the lower rear of the skull is smaller than normal, the cerebellum and brainstem can be pushed downward. The resulting pressure on the cerebellum can block the flow of cerebrospinal fluid (the liquid that surrounds and protects the brain and spinal cord) and can cause a range of symptoms including dizziness,

muscle weakness, numbness, vision problems, headache, and problems with balance and coordination.

There are three primary types of CM. The most common is Type I, which may not cause symptoms and is often found by accident during an examination for another condition. Type II (also called Arnold-Chiari malformation) is usually accompanied by a myelomeningocele—a form of spina bifida that occurs when

the spinal canal and backbone do not close before birth, causing the spinal cord to protrude through an opening in the back. This can cause partial or complete paralysis below the spinal opening. Type III is the most serious form of CM, and causes severe neurological defects. Other conditions sometimes associated with CM include hydrocephalus, syringomyelia, and spinal curvature.

## QUESTIONS TO ASK YOUR DOCTOR (BEFORE SURGERY)

1. How many Adult or Pediatric ACM Patients have you seen? (There are huge differences between the adult and pediatric form of this condition.)
2. What exactly do you plan on doing to me, and how many surgeries of this type have you done? (ACM is rare and it is often difficult to find specialists with 100s of surgeries under their belt)
3. How do your patients do post-op? What about long-term? (Watch out for doctors selling a miracle and promising you you will be instantaneously cured.)
4. What is your usual follow-up routine post-op?
5. How do you handle pain control for your patients?
6. Who do I call if I have problems down the road?
7. What happens if I still have symptoms after the surgery?
8. How soon will I be able to resume daily activities?
9. Is there one of your post-op patients I can speak with?
10. What is the reason that this procedure is necessary at this time?
11. What are the options if this procedure is not done?
12. What will/might happen if the operation is not done?
13. If the operation is done at this time, can it be done later? Advantages? Disadvantages?
14. What is the anticipated outcome of the procedure?
15. What exactly are the expected or possible benefits of doing the procedure?
16. What are the specific risks that this procedure involves?
17. What is the recovery process after this procedure?

## CHIARI DECOMPRESSION SURGERY

Decompression surgery is used to create enough space around the area of the herniation to improve the flow of spinal fluid and to a lesser extent, decrease the pressure on the spinal tissues.

This is accomplished by

(Figure 1) making an incision in the skin at the back of the head. (Figure 2) Taking away bone from the base of the skull, Craniectomy. (Figure 3) Taking away bone from the top vertebrae, Laminectomy. (Figure 4) Finally the dura (covering of the spinal cord) is

opened and patched with a 'dura graft', Duraplasty.

This is a very simplified version of the surgical process and each neurosurgeons' techniques differ from the next.

(Figures on the right)



Figure 1: Incision in Skin



Figure 2: Craniectomy

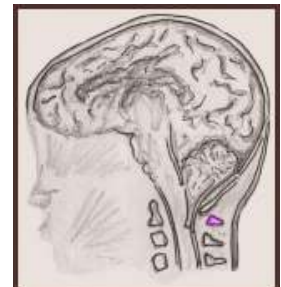


Figure 3: Laminectomy



Figure 4: Duraplasty



*“Do not limit your child out of fear, my parents never did and it made me more capable to cope with my situation.”*

## MY STORY BY CHRISTINE PETERSON

My name is Christine and I am 37 years old. I was born in Chicago and was diagnosed with Spina Bifida Oculita, Chiari Malformation type 1 and Progressive Communicating Hydrocephalus. Given the lack of knowledge and technology at that time I was turned away by Doctors and my parents were given little hope that I would survive past age 5.

My parents refused to give up and in 1970 I was shunted with a then experimental Lumbo-Peritoneal shunt. My situation improved drastically with the shunt and I did not have any complications for several years after that.

However between 1980-83 I had several shunt revisions due to infections. At that time under in-patient care they also removed the shunt to determine the degree of shunt dependency. I was very shunt dependent so they put a new one in. Twenty one years passed with no problems at all.

However, in 2004 something went wrong and I went on with the shunt intermittently malfunctioning. Five months later the shunt broke and closed off completely it was at that time that I found out I was an A-Typical case and that my ventricular system did not react the way it should with added CSF pressure. The doctors found out that I had a slit ventricle syndrome also.

My husband, Mom, Dad and brother were by my side in the ER telling the doctors that it was a problem with my shunt, but the doctors would not believe that since all of my CTs and MRIs had come back normal. Also my optical exam showed no Papilledema (flattening of the optic disc

related to increased CSF). Ventricular enlargement and flattening of the optic discs are usually the first signs detectable that a shunt may be malfunctioning. Then the seizures started followed by paralysis and eventually my heart briefly stopped beating.

About that time my neurosurgeon returned from out of town and rushed over to the hospital and told me he would replace my shunt with a Ventricular peritoneal shunt. I was terrified but I didn't care as long as it would relieve the pain and suffering. So they shaved my head and inserted the shunt. I woke up the next morning feeling better no longer suffering from headaches.

Again I wound up having the LP shunt removed and a programmable valve put in. I felt like a new person, but five days later I returned home from the hospital and a new kind of headache started. Along with the debilitating headaches I also experienced vision loss, hearing loss, numbness in my hands and forearms, Vertigo and many other symptoms.

I went through even more MRIs and other doctors were trying to figure out what was wrong with me. My neurosurgeon suggested that it might be Chiari Malformation and recommended decompression surgery. I was in total denial since I had no problems with Chiari for 37 years and could not believe that after all this time it would be responsible for making me feel this way. However, after exhausting all other possibilities I went ahead and had the decompression surgery.

It has been 2 months since the surgery and I feel great. I apparently had other symp-

toms from the Chiari that were diagnosed as Hydrocephalus. I was also diagnosed with carpal tunnel syndrome and the beginnings of Fibromyalgia. It turns out that the whole time it was the Chiari Malformation.

I woke up in recovery in pain from the surgery but feeling like a different person. All the things that were robbing me of my life were gone at last and that quickly. I don't even think my doctor thought the surgery would go so smooth. I have a scar on the back of my head, but I got to keep my hair this time. I was in quite a bit of pain for about one and a half weeks and then after I started getting around I felt a lot better. I had full neck mobility in about a month and now two months later it feels like I never had the surgery. It's almost like the last two years of my life was an awful nightmare I have finally waken up from.

I would like to stress to parents out there or adults going through the same thing, that I know the thought of a shunt or of surgery is a scary thing. It really isn't bad at all. I don't even know the shunt is there. I do all the things any other active, healthy person does. I have two healthy, beautiful daughters, I swim, dive, roller-skate, rough house, do yard work, ride rollercoasters, etc. Do not limit your child out of fear, my parents never did and it made me more capable to cope with my situation. Your child will only progress as far as you will let them. If you do not put limits on their possibilities than the sky is the limit.

# CIRCLE OF LIFE HEALTH FAIR

On September 16, 2006 Guardians Co-founder Marie Fischetti, with help from her cousin Peggy, was invited to participate in the Third Annual Circle of Life Health Fair, hosted by the Block Institute. Thanks to our dear friend Marilyn Amoroso we were able to disseminate information out to the public and raise some money for our cause by raffling off fall holiday (Halloween and Thanksgiving) ornaments made by Marie Fischetti.

The Block Institute is a wonderful non-profit organization that offers educational, vocational, and clinical rehabilitation for over a 1000 de-

velopmentally disabled children, adults and their families..

The Block Institute was established in 1962 and works to develop their members into fully functioning members of the community. The organization hopes to give each "student" the ability to achieve independence and integration.

The institute's staff consists of NYSC Special Education/Early Childhood teachers, Occupational/Physical/Speech therapists, Social workers, Psychologists, and a consulting dietician. They also have a medical staff consisting of a Registered Nurse, an

LPN, and a Developmental Pediatrician.

Their goal is to provide the best care and support to the individuals and their families. Their family services include monthly workshops, weekly parent groups, case management services, service coordination and individual parent and/or family meetings as needed.

We were honored to be associated with such a wonderful organization and hope to collaborate with the Block Institute in the near future. Again we would like to thank Marilyn Amoroso for her continued friendship and generosity.



Cousin Peggy helping the Guardians raise money at the Health Fair



## SIEMPRE EN NUESTROS CORAZONES Y PENSAMIENTOS

For those of our members and readers who do not speak Spanish this article is titled "Always in our hearts and thoughts." This story is about Emily ????? who helps us significantly by translating multiple emails/letters from English to Spanish and Spanish to English.

Each year we receive an abundant amount of emails and letters from people confused and concerned because their child or another loved

one is suffering from Hydrocephalus or as it is known in Spanish Hidrocefalia. A majority of the information out there is in English so Emily is the key to breaking down this communication barrier.

Emily is a bilingual 5th grade teacher living in New Jersey. She is happily married for over 20 years with two older boys Ivan 20 and Andrew 18. She professes to us that she loves to help others and remains an active volun-

teer for the Boy Scouts of America.

We are very grateful to Emily for taking the time out of her work and home schedule to help us whenever we need it. She is a great wife, mother and most of all human being. As the article says she will always be in our hearts and thoughts. Thank You Emily.

-From The Guardians

## MY JOURNEY WITH HYDROCEPHALUS (GLORIA MORGANO)

I had become depressed, sitting at home for a month in a wheel chair and was disinterested in everyone and everything around me. I could not understand how or why this was happening to me. As much as I loved to read, picking up a book was too much of a challenge. I deteriorated from walking with a cane, to a walker and now a wheelchair. What happened to the person I used to be? I had always been an active person. Now I could not raise a glass of water to my lips, nor could I get into my bed without my husband's assistance.

Then one evening, my husband and I were watching 60 minutes on CBS. They had a segment on Hydrocephalus. They showed a film about a gentleman that lost the ability to walk without shuffling his feet, walking erratically and needed assistance when walking any distance at all. He also suffered from short term memory loss and was incoherent. As we watched the film, I realized the similarity of our symptoms. Since I am a senior, and never heard of Hydrocephalus, I attributed the problem's I was experiencing to advanced age.

Our daughter went online and located the Hydrocephalus Foundation and also found a neurosurgeon who was a specialist in the field. After a visit with Dr. March Mittler, he told me that I had Hydrocephalus and would need surgery. He said in order to feel better I would need a shunt implanted into my head. He told me not to worry and that he has performed multiple shunt operations. He said he would take care of me and he did.

After the procedure, five days at the hospital, three months of Physical Therapy; I was finally

Ready to take my life back. Each day I improved and was able to do simple things like crossing my legs, to standing and eventually walking without assistance. I was elated. Each day I continually improved.

Thanks to CBS for bringing attention to this illness. Thanks to my loving family that encouraged and helped me all along the way and a special thanks to my doctor I am now living a normal life once again.

There is hope out there.

- Gloria Morgano

Guardians of  
Hydrocephalus  
Research Foundation

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**We're on the Web !**  
**WWW.GHRForg.org**



If you have a story of interest  
and would like it to be pub-  
lished in our next newsletter  
please send it to:

Editor-in-chief

Charles Guigno  
c/o GUARDIANews  
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Brooklyn, NY 11235

Or email it to:  
GHRF2618@aol.com

Also if you have a picture of  
yourself we would be happy  
to insert that alongside your  
story/article. Thank You.

*From everyone at the Guardians of Hydrocephalus Research Foundation we would like to show our appreciation to those who continue to support our organization. With your help we can continue distributing information and connecting people suffering with problems from Hydrocephalus with those Doctors that can help. If you would like to be a part of our organization or have a question you would like answered please visit our NEW!!! web site: WWW.GHRForg.org*

*Our web site has been recently renovated and contains all of our past newsletters, a message board and a guest book where anyone in the public can leave us any comments, suggestions or questions for us that we routinely check. We also have a section where we posted a variety of different helpful internet links with the ability to transfer you to that site directly from our page.*

*So we hope you enjoy our new web site and again we would like to thank all of you for your continued support !!!*

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## A VERY SPECIAL THANK YOU !

Dr. Rick Abbott  
Dr. Jeffrey H. Wisoff  
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Mr. and Mrs. Ronald Seaton  
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