

TAKE EACH
MOMENT AS
IT COMES

I cannot change my
yesterdays, they have
come and gone. I can
only hope to plan my
tomorrows, Since I
cannot be sure they are
mine. There are too
many unforeseen
events that I cannot
control. Too many
questions that I cannot
answer, So I can only
try my best To live
each moment as it
comes, Hopeful that
God will send Angels to
guide and protect me,
For I know that I can
not do it alone.

©1985 Frances Ruocco

(Her son was diagnosed
with hydrocephalus)

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GUARDIANews

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About the Guardians

The Guardians of Hydrocephalus Research Foundation (GHRF) was established in 1977 as a non-profit organization. Since then we have distributed over 10,000 information packets and received many phone calls every month answering important questions from concerned parents and worried individuals.

Our quest is to provide information to the public without cost so that a better understanding of *hydrocephalus* will be established. We provide counseling to families with children who have *hydrocephalus* to define specific problems that parents encounter and help resolve them as best as possible. We make many referrals to our doctors (more on page 3) who can assist individuals and their families through these tough times.

Since we are non-profit we do not, nor ever have, received government funding. Our funding comes straight from the donations and annual dues of our members. We have an office staff and our upkeep is often expensive. Therefore the annual dues we ask of our members, \$30.00 per year/per family, is crucial to our continued existence and efficient performance. It is necessary in order for us to help you !

Thank You for your continued support
We hope you enjoy our newsletter and find it
interesting and extremely useful.

-The Guardians of Hydrocephalus
Research Foundation

What is Hydrocephalus ?

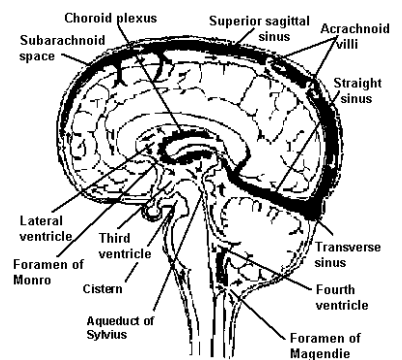
Hydrocephalus, or “water on the brain,” is a birth defect that occurs in about one out of every 500 births. Nationwide, more than 8,000 children are afflicted by this disease each year.

The so-called “water” of hydrocephalus is actually cerebrospinal fluid, a liquid which cushions and protects the brain and spinal cord from shock. The fluid is produced in the ventricles, or cavities, of the brain. Normally, it flows through the

the ventricles, bathes the surfaces of the brain and Spinal cord, and is absorbed into the bloodstream.

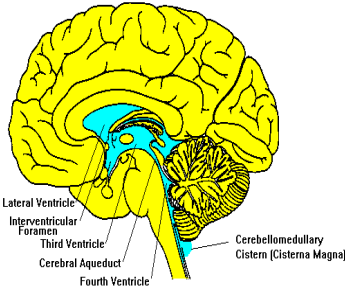
In hydrocephalus, however, the fluid gets trapped in the ventricles and does not enter the bloodstream. The excess fluid causes the ventricles to expand and the brain to become larger. As a result, pressure is exerted on the skull and the fontanels (a baby’s “soft spots”), and the head begins to grow. Unless

Relieved quickly, brain damage may result.



Normal Flow of Cerebrospinal Fluid

Promising new procedure to treat Hydrocephalus



Inside the Ventricular System

Endoscopic Third Ventriculostomy (ETV) is a new surgical procedure developed to treat hydrocephalus without the use of a shunt. ETV entails making a small perforation in the floor of the third ventricle enabling (CSF) cerebrospinal fluid to flow through the ventricular system freely. Although this method was conceptualized a long time ago it is only now with the technological advances of magnetic resonance imaging (MRI) ability and the improvement of endoscopic equipment that this technique is considered “the” alternative choice to shunt placement.

Endoscopic Third Ventriculostomy in the best-case scenario is considered a one-time only procedure. Unlike shunt placement, ETV does not require

multiple surgeries and if successful can promisingly avoid complications such as shunt blockage, infection and over-drainage. ETV patients will also be required to go through some additional surgeries, but only to maintain an adequate opening and ensure the drainage of cerebrospinal fluid.

The consensus on this procedure is that in order to be considered as a candidate for this surgery the patient must be older than six months (however many neurosurgeons will not perform this surgery on children below the age of two years), and ETV has a higher success rate for patients suffering from non-communicating hydrocephalus (where the problem is in the path of CSF flow).

We at the Guardians of Hydrocephalus Research Foundation suggest that you contact your doctor/neurosurgeon to find out if you or your child is eligible for ETV surgery. Also, Endoscopic Third Ventriculostomy is a very new topic in hydrocephalus research and we recommend that you look into this procedure extensively. But from what we have seen and read about, ETV seems to be a very promising substitute to shunt surgery and may offer freedom from shunt dependency.

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

***- Dr. Fred J.
Epstein***



Dr. Jeffrey H. Wisoff

About Dr. Jeffrey H. Wisoff M.D.

Dr. Jeffrey H. Wisoff is an Associate Professor of Neurosurgery and Pediatrics and the director of the Division of Pediatric Neurosurgery at NYU Medical Center. Dr. Wisoff had received his training in neurosurgical and pediatric neurosurgical training also at NYU under the direction of Dr. Fred J. Epstein

Dr. Wisoff specializes in

Pediatric brain tumors, chiari malformations, craniofacial disorders and hydrocephalus. Dr. Wisoff is the co-chairman of the Neurosurgery Committee and a senior member of the Brain Tumor Strategy Committee of the National Children's Oncology Group. He is the chair of the COG Low-grade Astrocytoma Protocol, a prospective,

International study of the surgical treatment of over 700 children with low-grade pediatric brain tumors.

Dr. Wisoff has been such a help for us at the Guardians for many years. We have sent many people to Dr. Wisoff for medical treatment. Although Dr. Wisoff is a busy man he always takes time out of his schedule to assist us.

He constantly sends us the latest medical information on hydrocephalus and will spend time on the phone answering the questions of any of our members. Dr. Wisoff is a dear friend and is such an important part of this newsletter. We appreciate all of his help and assistance.

Figure 1. The ventricular system in a Normal Brain

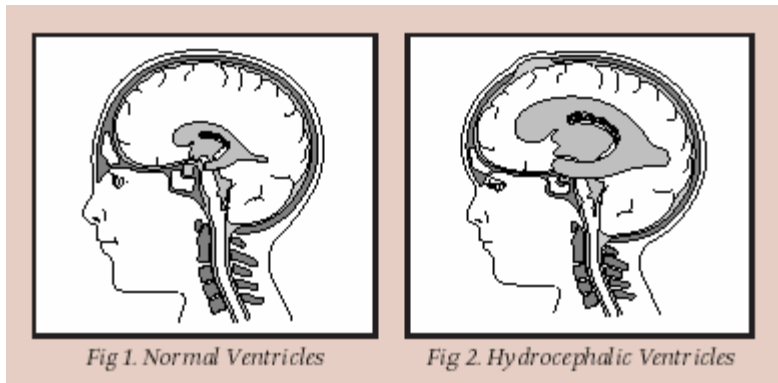
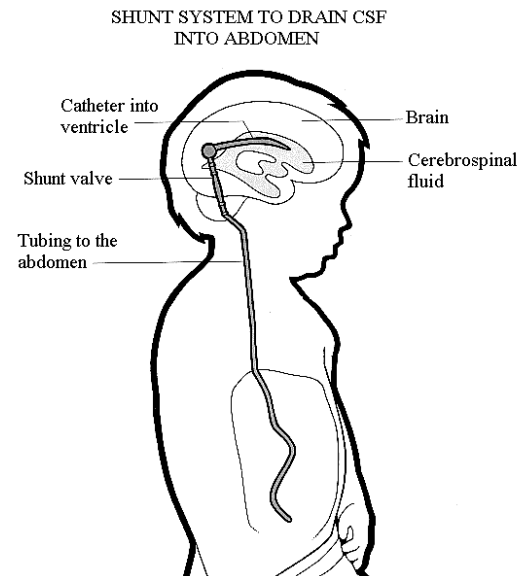


Figure 2. The ventricular system in a hydrocephalic brain

Figure 3. The signs and symptoms of hydrocephalus according to acquired age

SIGNS AND SYMPTOMS OF HYDROCEPHALUS	
<p>Acute</p> <ul style="list-style-type: none"> Change in level of consciousness Headache Nausea Vomiting Diplopia Blurred vision Cranial nerve palsies, ie, sixth 	<p>In neonates</p> <ul style="list-style-type: none"> Parinaud's syndrome Increasing irritability Bulging fontanelle Macrocrania Diastasis of sutures Distended scalp veins Poor head control
<p>Chronic</p> <ul style="list-style-type: none"> Gait/walking difficulty Paucity of thought/action Memory loss Urinary incontinence 	

Figure 4. The function of the shunt system in its displacement of CSF from the head to the abdomen



In infants (before 3 years of age) head size grows too rapidly and the head becomes enlarged. The baby's soft spot at the top of the head may be full or tense, and the veins might become distended. Typically, an infant's pediatrician should be measuring the child's head circumference at each office visit. If a child's head is growing too fast, it become apparent in comparison to normal development and further tests should be carried out.

The infant may be considered irritable, lethargic or unusually fussy; the appetite may be poor and vomiting may occur. The infant's eyes may be deviated downward or there may be a limited ability to look upward, or the eyes might even be crossed. This infant will encounter delays in child development, reduced movement of the legs, or persistence of kicking movements.

In an older child head size is not as much of a factor. However increased intracranial pressure from the build up of cerebrospinal fluid can cause headaches, irritability, sleepiness, nausea or induce vomiting, visual problems, neck pains, seizures (in extreme rare cases), change in behavior, personality or poor school performance. The child may be unable to concentrate or have some sort of memory problems. Lethargy, drowsiness, balance problems, and double vision are common symptoms.

In adolescents or adults hydrocephalus can cause dementia. There can be a loss of acquired intellectual functions, this will show up as difficulty at school or at work, loss of judgment, memory problems, or changes in personality and/or behavior.

If you or a loved one suffer from one or more of these signs and symptoms you should contact a doctor immediately for testing. If you catch hydrocephalus early surgeries such as shunt insertion or Endoscopic Third Ventriculostomy can stop or help with these deteriorating problems.

My Aunt Kathy by Jamie Fischetti

Being affiliated with a non-profit organization makes you a special person all in itself. To know that you can be the kind of person who gives freely to others is a beautiful gift. I would like to acknowledge one person who has done just that.

Kathy Soriano has been with the Guardians since 1977. She has been a vital part of our foundation. She would run the day-to-day operations at our headquarters in Brooklyn, New York. She knew the Doctors and Board Members affiliated with us on a first name basis. She exemplified the say-

ing "to know her is to love her." She would keep in constant contact with troubled families who called on us for help. Along with the support she has given she would make sure each person would receive as much information as humanly possible. She was ready and eager to listen and everyone knew that she was only a small phone call away. During fundraisers and charitable events Kathy would expect nothing less than for everything to be perfect, and because of her it always was.

The gift of giving is not

only to give with your mind and body, but with your whole heart, and that's what she did. We here at the Guardians would like to thank her for all of her hard work over the years. Her dedication can never be unappreciated and even though you are miles away you are still a part of our family. Aunt Kathy we love you and miss you !



Kyle's Story by Robert Van Riper

Kyle Van Riper was born May 11th, 1996, 25 weeks premature, at 1 pound 5 ounces. On May 12th (Mother's Day) Kyle's lungs collapsed, causing bleeding on the brain, which led to his hydrocephalus. The doctors told his parents he would never live and that they could unplug his life support at anytime. Kyle's parents told the doctors as long as his heart kept beating to try everything possible. A reservoir was placed and he was tapped twice a day for over 100 days and never got an infection. When he was 5 pounds he received his shunt. In 7 years he never had a problem with the shunt.

Kyle came off oxygen at 16 months, walked at 26 months, learned to talk in sign language and suddenly at age 6 he learned to talk by mouth and was potty trained all in 2 weeks. Not only

did he learn to talk, he talked in clear full sentences within a month of learning to speak.

In October of 2003, Kyle was becoming very tired and didn't want to go to school or even play anymore. He was tested for mono, which came back positive, but he still was not getting any better. On November 14th, Kyle was given a chest X-ray to look for pneumonia for a slight cough. The X-ray was read on the 15th by his pediatrician who noticed his heart was enlarged on the right side. He was rushed to the local children's hospital and admitted to PICU, but died suddenly of heart failure two hours after being admitted.

Well over 1,500 friends, family, classmates, students, nurses, doctors, attended his wake and memorial service. Kyle loved the firehouse, where his dad is a volunteer firefighter and the visits to the first

aid building to see the ambulances and police motorcycles. The police motorcycles escorted the funeral procession, with Kyle's casket riding inside his favorite fire engine with several firefighters, followed by multiple police units and ambulances. It was a beautiful but extremely sad moment as the firefighters removed Kyle from the firetruck.

Donations were asked to be made to the Guardians of Hydrocephalus Research Foundation in Kyle's name in lieu of flowers, since his shunt made him have the happiest life any child could ever ask for. Kyle was always smiling and that's how he will always be remembered

Guardians of Hydrocephalus Research Foundation
 Membership Application: \$30.00 per family/per year
 Fiscal Year: Nov 1, 2004—Oct 31, 2005
 (Please note: Membership in effect for one year)

Date: _____
 (Please print all information)

Family Name: _____

First Name: (Husband) _____ (Wife) _____

Address: _____

City: _____ State: _____ Zip: _____

Home Number:(_____) _____ Business Number:(_____) _____

Fax Number:(_____) _____ Email Address: _____

Would you like a pen pal: yes no Age: _____ female male

Company or Agency: _____

Child/Adult Name: _____ Date of Birth: _____

Doctors: _____

Hospital: _____ Medical Insurance: _____

Occupation (explain briefly): _____

Please Check One: parent relative friend benefactor

Dues Enclosed ? yes no _____

Would you like to join our Parent Network? yes no

Would you like to become a Satellite Information Center? yes no

Are you interested in helping with any of our committees? yes no

If so which one? Fundraising Newsletters Membership drive Volunteer

Signature: _____ Date: _____

Payment for membership dues can be made by cash, check or money order to:
 GHRF Headquarters, 2618 Avenue Z, Brooklyn N.Y. 11235



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Research Foundation**

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From everyone at the Guardians of Hydrocephalus Research Foundation we would like to show our appreciation to those who continue to help maintain this organization. With your help we can continue distributing information and connecting people with hydrocephalus with doctors that can help them. If you would like to be a part of our organization or have a question for us feel free to contact us over the phone or check out our web site. Through our web site our members can send emails to us or talk to one another through a bulletin board message service. Again we thank you!



The Guardians of Hydrocephalus Research Foundation

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