



# SPINA BIFIDA CLINIC NEWSLETTER

Issue #7

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Monday and Wednesday.

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If you have received this newsletter by mail and wish to receive it electronically, call or email Mimi, and she will add you to the Spina Bifida Clinic email list.

## **SEND US YOUR IDEAS FOR THE NEXT NEWSLETTER**

We encourage your comments and input. Please contact us to share your story or if you have a question or concern you feel should be addressed in an upcoming issue of the Spina Bifida Clinic Newsletter. We look forward to hearing from you!

### **Update from Mimi Ardis**

I am so sorry for the delay in this newsletter. I had several weeks of vacation in the past few months and time got away from me.

I am continuing the education portion of the newsletter-an overview of hydrocephalus, shunts, and headaches. It has turned into an extensive article but I feel it is a very important overview of shunts.

I will be starting the transition process over the next year with teens ages 12 and older. Children with spina bifida are medically complex. They have both physical and cognitive health needs. They often have problems with planning, organization, and processing. Those with spina bifida *and* hydrocephalus have more cognitive challenges than those with just spina bifida. The transition process will be a guide to involve your teen in their journey to adulthood.

#### **What does transition mean?**

Transition is when a change is made from one thing to another. Your teen is changing into an adult. A transition program helps your teen become as *independent as possible*. It also helps them create plans for their future. They will gain the knowledge, skills, and experience to take care of their own health care needs. To succeed, the transition process must have the support of the parent(s) and the youth.

#### **Care Coordination and Goals of Transition**

Coordination of care is done to make sure people get the health care they need. This is done by making sure that all those involved in the care, including the patient, know what is happening at all times. Transition will not work unless the whole family is involved.

We want transition to help your child pursue self-sufficiency, independence, and plan for adulthood.

I will be contacting parents prior to clinic to discuss the transition process. I will meet with the families at clinic to continue the discussion and give them a transition packet. The packet contains a large amount of information ranging from health care to education to independence, as well as employment. It has many useful resources regarding PUNS, social security, insurance options, and financial funding for needed resources.

Ideally, discussions should begin when the kids are 12 and should be implemented by the age of 14. I will be making every effort to stay on track with this timeline.

A quote from Ann Landers: *It is not what you do for your children, but what you have taught them to do for themselves, that will make them successful human beings.*

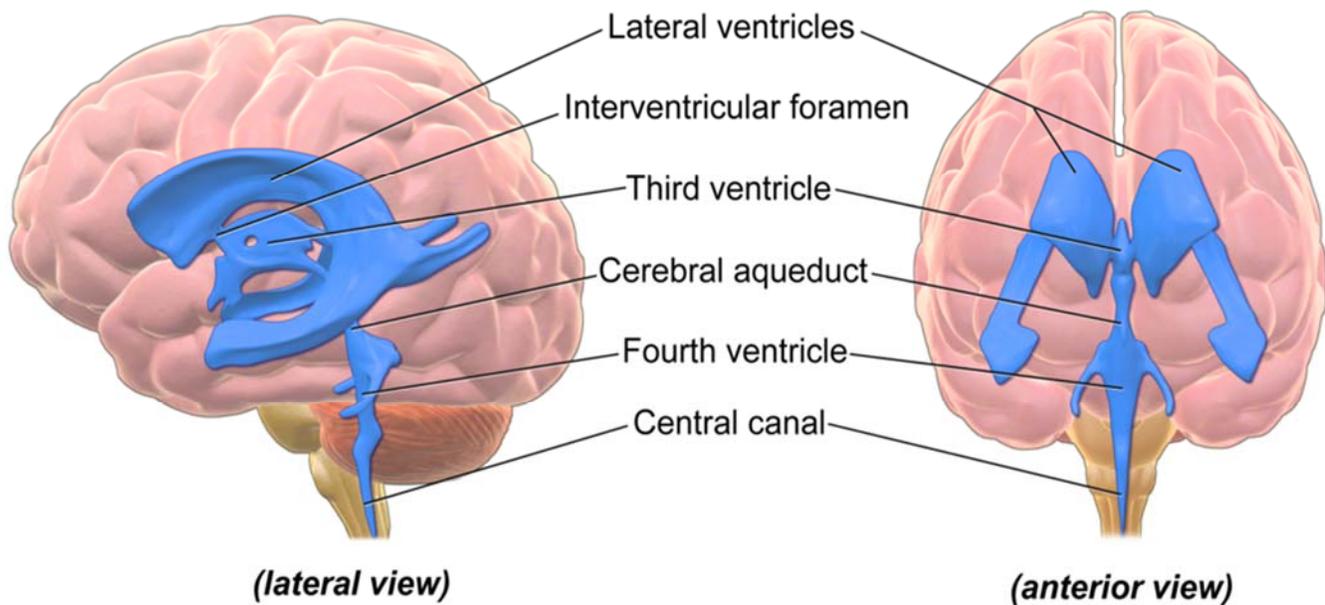
Hope your holidays were merry and bright.

Mimi

### **Hydrocephalus, Headaches, & Shunts...Oh My!**

Cerebral spinal fluid (CSF) is produced in the cavities (ventricles) of the brain. It circulates from the lateral ventricles to the third ventricle through the aqueduct of Sylvius into the fourth ventricle then into the space surrounding the brain and spinal cord. CSF cushions and protects the brain and spinal cord from injury and carries nutrients to the brain. It is eventually absorbed into the blood stream.

The word hydrocephalus originates from the Greek words hydro: water and cephalus: head. It is caused from too much CSF accumulating in the brain's ventricles. Either more fluid is produced than absorbed, or the fluid is unable to be absorbed due to a blockage or obstruction. Both of these cause the ventricles to enlarge increasing the pressure within the brain.



#### **Treatment of Hydrocephalus:**

The *most common treatment* for hydrocephalus is *an implanted shunt*. The shunt diverts CSF from the ventricles to another area in the body where it is absorbed. This decreases the built up fluid in the brain.

There are 3 main components of a shunt:

1. *Proximal catheter*---drains the fluid from the ventricles. The tubing leaves the brain through small hole in the skull and runs under the skin and connects to:
2. *Valve mechanism*---regulates the pressure and flow of fluid. It is generally located on top of the head or behind the ear and connects to:
3. *Distal catheter*---runs under the skin to abdominal cavity or other site where the CSF drains and is absorbed.

Most common complications of shunts include:

1. **Malfunction:** shunts can get blocked; the tubing can break, become disconnected, or may migrate to an area that does not allow for drainage.
2. **Infection:** some become infected with skin bacteria most often at the time of insertion.

*Another treatment* for hydrocephalus is an *Endoscopic Third Ventriculostomy (ETV)*. A small incision is made in the floor of the 3<sup>rd</sup> ventricle allowing CSF to drain. This normalizes the pressure so a permanent shunt is not needed. There are criteria that need to be met to have an ETV performed and be more successful: patient needs to be older than 6 months; have had a previous shunt; and have ventricular pathways that are obstructed.

### **Signs and symptoms of shunt malfunction, infection, or closure of ETV:**

It is important to note that signs of shunt malfunction may vary widely from individual to individual but will generally remain constant for each person. The symptoms exhibited with one episode will most likely be the same for subsequent episodes that may occur.

| <u>Infants</u>               | <u>Toddlers</u>              | <u>Children/Adults</u>        |
|------------------------------|------------------------------|-------------------------------|
| Head enlargement             | Head enlargement             | Headache                      |
| Vomiting                     | Vomiting                     | Vomiting                      |
| Bulging fontanel (soft spot) | Headache or rubbing head     | Vision changes                |
| Irritability and/or lethargy | Irritability and/or lethargy | Irritability and/or lethargy  |
| Swelling along shunt tract   | Swelling along shunt tract   | Swelling along shunt tract    |
| Redness along shunt tract    | Redness along shunt tract    | Redness along shunt tract     |
| Prominent scalp veins        | Changes in motor abilities   | Changes in coordination       |
| Fever may indicate infection | Fever may indicate infection | Fever may indicate infection  |
| Downward deviation of eyes   | Behavioral changes           | Changes in school performance |
| Feeding less                 |                              | Personality changes           |

A shunt malfunction must be considered any time symptoms of hydrocephalus return. It is estimated that up to 50% of persons with shunts will have complications requiring a shunt revision. *It is important that you contact your neurosurgeon's office for any signs of shunt malfunction for further management. Some cases of shunt malfunction are medical emergencies and need prompt attention. Dr. Lin office number is 309-624-4000.*

### **Headaches**

It is very common for persons with hydrocephalus (with or without a shunt) to have chronic headaches. Possible causes include:

1. Intermittent proximal shunt obstruction causing migraine like symptom. This is often referred to as "slit ventricle syndrome". The headaches can be severe lasting from 10-90 minutes often occurring late in the afternoon. They can be associated with vomiting and photophobia (light sensitivity) but tend to resolve on their own. Proximal shunt may need to be replaced.
2. Small ventricles-when the shunt fails, the ventricles can't grow to accommodate the increased fluid volume. These are worse in persons whose headaches don't resolve. The headaches occur mainly in the morning, may cause double vision, and get progressively more severe.
3. Extremely low shunt pressure can cause headaches that are minimal when lying down but worsen significantly when sitting or standing.
4. Migraines can occur in persons with hydrocephalus and are usually associated with a strong family history of migraines. Symptoms of migraines include: severe headache, vomiting, light insensitivity and/or visual difficulties, changes in consciousness.

### What Causes or Contributes to Headaches:

Three things make up and affect intracranial pressure (ICP): brain volume, blood volume, and cerebral spinal fluid (CSF). If any one of these go up the pressure in the brain will rise unless one of the other decreases. In persons *without* hydrocephalus or a shunt, the brain has the ability to be elastic. It can adapt to an increase in volume or pressure.

In persons with a shunt the brain tissue fills the intracranial space while the shunt drains the ventricles of CSF. This results in a very large brain in a skull with very limited space for intracranial pressure changes. If there are any increases in blood flow or volume, headaches can occur from increased pressure. Headaches can also occur when intracranial pressure is too low.

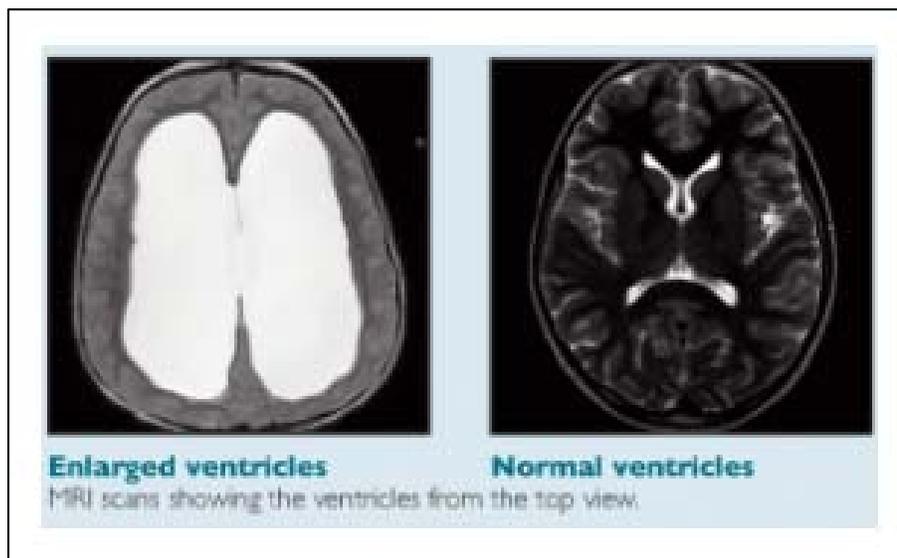
### Treatment of Headaches:

In many cases a head CT will be performed to look for ventricular enlargement, but although there may be no enlargement, the shunt could still not be functioning properly. Keeping track of the frequency and severity of headaches is helpful in establishing patterns.

With slit ventricle syndrome, the shunt can clog but the ventricles don't grow to allow for the extra fluid that is not being diverted by the shunt. The pressure in the ventricle builds up and releases, builds up and releases causing headaches to accelerate. Proximal shunt may need to be replaced.

If headaches get progressively worse, there may be an intermittent malfunction of the shunt caused from increased pressure in the ventricle. Proximal shunt may need to be replaced.

Headaches and hydrocephalus are common but not necessarily simple to treat. The first course of action is to contact your neurosurgeon for severe, acute, or chronic headaches as well as keeping a diary of dates, times, length, and severity of headaches. This information will help the physician in deciding a course of action.



References/Sources: Hydrocephalus Association 4340 East West Highway, St 905, Bethesda, MD 20814, Phone: 301-202-3811 website: [www.HydroAssoc.org](http://www.HydroAssoc.org) email: [info@HydroAssoc.org](mailto:info@HydroAssoc.org)

### **YMCA Camp Independence**

It's the time of year to start gearing up for Camp Independence. It is an overnight camp run by the YMCA of Metro Chicago in association with the Illinois Spina Bifida Association. It is designed especially for people with spina bifida, ages 7 through adult. Campers are encouraged to learn self-care skills, develop new friendships, and try new adaptive sports. It is state-of-the-art facility that is staffed 24 hours a day by a well-trained nursing staff. Camp's mission is to provide safe programs that build independence, confidence, leadership, self-esteem, and teach life skills. If you or your child are unsure about spending a week away from home why not try a winter camp weekend: ages seven to thirteen will be March 1-3.

For more information or to schedule a camp tour, call 847-546-8086 or contact the Illinois Spina Bifida Association at 773-444-0305. Another resource to ease your fears and answer questions is to join the Facebook group: *Camp Independence Parents Facebook Group*.

### **Funds Available through the Illinois Spina Bifida Association**

*Did you know that ISBA offers funds for equipment and emergency assistance?*

**Equipment Fund:** Families may request up to \$250 toward out of pocket costs for orthotic or other mobility equipment. To qualify, the equipment must be utilized by an Illinois resident with spina bifida. The 2018 ISBA Equipment Fund was made possible by generous gifts from "A Helping Hand" and Kiwanis Clubs. Funds will be available for 2019, check the ISBA website soon!

**Emergency Assistance Fund:** Illinois residents with spina bifida can apply for emergency financial assistance up to \$500. Money is paid directly to the vendor/supplier and documentation of need is required. Call ISBA at 773-444-0305 for more information.

Information about ISBA funds is available on their website: [www.i-sba.org](http://www.i-sba.org)

### **Illinois Spina Bifida Association Support Groups**

Illinois Spina Bifida Association offers support groups in the following areas/regions:

Peoria, Bloomington/Normal, Rockford, Southern Illinois, and Western Illinois

For information contact (773) 444-0305 or [info@i-sba.org](mailto:info@i-sba.org)

### **STAR Patient—Paul**

Paul was born on July 26, 2011 with spina bifida. He loves animals. He has 6 guinea pigs-3 boys and 3 girls, 2 basset hounds named Zoey and Emma, and 4 cats named Mittens (in the picture), Monty, Juneau, and Jax! Paul loves ice skating, swimming, baseball, karate, and performing arts (singing and dancing).



His favorite movie is the Greatest Showman and his favorite TV show is Fuller House.

### **STAR Patient—Josie**



Josie is a 14 year old girl who was born with Spina Bifida. Despite that diagnosis Josie has a very busy and active schedule. Josie enjoys listening to music and texting her friends. She also swims for the Special Olympics and plays sled hockey with a local team, Thunder. Josie is a really laid back girl unless she is playing hockey.

Josie's favorite thing to do is put on make-up, especially special affects make-up.

