

Brainstorms



A Newsletter Just for Families!

Wisconsin Seizure Control Network

Volume 1, Issue 1

Summer 2008

Through the Eyes of a 12 Year Old *by Jayden*

My life started on December 26, 1995. I had a great life until 3rd grade, when I started to have seizures. Without warning, my eyes would twitch, I couldn't talk or move, and my lips would quiver.

Sometimes my arms would raise up in the air. I would be very tired after my brief seizure. I did not respond to anyone while I was having a seizure. My parents and teachers were very concerned.

In 4th grade, I was gone from school a lot because of medical appointments. I was hospitalized many times to be monitored, tested, or scanned. Medications did not work for me.

In 5th grade, I was having many seizures and my medications were still not working. We found out that

the only possible cure for me was surgery. The tests showed which part of my brain the seizures were coming from.

I learned that during surgery, the doctors would remove the part of my brain that does not work properly. That is the part of my brain where the seizures start. I was very happy and excited to have surgery.

I had many friends that liked me. We would go skiing, go to water parks, and just play at home. I always seemed to have good times with my friends, even if I had seizures. My teachers and friends were very helpful and understanding.

I have always had an excellent family that cared, loved, and helped me. Every year our family tries to go on a big vacation. While my

seizures were so frequent, we still were active doing things that were safe for me. Every vacation we had a great time together.

I cannot tell you how happy I was to have the surgery. I have not had any more seizures. I love my life now that surgery has stopped my seizures. I am able to do more than I ever imagined I would do again. I hope they are gone for good!

Jayden had a right temporal lobotomy and frontal lopectomy in May 2007. He has been seizure free since. He is a happy, energetic, and healthy 12 year old boy living in central Wisconsin. His quality of life has greatly improved and he is very blessed to have his childhood back— His parents

Coming Up:

Regional Epilepsy Foundations

Southeast
(414) 271-0110

June 29th
8th Annual "Brainstorm" Run/Walk for Epilepsy,

Western
(800) 924-2105

May 10th
"Stroll in the Park" for Epilepsy, Irvine Park, Chippewa Falls

Central/Northeast
(800) 924-9932

Aug 16th
Stroll for Epilepsy, Oak Island Park, Wausau

Sept 13th
Stroll for Epilepsy, Bay Beach Park, Green Bay

Southern
(800) 693-2287

June 21st
"Poker Run," A Poker Tournament for Epilepsy, Janesville

South Central
(800) 657-4929

July 20th-25
Kids Camp, Rosholt

Would you like to receive this newsletter?

For a FREE Subscription, go to our website www.wisconsinseizure.net)

Or just mail us a note and we'll put you on the list!

***** PARENT TIP SHEETS *****

"Tip Sheets" are brief papers that contain important information for parents in condensed and convenient form.. Although some are a few pages, most are 1-2 pages long. These tip sheets were chosen based on common questions parents have or information that isn't often addressed with parents. The following tip sheets have been developed so far:

- 1 Tips for Parents: Lifestyle Factors
- 2 Tips for Teens: Lifestyle Factors
- 3 Tips for Parents: Seizure First Aid
- 4 Tips for Parents: Anti-epileptic Medicines
- 5 Tips for Parents: Traveling with a Child Who Has Epilepsy
- 6 Tips for Parents: Learning Difficulties

Some of the tips sheets have been translated into the Hmong language as well. The "Travel Tip Sheet" is included in this summer issue. We hope to include a different tip sheet in each newsletter. However, you can see all of the tip sheets on the Wisconsin Seizure Control Network website: <http://www.wisconsinseizure.net> You can also print them out to use or share with family and friends. If you have any suggestions for future tip sheets, please contact us at seizurenet@yahoo.com, or contact your regional Epilepsy Foundation office.

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CARE NOTEBOOK Organizes Important Medical Information

What is a care notebook? It is a tool to help you keep track of your child's healthcare needs and services. The one we have developed brings together as many parts of a child's epilepsy information as possible in one convenient binder. You can bring this binder to your child's medical appointments so that providers can learn more about your child and his or her needs. Some of the pages include: medication list, school action plan, emergency care plan, resource list, emergency contacts, and more.

Every care notebook will be different because every parent and child is different. You are encouraged to fill out your forms at your own pace, and only those that you feel are important. In this way the Care Notebook becomes a unique picture of your child. Once your care notebook is complete you will want to keep the information current. Extra pages or forms can be printed from our website at www.wisconsinseizure.net.

Some parents already have a system that works just fine for them, and they might want to check out this one to see if there are parts

they can add to theirs. But if you are still looking for a way to organize your child's paperwork and care, then this is for you !!



Information is power !

We are also working on a purse-size version that some might find easier. Information from the small version could then be transferred to the binder at home. I know having the information written down and that I could refer back to it has helped me to make better decisions for my daughter.

Here are some ways to use a care notebook:

1. Keep all records in one place
2. Help your doctor get to know your child and you understand terminology in your paperwork.
3. Keep your medication and emergency plans up to date so if you have one you'll be prepared.
4. Ways to refer back to treatments, behaviors, etc., so you can make better decisions.

To build your own Care Notebook, go to our website, look under "Patients and Families," and click on "Care Notebook." The pages are designed to be inserted into a large size binder with slip-pocket cover for inserting a cover sheet, and with pockets inside to hold odd-sized forms, prescriptions, etc., but you can customize it any way you want; for instance, you may want to have your child draw a picture for the front cover insert to make it truly reflect their personality (and to remind others that this is a child, not a "condition." Have fun!

Travel Assistance

The *J. Kiffin Penry Patient Travel Assistance Fund* provides reimbursement for travel expenses incurred by families who must travel more than 50 miles for the care of their child with epilepsy, and have exhausted all other personal sources of funding. The Fund is administered by the Epilepsy Foundation, and requires that an application be submitted to the local E.F. affiliate. The application can be found at www.epilepsyheartland.org/resources/finance.php

Does your child have an Individual Health Plan?

If your child has been diagnosed with epilepsy, a specific plan should be agreed upon and implemented with the child's school. If your child is already receiving special education (in other words has an active Individualized Education Program in place), you will need to institute a separate Individualized Health Plan (IHP) to assure that proper care is administered when a seizure occurs. Depending on the type of epilepsy, it may be advisable to include as part of the IHP an Emergency Care Plan (ECP).

"504 Plan" with IHP attached. The purpose of the IHP is to assure that school staff follow an agreed-upon procedure (neither over-reacting nor under-reacting) when a seizure occurs.

For more information, or if you have any questions about working with your school, contact Mike MacDonald, Education Specialist, Disability Rights Wisconsin (715) 699-4333

For a child who is not in special education, the parent and school—with input from the child's medical provider(s)—should develop a

Kids Korner



**Knock! Knock!
Who's there?
Dishes!
Dishes who???
Dishes de FBI — Open up!!!**

New website is Family Friendly way to "CONNECT"

Soon after we started the Wisconsin Seizure Control Network two years ago, we put up a basic website, but now we've completely revamped it — more color, more links, more pictures, more information. And we're still working on it. We have a lot of big ideas: Some are up and running and others are yet to come. For instance, we will be adding a forum where you will be able to "chat" with other parents who are going through (or have been through) the same kinds of challenges you are facing.

it's for YOU! Is it easy enough to use? Is it clear and concise? Did you find what you needed? Check it out, and let us know what you think!



You can help! We want your input, to make sure we're giving you what you need. After all,

www.wisconsinseizure.net

MEDICAL REPORT: Epilepsy Surgery—When is it reasonable?

By Mary Zupanc, M.D.

Epilepsy is much more harmful to a child than to an adult. When a baby is born, its movements and its sucking and swallow reflexes are all controlled by the brainstem. The cortex of the brain—the part we use to think and reason, is still a “blank slate.” Over the next two years, however, the child rapidly develops into a walking, talking, *thinking* human being, a toddler who can protest mightily if thwarted, and as we all know, has a mind of his or her own.

There is important developmental work to be done during these first two years of life, and important connections (synapses) that need to be made between brain cells. In addition, the inhibitory circuitry that “tones down” the excitatory work that is being done in the brain also needs to develop.

During these two years, the brain is also busy making a substance called myelin. Myelin envelopes the connections between brain cells and helps with the electrical conduction of the signals between cells—very similar to the insulation that we use around electrical wires to speed up transmission and keep the electrical pulses going only where we want them to go. These developmental processes can’t occur normally if there is ongoing interference such as the “electrical storms” of epilepsy. Instead, the brain gets “hard wired” for continued seizing. The result is abnormal cognitive (thinking) and motor (movement) development.

On the positive side, the same ability of the brain to make all of these important connections also lends itself to great healing if the child has an “insult” to the brain, such as meningitis (a central nervous system infection),

trauma, lack of oxygen, or even a stroke. The healing capability of the young brain is called “plasticity.” Even if the child has a physical injury, there is great potential for healing. The brain even has the capability of moving functions that were supposed to be programmed into one part of the brain to another part of the brain.



Therefore, when epilepsy is difficult to control and seizures persist, the time to intervene is EARLY, before the catastrophic effects of epilepsy take hold. This can often be accomplished through the use of various drugs, or in more difficult cases through other interventions such as the ketogenic diet or the vagal nerve stimulator. Sometimes, however, it is not possible to intervene effectively through any of these means because the injury

to the brain is too spread out and doesn't respond to any of the simpler interventions.

But if there is an identifiable lesion that can be removed or if the epileptogenic focus (the place where the seizure starts) can be identified through many new technologies available such as electroencephalogram, MRI scan, PET scan, and other technology, then the child should be considered for surgical intervention.

Pediatric neurologists are able to know within the first few months whether an epilepsy syndrome is going to be difficult or impossible to control by virtue of the history, seizure type, neuro-imaging, electroencephalogram (EEG), and last but not least, the child's individual response to antiepileptic medication.

Specifically, if an infant or child fails to achieve complete seizure control with the first two antiepileptic medications that are prescribed, when appropriately chosen, the chance that a third or fourth antiepileptic medication will work is less than 10%.

In spite of these statistics, there is a dramatic lack of knowledge and understanding about surgical intervention in epilepsy. Astoundingly, it currently takes an individual, on average, 17 years to be referred to an epilepsy center for evaluation for epilepsy surgery.

This is completely unacceptable, and we are working to change this mentality, not only among patients and their families but also among health care providers. Epilepsy surgery should not be an avenue of last resort or put off for years. At Children's Hospital of Wisconsin, 67% of children screened and accepted for surgery are seizure-free following surgery. In addition, the quality of life in these children is significantly improved following surgery.



Parent to Parent: A Match “Made in Heaven”

By Robin Mathea

Parent to Parent of Wisconsin is a statewide matching program funded through a grant from the Wisconsin Children and Youth with Special Health Care Needs Program of the Wisconsin Division of Public Health.

Parent to parent provides parent support to parents who have children with special needs through a 1:1 connection with another parent who has a similar experience and who knows first hand about the feelings and the realities that come with having a child with special needs. Support Parent Trainings are available for parents who feel they are ready to become a support

parent. Call for information about up-coming trainings, and help spread the word about this great opportunity!

For more information, to order a brochure, or to make referrals, contact:

Parent to Parent of Wisconsin
1020 Kabel Ave Rhinelander, WI 54501
(715) 361-2890

Website:
familyresourceconnection.org/ptpow.htm



“The right match can make that connection magical and empowering!”

— A Wisconsin Parent

Wisconsin Seizure Control Network

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Box 1997
Milwaukee, WI 53201-1997

Phone: 866- SEIZNET (734-9638)



Name and Address

What do YOU want in your newsletter?

Hi, my name is Jennifer Bertram and I have a daughter with Epilepsy. She is twelve years old and as a mom of a child with Epilepsy I know how scary, lonely and overwhelming every day can be. What I have learned from both my journey and talking to many people is that being connected to other parents of children with Epilepsy helps. Listening to one another can provide both support and information. My hope is that with this newsletter we can form a group of parents from around the state that will serve to encourage and inform each other.



I have been a Parent Partner of the Wisconsin Seizure Control Network because another way I have found to stay strong is to provide a parent voice, or perspective, to this organization and others. Wisconsin Seizure Control Network is an organization that wants to provide information to both professionals and families about Epilepsy. As I worked on this project for this year our main premise was to help underserved communities get connected with cultural agencies so that the communities could learn about Epilepsy in the way they learn best.

From my work with the Wisconsin Seizure Control Network it became clear that developing a statewide forum for parents would be beneficial. How do we do that? We hope this newsletter will be a start. What we hope will happen is that all of us will get the information we need and together we will find ways to get more. We will revel in our stories, ideas of what to put in, and help to keep this running. I hope together we can form a statewide group of parents that will be at our access to provide

support, hope, and information so that we can better care for our children with Epilepsy.

This is our first Newsletter. We hope you find it interesting and a good place to start. Please take the time to read it, visit our website, email me your ideas. I look forward to your feedback and information about what you would like in the next newsletter. If you feel comfortable provide me with your email address so we can start a monthly email to share ideas and stories.

Sincerely, Jennifer Bertram: Parent

Eemail: cabjlb@aol.com

Helpful Resources for School issues

Internet: Wrightslaw.com

Book: The Complete IEP Guide:
How to Advocate for Your Special
Ed Child (Paperback)