

# Epilepsia

Fall 2005

VOL 21, NO. 2

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### ESNI Announces Annual Fundraiser

On January 7, 2006, I will be competing in Walt Disney World's annual 13 mile, half marathon. I've been a runner and long distance walker for many years, and this year I decided I would put myself to the test on behalf of ESNI. I've also enlisted the support of my three daughters who will collect pledges and run for the agency.

Those of you on our mailing list have already received your announcement letter and pledge cards in the mail. I ask you to please consider pledging. Your support, no matter the amount, makes a difference! 100% of your contribution is tax-deductible and will be used for programs and services at ESNI.

Fundraising is a difficult task for any agency. ESNI has a small staff and board and raising support for a disorder affecting a very specific population is not easy, especially when a significant segment of our population fails to disclose the diagnosis for fear of reprisal, i.e. changes in insurance coverage, employment status, etc. This is the type of situation we are diligently trying to change at ESNI. We believe our programs of education, advocacy and, most importantly, counseling and psychotherapy will help to eradicate barriers.

We can't do this alone. We need your help. Please pledge to support my run for epilepsy and ESNI. You can choose to pay your pledge now and have the advantage of an additional charitable tax deduction for 2005. Perhaps you know someone who might be interested in supporting this event and would like additional announcements and pledge cards. Just call and I'll be happy to forward the information on your behalf.

I know how much our services have helped already. Daily returns of agency satisfaction questionnaires echo your positive experiences with ESNI. As our mission statement reads...ESNI works for the improved quality of life of persons whose lives are affected by epilepsy. Help us meet that mission today.

Thank you!



Maureen Galassie  
Executive Director, ESNI



## ESNI Affiliate of Combined Federal Campaign

Did you know that for the last 15 years ESNI has qualified for Combined Federal Campaign contributions?

We do, and those of you who qualify (as federal employees) can make a difference in our ability to deliver services to those affected by epilepsy by checking CFC #8291. It's as easy as that! You can also determine how you want your contribution deducted from your check—weekly, monthly, quarterly, etc.

Contact your federal employment personnel representative for further information on how to participate in this annual giving campaign.

## Study Shows Lamotrigine Poses Low Risk of Major Birth Defects

A study published in the March 22, 2005 issue of the medical journal, *Neurology*, reported that there are minimal risks of a birth defect when pregnant women with epilepsy take Lamotrigine (Lamictil).

Researchers studied 414 pregnancies where the fetus was exposed to Lamotrigine in the first trimester. Twelve cases of major birth defects were discovered. The researchers reported that this is equal to a 2.9% risk, which is about the same as the rate for the general population.

“Even though the number of women enrolled in this study was large, the number of pregnancies is still too

small to give us absolute answers,” said Patricia Penovich, M.D., of the Minnesota Epilepsy Group PA. “But the results can be somewhat reassuring to women.”

This study also reaffirmed the already-known high risks that come with taking valproic acid or sodium valproate while pregnant. The researchers reported that risks of birth defects jumped up to 12.5% if women taking Lamotrigine also took valproic acid.



# Can Seizures be Stopped Before They Start?



By Donna Bergen, MD  
Rush Epilepsy Center

For the past several years, some people

with serious involuntary movements due to

Parkinson's Disease or other illnesses have been treated successfully with electrical stimulation of the brain using surgically

implanted electrodes. Now similar techniques are being tested in adults with intractable seizure disorders.

Although many people with epilepsy achieve good seizure control with antiepileptic drugs, a sizable minority continue to have seizures despite the use of multiple medications. Neurosurgical removal of abnormal brain tissue can abolish or improve seizures in some, but such surgery is not feasible or successful in others. Recently, technological advances have made it possible to think not of removing brain tissue, but of disrupting abnormal brain activity with small pulses of electrical stimulation in order to prevent seizures.

Research studies of two such approaches are just beginning at epilepsy centers around the U.S. The techniques reflect two different treatment approaches.

“Deep brain stimulation” is nearest to the technique already used to treat Parkinson’s Disease, and uses the same type of stimulator and surgical techniques.

The stimulator itself is similar to a heart pacemaker, and like that device, it is surgically placed under the skin of the chest. A neurosurgeon guides two fine wires to a small area of the brain called the thalamus, and connects them under the skin to the stimulator. Like a heart pacemaker, the stimulator can be programmed from outside the patient through signals sent by a computer.

The stimulator intermittently sends tiny, brief electrical pulses to the thalamus, a brain structure whose cells are connected to many other

brain areas. If successful, such stimulation will interrupt the abnormal brain activity responsible for producing seizures.

The second type of brain stimulation being used actually records brain activity from electrodes placed inside the skull, either within the brain or just on its surface. These electrodes are meant to be placed at or near the brain “focus” responsible for producing seizures in the person being treated. The stimulator itself is surgically placed in a custom-made hole in the skull, the same shape and size as the device. This stimulator delivers its electrical pulses only when it detects the beginning of a seizure, and if successful, would interrupt the seizure discharge.



**These devices are just beginning to be tested in chronic epilepsy. If research studies find them to be effective and safe, brain stimulation will be a significant advance in the treatment of intractable seizure disorders.**



# Beating Bad Seizures

**Robert J. Mittan, Ph.D.**  
Director, Seizures & Epilepsy  
Education (SEE)

Anita Kaufmann Foundation,  
[www.theseeprogram.com](http://www.theseeprogram.com)

A recent study found that 47% of patients become seizure free on the first antiepileptic medication tried. Another 11% became seizure free after changing to another appropriate medication. Only 4% became seizure free after trying a third medication after the first two failed. The take home message of this study is that the doctor can tell relatively early on which patients are likely to have difficult-to-control seizures. Nearly 40% of patients in the study were in that category.

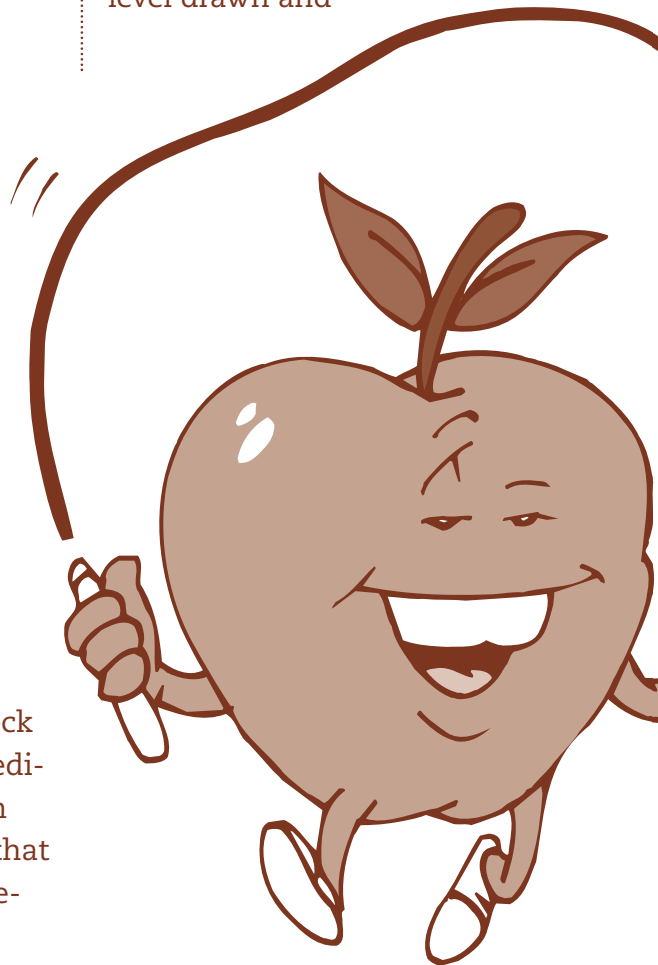
When a patient has failed to gain seizure control after two or three trials of well-chosen, well-managed medications and possibly one appropriate combination of medications, that person's seizures are called "refractory". The term

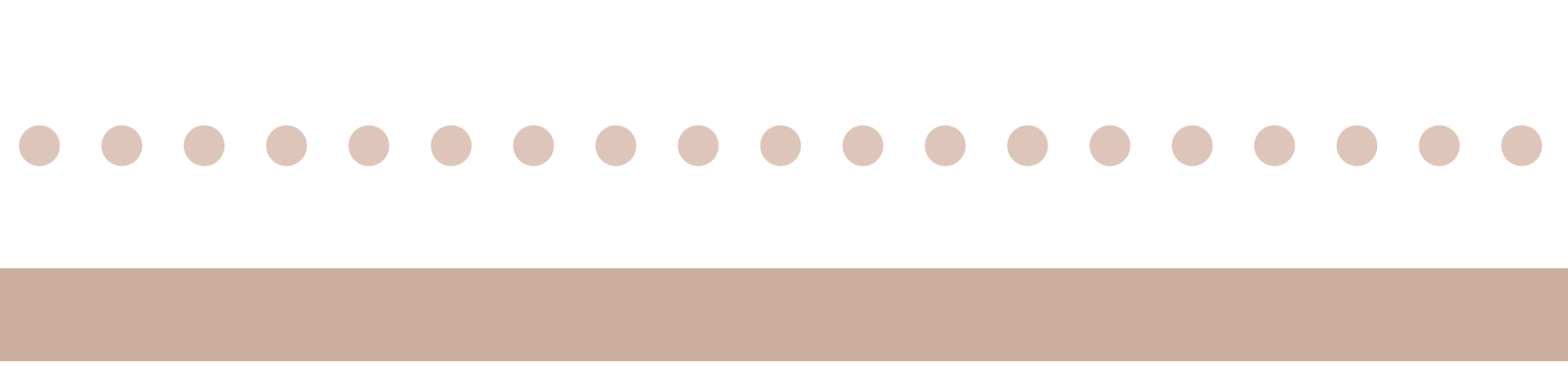
"refractory" refers to seizures that are resistant to control—in this case resistant to control with medication. There is some disagreement over how many medications should be tried before seizures are called refractory. Some epilepsy specialists think failure on two medications is enough. So what can be done?

The very first place to start is to ask, "Are we successfully maintaining blood levels of the medication in the recommended therapeutic range each and every day?" Research finds the most common cause for unnecessary seizures is failure to maintain proper blood levels. Yet, so many things can interfere with this effort even if you are paying close attention. Check for dosage, taking other medications in conjunction with AEDs (antiepileptic drugs) that could counter AED effective-


ness, herbal supplements, certain foods, etc.

Taking blood levels is critical. Is a sudden increase in seizures due to a drop in blood levels or is it due to something else? It is hard to tell unless you have a blood level drawn and





compare those results against what you have learned is therapeutically correct. Start looking at lifestyle issues if blood levels are correct, i.e. sleep deprivation, fatigue, hypoglycemia, etc., other medication or supplements, another illness, activities, too much or too little exercise. Seizure frequency can also vary on its own, for reasons we do not yet understand.



What if you are consistently maintaining blood levels of medication and following correct lifestyle recommendations and still having seizures? Then the question is whether or not you are receiving the right medication for your seizure type. There is a science and an art to selecting medications. First make sure the diagnosis is correct. Intensive monitoring may be in order.

Any seizure type can be difficult to control, some more than others. Myoclonic, atonic, and tonic seizures fall into this category. Complex partial seizures are the most difficult to control of the “common” types of seizures. Is mesial temporal sclerosis the culprit? Specialists are required to detect this problem and can often predict that medications are not likely to work and surgery is the treatment of choice. Seizure focus will determine which surgical treatment is recommended.

If medications have not worked and surgery is not an option, there are two additional approaches worth trying—the ketogenic diet and the Vagus Nerve Stimulator (VNS). These alternatives seldom succeed in making one seizure free, however many experience significant reductions in seizure frequency as a result of these treatments.

The most important suggestion: If you are not having treatment success despite good effort, see an epileptologist. Epilepsy is not one disorder, but many kinds of disorders. The availability of medications has doubled, brain scan technology has mushroomed, genetic contributions are being discovered, surgical techniques are evolving and brain stimulation is a new reality.

Lastly, talk to a therapist/counselor about the psychological challenges of epilepsy. Good information and determination are both effective in overcoming the numerous roadblocks associated with epilepsy. Learn everything you can. The more you learn, the more you will be in a position to succeed in conquering seizures.

### FDA Approves New Antiepileptic Medication

The U.S. Food and Drug Administration approved the new medication Lyrica on June 13, 2005 for adjunctive treatment of partial onset seizures in adults with epilepsy.

Partial seizures are the most common type among people with epilepsy, affecting nearly half of the 2.7 million Americans with the condition.

“There is a significant need for new antiepileptic drugs, as no new agent has been introduced in five years,” said Jacqueline French, M.D., of the Epilepsy Foundation’s Professional Advisory Board and Professor of Neurology at University of Pennsylvania Medical School. “Poor seizure control in patients with epilepsy has emotional and functional consequences that can significantly diminish quality of life. In clinical trials, Lyrica significantly reduced the frequency of seizures in patients who continue to experience

seizures despite their standard treatment with antiepileptic medicines.”

In three double-blind, controlled studies involving 1,052 patients, participants receiving adjunctive treatment with Lyrica experienced a reduction in seizure frequency by 51%. Prior to trying Lyrica, patients who were taking upwards of three other antiepileptic medications had been experiencing about 10 seizures per month.

Lyrica, produced by the pharmaceutical company Pfizer, Incorporated, was also approved in December, 2004 for treating diabetic peripheral neuropathy and postherpetic neuralgia. The most common side effects noted from clinical trials included dizziness, drowsiness, dry mouth, blurred vision, weight gain, difficulty with concentration and attention and swelling of the ankles, feet and legs.

### How to Develop a Health Plan for Use at School

Reprinted from *Exceptional Parent*, September, 2005

When Abby goes to school each day, she needs special accommodations for her medical condition—epilepsy. This means she leaves classes at certain times so she can receive her anti-seizure medications from the school nurse.

An estimated nine million children in this country have health care needs, according to the U.S. Department of Health and Human Services.

“Meeting a child’s health and medical needs can be an important part of providing an education,” said Carolyn Allshouse, coordinator of the Health Information and Advocacy Center at PACER Center in

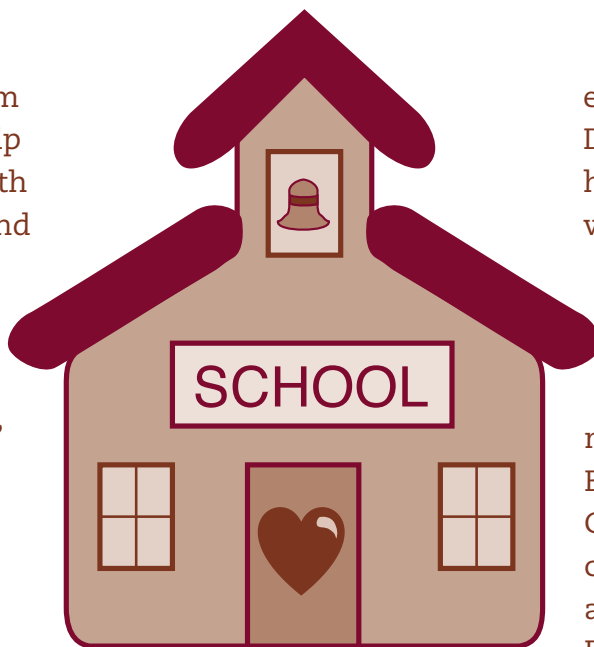
# FAMILY ISSUES

Minneapolis, MN. “Your individualized education program (IER) team may be able to help you explain your child’s health needs to other school staff and suggest ways to meet your child’s needs in school.”

Communicate with the school. “Let the school nurse, health aid and other school staff know about your child’s health care and medication needs,” Allshouse said.

Enlist your doctor’s help. Ask your doctor to explain your child’s diagnosis and health needs to the school and identify what non-educational accommodations might be needed. The doctor could put this information in a letter to the school or could participated in an IER meeting, either in person or by conference call. You will want to make sure that you are always part of conversations between your child’s doctor and school staff.

Develop a health care plan for the school. Work with your child’s doctor to develop a general health care plan or summary. It could include such things as: A) child’s name, age,



gender, grade; B) doctor’s name and phone number; C) child’s diagnosis; D) brief explanation of how the condition affects this child; E) child’s current medications; F) recommendations for accommodations to meet the child’s needs.

Bring copies of the health care plan to the IER meeting. “It is important that everyone involved with your child is aware of and understands your child’s health needs and how the school may need to respond,” Allshouse said. Allshouse also recommends that the school nurse attend this portion of the IER meeting.

Consider having an emergency information form. Depending on your child’s health condition, you may want to have an emergency information form on file at school. This form, signed by your child’s physician, provides additional information such as: A) diagnosis; B) Medications and allergies; C) names of treating physician(s); D) typical protocols and procedures for the child; E) procedures to be avoided, i.e. calling EMTs at any seizure onset.

A link to such a form, developed by the American Academy of Pediatrics and the College of Emergency Physicians, is available at [www.pacer.org](http://www.pacer.org) under “links”.

Sometimes, educational success begins with accommodating a child’s medical needs. As a parent, you can play a key role in meeting those needs with planning, communication and have the support of your IER team.



In addition to stress, feelings of anger, anxiety and depression are also common emotions during the holidays. All of this stress and emotional overload can take a toll on your health.



## Don't Let Holiday Stress Take a Toll on You!

By Molly Ashbaugh, MSW  
Advocacy Counselor

We all know the holidays can be a happy, yet extremely stressful, time. The holiday season is filled with busy schedules, hectic shopping, parties and family gatherings.



The best way to combat this is to make a plan to help make your holidays happy and stress free! Here are some tips on coping with holiday stress and depression adapted from the Mayo Clinic and the National Mental Health Association.

### **Stick to a budget.**

Try to make a list of expenses at least one month before the holidays, staying within your budget will ward off stress from bills later.

### **Keep daily routines and patterns.**

Organize your time, pace yourself.

### **Learn when to say no.**

Don't over schedule yourself!

### **Acknowledge your feelings.**

It's okay to feel tired, angry and sad and want to grieve. You do not have to be happy because It's the holiday season.

### **Seek help when feeling overwhelmed or blue.**

Talk to friends, family, neighbors, and church members, and/or your ESNI counselor.

### **Don't overdo the alcohol.**

Dangerous interactions with epilepsy medications aside, be aware that drinking too much will only increase your feelings of depression.

### **Accept others' differences.**

Understand that you do not have to get along with everyone all the time, even family members.

### **Keep it real.**

Expand your traditions and try something new, letting go and not being rigid will help you relax and enjoy the season.

### **Be aware of post-holiday let down.**

Take it one day at a time instead of putting all your focus on the "big day".

### **Reach out to others.**

Volunteer to make a difference in someone else's life.

### **Make time for yourself.**

Continue with your hobbies. Do not put your life on hold for the holidays.

### **When you need to, take a break!**

### **Best wishes for a happy and stress free holiday season!**



### Tips to Ease Your Child's Transition to Adulthood

by Marcia Kelly  
Pacer Center, Minneapolis, MN

#### 1 Help build your son's or daughter's self-determination and self-advocacy skills.

All young people should have a strong sense of their strengths, abilities, and interests. Make sure they understand their disability as much as possible. Talk about how their disability might affect them at work, in the community, and in their educational pursuits.

#### 2 Help develop your child's social outlets.

Social relationships and recreation are more than fun; they are important tools that help tie people into the community and provide a wider network of support. Although social isolation can be an issue for many with disabilities, transition planning that addresses

opportunities for social relationships and recreation can build a bridge to success.

#### 3 Expand your network and explore community supports.

As those with disabilities become adults, they need support from a variety of sources. Start now to develop helpful networks for your child. Who do you know in your family, social group, professional circle, religious community, or other spheres who could help provide social, recreations, work or volunteer experiences?

#### 4 Make sure your son registers with Selective Service at age 18.

All males—including those with disabilities—must register with Selective Service with 30 days of their 18th birthday.

Failure to do so can affect a person's ability to receive federal and state benefits, including student loans, job training and government jobs.

#### 5 Explore post-secondary accommodations.

Students who receive academic programming and support in high school through Individualized Education Programs will not automatically have the same support after they graduate. Although post-secondary institutions are required to provide reasonable accommodations to students with disabilities, they're not required to modify course work, if it would substantially change program requirements. When you and your student visit a prospective school, visit the campus's Disability Services Office.

## **6 Investigate SSI Programs**

Financial planning is an important part of transition. Many people with disabilities are beneficiaries of Supplemental Security Income (SSI), a federal program that provides a monthly benefit check that can help pay for living expenses. A lesser-known program of SSI is Plan for Achieving Self Support, PASS, may be helpful to some SSI recipients. It allows a person with disabilities to set aside income and resources in order to reach a work goal. These goals could include such things as enrolling in an educational or training program; obtaining supported employment; starting a business, or purchasing a vehicle to commute to work.

## **7 Encourage your child to build a resume by volunteering.**

Many young people struggle to find work experiences that help them compete in the job market. Volunteering is a great solution. Young adults can gain skills and build a resume that shows a prospective employer their abilities, initiative and dedication.

## **8 Help your child learn “soft” employment skills.**

In addition to the work skills people need for their jobs, they also need “soft skills”. These include such things as being able to accept direction, ask for help, deal with conflict and engage in interpersonal communication. They also include being prompt, having appropriate hygiene and dressing properly for the workplace.

An employer is more likely to be patient with an employee learning the technical aspects of a job if soft skills are in place. Practice at home.

## **9 Plan for health care management.**

Like most people, young adults with disabilities need to manage their health care insurance. You should develop a clear plan on how to address health care needs once your child reaches adulthood.



## **EPILIFE**

**Vol. 21, No. 2, Fall, 2005**

### **Published by**

Epilepsy Services for  
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# Epilepsy can be a difficult road to travel...

*...It need not be traveled alone*

## **Counseling**

ESNI offers psychological counseling to all persons whose lives are touched by epilepsy. ESNI clients come to understand that epilepsy is not a disease, but rather a brain disorder. They learn why seizures occur, how medical treatment acts to control them, and to what extent this disorder will affect their lives.

**All ESNI counselors are cross-trained in standard counseling techniques and are skilled in addressing the special psychosocial problems associated with epilepsy.**

## **Support & Discussion Groups**

Shared experiences are a great source of strength and encouragement. In peer, parent support and discussion groups led by ESNI counselors, the participants come to understand that the prejudices and other epilepsy-related problems they encounter in everyday life are neither new nor unique to them alone. They learn that, for thousands of years, these same problems have been experienced by countless others with epilepsy. More importantly, they learn how to cope and successfully resolve them.

## **Information & Referral**

A directory is available to persons seeking the services of an area neurologist. The directory is available without charge and is updated every year.

Many problems that persons with epilepsy face are unique. ESNI counsels and guides clients in areas as diverse as special housing, employment programs, and procurement of insurance. A counselor/client relationship is carefully built and zealously maintained for as long as a need exists.

## **Community Education**

ESNI provides a full range of informational and educational literature on epilepsy. It is available, without charge, to individuals, school nurses, teachers, libraries, or any interested person.

ESNI maintains pamphlet files on epilepsy at all public libraries in its service area.

Community education programs featuring neurologists speaking on medical aspects of epilepsy are presented to the public without charge at area hospitals. Professional in-services on epilepsy are provided to school staffs, teachers, employers

and staff of other human services agencies by skilled ESNI counselors. ESNI serves as an exhibitor at health fairs and similar events.

## **Vocational Assistance**

Persons with epilepsy often encounter unexpected obstacles in the job market. ESNI provides counseling and, when necessary, referral to special community resources such as sheltered workshops, the Department of Rehabilitation Services, the Private Industry Council, etc. Through ongoing support, clients are able to maximize their potential, and achieve realistic employment goals.

## **Advocacy**

ESNI is prepared to vigorously intercede on behalf of clients whenever and wherever needed. This includes employers, HMO organizations, schools, insurance providers, as well as national, state, county and community government agencies.

**Call ESNI at  
847-433-8960**

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