

2ND ANNUAL SEIZE THE ROAD HUGE SUCCESS FOR NORTH LOUISIANA

Last year, only about 50 people participated in the Epilepsy Foundation of Louisiana's first Seize the Road Blow Out the Flame of Epilepsy Bike Tour and Walk for North Louisiana, raising about \$5,000. This year, however, nearly 200 people came out for the event. And event organizers expect to raise nearly \$15,000.

The event kicked off at 8 a.m., Saturday

with cyclists and bikers riding out from the Stoner Avenue boat launch off Clyde Fant Memorial Parkway on courses to Caddo and Cross lakes. "The involvement has more than doubled," said Dotty Martino, the foundation's executive director. "The money will be used to expand

services locally." Those services include a new office at 900 Market St. in Shreveport, a staff and a toll-free number where people can get doctor referrals and medication advice. The number is (800) 960-0587. The foundation also sponsors training of teachers and school nurses on how to deal with



students who have epilepsy. Martino said it also wants to educate the public about epilepsy. "There are some huge misconceptions. People need to understand what to do and what not to do." One of the more common misconceptions is that when someone is having a seizure, something needs to be put in the person's mouth.

Another is that most people get epilepsy in their early years. Martino said half the people who have it get it in adulthood. Mary Ann Heinsohn, a Shreveport educator for the foundation, who also has epilepsy, said there is a great need for these educational programs.

"I know how this can affect someone in their personal life and at work. We want to have more events like

this. It's a win-win situation for everyone in the community."

- *Shreveport Times*

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Tips for Managing Your Child's Epilepsy

MEDICAL MANAGEMENT

Become organized! Keep all of your child's information in a large binder including: medication names and dosages, seizure log, test results, contact information including Physician phone numbers, Insurance information, Therapists and School information. Questions you may have for your next visit. Bring this with you to all Doctor Visits. Follow up on lab tests, if you have lab work drawn, call your Doctor for the results. Always leave written directions for medication with babysitters and caregivers. Avoid giving over-the-counter medication and

"natural" herbal supplements to your child without asking your Neurologist first. Also there are some Antibiotics that your child **CANNOT** take with their seizure medication, so be sure your Pediatrician knows which seizure medication your child is on.

ACTIVITY AND SPORTS

- Remember lack of sleep may increase their risk for having a seizure. It is recommended that children and teens get 9 hours of sleep per night. - Children whose seizures are well controlled generally don't have restrictions on activity or sports but this should

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**SAVE
THE
DATE!**

**SATURDAY,
APRIL 26, 2008**

4th Annual Seize the Day

5K run/walk &

Community Awareness Day

Start your team now!

Someone from the winning team will win a cruise for 2!

Visit our website to

start your team:

www.epilepsylouisiana.org

FOUNDATION NEWS

MESSAGE FROM THE DIRECTOR:

Sometimes hard work really pays off and because of this hard work the Epilepsy Foundation of Louisiana continues to reach milestones. We have just become certified as an agency meeting the "standards for excellence" from the Louisiana Association of Non-Profit Organizations (LANO). Thanks to Kelly Aprill for her technical help in achieving this goal. Please help me in welcoming two new Foundation members. Amy Nichols will begin working in Shreveport as an epilepsy educator helping to develop and conduct services for people in North Louisiana with epilepsy. Statewide, the Foundation has embarked on an outreach effort to gather information about medicine reactions when generic substitutions are made. This effort is being led by Karen Marchand in the Baton Rouge office. We welcome both of these talented people into the Foundation fold of dedicated staff and volunteers.

- Dotty Martino
Executive Director

Welcome Amy Nichols!

We are pleased to announce that Amy Nichols has joined our team. Amy is a native of the Shreveport area and is a wife and mother of three daughters. She has held numerous volunteer positions through the Junior League of Shreveport, her children's schools and her church. She joins our team as the Epilepsy Educator for North Louisiana. Amy says, "the main bit about myself is that my children are my life. I have loved every minute that I have been their mother, but they are moving on with their lives and I am now looking forward to giving the energy that I once shared with them to others". Please join us in welcoming Amy to the Epilepsy Foundation. I know that we will be seeing great things from her in the Shreveport area. Amy can be reached at amy@epilepsylouisiana.org.

Take the Challenge

The Huey & Angelina Wilson Foundation has challenged the Epilepsy Foundation of Louisiana to raise \$25,000.00. If we can raise \$25,000.00 they will match it. Therefore, we need your help in raising this money. To make a donation towards this challenge call our office at 800-960-0587 and ask for Dotty or Holly or simply go to our secure online donation form. To make an online donation go to www.epilepsylouisiana.org and click on How to Help".



Raise Money for Epilepsy & Go to Hawaii for FREE!

Here's how it works:

Anyone who raise more than \$1500 in sponsorship/contributions will be eligible for travel awards based on amount raised. More importantly, we will be partnering with many organizations around the country to promote this event and if you register identifying one of these agencies, all net proceeds from the money you raise will be split evenly between the Epilepsy Foundation of Hawaii and the partnering agency. Participating riders will receive the following packages at the following sponsorship levels.

- a. \$1500 – roundtrip airfare from **NEIGHBOR ISLAND** plus one night lodging on Oahu, airport transfer, participation in event
- b. \$2500 – Three nights lodging, airport transfer, participation in event (air transportation is NOT included)
- c. \$4500 – Roundtrip air transportation* from **MAINLAND US CITY**, three nights lodging, airport transfer, participation in event
- d. \$7000 - Roundtrip air transportation* for two people from **MAINLAND US CITY**, three nights double occupancy (both participants share room) lodging, airport transfer, participation in event

SUPPORT THE FOUNDATION BY SELLING ON EBAY

Dotty Martino, Executive Director

Once again, the Foundation is moving in creative ways to develop support for the services that are crucial for people with epilepsy and seizure disorder in Louisiana. As the only agency of its type that exclusively does this, we welcome your support which allows us to continue.



The new Epilepsy Foundation of Louisiana's "E-Store" is officially open. To visit our E-store simply go to www.epilepsylouisiana.org and click on **Sell now to support our cause logo**. This

exciting new fund raising effort allows us to sell donated items regularly and create our own internal source of revenue. What we need from you is consideration of a donation of items that you wish to give to us and allow for resale at the new E-Store. The process is simple. If you have an item to donate, go to ebay and list your item, choose support a cause and choose Epilepsy Foundation of Louisiana. If you do not want to list the item contact the Foundation at 800-960-0587 and speak to either Dotty or Holly. They will be able to complete the necessary paperwork for you to make the donation and make necessary arrangements about the donation. The Foundation will then in turn send you a letter documenting the donation once it is received at our

office, which is tax deductible. We do suggest that you consult your own tax advisor in regards to this type of donation to ensure its appropriateness as a charitable tax donation.

So please take some time, look around and think about something you might not really want any longer, and donate it to the Foundation. We will be selling items on E-Bay in our store. It's a great way to empty your overstuffed closets and help the Foundation at the same time. Or, you can take this letter to local vendors and ask them to donate a gift certificate for dinner, show, or any other exciting event in your area. These items are often regarded well and sell easily.

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always be discussed with your Physician. Children should always wear a helmet when riding a bike. Children should **NEVER** swim or bathe unsupervised. Adolescents must be seizure free for 6 months before driving. Parents should pick activities and sports that build self-esteem in children.

SCHOOL AND BEHAVIOR

-Talk to your child's school nurse about their individual seizure plan. -Sometimes attention, learning and behavioral difficulties are common in children with epilepsy. -Some anti-epileptic medications also can effect attention, learning and behavior in your child. - Physicians try to prescribe medications with the least side effects, so if your child develops an attention, learning or behavioral problem this may or may not be related to their medication. Talk to your child's Neurologist about any concerns or questions you have about their treatment and care.



Debbie Gahagan was raised in New Orleans. She graduated from LSU and Our Lady of the Lake School of Nursing. She received her Bachelor Degree in Nursing from Loyola University, New Orleans, and her Masters of Science in Nursing in Advanced Child Health from the University of South Alabama, Mobile. Debbie is board certified by the National Certification Board of Pediatric Nurse Practitioners and Nurses, and a Fellow in the National Association of Pediatric Nurses Practitioners. She has seventeen years of pediatric and pediatric intensive care nursing experience. Debbie joined the clinic in 2002.

HAVE A QUESTION FOR ONE OF OUR EXPERTS? EMAIL QUESTIONS TO INFO@EPILEPSYLOUISIANA.ORG.



PARTICIPATE IN EPILEPSY RESEARCH

THE FOLLOWING STUDIES ARE ONGOING &
LOOKING FOR PARTICIPANTS

Lexapro Study for Depression in Persons with Temporal Lobe Epilepsy

Forest Pharmaceuticals is sponsoring a clinical trial at the LSU Behavioral Sciences Clinic in New Orleans for persons who are 18 to 65 years of age with temporal lobe epilepsy and suffer from depression. Persons who meet the study criteria and are willing to participate will receive Lexapro for 10 weeks. Study visits and study medication costs will be covered by the Sponsor. Persons interested in getting more detailed study information should e-mail the study coordinator at epicenter@lsuhsc.edu. Please provide your name, e-mail address or telephone number and the study in which you are interested.

Lacosamide Monotherapy Trial for Partial Seizures

Schwarz Biosciences is sponsoring a multi-site clinical trial for persons 16 to 70 years with a diagnosis of partial seizures. Persons who meet the study criteria and are willing to participate will receive either 300 mg per day or 400 mg per day of Lacosamide for up to 20 weeks with a potential option to enter an open-label trial. Study visits and study medication costs will be covered by the Sponsor (Schwarz). Persons interested in getting more detailed study information should e-mail the study coordinator for the LSU Epilepsy Center of Excellence in New Orleans at epicenter@lsuhsc.edu. Please provide your name, e-mail address or telephone number and the study in which you are interested.

Depression & Epilepsy

If you are 18-65 and have been diagnosed with temporal lobe epilepsy and major depressive disorder then you may be eligible to participate in a clinical research trial being conducted by Dr. Erich Conrad at the LSU Health Sciences Center Anxiety & Mood Disorders Clinic. To learn more about this study, please call (504) 897-8559. Study participants will receive investigational study drug or placebo and study related tests at no cost. Compensation for time and travel may be available. Call the LSUHSC Anxiety & Mood Disorders Clinic at (504) 897-8559

NEW SEIZURE TRACKING SOFTWARE



NeoMed Software LLC (www.neomedsoft.com) launched EpiTrax, its advanced seizure diary software for seizure tracking, in April 2007. The easy-to-use, downloadable software was designed by Eric Schumacher, a former member of the board of the Epilepsy

Foundation of Greater Los Angeles, who has lived with complex partial seizures for more than 20 years. The application gives patients with epilepsy and their loved ones the ability to track, analyze and share every detail of their seizure activity while offering their physicians additional information to help diagnose seizures and apply proper therapies. Available for Windows only, EpiTrax costs \$49.99 and

can be downloaded from the NeoMed Software web site at www.neomedsoft.com.

EpiTrax has met with a great initial response from doctors and patients alike. "I was impressed by EpiTrax," said Dr. John Stern, Associate Professor of Neurology and Co-Director of the Seizure Disorder Center at UCLA's Geffen School of Medicine. "With EpiTrax, patients and their families can gather the detailed information that helps neurologists more clearly understand their patients' conditions. The reports that EpiTrax produces simplify patient-doctor communication and help doctors make better treatment decisions."

To buy your copy today, or to sign up for a 30-day free trial, go to: www.neomedsoft.com.



Seizure Type:
Complex Partial
Diagnosed: 7months



Louisiana Faces of Epilepsy

Amelia Grace is 6 years old and is a 1st grader at St. Aloysius in Baton Rouge. Amelia was diagnosed with epilepsy at 7 months old and was put on medication at having four seizures. Two years later Amelia was seizure free. At age four Amelia began having seizures again and had her first abnormal EEG and was put back on medication. Amelia is a happy 6 six year old . Here is what Amelia had to say about living with epilepsy.

- 1. **What is epilepsy?** *Amelia: "Epilepsy is seizures and you have to take medicine."*
- 2. **What is the hardest thing about having epilepsy?** *Amelia: "Sometimes you use the bathroom on yourself and remembering to take your medicine".*

- 3. **What would you like people to know about epilepsy?** *Amelia: "That there is an epilepsy walk".*
- 4. **What would you like people to know about you?** *Amelia's mom: "That she is a normal little girl that sometimes has seizures.*
- 5. **Does having epilepsy prevent you from doing anything you would like to do?** *Amelia: "No".*
- 6. **How would you describe a seizure? What does it feel like?** *Amelia: "You use the bathroom on yourself and feel tired".*
- 7. **Are your friends accepting of your epilepsy? Do people pick on you?** *Amelia's Mom: "Her friends are nice and don't care that she has seizures.*

Community Resource Spotlight: LSU Psychological Services

BY: KASSIE CAMPBELL, EFLA STAFF

William P. Johnston Hall, LSU Campus, **Phone:** (225)578-1494, **Hours:** Mon-Thurs 8am – 8pm; Friday 8am – 4:30pm

LSU Psychological Services Center (PSC) offers diagnostic and outpatient therapeutic psychological services for adults, adolescents and children. The center is open to anyone in the area and fees for services are based on a sliding scale considering income and ability to pay. The PSC is equipped to treat a variety of psychological and emotional disorders, such as depression, anxiety, eating disorders and substance abuse. Clients are seen by Clinical Psychology doctoral students. Students are directly supervised by faculty of the Dept of Psychology who are licensed clinical and school psychologists.

Clients are scheduled for an intake evaluation session as they call the PSC. Based upon this evaluation, clients are referred for appropriate treatment. Services include psychological testing and cognitive-behavioral group and individual therapy for adults, adolescents and children. Costs for individual therapy sessions range between \$15 and \$60 per session. Group therapy sessions are approximately half the cost of individual sessions. Therapy groups include those for depression, anxiety, smoking

cessation, stress management and substance abuse education and intervention.

Child services are provided to children between the ages of 2 and 17 and include various testing and treatment services. Psychoeducational, intelligence and achievement testing as well as testing for ADHD, learning disabilities and autism are offered. Cognitive-behavioral and behavioral therapy are provided for ADHD, depression, anxiety and autism. All child services are supervised by faculty specializing in child clinical and school psychology.

New Stimulation Devices for Epilepsy

- **Intercept Epilepsy Control System** is a new system targeted to treat drug resistant epilepsy and is sponsored by Medtronic, Inc. As an implanted device providing direct stimulation to the brain, the therapy is designed to disrupt the circuits suspected of influencing epileptic seizures. With three implantable components: a neurostimulator (implanted in the chest), extensions and leads, the total system stimulates the anterior nucleus of thalamus area of the brain. The electrical pulses generated by the system are delivered to the brain to combat the onset of a seizure. Similar treatment is FDA approved for Parkinson's disease and Essential Tremor Disorder in the U.S. The study has recently been completed with 110 patients implanted in the U.S. and Canada. Results are expected in early 2008

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- **Responsive Neurostimulator System (RNS)** is another device also in clinical trials sponsored by Neuropace, Inc. This device was also designed to treat persons with drug resistant epilepsy. The system detects abnormal electrical activity in the brain and delivers small amounts of electrical stimulation to suppress the onset of seizures. RNS is completely implanted under the skull with wires leading to implanted electrodes. The entire system is encompassed under the skin. Early results show that 29-64% of 38 subjects had greater than 50 percent reduction in seizure frequency, depending on seizure type. This study is actively recruiting participants with intractable partial onset epilepsy in several U.S. centers. Follow the link in the resources section to learn more.
- **Transcranial Magnetic Stimulation (TMS)** is currently used to treat depression and is now being studied for refractory epilepsies. The National Institutes of

Health is recruiting participants who have seizures originating from a neocortical focus near the surface of the brain for this study. TMS creates a brief pulse in a circular magnetic coil which produces a magnetic field passing through that coil. The magnetic field is then conducted through the skull and converted to an electrical current when it reaches the brain. This early stage trial is still limited to near surface seizure areas of the brain.

- **Surface Stimulation.** One final novel treatment involves the use of surface stimulation. Dr. Christopher DeGiorgio from the Neurology Department at UCLA reported that 4 of 7 subjects in a small study who completed three months of stimulation experienced a 50% or greater reduction in seizure frequency. The treatment included the use of trigeminal nerve stimulation using the Advanced Bionics EMS 4000 surface stimulation device. This is the first step is demonstrating the use of non-implanted devices for the treatment of epilepsy. Future studies in this area are currently unknown. **For more information visit www.neurotechnetwork.org**

Support Groups Around the State

New Orleans

7:00 p.m. - 8:00 p.m.
Third Thursday of the month
St. Frances Xavier Parish Center
444 Metairie Road, Metairie.

Baton Rouge

7:00 p.m.— 8:30p.m.
Third Thursday of the month
10101 Park Rowe Circle
Baton Rouge

Shreveport

Christus Schumpert
One St. Mary Place
Visit our website for dates
and times

Reach any of our offices at: **800-960-0587**

New Orleans Office

3701 Canal Street Ste. H
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504-486-6326
neworleans@epilepsylouisiana.org

Baton Rouge Office

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Visit Us Online at: **www.epilepsylouisiana.org**



Our Mission

The Epilepsy Foundation of Louisiana will ensure that people with seizures are able to participate in all life experiences; and will prevent, control and cure epilepsy through services, education, advocacy and research. The Epilepsy Foundation is a not-for-profit, volunteer health agency and an affiliate of the national Epilepsy Foundation.

Disclaimer: *The information in this newsletter is for informational purposes only, and should NOT be construed as any type of medical or legal advice or treatment. The Epilepsy Foundation of Louisiana does not recommend any one product, treatment, or trial. All cases of epilepsy are different and only a certified physician can properly treat any given individual.*