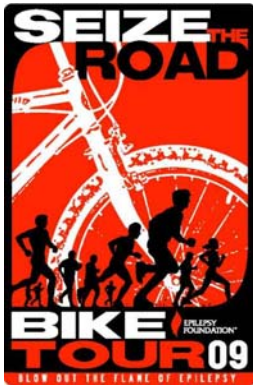




# Epilepsy Connection

## 2009 SEIZE THE ROAD BIKE TOUR AND FUN WALK



It's that time again. The 4<sup>th</sup> annual Seize the Road Bike Tour & Fun Walk for Education and Awareness for Epilepsy will be held on Saturday, September 26, 2009. The start will be at the Stoner Skate Board Park on Clyde Fant Parkway. The Bike Tour will rollout at 8 a.m. and the Fun Walk will begin at 9:00 a.m. There will be "Facts about Epilepsy" signs all along the different routes and lunch will be served afterwards for all participants.

The Bike Routes are 17, 41, 52 and 60 miles past Cross Lake and Caddo Lake. You will ride through the scenic north Caddo Parish taking you through the towns of Blanchard and Mooringsport. We will have a motorcycle crew escort the race through Shreveport and then the Caddo Parish Sheriff's Association will pick up the riders outside the city to direct the route. Along the Bike Tour Route there will be four (4) fully-stocked rest stops that will provide drinks, fruit, and cookies. The routes can be seen

at [www.seizetheroad.org](http://www.seizetheroad.org). The Fun Walk's participants will walk, jog or run along the path beside the Red River down to the fountains across from Sci-Port (the children's science museum). A fully-stocked rest stop will be furnished at the half-way point.

The fees for the race are \$25.00 (with a T-shirt) prior to September 21 and \$35.00 afterwards. Race day entry fees are \$25.00 (without a T-shirt). You can make a "Flame-worthy donation" for \$25.00 if you are unable to participate and would still like to receive a T-shirt. Children 12-years of age and under partake free with each paid adult participant.

How do you join us? How can you help? Want to start a team? Be a team captain? Challenge other groups to form teams! You can register by Mail at:

Epilepsy Foundation of Louisiana Attn: Seize the Road Bike Tour, P. O. Box 52205 Shreveport, LA 71135 (postmarked by Sept. 21<sup>st</sup> for \$25.00) By phone: (800) 960-0857 or (318) 402-6752

Online: [www.seizetheroad.org](http://www.seizetheroad.org) or [www.sportspectrumusa.com](http://www.sportspectrumusa.com)

- Race packets will be handed out at registration or may be picked up in advance from Sportspectrum Friday, September 25<sup>th</sup> from 10 a.m. through 6 p.m.

Start your team today and support epilepsy  
in North Louisiana.



### 2009 Expressions of Courage® Art Contest for People with Epilepsy

*Expressions of Courage*®, a national contest for people with epilepsy, showcases the talent and inspiration of people across the country living with epilepsy. The Epilepsy Foundation encourages people of all ages diagnosed with epilepsy to submit artwork for this year's contest. The contest will be open for entries from May 11, 2009 through August 28, 2009. A panel of epilepsy advocates, art industry representatives and healthcare experts will serve as contest judges and will announce the winning artwork in November. Entries are judged based on creativity and the ability to bring to life the experiences of living with epilepsy. Visit our website for more information [www.epilepsyloouisiana.org](http://www.epilepsyloouisiana.org).

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### BACK TO SCHOOL & EPILEPSY

School is right around the corner and it's time to Take Charge.

- Have a seizure plan
- Talk to your child's teachers.
- If your child has an IEP make sure it is complete and in place.

The Epilepsy Foundation of Louisiana offers FREE training to school staff, nurses, and teachers. If you are interested please contact us at

800-960-0587 or email [info@epilepsyloouisiana.org](mailto:info@epilepsyloouisiana.org)



# What Laws Apply to Children with Epilepsy?



Three laws in particular apply to children with epilepsy as well as children with other disabilities. The Individuals with Disabilities Education Act (IDEA)

governs the provision of early intervention services to infants and toddlers as well as education services to children ages three through 21. Section 504 of the

Rehabilitation Act of 1973 (usually referred to simply as Section 504) is a general anti-discrimination law that prohibits disability discrimination in federally funded and federally conducted programs and activities such as public schools. Finally, the Americans with Disabilities Act (ADA) is a law that prohibits disability-based discrimination in state and local government activities such as parks and recreation programs and schools, and in programs and public accommodations such as businesses, child care programs and doctors' offices.

## MAJOR PROVISIONS OF IDEA:

The IDEA guarantees a "free appropriate public education" to children with disabilities that "emphasizes special education and related services designed to meet their unique needs and prepare them for fur-

ther education, employment, and independent living." 20 U.S.C. 1401(d)(1)(A); 34 C.F.R. 300.1. Children are entitled to receive special education and related services in the least restrictive environment in which the services can be provided. The services are provided in accordance with an individualized education program (IEP).

## What is a "free appropriate public education?"

A free appropriate public education means special education and related services that are provided at public expense, under public supervision, at no cost to the child's parent or guardian. These services must meet the standards of the state department of education, and the applicable requirements of the IDEA and its implementing regulations, and must include an appropriate educational program for the child, provided in accord with the IEP. 20 U.S.C. 1401(a)(9); 34 C.F.R. 300.17. Generally, an "appropriate" education has been found by courts to be one that enables children to make meaningful educational progress.<sup>7</sup>

\* Information taken from *Legal Rights of Children with Epilepsy in School & Child Care*. For more information on this topic please contact our office at 800-960-0587 or through email at [info@epilepsyloisiana.org](mailto:info@epilepsyloisiana.org)

## Foundation News:

Stay up to date with all the epilepsy news around the state by signing up for our e alerts.

Visit our website for more information:

[www.epilepsyloisiana.org](http://www.epilepsyloisiana.org)

## EPILEPSY SUPPORT GROUPS AROUND THE STATE:

- **Baton Rouge:** 3rd Thursday of every month. (10101 Park Rowe) 7:00-8:30 pm
- **New Orleans:** 3rd Thursday of every month. (East Jefferson General Hospital, 4200 Houma Blvd., Foundation Board Room, Metairie)
- **Shreveport:** 2nd Tuesday, every other month (Christus Schumpert) 6:00pm
- **Lafayette:** 1st Wednesday of every month. (Southwest Medical Center, 4212 W. Congress, meeting room 1) 6:30pm



## Message From the Director

I am amazed at how fast time passes and sometimes I talk and wonder if anyone hears me!

Summer is almost over and it seems that we have just begun. There are new projects in the works at the Foundation and I would like to invite all of you to participate. The first is a new project that is rolling out nationally called "Talk About It". This is a dinner program that people sponsor/offer in their communities to help raise awareness and funding for local affiliates. Below is the logo and we have an entire set of materials if any of you want to sponsor one:



Please contact me if you are interested in sponsoring a dinner in your home or community so that we can begin working on it together.

Our second new adventure has begun in Baton Rouge. We now sponsor BINGO and call the games monthly at the Crystal Palace. We rotate calling Bingo with four other charities so contact us before coming

([www.epilepsylouisiana.org](http://www.epilepsylouisiana.org)) so that we can direct you to our games. It's a wonderful way to support the Foundation while having some fun with others playing the game. We will sponsor an "Epilepsy Night of Bingo" and will alert you of this scheduled event so all can come and play and hopefully meet other people with epilepsy.

Summer camp was held in Monroe at Med Camp, Inc. the week after the 4<sup>th</sup> of July. A great time was had by all and I want to thank any/all people that contributed to this event. Thanks to Parents Against Childhood Epilepsy (PACE) for their on-going support of this event. Their grant makes it possible for our children to participate in this important outing.

Services continue across the state. Shreveport continues to conduct its support group and will sponsor a bike tour in September [www.seizetheroad.org](http://www.seizetheroad.org).

Greater New Orleans' support group is moving to East Jefferson Hospital this month. Trainings across the state continue and we are making an impact.

I cannot close however, without thanking all of the folks that participated in Baton Rouge's Seize the Day race in April. We reached a milestone of having more than 1000 walkers/runners and raised money to support on going services. Thanks to Kassie, Holly, Dr. Hollman, Jolie, Kelly, and everyone else for their sweat and tears. Also, I cannot close without taking the time to once again remember Kathleen, who was recognized at the event. She passed away last year due to an accident during a seizure and her family/friends all joined us to remember her. It was and continues to be a sad reminder of why this work is so very important. Lets all take the time to remember Kathleen and how her life reminds us of just how fragile it can be and also how important this work is.

Thanks for listening,

*Dotty Martino, LCSW*

Dotty Martino, LCSW  
Executive Director



## FDA approves Lamictal®XR, a Once-daily Treatment for Epilepsy

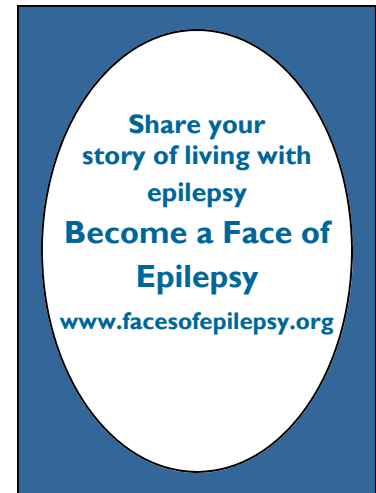
The FDA recently approved Lamictal®XR™ (lamotrigine) Extended-Release Tablets as once-a-day add-on therapy for epilepsy patients 13 years of age or older with partial onset seizures. *Lamictal XR* reduced seizures in patients who were inadequately controlled on current therapy. *Lamictal XR* reduced the frequency of partial seizures during a 19-week study. More patients who took *Lamictal XR* had a significant reduction in seizure frequency compared with placebo.

*Lamictal XR* is approved as add-on therapy for adult and adolescent patients who experience partial seizures with or without secondary generalization. Partial seizures, which are limited to one part of the brain, are the most common

type of seizure experienced by people with epilepsy. Partial seizures may sometimes spread to affect the entire brain, an occurrence classified as secondary generalization. The safety and effectiveness of *Lamictal XR* have not been established in patients under the age of 13.

Patients with partial seizures currently taking immediate-release *Lamictal* twice-daily can be converted directly to once-a-day *Lamictal XR* using the same total daily dose. *Lamictal XR* will be available in pharmacies this summer.

*Reviewed by Epilepsy Foundation Professional Advisory Board member, Brian Alldredge, PharmD.*



## Epilepsy Research

### Adjunctive Therapy Study with Oxcarbazepine XR for Partial Seizures

Supernus is sponsoring a clinical trial at the LSUHSC Epilepsy Center in New Orleans where eligible candidates will be 18 to 65 years and experiencing partial epileptic seizures. Those meeting the study criteria who are willing to participate will receive either one of two strengths of the study drug or placebo for up to 23 weeks as adjunctive treatment (in addition to their other antiepileptic medications) for their partial seizures. Study visits and study medication costs will be covered by the Sponsor. At the end of the study, there may be an option to extend treatment with the study drug. Anyone interested in getting more detailed study information should e-mail the study coordinator at [epicenter@lsuhsc.edu](mailto:epicenter@lsuhsc.edu). Please provide your name, e-mail address or telephone number and the study in which you are interested.

### Monotherapy Study with Lyrica for Partial Seizures

Pfizer is sponsoring a clinical trial at the LSUHSC Epilepsy Center in New Orleans where eligible candidates will be 18 years or older and experiencing partial epileptic seizures. Those meeting the additional study criteria and willing to participate will receive one of two doses of the study drug for 20 weeks as treatment for their partial seizures. Study visits and study medication costs will be covered by the Sponsor. At the end of the study, there may be an option to extend treatment with the study drug for about 6 months. Anyone interested in getting more detailed study information should e-mail the study coordinator at [epicenter@lsuhsc.edu](mailto:epicenter@lsuhsc.edu). Please provide your name, e-mail address or telephone number and the study in which you are interested.

*"This listing of epilepsy clinical trials is for information purposes only; and the reader assumes full responsibility and risk for the appropriate use of the information provided. The information concerning the trial has been provided by the investigator; the Epilepsy Foundation, its affiliates, officers, directors, employees and agents do not warrant or guarantee the accuracy or completeness of this information and specifically disclaims any liability therefore."*



## Children's Lives May be Endangered as Child Care Centers Refuse to Administer Emergency Medication

Landover, MD (March 13, 2008) — The Epilepsy Foundation recently joined in a lawsuit against a national chain of child care centers that refuses to administer a potentially life-saving medication to children with epilepsy. The suit was originally filed on behalf of an 8-year-old California boy when a Tutor Time Learning Centers, LLC, child care center refused to administer diazepam rectal gel (sold under the brand name Diastat AcuDial). The Foundation has joined the lawsuit as a plaintiff to represent the many children with epilepsy around the country who may have been prevented from attending any of the 200 child care centers affiliated with the Tutor Time chain because of their refusal to administer this medication.

Diastat AcuDial is the standard out-of-hospital FDA-approved medication for prolonged seizures, which may cause brain injury or death if not promptly treated. It was specifically approved by the FDA for administration by people without medical training—such as parents, child care workers and school personnel—who can do so safely and easily. Children with epilepsy are particularly susceptible to prolonged seizures that may cause serious brain injury or death if not promptly treated, yet the child care provider's only plan was to call 911. "Most child care providers quickly understand that administering this medication is the right and necessary action to

take," said Eric R. Hargis, president and CEO of the Epilepsy Foundation. "Unfortunately, many other providers do not understand and may put children at risk and create an unnecessary burden on families who cannot find safe child care."

Because the Americans with Disabilities Act prohibits discrimination against people with disabilities in public accommodations, including child care centers, Tutor Time must modify its policy against administering this medication to afford children with epilepsy equal access to the company's services. Tutor Time has provided no reasonable justification for its policy. "When a patient begins to have prolonged or recurrent seizures outside of their normal patterns, it's [a condition] that needs to be treated immediately," said James W. Wheless, M.D., professor and chief of pediatric neurology at the University of Tennessee Health Science Center. "In the United States, the amount of time that typically elapses between the onset of a seizure and a patient receiving treatment at a hospital can exceed one hour. That's too long [to rely on 911 for treatment]. [Diazepam rectal gel] is a safe, effective treatment."

A similar lawsuit against an Army-operated child care center that refuses to administer diazepam rectal gel is currently pending in Kentucky.

## Advocacy Update

On March 6<sup>th</sup>, a mere three months ago, I began writing monthly "Advocacy Updates". In these updates, I talk about both state and federal issues that involve legislation relative to epilepsy. I also read articles and share information I hope you find prevalent.

After looking back over these past three months, I have noticed we have definitely been making the news. In April we made the cover of *Newsweek* and had numerous articles in the edition. In May music legend, Prince, spoke for the first time about his childhood epilepsy. Then MSNBC gave coverage to "therapeutic substitution" and the roles you, your doctor and your pharmacist play in making decisions that affect your health care. Epilepsy has received "Today's Show" coverage and been on "PBS". And just this

month, in the newly released movie, "My Sister's Keeper" based on the best selling novel (of the same name) by Jodi Picoult; a main-character, Campbell Alexander, a highly-successful lawyer, has epilepsy, suffers a seizure outside the courtroom and uses the services of a seizure-alert dog. The movie is excellent, but all I could think about is how much national coverage epilepsy was getting from the movie.

The Foundation of Louisiana is working on developing a "grass roots" effort to continue the education and awareness through advocacy. Right now, my monthly updates only go out in an E-blast form to those who signed up to receive information about advocacy. If you are not re-

*(Continued on page 6)*

(Continued from page 5)

ceiving an Advocacy Update and would like to receive one, just email me at [amy@epilepsylouisiana.org](mailto:amy@epilepsylouisiana.org) or [holly@epilepsylouisiana.org](mailto:holly@epilepsylouisiana.org) to get on the list.

Last month I wrote about “therapeutic substitution” and generic brand medication verses name-brand medication. In July, I am going to share with you how to “Take Generics Safely”.

Everyone is doing a great job of getting the word out about epilepsy but we have to continue. We need to tell everyone: Epilepsy is a chronic neurological disorder characterized by a tendency to have recurrent seizures. We need to talk about it to lose the negative stigma associated with epilepsy. Go to our national campaign website, [www.Talkaboutit.org](http://www.Talkaboutit.org) where stars like John Mayer and Jennifer Garner are encouraging everyone to be open about epilepsy.

# BINGO

We now sponsor bingo and call games  
monthly at  
Crystal Palace

4065 Florida Blvd., Suite Z, Baton Rouge, LA

It's a great way to support the Foundation and have  
fun at the same time.

We rotate calling  
bingo with 4 other  
charities, so join us  
for one of our  
August sessions.

- August 1 - 2:00pm
- August 2 - 8:00pm
- August 3 - 2:00pm
- August 10 - 2:00pm
- August 11 - 2:00pm
- August 13 - 8:00pm
- August 14 - 2:00pm
- August 17 - 8:00pm
- August 18 - 2:00pm
- August 20 - 2:00pm
- August 23 - 8:00pm
- August 24 - 2:00pm
- August 27 - 2:00pm
- August 30 - 8:00pm
- August 31 - 2:00pm

Doors open 30 minutes prior to game.



**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.