

# THE ILLUMINATOR

A Publication of the Epilepsy Foundation of Kentuckiana

ISSUE 2 - 2010

LIGHTING THE PATH FOR A BRIGHTER TOMORROW

## TREATMENT OF FOUR CHRONIC HEALTH CONDITIONS REVIEWED IN KENTUCKY'S SCHOOLS

In 2009, Kentucky's *Program Review and Investigations Committee* assigned a group of individuals, called the *Legislative Research Commission (LRC)*, to conduct a review in the role that schools play in caring for students with four potentially life-threatening chronic health conditions. These conditions were epilepsy, asthma, diabetes and severe allergies. The *Epilepsy Foundation of Kentuckiana*, as well as the *American Diabetes Association*, *Juvenile Diabetes Research Foundation*, *American Lung Association*, *Kentucky Families with Food Allergies*, *Kentucky School Nurses Association*, *Kentucky School Boards Association*, *Kentucky Education Association* and *Kentucky School Counselors Association* were involved with this review process.

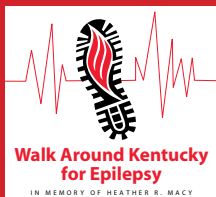
To assist the *LRC* with the review, the *Epilepsy Foundation* held a focus group of parents of children with epilepsy from different parts of the state to share their experiences with the public schools. Parents were able to voice their concerns and frustrations with their child's school directly to the *LRC*. The meeting contained many testimonials from the parents regarding the lack of knowledge and training school faculty and staff had to properly administer seizure first aid to students. Many parents reported that schools were not following individualized education plans (IEPs), 504 plans and/or health care plans for their child. Some parents shared that their child had been excluded from field trips and extracurricular activities if a family member was not present to assist in the event of a seizure.

The *LRC* compiled this information into a report and then presented it to the *Program Review and Investigations Committee* during their meeting in June, 2010. If you would like to see how Kentucky's schools measure up in the treatment of children with epilepsy, asthma, diabetes and severe allergies, go to [http://www.lrc.ky.gov/minutes/prog\\_rev/100708OK.HTM](http://www.lrc.ky.gov/minutes/prog_rev/100708OK.HTM) to review the minutes from this meeting.

The *Epilepsy Foundation of Kentuckiana* would like to thank members of the *Program Review and Investigations Committee* for charging the *LRC* with the investigation of school health services for students with these four chronic health conditions in Kentucky. While we feel this is a great first step for making sure children with epilepsy, asthma, diabetes and severe allergies are safe at school, the *EFKY* staff hopes the *Committee* will move forward to quickly make the necessary changes to improve health services for students impacted by these four chronic life-threatening health conditions. We would also like to thank the members of the *LRC* staff, Van Knowles, Lora Littleton and Rkia Rhib, for their commitment to this review, as well as the parents who shared their experiences with the *LRC* at our focus group.

Go to [www.lrc.ky.gov](http://www.lrc.ky.gov) to view a listing of committee members, or to leave a message regarding your own concern, call 1-800-372-7181.

The *Program Review and Investigations Committee* is a 16-member, bipartisan committee authorized under *KRS Chapter 6*. The *Committee* is empowered to review the operations of state agencies and programs, to determine whether funds are being spent for the purposes for which they were appropriated, to evaluate the efficiency of program operations and to evaluate the impact of state government reorganizations. State agencies are obligated to correct operational problems identified by the committee and must implement the committee's recommendations or propose suitable alternatives.



WRAP-UP AND  
PHOTO GALLERY  
INSIDE





## MISSION STATEMENT

The Epilepsy Foundation 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.

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## FROM THE EXECUTIVE DIRECTOR

The *Epilepsy Foundation of Kentuckiana (EFKY)* and *Brain Injury Alliance of Kentucky (BIAK)* were granted \$200,000 each in state funds from the *Kentucky Department of Veterans Affairs* to develop a program to provide high quality support services to veterans who have sustained a traumatic brain injury (TBI) and/or developed post-traumatic epilepsy (PTE). This program is very important as TBI has become the signature wound of the conflicts in Afghanistan and Iraq due to the wide-spread use of improvised explosive devices (IEDs). Tragically, as many as 50% of the service men and women that sustain a TBI in combat will also develop PTE, a seizure disorder caused by their injury.

The *EFKY* is dedicated to developing a comprehensive program for individuals impacted by TBI and PTE. The *EFKY* is also very excited to be working with the *BIAK* on various projects to develop this comprehensive support services program for veterans. Our agencies are currently collaborating on a training video for health care professionals regarding TBI and PTE. Many medical professionals are not as knowledgeable about TBI and PTE as would be a neurologist; therefore it is very important for our agencies to educate healthcare professionals who are treating veterans about the symptoms of these disorders in order to increase the speed of diagnosis and treatment of these conditions. The faster one receives the appropriate treatment for TBI and/or PTE, the better the chance of minimizing the effects of these disorders. The concept of the video is two-fold. It is designed to train both medical professionals who are actually going to the middle east to treat wounded soldiers, as well as physicians working in rural Kentucky about the symptoms and treatment of TBI and PTE. We believe this video will improve the quality of life for veterans with TBI and/or PTE and their family members, as well as anyone being treated for these conditions by a medical professional who has viewed this video.

Over the past 16 years of employment with the *EFKY*, I have had the privilege of watching this organization evolve into a pivotal service provider to thousands of children and adults affected by epilepsy and seizures. There have been many milestones that the agency has reached and while many have been highlights of my career, I think developing this program for our military men and women holds a most special place in my heart. It means so much to me as my father served 20 years in the *Air Force*. My experience as a military brat has definitely shaped who I am today, as well as made me passionate about providing services to our veterans.

I would like to personally thank Commissioner Lucas and his dedicated staff for working with the *EFKY* and *BIAK* to develop this program, as well as Senator Dan Seum and each member of the *Kentucky General Assembly* responsible for securing these funds for the *EFKY* and *BIAK* to make this program for veterans a reality. I would also like to thank my Dad, as well as all of our service men and women who have served or continue to serve our country. Thank you from the bottom of my heart!

# 2010 Shannon O'Daniel Memorial Scholarship Recipient

The *Epilepsy Foundation of Kentuckiana* is pleased to announce that Barbara Vanderveer of Glasgow, Kentucky is the 2010 *Shannon O'Daniel Memorial Scholarship* recipient. Barbara is a graduate of *Glasgow High School* and is currently attending *Western Kentucky University*. She is planning to major in Sports Broadcasting and considering her love of sports, she feels this is a perfect career choice.

Barbara has been a competitive swimmer most of her life and when she was diagnosed with epilepsy at age 6 her physician recommended that it was best if she did not participate in swimming. Determined to not let epilepsy change her life she refused to stop swimming and went on that year to be the high point winner in her division at the Kentucky YMCA State Championship. As she got older, she continued swimming and while she had some complications with her seizures, she never allowed herself to be embarrassed or quit.

Barbara has not let epilepsy get in the way of her life and her love of sports. She views her epilepsy as a gift because she feels that epilepsy has made her stronger and even more determined to achieve her goals. Congratulations Barbara and best wishes in your future endeavors!



## 2010 Good Works Grant from the Honorable Order of Kentucky Colonels



In September, the *Epilepsy Foundation of Kentuckiana* received a 2010 *Good Works* grant in the amount of \$2,985 from the *Honorable Order of Kentucky Colonels* to purchase a new projector for the education department, as well as to purchase educational materials to compile 250 informational packets for newly diagnosed adults with epilepsy throughout Kentucky and southern Indiana. These packets will be distributed to area neurologists for dissemination to individuals in need. The *Epilepsy Foundation of Kentuckiana* would like to thank the *Honorable Order of Kentucky Colonels* for this funding opportunity and can ensure that the funds will be used to make a difference in the lives of individuals affected by seizures and epilepsy throughout Kentucky and southern Indiana.

## Support the *Epilepsy Foundation of Kentuckiana* at Work



Does your employer allow you to give workplace donations to *Community Health Charities of Kentucky*? *Community Health Charities of Kentucky* raises funds to support over twenty well known health service agencies throughout Kentucky. In return, these health agencies, including the *Epilepsy Foundation of Kentuckiana*, provide vital support services to individuals in need. The *Foundation* relies on this financial support from *Community Health Charities* to help meet its mission, along with funds received from those participating in payroll giving campaigns with *Kentucky Charitable Campaign (KECC)* and *Combined Federal Campaign (CFC)*.

By designating your gift to the *Foundation*, you are directly benefitting the over 90,000 individuals affected by epilepsy or a seizure disorder living in Kentucky and southern Indiana. For those of you who already support the *Foundation* through payroll giving, we genuinely thank you! If donating to the *Foundation* through payroll deduction is not currently an option for you, please ask your employer to contact *Community Health Charities of Kentucky* at [www.kentucky.healthcharities.org](http://www.kentucky.healthcharities.org) or 502-581-0203 to set up a payroll giving program at your place of business.

**NOTE:** If you donate through *CFC*, please use **CFC Code: 79414** to ensure your gift is designated to the *Epilepsy Foundation of Kentuckiana*.

# ADA REGULATIONS REGARDING SERVICE ANIMALS CHANGE ON MARCH 15, 2011

On July 23, 2010, Attorney General Eric H. Holder, Jr. signed final regulations revising the *United States Department of Justice's ADA* regulations, which included a revised definition of "service animal." This final rule was published in the Federal Register September 15, 2010, and the effective date is six months after that publication. Until the effective date, existing service animals of all species will continue to be covered under the *ADA* regulations.

Effective March 15, 2011, "Service animal means any dog that is individually trained to do work or perform tasks for the benefit of an individual with a disability, including a physical, sensory, psychiatric, intellectual or other mental disability. Other species of animals, whether wild or domestic, trained or untrained, are not service animals for the purposes of this definition. The work or tasks performed by a service animal must be directly related to the handler's disability. Examples of work or tasks include, but are not limited to, assisting individuals who are blind or have low vision with navigation and other tasks, alerting individuals who are deaf or hard of hearing to the presence of people or sounds, providing non-violent protection or rescue work, pulling a wheelchair, assisting an individual during a seizure, alerting individuals to the presence of allergens, retrieving items such as medicine or the telephone, providing physical support and assistance with balance and stability to individuals with mobility disabilities and helping persons with psychiatric and neurological disabilities by preventing or interrupting impulsive or destructive behaviors. The crime deterrent effects of an animal's presence and the provision of emotional support, well-being, comfort or companionship do not constitute work or tasks for the purposes of this definition."

## KEY CHANGES INCLUDE THE FOLLOWING:

1. Only dogs will be recognized as service animals.
2. Service animals are required to be leashed or harnessed except when performing work or tasks where such tethering would interfere with the dog's ability to perform.
3. Service animals are exempt from breed bans as well as size and weight limitations.
4. Though not considered service animals, businesses are generally required to accommodate the use of miniature horses under specific conditions.

## EXISTING POLICIES THAT WERE CLARIFIED OR FORMALIZED INCLUDE THE FOLLOWING:

1. Dogs whose sole function is "the provision of emotional support, well-being, comfort, or companionship" are not considered service dogs under the *ADA*.
2. The use of service dogs for psychiatric and neurological disabilities is explicitly protected under the *ADA*.
3. "The crime deterrent effects of an animal's presence" do not qualify that animal as a service animal and "an animal individually trained to provide aggressive protection, such as an attack dog, is not appropriately considered a service animal."

## Types of working dogs

There are several different kinds of service dogs, including: guide dogs, hearing dogs, mobility dogs, seizure alert/response dogs, psychiatric service dogs and autism dogs.

## ONE OF LOUISVILLE'S PET HEROES FILMED BY CANADIAN FILM COMPANY!



On January 20, 2004, Tia Dawn Jenkins was alerted to a kitchen fire by her cat, Samantha. Samantha was able to get Tia's attention by meowing loudly in the kitchen doorway. Tia called 911 then quickly became disoriented by the smoke that was filling her apartment. With her meows, Samantha guided Tia to her pet tortoise, Shelly. Tia then scooped up Shelly and Samantha and got out of the apartment safely, which is all pretty miraculous considering Tia is sight impaired.

Many pet owners would be surprised if a cat saved their life, however Tia was not shocked by Samantha's heroic actions at all. This was not the first time Samantha has alerted Tia, who also has epilepsy, to a dangerous situation. For years, Samantha has been alerting Tia to her impending seizures by batting at her with her paws. This seizure alert behavior has been extremely beneficial by allowing Tia to get in a safe place and protect herself before her seizures begin. You might say that Samantha has become Tia's lifeline.

Over the summer, producers of the popular Canadian television show, *Pet Heroes* contacted the *Epilepsy Foundation of Kentuckiana* after coming across an old *Courier Journal* article detailing Tia and Samantha's story. Through the *Foundation*, they were able to contact Tia to see if she was interested in allowing them to film her and Samantha for a segment on their show about *Super Pets*. Tia was very excited and immediately agreed to participate. The producers even invited *Foundation* staff to be part of the segment after they learned that the *EFKY* had assisted Tia in getting Samantha certified as a service animal a number of years ago. The *Pet Heroes* film crew was fantastic to work with and Tia and the *EFKY* staff had a lot of fun during the filming of the story.

Even though *Pet Heroes* is only shown in Canada, it was a privilege to be part of the filming of this segment with Tia and *Super Pet Hero*, Samantha! Once this segment airs in Canada, the *EFKY* is hoping to receive a copy and share it on our website. Stay tuned!

Unfortunately, changes to the *Americans with Disabilities Amendments Act* regarding service animals could have a significant impact on Tia and many other disabled individuals who have service animals that are not dogs. If these new regulations affect you, please call the national *Epilepsy Foundation* at 800-332-1000 to voice your concerns.

# SOLDIERS WITH BRAIN INJURIES AT HIGHER RISK OF EPILEPSY DECADES LATER



Soldiers who receive traumatic brain injuries during war may be at a higher risk of epilepsy even decades after the brain injury occurred. The new research was published in *Neurology*, the medical journal of the *American Academy of Neurology*. "Given the better chances of survival in soldiers fighting in conflicts today, our research suggests that all veterans with a traumatic brain injury should

be routinely screened for post-traumatic epilepsy, even decades after the injury," said study author Jordan Grafman, Ph.D., of the *National Institute of Neurological Disorders and Stroke* in Bethesda, MD.

Post traumatic epilepsy is the most common cause of new-onset epilepsy in young adults, with nearly 30,000 new cases per year in the United States.

For the study, researchers asked 199 veterans who experienced a brain injury 35 years prior whether they ever had a seizure. They were also given intelligence tests. The group underwent scans to detect brain lesions.

Of the 199 people, about 44 percent developed post-traumatic epilepsy.

"For a surprising 13 percent, the post-traumatic epilepsy didn't show up until more than 14 years after the brain injury," said Grafman, "This research strongly suggests that veterans with brain injury will require long term neurology care."

The study also found that the type of seizure changed over time, often becoming more severe or causing loss of consciousness.

Reprinted from *Epilepsy USA, The Magazine of the Epilepsy Foundation* 2010: Issue 5.

## 2011 Shannon O'Daniel Memorial Scholarship Award



The *Epilepsy Foundation of Kentuckiana* is now accepting applications for the 2011 *Shannon O'Daniel Memorial Scholarship Award*. The one-year, \$1,000 scholarship is awarded to a deserving student who meets the following criteria:

- Is under a physician's care for epilepsy (also called seizure disorder)
- Is a college-bound high school senior
- Lives in Kentucky (excluding Boone, Campbell, Grant, & Kenton counties) or lives in Clark, Floyd, or Harrison Counties in Indiana.

For a copy of the application, please contact Beth Blakeley, Director of Education, at 502.584.8817 / 866.275.1078, ext. 124 / [bblakeley@efky.org](mailto:bblakeley@efky.org) or download a copy at [www.efky.org](http://www.efky.org).

**Mailed Application Submission Deadline: MUST be post-marked by May 1, 2011**

Shannon O'Daniel was a senior in college and just credits away from graduating when she died from what was attributed to SUDEP (Sudden Unexplained Death in Epilepsy). Shannon struggled to overcome the seizures that frequently disrupted her life. She did so with a determination to achieve her dreams, one of which was to receive her college diploma. In the aftermath of her tragic death, this scholarship was created to honor Shannon and her achievements.

## Join the *Epilepsy Foundation of Kentuckiana's* Youth Council!



Are you high school or college-age and affected by epilepsy? Do you want to speak up and speak out about epilepsy in your community?

The *Epilepsy Foundation of Kentuckiana* is excited to

announce that it has recently received a grant from the national *Epilepsy Foundation* and the *Centers for Disease Control and Prevention* to start a Youth Council. This group is open to all high school through college-age individuals who either have epilepsy, a parent with epilepsy, a sibling with epilepsy or are a friend to an individual with epilepsy. If you would like to join the Youth Council, please contact Beth Blakeley, MS, Director of Education at 502-637-4440 / 866-275-1078 x14 / [bblakeley@efky.org](mailto:bblakeley@efky.org). Meetings will begin in January!

This program was made possible by a grant from the *Epilepsy Foundation* and the *Centers for Disease Control and Prevention (CDC)* under grant number U58DP0006060-06. Its contents do not necessarily represent the official views of the *CDC*.



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# 2010 Walk Around Kentucky for Epilepsy

The *Epilepsy Foundation of Kentuckiana* would like to thank all who participated in the *Walk Around Kentucky for Epilepsy*. The Walks held in Owensboro, Louisville and Lexington collectively raised **\$65,163.00!**

All funds raised from the *2010 Walk Around Kentucky for Epilepsy* benefit the *Foundation's* educational and client support services. The success of our 2010 *Walk* campaign was accomplished through the hard work and dedication of our walkers, volunteers and supporters, and we thank you!



**Walk Around Kentucky  
for Epilepsy**

IN MEMORY OF HEATHER R. MACY



Mark your calendar for the 2011  
**Walk Around Kentucky for Epilepsy!**

June 11 – Owensboro Walk at Legion Park  
June 18 – Louisville Walk at the Louisville Zoo  
June 25 – Lexington Walk at Keeneland Race Course

# Lauren's Club: How a Peer-Mentoring Club Changed My Daughter's Life

by Becky Mischler



Two years ago, when our daughter was in the eighth grade at *Beaumont Middle School* in Lexington, Kentucky, the teacher of the Functional Mentally Disabled (FMD), Ms. Mary Molsky, started a peer mentoring club called *The Gummy Bears*. This club was designed to allow regular education students to help students with special needs reach their full academic potential and enhance their social skills by acting as mentors and tutors. Student mentors were instructed on how to work with students with special needs in and out of the classroom, as well as in the community. Student mentors in *The Gummy Bears* club began visiting the classroom of the FMD in the mornings before school started and also throughout the day as time allowed. They interacted with the students with special needs by playing games, working puzzles, reading books to them and helping them with their course work. As the mentors became more familiar and comfortable with the special education students, an interesting thing happened. Mentors began to talk to their friends and teachers about the club. Soon, more and more of the student body, faculty and staff became more accepting and comfortable with the students with special needs as well!

Thanks to Ms. Molsky and *The Gummy Bears* club, Lauren matured and progressed more that year than any other year at *Beaumont Middle School*. Our daughter Lauren has always been very much a "social bug" and had a lot of acquaintances, however through the club, she began to actually develop friendships. Her new friends invited her to do activities outside of school, such as go to the movies. It was such a wonderful feeling for her father and me when we would go out in the community with Lauren and students of her school would come up and talk to her. She would get so excited.

As the school-year progressed, I watched many of the club members develop values and skills that will benefit them throughout life. They developed confidence, leadership skills and courage. They were not afraid to help others see and understand that just because someone is different, they still have feelings and a need for friendship. It was fantastic to watch Lauren develop friendships through *The Gummy Bears* club and to be accepted by her peers. It was heartwarming when one of the club members was on the cheer team and asked the cheer coach and Ms. Molsky if Lauren could join the team. They worked it out and Lauren got to cheer with the squad at all of the boys and girls home basketball games. The rest of the girls on the team, the coaches and parents were all very supportive and made sure Lauren was treated just like everyone else. Soon, other students with FMD began participating in extra-curricular activities. One got to dress in uniform and sit with the football team at home games and another started running track and participating in shot put.

It was so exciting to see these children getting to participate in activities where they might not be accepted without *The Gummy Bears* club. With a little patience and understanding, the peers helped the students with disabilities reach their potential and beyond, showing many people what children with special needs are capable of with a little extra help. In talking with several parents of *The Gummy Bears* club members, they would comment that the club was really a win-win situation for all of the kids involved, and I totally agree.

As the school year was coming to an end that year, many club members who were moving on to high school, as well their parents, were concerned about whether or not this kind of club could be established at the high school. Due to the dedication of the students and their parents, a similar club, called *The Bulldog Buddies* was founded at the high school the following school year. Besides helping in the classroom of the FMD, the club also meets twice a month to plan activities and play games. Activities this year have included a back to school picnic, a bowling party, a trip to the orchard, a Halloween party and a Prom for individuals with physical and/or mental disabilities.

I am happy to say that Lauren is now a sophomore in high school and continues to make progress in several areas, especially socially. Before *The Gummy Bears* club began Lauren's 8<sup>th</sup> grade year, she did not look forward to going to school however, due to the friendships she has made, she has enjoyed it ever since! Learning seems to come more naturally for her when she works with and is encouraged by her peers. I cannot stress enough how much having a peer mentor group has changed Lauren's life. I definitely recommend that all parents of children with special needs push to get a peer mentoring club started in their child's school. You will be glad you did!

If you are interested in how to start a peer mentoring club, you can reach Mary Molsky by calling *Beaumont Middle School* at 859-381-3094 or via e-mail at [marymolsky@fayette.kyschools.us](mailto:marymolsky@fayette.kyschools.us).



## Youth Epilepsy Support Group

- WHO:** School age & affected by epilepsy... maybe you have epilepsy, or your brother, sister, or parent does. If so, we're just the group for you!!!
- WHEN:** Monthly
- WHERE:** Changes each month, so call for details!
- WHY:** To have fun, make friends, and talk & hang out with those who understand!!!

To attend, please contact Connie Costelle at  
(502) 637-4440 / (866) 275-1078 ext. 10 or e-mail [ccostelle@efky.org](mailto:ccostelle@efky.org)

EPILEPSY FOUNDATION KENTUCKIANA'S YOUTH SUPPORT GROUP IS SUPPORTED BY A GRANT (#774C) FROM KOSAIR CHARITIES.



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An independently incorporated affiliate of the Epilepsy Foundation

## SAVE THE DATE!

In honor of *Saint Valentine* being the patron saint of epilepsy, the *Epilepsy Foundation of Kentuckiana* will be hosting a free educational program just for women on Saturday, February 26, 2011. The program, *Women and Epilepsy: Making it Work* will be sponsored by *UK HealthCare Kentucky Neuroscience Institute* and *UCB, Inc.*, and is designed to educate women with epilepsy and seizures regarding the unique issues they face with epilepsy and its treatment. The program will also explain the importance of communicating with the physician and how to self-advocate in the treatment of epilepsy and seizures.

For more information, please contact Beth Blakeley, MS, Director of Education at 502.637.4440 / 866.275.1078 x14 / [bblakeley@efky.org](mailto:bblakeley@efky.org) or stay tuned to the *Foundation's* website [www.efky.org](http://www.efky.org), for more information as it becomes available.

**UKHealthCare**  
Kentucky Neuroscience Institute



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