

ALVIN P. FLANNES SUMMER CAMP CELEBRATES 20 YEARS!

2009 marked our 20th year providing a free summer camp for children with epilepsy. 20 kids participated in a full camp experience, 17 of them for the first time. Mr. and Mrs. Mike Flannes joined us as we celebrated the anniversary of camp in honor of his father, the late Alvin P. Flannes, who played an instrumental role in the establishing this life changing service for Mississippi kids living with epilepsy.



NEW WEBSITE LAUNCHED

Please take full advantage of the Epilepsy Foundation of Mississippi's new website. We will constantly update it with the latest breakthroughs in epilepsy treatment, special events, symposiums, and support group meetings. We are introducing a blog which will have the latest articles on epilepsy, as well as a forum through which one can ask questions about seizure disorders. Qualified physicians will respond to medical questions. Staff members who have lived with epilepsy themselves or have loved ones with epilepsy will be available to provide support and answers for lingering questions a client may have.

NEW/RENEWING MEMBERS

- | | |
|--------------------------------|------------------------------------|
| Mr. & Mrs. Bob Drummond | Mrs. Patricia E. Anderson |
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WHY I CHOSE A CAREER WORKING WITH PEOPLE WITH EPILEPSY

BY TERESA HILL, MSN, NP-C

I remember being on the playground at Alta Woods Baptist Church with my kindergarten class. I remember swinging higher and higher, you always wanted to be the one to swing the highest. I remember lots of commotion, a rag on my face, teachers trying to get an ambulance through the noon kindergarten pickup traffic. My mother was there within minutes, "no this was not the first time this has happened" she explained, "it has been a couple of years since the last one". She scooped me in her arms and took me to my pediatrician, for whom she had worked for many years, more family than mere medical provider.

That is my first memory of having an actual seizure. I had been told of others but had no recollection of them. "Bad hair days" otherwise known as EEG studies and the initiation of Phenobarbital followed – 1 in the morning and 2 at night up until the age of 16 yrs. Old. They wouldn't have dared used those new, unproven medications Tegretol and Depakote.

Little did I know that these events would ultimately steer me into a career centered on caring for patients and their families dealing with seizure disorders, epilepsy, and other neurological conditions. I was never told that I was different. I was never discouraged from trying new things. I was never told I couldn't achieve a goal due to my diagnosis of seizures. I still did not see how my past history of seizures would become a factor in my career choice.

After receiving a Bachelor's of Business Administration from Mississippi State, I went to work for a Family Practice and then an OB/GYN. I realized I wanted to be helping the patients seen in the clinic with their physical illnesses not their insurance issues. I enrolled at MUW and completed my nursing degree

followed by going to work on the pediatric floor at Baptist Hospital in Jackson.

I loved caring for the young patients and teaching their parents about their illnesses and treatments. Due to the arrival of our first daughter and conflicting work schedules with my husband, I began to look for a "day job" with regular hours. A fellow nurse told me of an opening for a nurse within the Department of Pediatrics, Division of Pediatric Neurology at UMC. I wasn't even aware of the Pediatric Neurology specialty; I was always followed by my pediatrician for my seizures. How perfect this could be, combining my past experience with a career I loved. I was hired in February 1997 as the nurse to four pediatric neurologists and one fellow. It was trial by fire but I made it through.

In the fall of 2002, with the blessings of my physicians for whom I worked, I entered the master's program at UMC. In August 2004 I transitioned into the role of Family Nurse Practitioner with the Division of Pediatric Neurology. I have the privilege of working with wonderful families from all over the state of Mississippi. My favorite week of the year is spent with "my kids" at the Alvin P. Flannes Epilepsy Camp. The children never cease to amaze me with their immeasurable spirit, enthusiasm, and determination.

WIN A HARLEY DAVIDSON

The Epilepsy Foundation of Mississippi will be raffling off a 2008 Harley Davidson Sportster XL883L at our Off the Leash fundraiser, November 7, 2009, at Lakeshore Park in Brandon, MS. The first tickets will be sold July 19th at Harley Davidson of Central Mississippi located at 3509 1-55 S. Tickets are \$25 each and you must be 21 years of age to enter. Winner is responsible for taxes, title, & licensing of motorcycle. All proceeds go to the Epilepsy Foundation of Mississippi benefiting Mississippians with epilepsy. If you would like to sell or buy tickets please call Tres at 601-936-5222 or 800-898-0291.



CALENDAR OF EVENTS

Tupelo Support Group

All Saints Episcopal Church, Tupelo, MS
1st Monday of the month at 6 pm unless a holiday

August 1, 2009

Living Well with Epilepsy Symposium
Holiday Inn Trustmark Park – Pearl
9:00 am - 4:00 pm
Registration at 8:00 am

August 11, 2009, 6:30pm

Rankin/Hinds/Madison Support Group
Epilepsy Foundation of MS office

October 10, 2009

Tupelo Walk for Epilepsy
Ballard Park, Tupelo, MS

October 13, 2009

Meet & Greet

November 7, 2009

2nd Annual Off the Leash for Epilepsy Fundraiser
Lakeshore Park, Brandon, MS

For information regarding the events above
call 601.936.5222 or visit www.epilepsy-ms.org

CONTRIBUTIONS

Mr. & Mrs. Bill Mounger

Mr. & Mrs. Shairod Robinson in Honor of
Teresa Hill, MSN, NP-C

Mr. & Mrs. Charles H. Johnson, Jr. in Honor of Kristin Lape

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DRUG PREVENTS SEIZURE PROGRESSION IN MODEL OF EPILEPSY

ScienceDaily (May 5, 2009) — Carnegie Mellon University researchers have identified a new anticonvulsant compound that has the potential to stop the development of epilepsy. The findings are published in the current issue of the journal *Epilepsia*.

The research discovery builds on previous work identifying a specific molecular target whose increased activity is associated with seizure disorders, a potassium channel known as the BK channel.

“We have found a new anticonvulsant compound that eliminates seizures in a model of epilepsy,” said Alison Barth, associate professor of biological sciences at Carnegie Mellon’s Mellon College of Science. “The drug works by inhibiting ion channels whose role in epilepsy was only recently discovered. Understanding how these channels work in seizure disorders, and being able to target them with a simple treatment, represents a significant advance in our ability to understand and treat epilepsy.”

Epilepsy is a neurological disorder marked by abnormal electrical activity in the brain that leads to recurring seizures. A person who has a first seizure is statistically much more likely to have a second, and with each subsequent seizure, the chance of having another seizure grows. A person is often diagnosed with epilepsy after having two or more seizures that have no other apparent cause.

In prior studies, Barth and colleagues were the first to link BK channels, ion channels that allow electrically charged potassium ions to move out of cells, to sporadic epilepsy. Previous studies had shown that these channels were genetically altered in a few rare individuals who suffer from the disease, but Barth and colleagues demonstrated that seizures themselves could lead to the same alterations in BK channel function.

Potassium ions move through the channels, starting and stopping the electrical impulses that allow neurons to communicate with one another. The Carnegie Mellon researchers found that after a first seizure, BK channel function was markedly enhanced. As a result, the neurons became overly excitable and were firing with more speed, intensity and spontaneity, leading Barth to believe that the abnormal increased activity of the channels might play a role in causing subsequent seizures and the emergence of epilepsy.

In the current study, Barth tested this theory by blocking the ion channels using a BK-channel antagonist called paxilline. Using an experimental model for epilepsy, Barth asked whether paxilline could reduce or prevent experimentally induced

seizures, as it could normalize aberrant brain activity induced by previous seizures. Remarkably, Barth and colleagues Jesse Sheehan and Brett Benedetti discovered that the compound was effective at completely blocking subsequent seizures.

“The drug is orally available, and works in the low nanomolar range,” said Barth, noting that these characteristics, which mean the drug is effective in low concentrations and can be taken as a pill, make it an especially promising compound for treatment in epilepsy patients. While most anticonvulsants currently used to treat epilepsy work to directly inhibit the activity of neurotransmitters that causes seizures, few compounds interact with specific ion channels, especially potassium channels. The researchers believe that targeting the BK channels and the abnormal brain activity that they induce might one day be used as a way to prevent the progression of seizure disorders over time, thus attacking the root cause of epilepsy.

According to Barth, the next steps will be to further investigate paxilline to see whether it is an effective anticonvulsant treatment for multiple types of seizures. The investigators continue to look at how BK channels are regulated by seizures to better understand the development of epilepsy.

Co-authors of the study include Sheehan and Benedetti, doctoral students in the Department of Biological Sciences and Center for the Neural Basis of Cognition at Carnegie Mellon. The study was funded by the National Institutes of Health, the Milken Family Foundation for Translational Research and the Alfred P. Sloan Foundation.

Adapted from materials provided by Carnegie Mellon University. Carnegie Mellon University (2009, May 5). Drug Prevents Seizure Progression In Model Of Epilepsy. *ScienceDaily*. Retrieved June 10, 2009, from <http://www.sciencedaily.com/releases/2009/05/090504122155.htm>

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