

BRAIN BUZZ

A Quarterly Update for Our Patients...From Your Partners in Good Brain Health

HIGHLIGHTS FROM THE COMPREHENSIVE EPILEPSY CENTER



Message from the Director

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Medical Director, Clinical Neurophysiology Laboratories



2013 was an exciting year, and 2014 is looking even brighter, with many new technologies, clinical trials, and services for our patients! As the Director of the Comprehensive Epilepsy Center, it has been my feeling that a holistic approach—including a full range of diagnostic options and treatments—is needed to help people with epilepsy. A comprehensive center strengthens the relationships between all the different services that treat our patients. I am very pleased to say our team continues to be outstanding. Below are some recent highlights:

- MUSC achieved Level 4 status in 2008 by the National Association of Epilepsy Centers, and we have kept this certification each year since.

- MUSC is the most accredited Neurophysiology Center in the United States. MUSC is now accredited in EEG, EMG, Neuro-intraoperative monitoring (NIOM), Intra- and Extra-cranial vascular neurodiagnostics, and Long term EEG and EMU monitoring. MUSC is the only medical center in the Nation with all of these credentials.

- My colleagues and I took part in the 1st North American training course on **Stereo-electroencephalography (SEEG)** in Montreal. SEEG is a minimally invasive surgical procedure used to identify areas of the brain where epileptic seizures begin in a three dimensional (3D) space. We are one of only a handful of centers in the US who offer this procedure.

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- FDA granted Premarket Approval (PMA) for the NeuroPace® RNS® System to treat Medically Refractory Epilepsy. Our center was a pivotal site for the clinical trials of this device.

- High-Density Electroencephalogram (HD-EEG) uses 256 channels of EEG to help find the part of the brain where seizures start, non-invasively. MUSC is the only Epilepsy Center in the Southeast clinically offering this technology for patients.

- EEGs are now being offered in the north area, in addition to our downtown and Mt Pleasant offices. We are looking into starting outpatient clinics in North Charleston and West Ashley.

We are very excited about all of the new and upcoming diagnostic and treatment options at our center, and for the hopes this may offer patients with epilepsy.

Clinical Trials

There are many reasons why people should consider participating in clinical trials.

1. Clinical trials are a chance for patients to get treatments that are not yet available to the public.

2. Clinical trials may offer free appointments, testing, and treatment options. In some cases patients are even paid to be in a trial.

3. Clinical trials increase our knowledge about a condition, and that can help increase treatment options for everyone in the future.

Below are the clinical trials taking place at MUSC right now. New studies open and close all of the time, so ask your provider if there are any trials that might be right for you.

Brain Sentinel Trial:

A study looking at a seizure detection and warning system for generalized tonic-clonic (GTC) seizures. The patient must:

- Be admitted to the hospital EMU for scheduled vEEG monitoring
- Be between 2 and 99 years of age
- Have a history of GTC seizures (full body convulsions or “grand mals”)
- Be able to wear the arm band

“Principal Investigator” Study leader: Dr. Jonathan Halford

HEP Trial:

This is an observational study to find biomarkers to help predict disease outcomes of patients with new onset focal epilepsy. A biomarker is something from the body that can be measured, like a blood test. The patient must:

- Be between 12 and 60 years of age
- Be recently diagnosed with focal epilepsy, and on an anti-seizure drug for less than 4 months
- Have had 2 or more seizures in the past 12 months
- Have had an abnormal EEG that suggests epilepsy

“Principal Investigator” Study leader: Dr. Gabriel Martz

FATES Study:

This study is looking at a test called a Functional MRI, also called an “fMRI.” Researchers are trying to learn if this test can help predict how patients will respond to surgery on the left temporal lobe. Patients in this trial will get a neuropsychological evaluation and have an fMRI. In order to participate, the patients must:

- Have epilepsy that has not responded to medication
- Have onset of seizures in the left temporal lobe
- Be planning to have a left anterior temporal lobe resection
- Be ages 16-60
- Speak English fluently
- Have a Full-Scale IQ →70
- Be able to undergo an MRI

“Principal Investigator” Study leader:

Dr. Leonardo Bonilha

For more information, or if you are interested in participating in any of our current clinical trials, please speak with your healthcare provider, or contact our Clinical Trials Coordinators:

Kimberly Schnabel @ 843-792-3855, or Sheri Davis @ 843-792-2845.

Patient Story: Addison Varney

August 19, 2011 was a day that changed Heather Varney's life in more ways than one. Heather gave birth to her first child, a little girl named Addison Varney. After leaving the hospital, Heather took her daughter home to adjust to the changes of motherhood. Three days later, Heather was bringing Addison to her first baby checkup at MUSC when things took an unexpected turn for the worse. Heather noticed Addison foaming at the mouth, being lethargic, having staring spells, and losing weight. Upon arrival to MUSC, Addison's vitals crashed and she was rushed to the Children's Hospital Emergency

Room. Doctors were able to revive baby Addison, and after lots of testing, they discovered she had suffered a hypoglycemic brain injury and was having seizures.

Addison was admitted to MUSC where she remained for the next three weeks. New mother Heather began to notice that Addison responded better to therapy and treatment when she listened to music. The source of this music came from a pink musical seahorse that Addison's grandfather brought her while she was in the hospital. As time passed, Heather would use the musical seahorse to help Addison reach developmental milestones so she could leave the hospital.

During this difficult time, Heather did everything she could to get help for Addison. She convinced her primary care providers to refer Addison to many therapists to help her with development. During this process, Heather discovered her own passion for learning how to help Addison improve physically.

Today, Addison has beaten all of the odds. At two and a half years old, Addison is starting ballet lessons, loves horse-riding and water activities. Addison attends routine visits in MUSC Neurosciences department for checkups and is on antiepileptic medications to control her seizures. Heather and Addison's journey at MUSC has been a wonderful experience and Heather says that without the love and support she and Addison have received from MUSC, their lives would not be the same.

After Heather's experience at MUSC, she has decided to go back to school to become an Electroneurodiagnostic Technician (END). Her journey with Addison has inspired her to further her knowledge of epilepsy so that she can help other children and adults who suffer from this disease. After becoming an END, Heather has even thought about furthering her education in Neurosciences so that she can continue to give back and help other families the way MUSC helped Addison.



(Addison has the musical pink seahorse in the picture with her)
Photo credit: Kelly Harris, MUSC employee

Our Team



Jonathan Edwards,
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David Walsh, MD



Julie DesMarteau,
PA



Elizabeth Koontz,
NP



Gigi Smith, PhD,
NP

South Carolina Advocates for Epilepsy (S.A.F.E.)

S.A.F.E. is a non-profit organization whose mission is to ADVOCATE on behalf of epilepsy patients and their families/caregivers; EDUCATE people from all walks of life about epilepsy and seizure first-aid; INSPIRE patients, families, caregivers, and community members to make a difference for themselves and others who deal with epilepsy on a daily basis. S.A.F.E. strives to eliminate the humiliation often associated with seizures and epilepsy by providing seizure first-aid training to employers, schools, churches, and sports or civic organizations throughout South Carolina.

S.A.F.E. is the only epilepsy organization in South Carolina with groups meeting in Charleston, Columbia, Greenville, Myrtle Beach and Hilton Head. Join us on the 2nd Saturday of each month at Cathedral of Praise Church, located on Ashley Phosphate Road. Meetings are held from 11am to 1pm in Bldg A, Room 103.

Our Upcoming S.A.F.E. awareness event:

“Epilepsy – Beyond the Diagnosis”, held on April 26th. Open to all epilepsy patients, whether newly diagnosed or diagnosed years ago, and family members or caregivers. National epilepsy experts and local neurologists will be speaking on current and exciting topics. More details to follow soon! Mark your calendar now!

For more information, be sure to visit the S.A.F.E. website (www.scepilepsy.org)

Foundation Update: Meet Meredith Gale

In January 2014, Meredith Gale joined MUSC Neurosciences as their Development Director. Meredith is a graduate of the College of Charleston and majored in Psychology and Criminal Justice, which included a 2001 internship here at MUSC in our Crime Victims Center. After graduation Meredith worked with a New York City-based designer and traveled the country hosting sales and marketing events. After several years on the road and an enjoyable stint in the publishing business, Meredith decided to follow her passion for not-for-profit organizations. She accepted a position with the American Red Cross, bringing her back to the Charleston area. A year after her return to Charleston the American Heart Association reached out to her with an offer to join their local team and after four years in their Charleston office she was offered a promotion to work as the Vice President of Social Events Fundraising in their Palm Beach, Florida market. After two years in Palm Beach, Meredith and her husband returned to Charleston to start their family, and joined the MUSC Neurosciences family.

Meredith loves working in Development and is passionate about changing what's possible in Neurology and Neurosurgery at MUSC. Meredith says, “I am very fortunate to work at MUSC where we have so many grateful patients and good neighbors who are interested in supporting our work to change what's possible in healthcare and I can't wait to help make their desires for research and medical advancements come to life. With this collaborative spirit, our teams of physicians, surgeons and researchers have been able to make unprecedented breakthroughs in epilepsy and elsewhere which we are able to share with patients across the state and colleges across the country... I'm just thankful to be a part of this amazing effort.”

