EPILEPSY FOUNDATION OF VIRGINIA
NOT ANOTHER MOMENT LOST TO SEIZURES
WWW.EFVA.ORG

EPILEPSY FOUNDATION Virginia

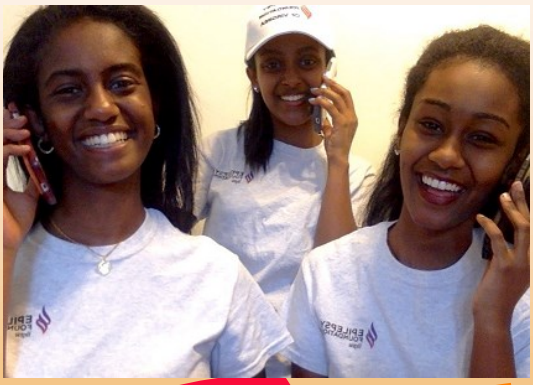
NEWSLETTER MAY 2016

THANKS TO LUNDBECK FOR financing 10 walks in autumn, 1 in spring, the Grand Fondo bike ride, and the art therapy sessions which will take place in Eastern and Northern Virginia this summer. Thanks to UCB AND SUPERNUS for supporting all 12 walks/bike ride. Thanks to Upsher-Smith for supporting 10 events and Eisai for pledging for 10 events.

SPREADING EPILEPSY AWARENESS WILL HELP EPILEPSY HEROES WITH MEMORY PROLEMS YHIS SUMMER.

The University of Virginia has just approved a contracted independent agency called: SPREADING EPILEPSY AWARENESS (SEA)
The three student volunteers are preparing to help epilepsy heroes with memory problems and receive tips on what you do. Improving memory may help heroes get a job or improve job performance. Weekly telephone calls during the summer will follow the Epilepsy Foundation of Virginia memory booklet and additional memory tips by epilepsy heroes will be considered. Participants from 16-86 are welcome to participate. Please contact our office if you wish to participate. An e-mail is sufficient. srb3m@virginia.edu The SEA members will start calling June 1, 2016.

Missy and Dennis Terry and the Williamsburg epilepsy support group have baseball tickets for the June 5th Epilepsy Awareness Day at the Richmond Squirrels baseball game with the first pitch being thrown out at 12:05. If they sell 100 tickets they will get to throw out the first pitch. They are well on our way of selling over 100 tickets. Please support this effort and see if there is any interest from your area to sell some tickets! The tickets are $8 each and $3 of every ticket sold will go to EFVA. Please let Terry know if you will support this effort. Please contact Terry at Dennis.Terry@parsons.com or come to the support group on Saturday May 7 at 5 P.M. in 139 Elizabeth Harrison Lane Williamsburg, VA 23188



PARENT OF CHILD WITH CSWS WISHES ALL SCHOOL RESTRAINT POLICIES TO GO. Joshua was born in 2010, a happy and healthy 9lb boy. At first, Joshua grew into a loving and sweet little boy who loved books, trains, and puzzles and playing with his older siblings. By the age of four Joshua began to subtly decline in his social skills becoming more anxious, withdrawn, and easily angered. He also developed a stutter and began to have brief staring spells. When Joshua turned five years old he had his first convulsive seizure and the world as we knew it changed forever. Suspecting Joshua may have seizure disorder, we immediately consulted a neurologist. and we learned that Joshua was suffering from Continuous Spikes Waves of Slow Wave Sleep Syndrome (CSWS) Syndrome. CSWS is a rare epileptic encephalopathy affecting school age children that can cause seizures, regression of behavior, language and motor skills and other developmental issues. Behavioral change is one of the most striking features of this syndrome and autistic like behavior can occur. As one can imagine, we were devastated by this diagnosis, yet we took comfort knowing that he is getting the finest medical care and therapy available to him.

We began seeking school accommodations for Joshua's condition in his Individualized Education Plan (IEP). During our discussions with school officials at one of our IEP meetings, we learned that that my son's school district had recently adopted a new Seclusion and Restraint Policy. "Seclusion and Restraint? What is that?" I asked my attorney. She informed me that Seclusion and Restraint policies permit schools to legally discipline children by physically restraining them against their will and secluding children in locked isolation areas without adult supervision often for hours at a time. She explained that these isolation areas may consist of jail like metal structures or padded areas of a room depending on your school. The use of mechanical restraints such as straps and handcuffs are often permitted depending on the school policy. We also learned the following: 1) The policy may or may not allow for the parent to be notified when such a restraint or seclusion occurs; 2) Some schools apply these policies in only emergency situations, to prevent physical harm to self and others, while others use them in non-emergency situations such as when a child is disrupting the learning environment or to protect property; 3) Every year children, mostly the disabled, are being injured and even die at the hands of school officials trying to restrain them; and 4) There are usually no exceptions to this policy, not even for children with life threatening illnesses such as Epilepsy.

Learning this information caused us to become concerned for Joshua's safety in school. Behavior issues are common with certain epilepsy syndromes. We thought about what might happen to Joshua if he had a seizure while being restrained or while alone in isolation. We knew we had to do something, so, we decided to write a letter to our School Board asking them to rewrite our district's Seclusion and Restraint policy to include a mandatory medical exclusion for children with life threatening illnesses such as Epilepsy. Our neurologist explained to them how dangerous it would be to place a child who has seizures in isolation. The Board arranged for us to have a meeting with the Director of Student Services to discuss the matter. In this meeting our Director declined to rewrite the policy; but agreed that a medical exclusion could be written into Joshua's IEP as an accommodation provided we bring a letter from our neurologist to justify it. So that's exactly what we did. Joshua's IEP now reads as follows: "Due to Joshua's epilepsy and risk of provoking a seizure, school officials will only seclude Joshua with an adult inside the room with him at all times, or restrain him in a manner deemed medically safe for his condition, and only applied in an emergency situation where his behavior places him at risk of causing significant harm to himself or others. " Ultimately, we would like to see seclusion and restraint practices banned from all schools. However, in the meantime, we remain hopeful that the medical exclusion written into Joshua's IEP will be sufficient to keep him safe.
Mother, Vinez

PLEASE ALL PARENTS WHO HAVE PROBLEMS WITH SCHOOL RESTRAINT POLICIES, WRITE EFVA AT srb3m@virginia.edu.

Dear PAME friends,

In case you have not already heard, the Partners Against Mortality in Epilepsy (PAME) 2016 meeting is just around the corner. We are grateful for your previous meeting attendance and hope you will consider joining us again this year. The meeting will take place June 23-26, in Alexandria, VA, just outside of Washington DC. **The Epilepsy Foundation of VIRGINIA will host a tour of old town Alexandria together with a historian. We shall also discuss Patsy Custis, Washington's stepdaughter who presumably died of SUDEP. The tour will start at 9.30 on Thursday June 23 in the hotel lobby. Tour is free for conference attenders and epilepsy heroes.**

The goal of PAME remains the same: to bring together providers, researchers, patients and their families to share information, advance research, facilitate collaborations, and foster action to prevent all epilepsy related mortalities. People living with epilepsy, their families and bereaved family members are critical partners in realizing our shared goals.

We are excited by this year's meeting and believe it will provide for new opportunities to learn and connect with others. A real effort has been made to ask new questions and to create a dynamic meeting format. We will have smaller breakout session that will promote more interaction and dialogue, while covering more topics and engaging a wider audience.

Additionally, this year we have added an advocacy day where families, researchers and providers can visit legislative leaders to increase awareness of epilepsy-related mortality and identify opportunities for prevention. If you are interested in learning more or in registering for the meeting, please visit: http://pame.aesnet.org
Early bird registration discounts end May 17th

EPILEPSY FOUNDATION
Virginia

Dr. Lyons and clinical coordinator Stacy Thompson cannot wait.

The Drug Enforcement Administration (DEA) says it plans to decide within the next several months whether to change the federal status of marijuana, according to a letter sent to lawmakers early April.

Marijuana is currently classified as a Schedule I drug, alongside the likes of LSD and heroin, which means it is deemed to have a high potential for abuse and no accepted medical use. Rescheduling could make it easier for researchers to study potential uses of the drug, a move that medical marijuana advocates would cheer.

The letter to lawmakers, signed by the head of the Drug Enforcement Agency, the Department of Health and Human Services, and the Office of National Drug Control Policy, states that the DEA has received scientific and medical evaluations as well as a scheduling recommendation from HHS and that it hopes to release a determination on rescheduling “in the first half of 2016.” Clinical research coordinator Stacey Thompson cannot wait. She was the coordinator for a study of epidiolex (produced by GW pharmaceuticals). This veteran of 75 clinical trials has never spent so much time as the small study with Dr. Bailey as principal investigator. Applications, certificates, several site inspections, power of attorney in case of illness, double paperwork when ordering the drugs. Dr. Lyons was also subjected to the same regime. But he said "We've had a significant reduction in number of seizures, severity of seizures and increase in the number of seizure-free days, and just as importantly, improvement in cognition," said Dr. Paul Lyons, an epileptologist at Winchester Neurological Consultants. For the last four months, Lyons has been conducting the with a test group of 14 children who have severe epilepsy. During that time, no one, including Lyons and the children's parents, knew which subjects were taking 20mg per kg of body mass of Epidiolex twice a day, and which had been taking a placebo. Tonya Viands' 11-year-old son Jaden received the medication, and he was walking happily next to his mother before she spoke to the group about Jaden's success. But four months ago, walking was out of the question for Jaden."[Epidiolex] literally brought my son back to life - it really did," Viands said. "He just kind of sat in the chair and drooled. He didn't have any interest in anything. It literally brought him back to life." Please join the EF and a large number of groups by advocating for safe access to CBD oil and other medically relevant part of the marijuana plant.

http:www.//safeaccessnow.org

Above Stacy Thompson and Dr. Lyons (lower) have completed part of their very complicated studies.

100 + epilepsy heroes on the Virginia Beach boardwalk. Thanks Cody, Patty and many others for organizing.

Date: **6 Saturdays, July 9,16,23,30, August 6,13**
Time: **12 – 3 PM**
Place: **The Denbigh House, 12725 McManus Blvd, Ste. 2E, Newport News, VA 23602**
Admission: **Free**, a limited amount of space available. **Participants come to all six sessions.** Please note that this program is offered exclusively to people with epilepsy.

The Epilepsy Foundation of Virginia is excited to bring you the opportunity to express yourself through art as part of a multi-week art therapy program. You'll work with art therapists and other people with epilepsy in a group setting to create artistic pieces using a variety of mediums, strengthen your artistic voice and learn from others in an open, welcoming environment. Your artwork may also help raise awareness about the realities of life with epilepsy.

More than 2,000 people from across the country have participated in *Studio E* since it was introduced in 2011. Don't miss your chance to experience this meaningful art therapy program.

If you would like to sign up for *Studio E*, please contact Patty Hood, efva.hr@gmail.com, 757-652-6565, by June 25, 2016
For more information about the program, visit **efva.org**

Your Partner in Epilepsy™

Our thoughts are with epilepsy hero Conner, who is slowly coming out of a bad set of viruses.

Carolyn Gray of LivaNova spoke on purple day.

On purple day in Virginia Beach, Mother Tracy Thomas gave a very moving speech as did Cody Hayden, (left) Olivia Brichter, and many other beautiful families.

Join the Epilepsy Foundation of Virginia for

studio e: The Epilepsy Art Therapy Program

Artistic expression can be powerful for people with epilepsy. Art can say things that words can't.

"Through the process, I discovered a lot of talent and passion in myself that I didn't even know existed." – *Studio E Participant*

Date: **Sunday's July 24-August 28**
Time: 2pm-5pm
Place: **2990 Telestar Court Falls Church, VA.**

Admission: Free, a limited amount of space available.
Please note that this program is offered exclusively to people with epilepsy.

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If you would like to sign up for *Studio E*, please contact **Gina Washington** at **gina1215@Comcast.net** or **703-349-2790** by **July 1, 2016**

For more information about the program, visit **www.efva.org**