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SAVE THE DATES

**TESS Research Foundation Grant Opportunity**

Applications are invited for the TESS Research Foundation Grant for research on SLC13A5 Deficiency, a Citrate Transporter Disorder. The purpose of this grant is to fund research (Up to maximum $100,000 USD) focused on understanding the disease mechanism and finding treatment options for the epileptic encephalopathy caused by mutations in the SLC13A5 gene.

The last date for submitting the application is December 1, 2018.

Details of the application guidelines can be found at TESSresearch.org

**2nd SYNGAP1 International Conference**

November 27-28, 2018
(The Young Investigator workshop on November 26th)
The Scripps Research Institute-Florida - Jupiter, Florida

Learn more and Register here.

**Epilepsy Foundation Funding Opportunities**

Do you have an innovative idea to help people with epilepsy and seizures?

Join our mission to help overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.

- **Shark Tank Competition** – Letters of Intent due December 14th
- **New Therapies Commercialization Grants** – Letters of Intent submission opens December 14. LOIs due January 28, 2019
- **Epilepsy Innovation Seal of Excellence** – Letters of Intent submission opens December 14. LOIs due January 28, 2019

Visit here to find more information & how to apply.

Questions? Contact grants@efa.org

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**American Epilepsy Society (AES) Annual Conference**
November 30 - December 4, 2018
New Orleans, Louisiana
Learn more here.

**Annual REN meeting at AES Conference**

The REN Executive Committee is in the process of framing an agenda for a workshop at the 2018 American Epilepsy Society meeting Saturday, December 1st from 7:30-9:30am.

We will focus on the topic: Centers of Excellence for Rare Epilepsies.

Watch this space! Dr. Kathleen Farrell will reach out to all Steering Committee groups as more details become available.

**Upcoming Epilepsy Foundation informational webinars**

**Tuesday, November 6, 8-9PM ET**
Neurostimulation in the Treatment of Drug Resistant Epilepsy

Learn more and Register here
Infantile Spasms Awareness Week - December 1-7, 2018

**STOP** Infantile Spasms

See the signs: *Clusters of sudden, repeated, uncontrolled movements like head bobs or body crunching.*

Take a video: *Record the symptoms and talk to your doctor immediately.*

Obtain diagnosis: *Confirm an irregular brain wave pattern with an EEG test.*

Prioritize treatment: *End spasms to minimize developmental delays*

Watch and share an informational video on how to ‘STOP’ Infantile Spasms [here](#).

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Epilepsy Foundation Public Policy Update

- Britt Dorfman, Government Relations and Grassroots Associate

**Drug Enforcement Administration Reschedules Epidiolex®**

The U.S. Food & Drug Administration (FDA) approved Epidiolex®, the first ever drug derived from cannabidiol (CBD), on June 25, 2018. Epidiolex® was approved for the treatment of Dravet and Lennox-Gastaut Syndromes. On September 27, 2018, the Drug Enforcement Administration (DEA) rescheduled Epidiolex® as a Schedule V substance, which is in line with the FDA's recommendation and is a big win for the epilepsy community. Schedule V drugs, substances, or chemicals are defined as drugs with lower potential for abuse than Schedule IV and consist of limited quantities of certain narcotics which are known to cause dependency. This is the lowest tier of the drug schedule. Other medicines such as certain cough syrups or antidiarrheals are also Schedule V. Schedule V medications to treat epilepsy include pregabalin (Lyrica®), lacosimide (Vimpat®), and brivaracetam (Briviact®).

Now that Epidiolex® is both FDA-approved and scheduled by the DEA, it should be ready for distribution on the market in by the end of the year. However, the DEA's determination does not override state-controlled substance laws. If a state considers cannabis a Schedule I substance under its laws, Epidiolex® cannot be prescribed until it is rescheduled by the state. The Epilepsy Foundation is actively working with legislators and regulators in these states to secure access to this potential treatment option.

Read FAQs about FDA-approved therapies derived from CBD [here](#). The FAQ will be updated periodically so make sure to check out the link below from time to time.

Read more about our advocacy efforts on FDA-approved therapies derived from CBD at [http://advocacy.epilepsy.com/statefdapathway](http://advocacy.epilepsy.com/statefdapathway).
Health Spending Package Signed into Law

In late September, Congress passed, and the President signed H.R. 6157, the fiscal year 2019 spending bill that encompasses appropriations for the Departments of Defense and Labor, Health and Human Services (HHS) and Education.

The budgets for the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH) fall under HHS. Overall, the NIH received a $2 billion increase and the CDC received a $126 million increase from last year. The epilepsy programs at the CDC received $8.5 million while the Special Projects of Regional and National Significance (SPRANS) received a set-aside of $3.6 million for epilepsy programs. The CDC received $5 million to establish the National Neurological Conditions Surveillance System, which will provide better information like incidence and prevalence on neurological conditions including epilepsy.

Learn more about federal funding for epilepsy programs and research at [http://advocacy.epilepsy.com/federal-funding-for-epilepsy](http://advocacy.epilepsy.com/federal-funding-for-epilepsy).

Open Enrollment for Medicare and the Marketplace Plans

It’s that time of year again – open enrollment! During this time, you can enroll in a Marketplace health insurance plan or in certain Medicare plans. Each year, plans make changes to benefits and costs, and new plans are available, so your current plan may or may not be the best plan for you in 2019. Therefore, it is important to review your coverage options at this time and make sure you’re enrolled in the health insurance plan that works best for your health care and prescription drug needs.

The annual open enrollment for Medicare prescription drug coverage (part D) and Medicare Advantage began on October 15, 2018 and will run through December 7, 2018 for coverage beginning January 1, 2019. Visit [medicare.gov](http://medicare.gov) or call 1-800-MEDICARE (1-800-633-4227) to learn more.

The open enrollment period for the Health Insurance Marketplace runs from November 1, 2018 until December 15, 2018 for coverage beginning January 1, 2019. Learn more about your options at [healthcare.gov](http://healthcare.gov) or 1-800-318-2596 (TTY: 855-889-4325). Individuals may be eligible for premium tax credits that will help make coverage more affordable. Please note that the healthcare.gov website is scheduled to be down every Sunday during open enrollment from 12 a.m. until 12 p.m. except the last Sunday due to maintenance-so consumers should plan to enroll around those time constraints.

Learn more about Open Enrollment and find resources at [http://advocacy.epilepsy.com/openenrollment](http://advocacy.epilepsy.com/openenrollment).
The Epilepsy Foundation is excited to share our new nationwide, multi-year campaign “Let’s Use Our Brains to End Epilepsy®. The core message is that “Epilepsy can affect anyone with a brain. Anyone with a brain can affect epilepsy.” The campaign highlights that the brain is the source of epilepsy, and the brain is the source of the solutions to End Epilepsy. The objective is to place the focus on the brain to change the conversation around seizures, and rally everyone to End Epilepsy.

At the heart of the campaign launch (Oct-Dec) are 14 "Ambassadors" with different stories of epilepsy, and each story is shared over one week. The Ambassadors are a diverse group of children, teens and adults with epilepsy and parents of children with epilepsy. Beginning in January 2019, we will feature the stories of other Ambassadors – including, we hope, families who are part of the Rare Epilepsy Network who want to share their stories.

Our Public Service Announcement features our Ambassadors sharing the campaign Manifesto. We also have a campaign website: EndEpilepsy.org which will increasingly serve as our engagement platform for people to take action to End Epilepsy, including our nationwide Walk to End Epilepsy.

National Epilepsy Awareness Month 2018    #NEAM2018   #Use Our Brains   #EndEpilepsy

How You Can Help

**Build Awareness** - Spread the word that epilepsy can affect anyone with a brain, and anyone with a brain can affect epilepsy. Show how you are using your brain to End Epilepsy. Share the campaign's Public Service Announcement.

**Educate About Seizure First Aid** - Show others how they can use their brains to take care of someone having a seizure: Seizure First Aid - Stay. Safe. Side. (Seizure First Aid Poster at EndEpilepsy.org - see next page!)

- **STAY** with the person having a seizure.
- Make sure they are **SAFE**.
- If they convulse, turn them on their **SIDE**.
- Never put anything in their mouth and if the seizure persists longer than 5 minutes, call 911.

**Encourage Others to Take Action** - Share the campaign stories (and your story!) and encourage others to take action.

Follow us @EndEpilepsy and share, tweet and re-post our messages with #EndEpilepsy.

Join us in the fight to End Epilepsy! Learn more and find ways to take action: EndEpilepsy.org
SEIZURE FIRST AID
STARTS WITH USING YOUR BRAIN

STAY with the person until the seizure ends.

Keep the person SAFE and start timing the seizure.

Turn the person on their SIDE if they start convulsing or are not awake.

CALL 911
  • If the seizure lasts longer than 5 minutes
  • If another seizure starts or the person is injured or in distress

☐ Do NOT hold someone down or restrain them
☐ Do NOT put anything in their mouth

Simple Seizure First Aid. STAY. SAFE. SIDE.
Learn more at: ENDEPILEPSY.ORG

END EPILEPSY

DETAILED SEIZURE FIRST AID
STAY with the person until the seizure ends • Remain calm • Check for medical ID • Keep the person SAFE • Move nearby hazards and guide them away from danger • If the person starts convulsing, is not awake, or can’t respond, ease them to the ground • Turn the person on their SIDE and continue to make sure they are SAFE • Loosen anything tight around their neck • Put something soft under their head • Time the seizure • Most seizures end in a few minutes and don’t need emergency medical help • STAY with them until they are awake and alert • After the seizure, reassure the person and explain what happened • Offer to call someone for them • CALL 911 if the seizure lasts longer than 5 minutes • CALL 911 if the seizure repeats or breathing is difficult • CALL 911 if seizure happens in water • CALL 911 if person is injured, pregnant, sick or does not return to full awareness • Do NOT hold someone down or restrain them • Do NOT put anything in their mouth.
CANNABIDIOL AS AN ADD-ON THERAPY IN TUBEROUS SCLEROSIS COMPLEX

WHAT
Safety and efficacy of cannabidiol (CBD)

WHO
People aged 1 year to 65 years with Tuberous Sclerosis Complex (TSC)

WHERE
Epilepsy Centers throughout the United States

HOW
16 weeks of treatment with either CBD or a placebo
Followed by the opportunity for all participants to receive CBD for an initial period of 1 year

IMPORTANT CONSIDERATIONS
You must be willing for your primary care doctor and other responsible authorities to be notified of your participation in this study, if it is required by law in your state. Your liver function will be monitored throughout the study. If you are pregnant, taking an mTOR inhibitor, or have liver impairment, you are not eligible to participate due to increased risk with CBD.

READ MORE
Cannabidiol study: https://www.epilepsy.com/clinical_trials/cannabidiol-add-therapy-tuberous-sclerosis-complex

Staccato Alprazolam Terminates Epileptic Seizures (STATES)

EPILEPSY FOUNDATION CLINICAL TRIALS PORTAL
Enrollment Update

Enrollment is currently closed.

Updates for the next phase of REN will be made available in the new year!

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Enrollment is currently closed.

Updates for the next phase of REN will be made available in the new year!
ABOUT US

To expedite research into the rare epilepsies, 31 rare epilepsy groups have joined forces with the Epilepsy Foundation, Research Triangle Institute and Columbia University to create the first ever Rare Epilepsy Network (REN). With seed funding from the Patient-Centered Outcomes Research Institute (PCORI), the REN is building a patient registry to collect information about rare epilepsy patients to better understand these conditions, improve treatments, and improve the lives and quality of care of patients living with them.

CONTACT US

By phone: (888) 886-3745
By email: ren@efa.org
Visit us on the web at: http://www.epilepsy.com/ren