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SAVE THE DATES

2018 Epilepsy Foundation Pipeline Conference and Community Day

February 22-24, 2018
San Francisco, CA

NIH Rare Disease Day

March 1, 2018
Bethesda, MD

12th National Walk for Epilepsy* (read more on page 5)

April 14, 2018
Washington, DC

Epilepsy Learning Healthcare System: Community Engagement Core Meeting

March 20-21, 2018
Columbus, OH

2018 Epilepsy Foundation Pipeline Conference and Community Day

Your Voice, Your Day

Every two years, the Epilepsy Foundation hosts a one-day educational conference dedicated to people with epilepsy, their families and friends, and community advocates for a day of learning, support, and networking.

This year's Community Day will take place on February 24, 2018, at the Westin St. Francis Hotel in San Francisco, California.

Community Day occurs immediately after the Epilepsy Foundation Pipeline Conference. This year's Community Day is hosted with the Epilepsy Foundation and Epilepsy Foundation of Northern California.

Information: Learn about new therapies and wellness approaches and share challenges of living with epilepsy and associated problems.

Empowerment: Take control and become an active member of your care team to work toward no seizures

Hope: Understand the importance of research and how you can help.

Community: Join friends, families, and advocates for a day of learning, support, and networking.

Register here!
**PCDH19 Alliance Professional and Family Conference**

And, the PCDH19 Alliance Research Grant Program is accepting applications NOW. Deadline May 1st. Learn more and apply [here](#).

**KCNQ2 Awareness Week: March 5th - 11th**

Click above to learn more about this virtual event, and how you can participate. This can be as simple as sharing a hashtag, tweet or Facebook post.

**Bridge the Gap SYNGAP Annual Golf Classic**

Registration opens January 28th.

**4th International CDKL5 Family Education & Awareness Conference**

June 29-30, 2018
Hyatt Regency Aurora-Denver Conference Center
Request for Applications: The 2018 Lennox-Gastaut Syndrome Foundation Research Award

The LGS Foundation Research Award provides funding for young investigators, physician residents, and clinicians who seek to advance our understanding of Lennox-Gastaut Syndrome (LGS). Grants may be one-year or two-years and support research projects that answer questions related to the underlying biology, clinical aspects, therapies, and/or causes of LGS. Grant recipients are asked to give a presentation at the LGS Foundation's annual research meeting at the American Epilepsy Society the following year to discuss their work. The LGS Foundation does not require an LOI, however, we will evaluate LOI's from investigators prior to submission of a full application.

Areas of Interest:
- Causes of Lennox-Gastaut Syndrome
- Therapies for Lennox-Gastaut Syndrome
- Quality of Life for individuals living with LGS and their families
- Epidemiology and better data collection/management of data from individuals of LGS
- Phenotyping and Genotyping of LGS
- Underlying biology of LGS

Budget: Requests may be made for up to $30,000 for one year, or $50,000 for two year projects. Indirect costs are not supported.

2018 FUNDING PROGRAM

<table>
<thead>
<tr>
<th>Program Opens</th>
<th>January 1, 2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full Applications Due</td>
<td>April 1, 2018</td>
</tr>
<tr>
<td>Award Announcement</td>
<td>June 2018</td>
</tr>
<tr>
<td>Anticipated Project Start Date</td>
<td>September 2018</td>
</tr>
</tbody>
</table>

Application Instructions:

Applications must be submitted by the deadline to Tracy@LGSfoundation.org and must include the following:

1) Title Page: Enter proposal title and PI information.
2) Abstract: Provide a lay summary and a scientific summary of the project.
3) Budget Period Detail: Provide a detailed budget and justification. All expenses must in U.S. dollars.
4) Proposal (NIH format is acceptable)
5) Biosketch for each PI
6) Letters of support or collaboration as relevant

Inquiries: Questions regarding these guidelines are welcome and should be directed to Tracy Dixon-Salazar at Tracy@LGSfoundation.org.
**Call to connect: Doose Syndrome**

If you have Doose Syndrome (myoclonic astatic epilepsy) or a variant, please come and connect with your tribe on [Facebook](https://www.facebook.com).

**Epilepsy non-profits have the opportunity to unify at the National Walk for Epilepsy, to benefit the Rare Epilepsy Network**

The Epilepsy Foundation’s National Walk is a time to unite with other partners dedicated to epilepsy research, especially non-profits supporting the rare epilepsies. Participating in the National Walk for Epilepsy allows your organization to spread awareness for epilepsy by walking, donations or having a table. Any funds raised will be restricted to funding the Rare Epilepsy Network.

*How to get involved:*
- Create a team. All funds raised will be restricted to supporting REN.
- Share [www.walkforepilepsy.com](http://www.walkforepilepsy.com) with your network of family and friends.
- Table at the Walk as an Epilepsy Community Partner at the National Walk. There will be an exclusive Community Partner tent located in a prime location in Walkers Village. The Walk offers a great opportunity to interact with the participants while creating more awareness for your organization. Please contact Jeff Moore, Director of Corporate Alliances, at (630) 606-1346 or jmoore@efa.org for more information.

**Epilepsy Foundation Advocacy News**

The Epilepsy Foundation’s annual Teens Speak Up! & Public Policy Institute conference will take place on April 15-17, 2018, following the National Walk for Epilepsy on April 14. The policy conference is the Foundation’s signature advocacy initiative. Every year we bring together more than 150 advocates, including Epilepsy Foundation affiliate and chapter staff, parents, teens, doctors, and volunteers from across the nation. Through this initiative, we are able to strengthen our advocacy network and share updates on the state of federal epilepsy research & programs and access to quality care, as well as give our families an opportunity to share their stories of living with epilepsy with Congress. To learn more, please visit [advocacy.epilepsy.com/TSU-PPI](http://advocacy.epilepsy.com/TSU-PPI).

The Epilepsy Foundation applauds congressional action on a multi-year reauthorization of the Children’s Health Insurance Program (CHIP). On January 22, 2018, Congress passed and the President signed a continuing resolution that included a six-year reauthorization for CHIP. This critical program provides quality, low-cost health insurance to children from low-income families, as well as children from middle-income families with complex chronic conditions and disabilities. CHIP provides coverage for 8.9 million American children, including 2 million children with chronic conditions like epilepsy. Learn more about CHIP at [advocacy.epilepsy.com/CHIP](http://advocacy.epilepsy.com/CHIP). Thank Congress for reauthorizing CHIP!

If you’d like to stay up-to-date on policy issues important to the epilepsy community, please take a minute to sign up for our [Speak Up, Speak Out! advocacy network](https://www.advocacy.epilepsy.com). You will receive the monthly advocacy newsletter, Highlights from the Hill, and updates on state federal advocacy activities so you can take action and make your voice be heard.
What is This Study About?
This three-month study will look at people between 18-45 years old, taking their own antiseizure medications in addition to either the study drug (pregabalin) or a placebo. The aim is to look for changes in vision. Visual fields (the area you can see with each eye) and visual acuity (how clear your vision is) will be measured in people before, during, and after the study.

Who Can Participate?
The study is open to people of all ages. Participants must be 18 years old and have had at least one seizure in the last 6 months. People with a history of seizures may not be eligible. The study is open to people of all ages. Participants must be 18 years old and have had at least one seizure in the last 6 months. People with a history of seizures may not be eligible.

How Can I Participate?
This study is looking at how effective and safe eslicarbazepine acetate is in people 18 years old with focal or partial-onset seizures, when it’s added to their current anti-seizure medication(s).

Are There Risks?
- People with Asian ancestry may carry a genetic marker (called allele HLA-B*1502), which may put them at increased risk of serious dermatologic reactions (e.g., Stevens-Johnson Syndrome).
- The treatment may not improve a person’s seizures.
- The dosing plans and safety checks that are designed to protect participants are detailed in a protocol that was designed by researchers and doctors and reviewed by an Institutional Review Board (IRB). If the participant is unable to tolerate treatment with ESL, the study team will help them to taper off the medication slowly where possible, unless abrupt discontinuation is necessary.

For more information, visit https://clinicalconnection.com/clinical-trials-from-other-databases/study-location-selection/431534.

Eslicarbazepine Acetate (ESL)
Eslicarbazepine Acetate (ESL) as an Add-On Therapy In Partial Onset Seizures

What is This Study About?
This study is looking at how effective and safe eslicarbazepine acetate is in people 18 years old with focal or partial-onset seizures, when it’s added to their current anti-seizure medication(s).

Seizures will be recorded in seizure diaries and by the wearable seizure detection device. This device will be given to participants to use during the study.

Who Can Participate?
18+ years old
- Has NEVER taken ESL before
- Has had at least 3 focal-onset (partial) seizures in the last 6 months

Participants will be assigned to one of the two study arms or groups:
- Taking a stable dose of levetiracetam or lamotrigine for at least one month before screening, with no history of adjunctive (or add-on) treatment
- Taking a stable dose of 1 or 2 anti-seizure drugs (except oxcarbazepine)

Diagnosis of epilepsy with one or more of the following seizure types:
- simple partial-onset (focal) seizures with motor symptoms
- complex partial-onset (focal) seizures with impaired awareness
- partial-onset (focal) seizures that go into generalized seizures after completion of this study, the study drug is commercially available and may be covered by insurance providers, and Medicare and Medicaid. Subjects will need to confirm with their individual insurance provider if they are covered under the terms of their policy with their provider. Sunovion Pharmaceuticals Inc. offers a Patient Assistance Program to help to help subjects who are eligible to get help paying for their prescription.

Who is Eligible to Join the Study?
- People between the ages of 18-75
- Diagnosis of epilepsy with partial (focal) seizures
- Currently being treated with one to three anti-seizure medications
- If you are eligible for the study, all study visits, testing and medication will be provided to you, at no cost to you or your insurance.
- Transportation support is available to help you get to and from your study visits.
- Compensation for your time and inconvenience is available.
- Subjects who complete the study or who are withdrawn by the sponsor prior to completion may be eligible to receive six months of their anti-epileptic medications as prescribed by your doctor, at no charge to you or your insurance company.

For more information, visit https://clinicalconnection.com/clinical-trials-from-other-databases/study-location-selection/431534.
CURRENT RARE EPILEPSY STUDIES ON THE EPILEPSY FOUNDATION CLINICAL TRIALS PORTAL

FENFLURAMINE ASSESSMENT IN RARE EPILEPSY (FAiRE)

ZX008-1501/1504 The FAiRE program is exploring whether an investigational drug (ZX008) can improve seizure control in children and young adults with Dravet syndrome.

GOAL

ZX008-1501/1504 TRIALS:
Test if ZX008 is a safe and effective treatment for children and adolescents with Dravet syndrome, when added on to their other seizure medications.

OUTCOMES TO BE LOOKED AT:

• A decrease in the number of convulsive (also called tonic clonic) or non-convulsive (for example absence or focal) seizures compared to before the study medication was started
• More days without convulsive seizures
• Less frequent use of rescue medication
• Less frequent hospitalizations specifically to treat seizures

ELIGIBILITY CRITERIA INCLUDE:

• Age 2-18 years (inclusive)
• Documented medical history that supports a clinical diagnosis of Dravet syndrome
• First seizure happened in the person's first year of life
• Uncontrolled seizures despite current medication

Participation entails:

• Continuation of person's normal background anti-seizure medication(s)
• Treatment with either placebo or study medication
• Use of a seizure diary to record seizure activity and medication details
• Regular health checks: may include electrocardiograms (ECG) (test of heart rhythms), echocardiograms (an ultrasound of the heart), physical examination (including blood pressure and heart rate), and nervous system assessments.

Zogenix FAiRE Program
Learn more & Participate HERE now!

Preventing Epilepsy Using Vigabatrin In Infants With Tuberous Sclerosis Complex

This Phase IIb trial will test whether earlier treatment versus standard treatment with vigabatrin in infants with Tuberous Sclerosis Complex (TSC) will have a positive impact on developmental outcomes at 24 months of age. It also tests whether early treatment prevents or lowers the risk of developing infantile spasms and refractory seizures. It is a randomized, double-blind, placebo-controlled clinical trial design. Infants under the age of 6 months diagnosed with TSC but without history of seizures or infantile spasms may be eligible.

If interested: See more information at ClinicalTrials.gov Identifier: NCT02849457

Contact:
Jessica Krefting, RN 205-975-2890 jessicakrefting@uabmc.edu or Regina Ryan, MS 205-975-2890 reginaryan@uabmc.edu
Enrollment Update

Please feel free to share this newsletter to others with rare epilepsies! They can enroll HERE now!

<table>
<thead>
<tr>
<th>Syndrome</th>
<th>No.</th>
<th>Syndrome</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aicardi Syndrome</td>
<td>95</td>
<td>MERFF</td>
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<tr>
<td>Angelman Syndrome</td>
<td>1</td>
<td>Ohtahara Syndrome</td>
<td>14</td>
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<tr>
<td>Batten Disease</td>
<td>3</td>
<td>PCDH19 Female Epilepsy</td>
<td>39</td>
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<tr>
<td>CDKL5 Disorder</td>
<td>32</td>
<td>Phelan-McDermid Syndrome</td>
<td>42</td>
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<tr>
<td>Congenital Bilateral Perisylvian Syndrome</td>
<td>2</td>
<td>Progressive Myoclonic Epilepsy (PME)</td>
<td>7</td>
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<tr>
<td>Continuous Spike and Wave of Slow Sleep</td>
<td>6</td>
<td>RAS Pathway Disorders</td>
<td>1</td>
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<tr>
<td>Doose Syndrome</td>
<td>61</td>
<td>Rasmussen’s Encephalopathy</td>
<td>1</td>
</tr>
<tr>
<td>Dravet Syndrome</td>
<td>176</td>
<td>Rett Syndrome</td>
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<tr>
<td>Dup15q Syndrome</td>
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<td>Ring 14 Syndrome</td>
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<tr>
<td>Early Myoclonic Encephalopathy</td>
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<td>Ring 20 Syndrome</td>
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<td>Electrical Status Epileptics of Slow Sleep</td>
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<td>Severe Myoclonic Epilepsy of Infancy</td>
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<tr>
<td>Glut1 Deficiency</td>
<td>3</td>
<td>SCN2A Mutation</td>
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<tr>
<td>Hypothalamic Hamartomas</td>
<td>85</td>
<td>SCN8A Mutation</td>
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<td>Infantile spasms/West Syndrome</td>
<td>52</td>
<td>SLC13A5 Mutation</td>
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<td>Jeavon’s Syndrome</td>
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<td>SYNGAP1 Mutation</td>
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<tr>
<td>KCNQ2 Mutation</td>
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<td>Tuberous Sclerosis Complex</td>
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<td>Landau-Kleffner Syndrome</td>
<td>9</td>
<td>Unverricht-Lundborg Syndrome</td>
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<tr>
<td>Lennox-Gastaut Syndrome</td>
<td>200</td>
<td>Encephalopathy with seizures and major delay in development</td>
<td>26</td>
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<tr>
<td>Lissencephaly</td>
<td>4</td>
<td>Other mutation associated with seizures</td>
<td>95</td>
</tr>
<tr>
<td>Mitochondrial Disorders (Alper’s Disease, Leigh’s Disease)</td>
<td>1</td>
<td>TOTAL</td>
<td>1360</td>
</tr>
</tbody>
</table>

Note: The total number of enrollments is 1360.
ABOUT US

To expedite research into the rare epilepsies, 26 rare epilepsy foundations 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