Inside this Issue:

I. Upcoming events & News....................... p 2-5

II. Spotlight: SUDEP Biomarker Challenge.. p 6

III. Active clinical trials and studies........... p 7

IV. Enrollment update .............................. p 8

V. About REN / Contact us ...................... p 9
2nd Epilepsy Precision Medicine Conference
Washington, DC
September 16-17, 2019
More details to come in the following months!

Child Neurology Society 48th Annual Meeting
Charlotte, NC
October 23-26, 2019*

The Child Neurology Society Annual Meeting is the meeting of choice for child neurologists and professionals in other fields of study related to neurologic and neurodevelopmental disorders in children and adolescents.

*ELHS Learning Session #3 will take place October 27th, immediately following CNS. See page 5!

2020 Epilepsy Foundation Pipeline Conference & Community Day
Santa Clara, CA
February 20-22, 2020
More details to come in the following months!
NORSE Institute: Recent milestones
- Nora Wong

A NORSE (New Onset Refractory Status Epilepticus) research roadmap was published in *Neurology* April 2019 by members of the medical advisory board.

$100,000 was awarded to Eric Payne, MD, MPH and Charles Howe, PhD, Mayo Clinic (Rochester, MN) to study NLRP3 inflammasome dysfunction as a cause for FIRES and NORSE in May 2019. The RFP was done through NORD (National Organization of Rare Disorders) with a preference for translational research to attract basic scientists to study NORSE.

New RFP through NORD announced for combined total of $100K for clinical or translational research in NORSE/FIRES. Deadline for preliminary proposals is June 18th! Click [HERE](#) for more information.

Lennox Gastaut Syndrome Foundation Conference
- Tracy Dixon Salazar

The LGS Foundation hosted their sixth international family and professional conference on Lennox-Gastaut Syndrome last month in Seattle, WA. Over 300 attendees from around the world traveled to attend this comprehensive, three day meeting. Some of the world’s leading clinicians, scientists, and epilepsy professionals spoke on an array of topics related to treatments, scientific advancements, services, and more.

The LGSF conference is held every 18 months within the United States and moves to a different location for each meeting. For those who were unable to attend this year’s conference, videos and slides of all sessions will be posted shortly. The LGS Foundation is also excited to announce that the next conference will be held in Austin, TX, in November, 2019!

In addition to dozens of educational presentations, the LGSF also organized a number of social events for the families including sessions just for the moms, dads, and siblings, an evening reception, a dinner and dance party with the famous “dancing doc”, and the LGS Olympics, a new activity for 2019. Childcare was also available on site for those living with LGS and their siblings.

For more information, visit [www.lgsfoundation.org/conference](http://www.lgsfoundation.org/conference) or check out their [Facebook page](#).
Epilepsy Foundation News

Rare Voices @ the Epilepsy Foundation

The Epilepsy Foundation is continually looking for opportunities to include the rare voice and REN organizations in our conferences, as well as meetings the Foundation is participating in externally.

Some recent examples of REN members participating on panels and as speakers follow below:

- **2019 Roundtable for Epilepsy** (March 21-22) Vanessa Vogel-Farley (Dup15q Alliance); Page Nues (Rett Syndrome Foundation), Kim Nye (Tess Research Foundation); Megan Roberts (KCNQ2 Cure Alliance)
- **Epilepsy Foundation Rescue Therapies Workshop** (April 26) Yssa DeWoody (Ring14); Tracy Dixon-Salazar (LGS Foundation)
- **Epilepsy Foundation Data Workshop** (April 28 – 29) Tracy Dixon-Salazar (LGS Foundation); Ilene Penn Miller (Hope for HH)
- **Teens Speak Up! Advocacy Panel** (April 28) Ilene Penn Miller (Hope for HH)
- **Epilepsy Learning Healthcare System Learning Session #2** (May 6) Monika Jones (Brain Recovery Project: Childhood Epilepsy Surgery Foundation); Vanessa Vogel-Farley (Dup15q Alliance)

Join us on Facebook Live on Wednesday, June 12, 2019, at 8:00 p.m. ET.

Learn about and prepare for epilepsy camps, traveling, and summer fun.

*We’ll have tips for families living with epilepsy.*

- How can camps help people with epilepsy?
- What kind of camp should I look for?
- How do I prepare for sending my loved one to camp?
- I love to be outdoors in the summer – will epilepsy get in the way?
- What tips for traveling with epilepsy should I be aware of?

Host: Patty Osborne Shafer RN, MN, Senior Director, Epilepsy Foundation

Guest: Nikki Baker MNM, Program Director, Epilepsy Foundation Minnesota

Nikki has been with the Epilepsy Foundation of Minnesota for 16 years in various roles, including camps for people with epilepsy. Nikki has her Bachelor of Science degree in Public Health and her master’s degree in Nonprofit Management. Throughout her career, she has specialized in working with youths of all ages and shaping programming in the state of Minnesota and Eastern North Dakota.
Epilepsy Learning Healthcare System (ELHS) News

Confirmed clinical sites now include:
• Barrow Neurologic Institute (AZ)
• Beth Israel Lahey Health (MA)
• Children’s Hospital of Atlanta (GA)
• Children’s Hospital of Philadelphia (PA)
• Partner’s Healthcare (MA): Brigham & Women’s and Massachusetts General Hospitals
• Penn State Hershey Children’s Hospital (PA)

The 2nd ELHS Learning Session took place on Monday May 6th in Philadelphia, PA. Ms. Monika Jones (The Brain Recovery Project Childhood Epilepsy Surgery Foundation) and Ms. Priscilla Kobi (Epilepsy Foundation) graciously provided Ignite Talks sharing their experiences with epilepsy - focusing the attendees on the reason for the work.

Site teams (made up of clinicians and patient & family partners from the Community Engagement Core) are currently working on improving seizure documentation both on the clinician and patient sides.

The next phase of work will focus on medication adherence (a key driver of seizure control) - this will begin with an evidence review and roll-out of the next change package at the October 27th ELHS Learning Session in Charlotte, NC.

For more information on the Community Engagement Core of the ELHS please contact Ms. Alison Kukla. Work is currently underway to connect REN and other organizations, as well as local Epilepsy Foundation teams, with clinical sites as they come on board - please share with your networks news of this opportunity!

For more information on the Clinical Core, please contact Dr. Kathleen Farrell.
Each year, more than 1 out of 1,000 people with epilepsy die from sudden unexpected death in epilepsy (SUDEP). If seizures are uncontrolled, the risk of SUDEP increases to more than 1 out of 150. SUDEP is the leading cause of death in young adults with uncontrolled seizures.

Among the 65 million people worldwide living with epilepsy, nearly one-third have ongoing seizures despite existing therapies.

To accelerate the identification of effective treatments for SUDEP, the Epilepsy Foundation SUDEP Institute is sponsoring a $1 million challenge to develop a predictive biomarker to identify people at risk for SUDEP. If we can know who is at risk, we can develop prevention strategies and intervene before it is too late.

With the help of our partners at InnoCentive, all of the challenges allow us to take advantage of interdisciplinary approaches and alternative perspectives. Through combining and contrasting ideas, the best and most valuable solutions will be identified and financially supported.

### CHALLENGES TO DATE:

**Challenge 1: Advocacy Campaign**
Empowering people with epilepsy, $15k awarded

**Challenge 2: Self Management Tools**
Preventing epilepsy seizures, EpSMon (Epilepsy Self-Management) mobile app created

**Challenge 3: Identifying Potential Biomarkers**
Predictive biomarkers of epilepsy seizures, $75k awarded

**Challenge 4: Bringing Biomarkers to Clinical Practice**
Developing predictive biomarkers of SUDEP

- **Milestone 1** Project plan, $40K awarded
- **Milestone 2** Proof of concept, $80K awarded
- **Milestone 3** Validation data in humans of predictive value for SUDEP $800,000 prize

**Current Challenge!**

The Final Milestone of our Final Challenge is live now and open until October 10, 2020!

Biomarkers may be genetic, structural within the body, metabolic, physiological, or something else that is quantifiable.

The winning biomarker will be easily and safely measured, cost-efficient to detect, modifiable with intervention (something we can actively treat or prevent), be consistently associated with SUDEP or life-threatening seizures, and will drive human intervention. For example, the biomarker may identify a high-risk patient group to allow testing of existing interventions such as seizure detection devices.

Please, help us reach for the stars now by investing in this winning solution - and help us save lives.

Learn more go to epilepsy.com/sudep
New this month on the Epilepsy Foundation

**CLINICAL TRIALS PORTAL**

Learn more HERE!

Do you know of another trial or study that should be featured on the Portal? Email Dr. Kathleen Farrell at kfarrell@efa.org

Other trials/studies currently featured:

- **Cannabidiol study**: [https://www.epilepsy.com/clinical_trials/cannabidiol-add-therapy-tuberous-sclerosis-complex](https://www.epilepsy.com/clinical_trials/cannabidiol-add-therapy-tuberous-sclerosis-complex)


- **Perampanel study**: [https://www.epilepsy.com/clinical_trials/perampanel-study-infants-epilepsy](https://www.epilepsy.com/clinical_trials/perampanel-study-infants-epilepsy)
**Ren Enrollment is currently closed.**
**More information to come in the coming months!**

### Enrollment Update

<table>
<thead>
<tr>
<th>Syndrome</th>
<th>No.</th>
<th>Syndrome</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aicardi Syndrome</td>
<td>100</td>
<td>Ohtahara Syndrome</td>
<td>18</td>
</tr>
<tr>
<td>Angelman Syndrome</td>
<td>5</td>
<td>PCDH19 Female Epilepsy</td>
<td>41</td>
</tr>
<tr>
<td>Batten Disease</td>
<td>3</td>
<td>Phelan-McDermid Syndrome</td>
<td>43</td>
</tr>
<tr>
<td>CDKL5 Disorder</td>
<td>32</td>
<td>Progressive Myoclonic Epilepsy (PME)</td>
<td>8</td>
</tr>
<tr>
<td>Congenital Bilateral Perisylvian Syndrome</td>
<td>2</td>
<td>RAS Pathway Disorders</td>
<td>1</td>
</tr>
<tr>
<td>CSWS/ES EES</td>
<td>17</td>
<td>Rasmussen’s Encephalopathy</td>
<td>5</td>
</tr>
<tr>
<td>Doose Syndrome</td>
<td>76</td>
<td>Rett Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Dravet Syndrome</td>
<td>177</td>
<td>Ring 14 Syndrome</td>
<td>8</td>
</tr>
<tr>
<td>Dup15q Syndrome</td>
<td>62</td>
<td>Ring 20 Syndrome</td>
<td>4</td>
</tr>
<tr>
<td>Early Myoclonic Encephalopathy</td>
<td>1</td>
<td>Severe Myoclonic Epilepsy of Infancy</td>
<td>7</td>
</tr>
<tr>
<td>Glut1 Deficiency</td>
<td>4</td>
<td>SCN2A Mutation</td>
<td>4</td>
</tr>
<tr>
<td>Hypothalamic Hamartomas</td>
<td>91</td>
<td>SCN8A Mutation</td>
<td>25</td>
</tr>
<tr>
<td>Infantile spasms/West Syndrome</td>
<td>67</td>
<td>SLC13A5 Mutation</td>
<td>3</td>
</tr>
<tr>
<td>Jeavon’s Syndrome</td>
<td>9</td>
<td>Sturge Weber Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>KCNQ2 Mutation</td>
<td>9</td>
<td>SYNGAP1 Mutation</td>
<td>18</td>
</tr>
<tr>
<td>Landau-Kleffner Syndrome</td>
<td>10</td>
<td>Tuberous Sclerosis Complex</td>
<td>256</td>
</tr>
<tr>
<td>Lennox-Gastaut Syndrome</td>
<td>207</td>
<td>Unverricht-Lundborg Syndrome</td>
<td>3</td>
</tr>
<tr>
<td>Lissencephaly</td>
<td>4</td>
<td>Encephalopathy with seizures and major delay in development</td>
<td>23</td>
</tr>
<tr>
<td>MERFF</td>
<td>3</td>
<td>Other mutation associated with seizures</td>
<td>110</td>
</tr>
<tr>
<td>Mitochondrial Disorders (Alper’s Disease, Leigh’s Disease)</td>
<td>1</td>
<td>TOTAL</td>
<td>1459</td>
</tr>
</tbody>
</table>
ABOUT US

To expedite research into the rare epilepsies, 33 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

Epilepsy Foundation 24/7 Helpline
1-800-332-1000

By email: ren@efa.org

Visit us on the web at:
http://www.epilepsy.com/ren