REN Organizations

Aaron’s Ohtahara Foundation
Aicardi Syndrome Foundation
Alternating Hemiplegia of Childhood Foundation
Bridge the Gap SYNGAP
Carson Harris Foundation
CFC International
Chelsea’s Hope
International Foundation for CDKL5 Research
Doose Syndrome Epilepsy Alliance
Dravet Syndrome Foundation
Dup15q Alliance
Hope for Hypothalamic Hamartomas
Infantile Spasms Community
International Rett Syndrome Foundation
The Jack Pribaz Foundation
KCNQ2 Cure Alliance

Lennox-Gastaut Syndrome Foundation
NORSE Institute
PCDH19 Alliance
Phelan-McDermid Syndrome Foundation
Pitt-Hopkins Research Foundation
RASopathies Network
Ring 14 USA Outreach
Ring 20 Chromosome Alliance
The Cute Syndrome Foundation
TESS Foundation
Tuberous Sclerosis Alliance
Wishes for Elliott

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SAVE THE DATES

REN AES Workshop

“Outcomes in Epilepsy”

November 30, 2017
Washington, DC

71st Annual American Epilepsy Society (AES) meeting

December 1-5, 2017
Washington, DC

2018 Epilepsy Foundation Pipeline Conference and Community Day

Pipeline Conference: 2/22-23/18
Community Day: February 24th
San Francisco, CA

12th National Walk for Epilepsy*

April 14, 2018, Washington, DC

(* Read more on page 4!)

Bridge the Gap SYNGAP

1st Annual Step-up for SYNGAP1 - Walk at the Houston Zoo

December 9, 2017 - Houston, TX

Learn more and register here.

Hope for Hypothalamic Hamartomas

2017 Family Forum

December 2-3, 2017 - Washington, DC

For more information and to Register, click here.
**The Epilepsy Leadership Council (ELC): Leadership workshop**

*Author: Joanna Crooks*

**Epilepsy Leadership Council (ELC)** members from across the country came together in September to identify key opportunities for collaboration in research and advocacy. The strategic planning workshop provided a forum for members to hear about a variety of current collaborations between ELC members and to discuss new research and advocacy partnership possibilities for 2018.

Supporting and promoting research is a priority for the ELC. Participants expressed continued support for working together as a coalition to leverage existing resources and accelerate research in the epilepsy community. The group strategized about a wide range of initiatives to support research including data collection and sharing, collaborative research funding, providing input in preparation for the NINDS Curing the Epilepsies Conference in 2020, and facilitating connection between clinicians and researchers from a variety of organizations to identify overlapping knowledge gaps and opportunities for joint research.

Another priority for the ELC is to identify opportunities to provide input on state and federal policy that impacts the epilepsy community. As a coalition of more than 30 organizations, the ELC is positioned to provide a unique perspective on legislative and regulatory policy that affects patients, families and caregivers, health care providers, and researchers.

At the workshop, participants reviewed a variety of legislative and regulatory issues including access to care, federal research funding, cannabidiol research and access, and state SUDEP legislation. ELC will continue to work together to identify opportunities to educate policymakers about key issues affecting the epilepsy community.

ELC is in the process of reviewing and prioritizing the projects that were identified at the workshop and will kick off implementation efforts in December at the ELC luncheon at the AES annual meeting. The ELC will continue to work together to support research and shape policy in order to improve the lives of those living with epilepsy.
**TSC Voice of the Patient Report**  
*Author: Steve Roberds*

The Tuberous Sclerosis Alliance recently submitted to the FDA a Voice of the Patient report resulting from their externally-led patient-focused drug development meeting. This report, available at [http://www.tsalliance.org/pfdd](http://www.tsalliance.org/pfdd), provides a detailed summary of the patient testimony presented at the meeting and communicates needs and improvements patients want and hope to see in their daily lives.

**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 and CURE partnership: “My Shot at Epilepsy Challenge”**

The Epilepsy Foundation was recently invited to partner together with CURE to benefit from an effort being launched by performer, Miguel Cervantes, and his wife Kelly. Miguel decided to utilize his fame as the lead in the Chicago production of “Hamilton” to raise awareness during National Epilepsy Awareness Month. He and Kelly wish to help fund epilepsy new therapies and research through a campaign Miguel and Kelly named, “My Shot at Epilepsy Challenge”. Miguel and Kelly’s young daughter, Adelaide, has been diagnosed with infantile spasms.

Net proceeds from the “My Shot at Epilepsy” challenge campaign will support the new collaboration between the Rare Epilepsy Network and CURE’s Epilepsy Genetics Initiative. Additional proceeds will be shared equally between CURE and the Epilepsy Foundation honoring the Cervantes’ request to support new therapies and research.

**Epilepsy Foundation - Cannabinoid Signaling in Epilepsy: Pathways to Therapy Workshop**

*Authors: Kathleen Farrell, Brandy Fureman, Megan Huizenga*

On October 9-10, 2017 at Stanford University, the Epilepsy Foundation brought together key stakeholders in the epilepsy community, cannabinoid research and clinical practice realms to discuss the current state of the science behind cannabidiol (CBD) for seizure control. Workshop participants also helped to determine what questions still remain about anti-seizure effects of cannabinoids, and offered suggestions about how to address those unknown areas.

Clinicians from the epilepsy space discussed what they are seeing in a clinical setting with cannabinoids. Clinically, the reports from the Epidiolex (CBD) clinical trials at GW Pharmaceuticals/Greenwich Biosciences provide evidence for anti-seizure effects with CBD treatment in the epilepsy populations studied so far. However, like other anti-seizure medications, cannabidiol's therapeutic efficacy is not consistent across patients or seizure and epilepsy type. Similarly, preclinical research reports several animal models mimicking the clinical trial data and others failing to re-produce an anti-seizure effect.

Researchers from around the country reviewed what is known about the endocannabinoid signaling system and the role it may play in epilepsy. An introduction to cannabis-plant biology was given, and emphasis placed on the importance for patients to follow the science and not necessarily the names of cannabis strains they are told have higher CDB content (and often do not or also have very high tetrahydrocannabinol (TCH) content). Patient advocates shared their families’ experiences with severe epilepsy, and their own work to stress rigorous testing and controlled study during the early days of cannabidiol's dramatic emergence into the popular consciousness of the rare epilepsy community. A representative from the Drug Enforcement Agency (DEA) provided greater insight into the process of obtaining a Schedule 1 license, necessary to conduct research in cannabinoids. Researchers in attendance who have successfully completed the application process expressed willingness to share their experiences with others as they navigate scheduling. (Please contact the Epilepsy Foundation if you would like to connect with these researchers).

There is an overarching goal to standardize preclinical seizure testing to better evaluate how findings from animal models can inform the development of treatments for the human condition. This includes, but is not limited to, understanding the complete signaling cascade of the endocannabinoid system, use of animal models that recapitulate the molecular and behavioral symptoms of patients, and determining how CBD interacts with the endocannabinoid system to produce anti-seizure effects. Exciting new technologies to explore the function of brain networks and entire signaling systems may be very helpful in further understanding the potential roles for cannabinoids as therapies for epilepsy.

By identifying key knowledge gaps, areas of high research interest have been outlined to move forward on the pathway to improved therapies.
You are welcome to download and share this infographic!

If you’re on Twitter, use the hashtag #DareToSaySUDEP to raise awareness and promote SUDEP education amongst your friends, family.

Visit the SUDEP Institute homepage to learn more about SUDEP, and ways you and those you know and love can prevent it.

Join the Epilepsy Foundation for a “Talking about SUDEP” WEBINAR on Tuesday, Nov. 14th at 8pm EST.

Register here!
**SUDEP Symposium and Education Initiative**

Author: Cyndi Wright

The 2017 Child Neurology Foundation (CNF) SUDEP Symposium took place on October 7, in Kansas City. This SOLD OUT event brought together providers, families, and advocates.

Prior to the symposium, over 1,000 parents and caregivers completed a survey about communication between medical professionals and families about epilepsy. A survey was also distributed to CNS members to determine SUDEP knowledge and the causes of provider hesitancy to disclose the risk of SUDEP. Initial findings from these surveys were shared at the event and will also be used to help develop future programming.

Symposium topics and speakers:

- **SUDEP Awareness: From the perspectives of providers and families** – William H. Trescher, MD
- **SUDEP in Children: What child neurologists need to know about the risk for SUDEP and how to reduce risk** – Elizabeth Donner, MD, FRCP
dc
- **State of Science: What do we know today about SUDEP?** – Jeffrey Buchhalter MD, PhD
- **Moderated Discussion – Perspectives: Living with the knowledge of SUDEP** – Jennifer Silva and Margaret Storey, PhD
- **The Art of Health Care Communication: Applying communication science to the daily practice of child neurology** – Sarah Friebert, MD
- **Making a Difference: Resources to help save lives** – Tom Stanton

Two new SUDEP resources: “Considering a Seizure Alert Device?” and “The SPIKES Strategy” were unveiled at the event. They are available for download by clicking their links!

**Epilepsy Foundation SUDEP Institute awards $80,000 in second milestone of final Biomarker challenge!**

The Epilepsy Foundation SUDEP Institute announces the following winners of the second milestone of the fourth and final SUDEP biomarker challenge:

1. Barbara L. Kroner, PhD, John M. Schreiber, MD, Lowell H. Frank, MD: *Early Detection of Myocardial Injury as a Biomarker for SUDEP in Living Epilepsy Patients*

2. Kristen H. Gilchrist, PhD, Meghan Hegarty-Craver, PhD, William Gaillard, MD: *Cardio-Respiratory Biomarkers of SUDEP from an Unobtrusive Wearable Monitor*

3. Peter Carlen, MD, Berj Bardakjian, PhD, Stiliyan Kalitzin, PhD, Martin del Campo, MD: *Multivariate computer based classification of biomarkers for SUDEP*

4. Carolina Ciumas, PhD, Philippe Ryvlin, MD, PhD, Samden Lhatoo, MD: *PRESUDE - Brainstem MRI biomarker to Predict the risk of Sudden Unexpected Death in Epilepsy*

Each group has been awarded $20,000 for their submission. The third and final milestone is now underway and is a race to the finish! Read more and apply [HERE](#)!
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>
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<th>Syndrome</th>
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9
ABOUT REN

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
and https://ren.rti.org/

Top 10 Reasons to Participate in the

1. Help researchers understand your rare epilepsy
2. Enable faster and more efficient epilepsy research
3. Help researchers identify individuals at risk
4. Find better treatments for your rare epilepsy
5. Improve the quality of care for people living with Lennox-Gastaut Syndrome and other rare epilepsies
6. Help change the way rare diseases are studied
7. Help others obtain an early diagnosis and avoid delayed or misdiagnosis
8. Unlock the cause and lead to the cure for your rare epilepsy
9. Share your story with researchers who really LISTEN
10. Participate in your pajamas!