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SAVE THE DATES

American Epilepsy Society (AES) Annual Conference
November 30 - December 4, 2018
New Orleans, Louisiana
Early-bird registration is open until October 15th. 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, with a tentative date of 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
- Wednesday, August 15th at 8pm Eastern: My Seizure Diary tool
- Wednesday, August 29th at 8pm Eastern: Back to School
More information will be available on epilepsy.com, and Dr. Farrell will send links to the Steering Committee once available.

SLC13A5 Deficiency Research Roundtable 2018
August 20, 2018 - Stanford, California
This one-day roundtable is a great opportunity for researchers, clinicians, pharma and non-profit leaders to learn more about SLC13A5 Deficiency, get the latest research updates, help identify gaps in bench-to-bedside research, brainstorm future research priorities and strengthen outreach to raise awareness for SLC13A5 Deficiency.
For more details on how to participate or sponsor, go to https://tessresearch.org/conference-2018

5th Annual KCNQ2 Cure Alliance Family & Professional Summit
September 15-16, 2018 - Anaheim, California
This 2 day event will bring together families, caregivers, professionals, researchers, and industry partners to further research and improve the lives of those with KCNQ2 encephalopathy. Key presenters will include doctors Ingrid Scheffer, Sarah Weckhuysen, Ed Cooper, Phillip Pearl, and others.
Registration is open here. A special thanks to platinum sponsor Xenon Pharmaceuticals.

2nd SYNGAP1 International Conference
November 27-28, 2018
(Young Investigator workshop on November 26th)
The Scripps Research Institute-Florida - Jupiter, Florida
Learn more and Register here.
FasterCures: Health Citizenship - A New Social Contract to Improve the Clinical Trial Process

“Over a quarter of a million clinical trials are currently registered on clinicaltrials.gov. It’s no wonder that society has high hopes for the next cure for cancer, a breakthrough in Alzheimer’s disease treatment, and more effective prevention of common conditions such as strokes.

Despite wide agreement that the timely registration and reporting of clinical trials are necessary to ensure transparency of and accountability for the ethical conduct of consent-driven research, few clinical trials are registered in a timely fashion and even fewer report results. When clinical trials are not prospectively registered, it is difficult to track protocol amendments and statistical analysis decisions that often adjust as the research unfolds. In addition, with only 13 percent of clinical trials reporting results within the mandated 12-month window, the ethical obligation of timely public reporting of results remains unfulfilled for the vast majority of studies.

If clinical trials are the backbone of our system for developing new approaches to prevent and treat disease, transparency and trust are the lungs. A vibrant system is impossible without a new social contract among all the stakeholders, especially clinical researchers, patients, and primary care physicians.”

Read the full article here, and then check out the newly listed clinical trials on the Epilepsy Foundation Clinical Trials Portal on page 7!

FDA Approval of Epidiolex

On June 25, 2018, The U.S. Food and Drug Administration approved Epidiolex (cannabidiol) [CBD] oral solution for the treatment of seizures associated with two rare and severe forms of epilepsy, Lennox-Gastaut syndrome and Dravet syndrome, in patients two years of age and older. This is the first FDA-approved drug that contains a purified drug substance derived from marijuana. It is also the first FDA approval of a drug for the treatment of patients with Dravet syndrome. Read more here.

2019 #EpilepsyWalk

On Saturday, April 27, 2019, the #EpilepsyWalk for awareness and fundraising will take place on the National Mall in Washington, DC. Walker’s Village will at the Smithsonian National Mall metro station.

The national #EpilepsyWalk is a fundraising event with inspirational, healthy, and fun community celebration of music and entertainment with friends, family, corporations and organizations celebrating their fundraising success and support for the epilepsy community. Funds raised are for much-needed research, programs, services and education about epilepsy. People from nearly 50 states across North America converge on the National Mall each Spring as they take steps to end epilepsy. The Epilepsy Foundation is celebrating 50 years of programs and services supporting the epilepsy community!

Use the Walk to share your story and raise money for services for people living with epilepsy, training on proper seizure recognition and first aid, advocacy to ensure health care options remain strong for people living with seizures, and research for better treatments and cures. Register today at walkforepilepsy.org and spread the word on Twitter with the hashtag #EpilepsyWalk!

Social media push for REN enrollment

Please help share the opportunity of participating in REN, as our group enters it’s final phase of the current PPRN grant. We have more to do, and want to ensure as many families get to share their story as possible to further research in rare epilepsies. Consider sharing one of the following messages via your social media channels:

More than 1,400 people have enrolled in the Rare Epilepsy Network database. You can enroll anywhere and at any time convenient for you – don’t miss this last opportunity to share your experience! Please help us spread the word to your friends and loved ones! Learn more at https://ren.rti.org

Are you ready to be a part of the Rare Epilepsy Network? Learn more about the REN and how to participate at https://ren.rti.org – and don’t forget to share with your friends and loved ones!
Update: Epilepsy Learning Healthcare System

- Dr. Kathleen Farrell, MB BCh BAO - Director of Clinical Research, Epilepsy Foundation

The Epilepsy Foundation and its partners, with the support of the Anderson Center for Health Systems Excellence at Cincinnati Children’s Hospital, and PCORI is creating a Learning Health System (LHS) in epilepsy.

An LHS is a quality improvement network in which health data is collected as part of routine care, analyzed, and used as the baseline for continuous quality improvement. In an LHS network, people living with epilepsy, clinicians, and researchers work together to choose and deliver care based on best evidence and to drive discovery and learning as a natural outgrowth of every clinical encounter with the expectation that it will accelerate the translation of knowledge to outcomes. Creating a LHS requires re-organizing health systems so that clinical care and research are connected purposefully in order for care to inform research and research to inform care.

On June 21-22, the Epilepsy LHS (ELHS) core team joined the three fellow developing networks for a Design Meeting in Chicago, Illinois. The purpose of the meeting was to identify the set of specific changes that teams who participate in the Learning Health System Network need to undertake to achieve breakthrough improvement. It offered an opportunity to discuss the evidence, hear expert opinion, refine the underlying conceptual framework for the ELHS, and identify relevant measures to track the network progress. Each network team focused on the selection of outcomes that matter most to patients and families, to review measures of success, and to identify promising changes to health care systems, including health care services and research.

ELHS participants included people living with epilepsy, parents of a child with epilepsy, physicians and nurses in epilepsy and neuropsychiatry, epidemiologists and researchers. This broad range of backgrounds served to think in a multidimensional way, considering all stakeholder perspectives - both the lived-experience and experience working in the epilepsy space. People living with epilepsy and their families/caregivers make up the ELHS Community Engagement Core, who provide powerful insight into priorities, questions and issues faced by those affected by epilepsy.

Following the Institute of Healthcare Improvement (IHI) Model for Improvement, the main focus of the discussions was to refine the purpose of the ELHS, assess the current system, and gather input on changes the network should pursue and via what measures of change. Achieving breakthrough improvement depends upon having the will to change the current state to one that is better, the development of ideas on which to base the design of new systems and putting into practice approaches which enable the execution of the ideas.

As an outcome of the Design Meeting, the ELHS is proud to share its global aim: Our vision is for all people with epilepsy to live their highest quality of life, striving for freedom from seizures and side effects, and we won’t stop until we get there. Our mission is to design and implement a system of co-production that will improve outcomes for people with epilepsy and their families/caregivers in the following specific ways: improve quality of life, improve seizure control, improve seizure freedom and reduce epilepsy mortality.

The next phase of developing the ELHS includes recruitment and selection of healthcare centers around the United States. The core ELHS team at each healthcare center will consist of a physician site lead (an ELHS champion with enthusiasm and time for ELHS activities), a nurse, nurse practitioner, study coordinator, and activated people living with epilepsy and family members/caregivers. Data collection will begin in the autumn. A website for the ELHS is currently in development, with an expected launch of early-September. If you are interested in learning more about the Community Engagement Core, please contact its lead, Ms. Alison Kukla at alisonkukla@gmail.com or Dr. Kathleen Farrell at kfarrell@efa.org

More updates to come in the next newsletter!
Summer! School is out and families look forward to spending time together enjoying the warm weather and outdoor activities. You may be relaxing at home this summer, making new friends and building skills at a camp, or traveling the world chasing adventure. Whatever activities you choose, take time to think about keeping everyone healthy and safe.

Epilepsy impacts each person differently. It is important to consider seasonal health and safety issues that people with seizures may have. Advanced planning is key. What kind of support do you need? What changes or modifications may be needed for the type of activities you'll be doing? Take time to consider:

- Seizure type
- Seizure frequency
- Treatment for seizures (medications, diets, devices)
- Seizure triggers
- Individual abilities
- Ability to think and respond following a seizure
- Potential need for access to timely emergency or hospital care

Take a moment to read more below about strategies to help keep you safe while enjoying summer activities.

### Swimming and Water Sports

Swimming and water sports are a great way to relax, refresh, have fun, and exercise! Being in and around water requires safety precautions for everyone, including someone who has seizures. According to the Centers for Disease Control and Prevention (CDC), there are approximately **10 drowning deaths** in the United States each day. Water safety tips include:

- All adults and children with epilepsy, regardless of seizure frequency or severity, should speak to their neurologist about water safety. Some may be advised not to swim at all. Others may be allowed to swim and participate in water activities with precautions and supervision.
- Learn to swim! If your doctor has ok’d water activities and you enjoy being in or around the water, then become a strong swimmer.
- Swim with a friend or family member who is familiar with your seizures and is strong enough to help you. If you have a seizure in water, you'll need someone able to hold your head out of the water during and after the seizure. Adults must closely supervise children around water.
- If possible, swim in a designated area (pool or roped off area of open water) supervised by a lifeguard. Tell the lifeguard you have epilepsy and what should be done if you have a seizure.
- Avoid swimming when you are tired or don't feel well.
- Swimming in the ocean, or other open water, is not as safe as swimming in a pool. In the ocean there are currents, tides, sudden changes in water depth, and colder water temperatures that can lead to problems. Every person, including those with epilepsy, needs to be aware of their surroundings and take extra care in open bodies of water.
- If a person has a seizure in open water, it may be harder for someone to see that you are having a seizure or to get to you quickly.
- Wear a life jacket for all water activities, including boating, water skiing, rafting and fishing. Check all life jackets and personal flotation devices to make sure they fit well and work properly.
- If a person has a seizure in water and is not fully aware or conscious, this can be a life-threatening situation. Even if the person appears to fully recover, call an ambulance (911) as the person requires a full medical evaluation.
- Plan time to learn CPR (cardiopulmonary resuscitation), especially if you plan to spend plenty of your summer in and around water. In the time it takes for paramedics to arrive, CPR skills could save someone's life.

### Cycling

Riding a bicycle is a great way to spend time outdoors, commute in the nice weather, and get in some healthy exercise. If you have seizures, depending on the type and severity, some safety tips include:

- Every person who rides a bicycle should wear a helmet and reflective clothing.
- Choose the safest route. It may be better to avoid cycling on busy roads and instead enjoy the safety of a dedicated bike path.
- Share your planned biking route with someone before going out, especially if you are biking alone. Carry a phone, smart watch, or other device with a GPS tracking feature.
- Remember to drink water and stay well hydrated on long rides.
- For long rides, plan ahead so you can take your seizure medication at the regular scheduled time.
- Speak with your neurologist or nurse about your plans to cycle. Ask for advice about safety and how to avoid risks based on your seizure history.

### High Temperatures

Summer can bring extreme temperatures. Some people with epilepsy may be sensitive to heat. Staying cool is important. Considerations for staying cool in warm weather include:

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**Summer Safety for People with Seizures**

- Dr. Elaine Kiriakopoulos, MD MSc - Drug Resistant & Rare Epilepsies Editor, epilepsy.com
Limit sun and heat exposure. Plan activities in the early morning or late afternoon and evening. This helps you avoid the warmest temperatures in the middle of the day.

- Dress in lightweight and light-colored clothing.
- Drink water before, during, and after physical activity to help keep your body temperature cool.
- When temperatures are high, spend time in buildings with air conditioning, such as museums, indoor playgrounds, libraries, or shopping centers.
- If a person has extreme heat intolerance, wearing a cooling vest may be helpful.
- Listen to your body. If you feel weak, dizzy, or thirsty, find a place to rest in the shade. Drink water, tell someone (family member, lifeguard, camp counselor, coach, or friend) how you are feeling and take a break. Ask them to stay by your side until you feel better.

**Amusement and Water Parks**
Families often like to spend time at amusement and water parks during the summer. Many people with epilepsy can participate in these activities without difficulty, but some people need to plan ahead to stay safe. Some things to consider before heading to the park include:

- How do your seizures affect you? What risk might an amusement park ride or water slide ride present if you were to have a seizure while participating?
- Have a friend or family member with you who is strong enough to help if you have a seizure.
- What activities at the park might be similar to your seizure triggers? For some people, excitement or stress due to rides, noise, or crowds may trigger a seizure. Some amusement park rides have flashing lights that can be a trigger for some people with photosensitive epilepsy.
- Read all signs before going on any ride. Make sure the ride is suitable and safe for you. Consider how having a seizure during the ride may affect your ability to respond, your safety, and the safety of others.
- Follow the water safety rules listed above for swimming when you are having fun at the water park.

**Yard Safety**
Staying safe at home should be a priority for everyone. People with uncontrolled epilepsy may sometimes need extra safeguards in outdoor spaces. A few things to consider:

- Use lawn mowers and other power garden tools with caution. A lawn mower, grass, or hedge trimmer that switches off automatically when the handle is released may help reduce injury if you have a seizure. If your seizures are not well controlled, talk to your health care team about safety limits and precautions for outdoor garden tools.
- Be aware of the risk of burns and scalds when using an outdoor grill or barbecue. Take precautions for safety around sources of heat.
- If you or a loved one has seizures that cause them to fall, avoid rough concrete or gravel surfaces. Consider grass, bark mulch, or wooden decking as safer options to reduce the risk of injury from a fall.
- Make sure appropriate safety railings are in place on elevated decks and patios.
- If you wander or fall during a seizure and you live near an open body of water or if you have a pool, use a fence as a safety barrier.
- Outside home improvement projects (painting, window washing, gutter cleaning, etc.) are often on the summer to-do list. If you have seizures that impair your awareness or cause you to fall, avoid climbing ladders.

**General Summer Safety Guidelines**

- Talk to your epilepsy doctor or nurse about your plans for summer and ask their advice about choices you may need to make.
- Share your plans for summer fun with the people closest to you and invite them to participate with you.
- Inform lifeguards, camp counselors, coaches, and travel guides of your epilepsy and your seizure action plan.
- Stay hydrated before, during, and after activity.
- Eat nutritious meals. Plan ahead with healthy snacks and a good water supply for extended periods of activity.
- Always take your seizure medications as directed, regularly and reliably.
- Keep good sleep habits and avoid strenuous activities if you are not well rested.
- Wear appropriate protective gear for activities (e.g., bike helmet, life vest, etc.).
- When around water, have someone with you who knows what your seizures are like and is able to help if a seizure occurs.
- If you are going for a walk, hike, jog, or bike ride alone, follow standard safety guidelines. Always tell someone your route and how long you expect to be gone.
- Wear or carry something (e.g., medical alert bracelet, necklace, wallet card, smart watch, or phone) that identifies you have epilepsy and has instructions for a first aid seizure plan.
- Avoid activities that are known to place someone with epilepsy at high risk: boxing, high altitude activities like rock and mountain climbing, bungee jumping, scuba diving, sky diving, hang gliding, and paragliding.
NEW STUDIES ON THE EPILEPSY FOUNDATION CLINICAL TRIALS PORTAL

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 extra 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
HEP2 Resistant focal seizures study: https://www.epilepsy.com/make-difference/research-and-new-therapies/epilepsy-foundation’s-human-epilepsy-project-resistant

HUMAN EPILEPSY PROJECT (HEP2) RESISTANT FOCAL SEIZURES STUDY

200 people with treatment-resistant focal epilepsy from around the United States have the opportunity to change the lives of millions by joining in the newest Human Epilepsy Project study on focal seizures. Could you be one of them?
Enrollment Update

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Please feel free to share this newsletter to others with rare epilepsies!

They can enroll HERE now!
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

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