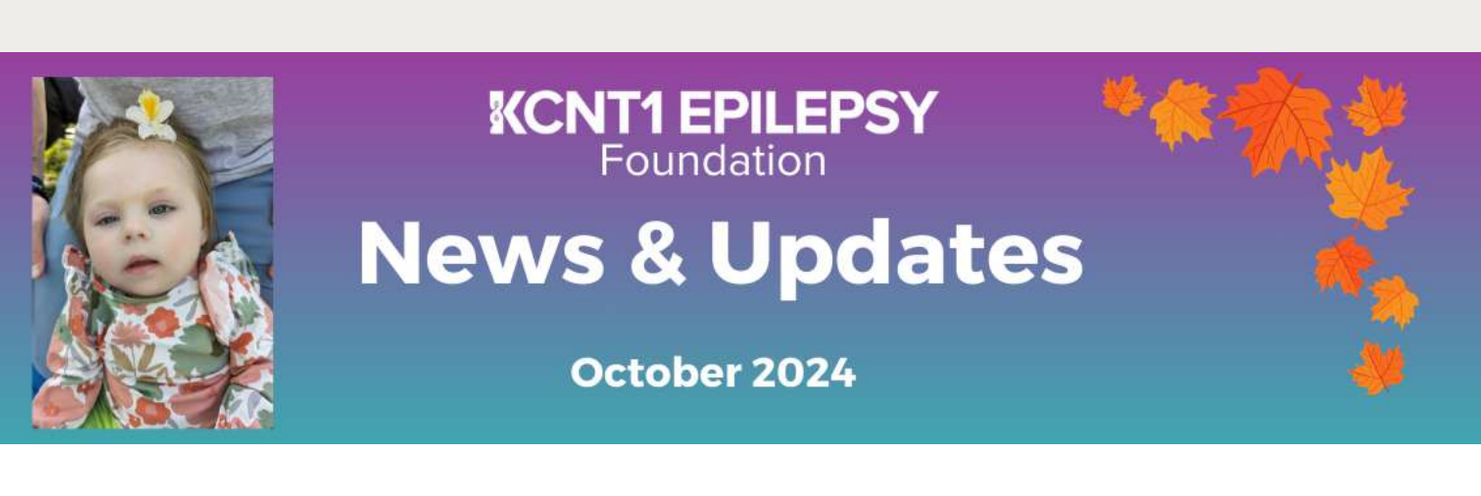


Dear friends and family,

As we welcome the crisp air and vibrant colors of fall, we're excited to share that October is packed with opportunities to come together, connect, and have fun! So, grab your pumpkin latte, get cozy, and get ready to read this long newsletter and sign up for some fantastic activities—we have a virtual event or family meeting happening nearly every week this month. Whether you're looking to learn, share, or simply catch up, there's something for everyone!

One event we're especially looking forward to is our **Family Game Night**, where we'll be diving into the world of Minecraft! It's a great way for families to bond, explore, and have some fun together online. We can't wait to see all of you there!

As we fill this month with fun, we also want to acknowledge that for many in our community, the journey can be challenging. Frequent hospitalizations, difficult treatments, and weathering the storms of uncertainty can weigh heavily. Please know that we're here for you—whether you need support, resources, or just someone to talk to. **You are not alone**.

If you're in a place to offer your experience and support to others, we invite you to consider volunteering. We can talk about various ways you can help guide other families through their journeys. Reach out to us for more details on how you can make a difference.

And don't forget, we're getting into the festive spirit! We're encouraging everyone to **share photos of your kids in their Halloween costumes** on our Facebook page. Let's fill our feed with spooky, fun, and creative costumes!

We are so grateful for your continued support and engagement. It takes a strong, committed village to uplift each other, fund vital research, and explore new treatments. Together, we create a powerful network that fosters hope and progress. **Your participation is what makes these events so specia**l, and we can't wait to see everyone involved. It's through collective effort that we continue to grow stronger as a community.

Wishing you a wonderful fall, and looking forward to seeing you online!

Warm regards,

Sarah Drislane

Executive Director

Events

SHE/ADNFLE Families Meeting with Researchers

Tuesday, October 8, 11am EST

Share your experience with researchers who plan to study the progressive health effects of KCNT1 in people with a Sleep-related Hypermotor Epilepsy or nocturnal frontal lobe epilepsy. This will help them design their research and help you get answers and better treatments! Help us prepare the agenda by completing this anonymous survey.

Meeting Link

Sibling Circle

Sunday, October 13, 2:00 EST

Sign up to join our moderator, Jessica Kruger, and meet other siblings 5-17 for fun and friendship.

Register Today

What We Are Learning From Your Data Today...and Tomorrow

Tuesday, October 15 8:00pm Eastern

As part of our *Pathway to Trials* series, Brad Bryan will present preliminary analysis of our registry and Citizen data and how your data will continue to drive research.

Link to Attend

Dads and Granddads Casual Meet Up

Sunday, October 27, 2pm Eastern

Join fellow dads for a casual meet-and-greet. No agenda! Talk about sports, kids, whatever!

Register to attend

Support Session for Bereaved Families

Tuesday, October 29, 8pm Eastern

Join us again for a special moderated session with Brad Thompson for a guided discussion on navigating your grief journey.

Register to attend

Have a KCNT1 warrior who is age 16 or older?

Tuesday, November 12, 8pm Eastern

Join us for a special family meet-up! This is a space for families with teens and young adults transitioning from pediatric to adult care. Connect with other KCNT1 families, share experiences, and discuss the unique challenges of this phase.

To help us get to know our community better and plan the meet-up, please take a moment to fill out this survey:

Epilepsy Awareness Day at Disneyland, Anaheim, California

November 18 & 19

We will have a booth this event and a fun family meetup. More information to come! The largest gathering of epilepsy physicians and patients on earth! We will have a booth and are looking for volunteers!

Learn More!

Science and Research News

KCNT1 Seed Grant Award

By Ali Rosenberg, PhD, Scientific Outreach Officer

We're thrilled to share that Dr. Jillian McKee and her team at the Children's Hospital of Philadelphia (CHOP) are the winners of our 2024 seed grant for their project called "Clinical trial readiness through delineation of longitudinal disease histories in KCNT1-related disorders."

Dr. McKee and her team will use new tools to analyze and understand already-collected data from patients with KCNT1-related epilepsy. Some of this data comes from the electronic medical records collected by the Citizen platform, which is just one reason it's so important for our US-based families to enroll in Citizen! (You still have time to enroll in Citizen and be included in this important study- please see the link in this newsletter, and contact us if you need assistance.) This research study will reconstruct a "natural history" of KCNT1, analyzing many factors including patient symptoms, medications used, and genetic variants. The goal is to better understand the course of KCNT1 disease, which will help future researchers to design KCNT1-specific clinical trials and help healthcare providers select the most appropriate treatments and predict outcomes for individuals with KCNT1. This study fills a much-needed information gap for our community, and at a critical time, as we begin to focus the Foundation's efforts on clinical trial readiness.

We also wanted to give special mention and thanks to our KCNT1 Community Reviewers, who were most excited about an application to develop a KCNT1 gene therapy. The Foundation initiated funding for this research group in 2023, and we hope to see initial results this year-- and to continue to support this work in the future. We will send another update in the next newsletter!

Our Citizen Health Numbers Are Rising!

We have increased enrollment from 62 to 74! We are striving for 100 for more statistically powerful numbers!

Medical records and genetic data can provide valuable insights into how KCNT1-related conditions manifest and progress, showing the "natural history" of the disease. Analyzing patterns can help us identify effective treatments and improve quality of life for our kids. Come see the preliminary analysis of your Citizen data on October 15th. If you are based in the U.S. please enroll in Citizen Health today and help us build a database of insights.

Enroll in Citizen Health, here.

Community News

Pathway to Trials: Clinical Trial Readiness Education

If you missed our most recent family meeting about clinical trials, you can view it at the link below. Ali Rosenberg and Brad Bryan provided an overview describing how the KCNT1 community can prepare for upcoming clinical trials. They cover key areas such as:

Clinical Trial Readiness: Learn why it's crucial to have detailed medical records, complete genetic testing, and register in patient databases for quick enrollment.

Patient Data : Understand the importance of accurate patient numbers and contact information to support clinical trials and research, encouraging more families to participate in patient registries.

Clinical Trial Participation: Learn what to expect in clinical trials, including in-person visits, caregiver involvement, and potential coverage of treatment costs.

Reach out if you have any questions.

Watch on YouTube

Chan Zuckerberg Institute Selects Us!

We are excited to announce that the KCNT1 Epilepsy Foundation has been selected to join the Chan Zuckerberg Rare As One Network, and to receive a grant! This incredible opportunity will help us build a stronger, more sustainable organization by bringing us into the network of 94 patient advocacy groups and the CZI network and resources. Plus, it will provide some funding to help expand our professional staff and infrastructure. While this grant is a significant boost for us, it does not directly fund research. We will continue to rely on community support to raise funds specifically for research projects. This grant allows us to operate more effectively, giving us the tools to better support families and advance our mission for accelerate the development of new treatments!

See press release.

KCNT1 Families Welcome KCNT2 Families

KCNT1 and KCNT2 variants can both genetic disorders that affect how brain cells communicate. Although KCNT2 is even rarer, some kids with KCNT2 can experience similar challenges to those with KCNT1, such as epilepsy that affects their development and causes frequent seizures. However, some children with KCNT2 may have milder symptoms, like behavioral issues rather than severe seizures. Because both disorders disrupt similar pathways in the brain, some of the treatments that are being developed for KCNT1 could potentially help children with KCNT2, even though they have different forms of the disease.

That's why we are inviting KCNT2 families to join our private Facebook support group and attend our informational webinars. Since both KCNT1 and KCNT2 can affect children in similar ways, we believe there's a lot of shared understanding and experiences between the families. We know our community is welcoming, and KCNT2 families will find support, resources, and connection here, just like the KCNT1 families have.

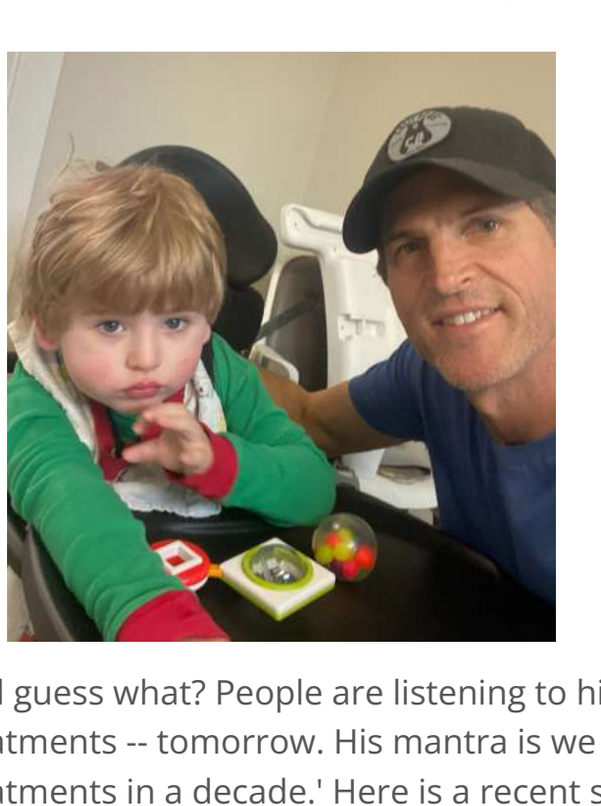
Your Voice Matters

Important Poll: Where Would You Travel for a Clinical Trial?

Whether you'd drive, fly, or are still unsure if you'd be interested in a clincial trial—that's totally fine. We're here to provide you with the information you need when the time comes, so you can make the best decision for your family. What exactly is a clinical trial? What's the difference between Phase 1 and Phase 2? How do inclusion and exclusion criteria work? What are your goals for your child? And how much risk are you willing to consider for a small or significant improvement? These are deeply personal choices, and we're here to support you every step of the way. Join our *Pathway to Trials* series of meetings, explore our resources, and get ready—several companies are nearing trial stages! Plus, you can influence where trials could be located by completing our anonymous poll!

Take the anonymous poll!

Grateful For Our Co-Founder and Advocate, Justin West



Five Years of Advocacy is Paying Off for Everyone

For nearly five years now, our co-founder, Dr. Justin West, has been advocating on behalf of his son and the entire KCNT1 community. He takes time away from his family to travel to meet drug developers, researcher and to attend key conferences to raise awareness about KCNT1 and the importance of patient voices in clinical trials.

And guess what? People are listening to him. He works to emphasize the dire need for new treatments -- tomorrow. His mantra is we want 'better treatments tomorrow, not perfect treatments in a decade.' Here is a recent sample of his advocacy:

RAPS Meeting where he joined federal regulators to highlight the need for patient involvement in the regulatory process to ensure access to new treatments.

Praxis DEEP Dive: He joined global epilepsy experts to discuss clinical trials and promising treatments for rare genetic epilepsies like KCNT1.

Evolution Summit: Dr. West emphasized how integrating patient perspectives can improve clinical trial outcomes for rare diseases.

Next Up: Duke-Margolis Institute Webinar: Dr. West will join a panel to discuss dose-finding in rare disease drug development and share patient and clinician perspectives.

We're proud of his ongoing advocacy! Please remember to thank him when you have the chance! **To learn more about Justin and where his passion comes from, read our special anniversary interview** here.

Fun and Fundraising News & Updates

Join Our Family Game Night!

We're excited to try an **online game night** to bring families together for fun and to connect! Whether you're a gaming pro or a complete beginner, this is a chance for parents and kids to enjoy games like Minecraft.

We need your input to get started! Please take a moment to fill out our quick survey to express your interest in organizing or participating, and let us know what games you'd like to play.

We look forward to gaming with you! Let us know if you are interested here!

Get Ready to Support Giving Tuesday on Dec 3rd

In 2022 we had 45 supporters on Giving Tuesday. In 2023, thanks to YOU, we had 90 supporters! What can we do in 2024?

Last year our winning teams included Alex Wild, Samantha MacMechan, Laura Aguilar, Lisa West, Michele Martel McKendall, Shifra Wagner, Lorena Avonce, Rotem Miller, Krystle Stanley, Kady Lucetti and Tammy Williams! Can we count on you this year? Email us!

Keep your eye open for the opportunity to join our fundraising campaign to raise funds for research tools! This can include cell lines, animal models, and even EEG and blood collection for a special project. **By supporting our campaign this Giving Tuesday, you'll help provide researchers with the tools they need to find life-changing treatments for our children.**

Grateful for the Arpin Strong/Arpin International Charity Golf Tournament

We are thankful for being selected as one of five beneficiaries of Arpin's golf tournament. Thanks to the families and Board members who supported the event with donations of raffle items and sponsorships. **We ask our parents to show their appreciation of the Arpin International team by visiting their Facebook page and thanking them for their support!**

Grateful for 5th Annual Bike the Pike Family Fundraiser

We're thrilled to hear about the success of the fifth annual **Bike the Pike Family Fundraiser**. A huge thank you to Tyler Higgins and friends for organizing another successful event, and to all our corporate sponsors for their generous support.

With over 100 participants this year, each pedal pushed us closer to better treatments for KCNT1 epilepsy. Your commitment and enthusiasm are truly inspiring. Visit the instagram @bikethepike

Together, we are making a difference. Here's to more progress and hope!

Facebook Fundraisers Are Important to Support Our Mission

Hosting fundraisers on Facebook is an impactful way to support our mission, allowing us to raise crucial awareness and funds. Donations are tax-deductible and securely handled by the PayPal Giving Fund, and fundraisers can even reach supporters in other countries.

A special thank you goes out to everyone who has hosted a fundraiser for us this year! We also deeply appreciate those who have raised money for us in the past; your ongoing support is truly invaluable.

To make your fundraiser even more meaningful, consider hosting it around a special milestone, such as your KCNT1 Warrior's birthday. This creates a beautiful tribute, allowing friends and family to contribute in honor of your loved one while supporting a cause that is close to your heart.

Planned Giving Month

Although not a traditional Hallmark holiday, National Estate Giving Month (October through December) offers a meaningful opportunity to plan for the future while supporting causes you care about. By including a charitable organization like ours in your will, you can leave a lasting legacy that supports families affected by rare diseases. There are also tax-wise ways to give, like making a donation from your IRA or through a donor-advised fund, and it's easy to do right from our online giving form. Whether through a legacy gift or another giving option, your support helps drive important research and care that will impact lives for years to come. Consult your tax professional for more information.

We hope each of you will become an ambassador for our mission, spreading the word and helping us reach more people. Parents have an important role in supporting the research and drug development process by sharing their ideas, data and time. Together, we are making a difference in building a brighter future for our children and families. **Together we can do this!**

Donate

Our Contact Information
{{Organization Name}}
{{Organization Address}}
{{Organization Phone}}
{{Organization Website}}

KCNT1 EPILEPSY
HOPE IS ON THE HORIZON