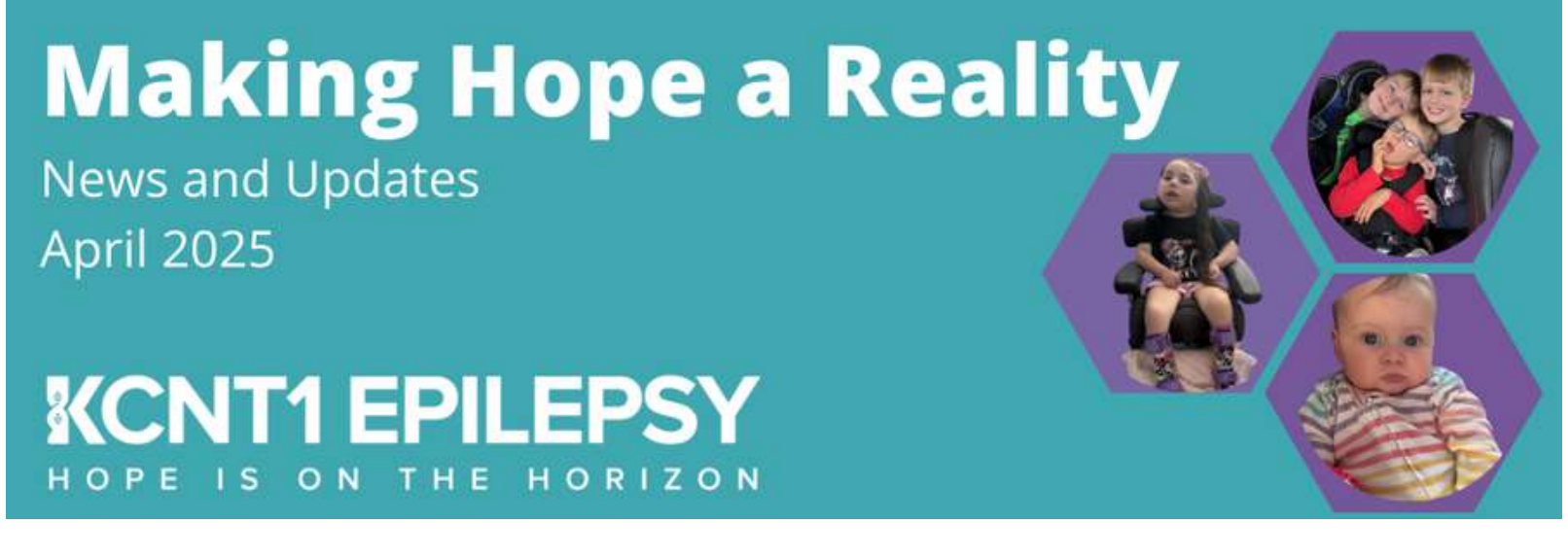


Dear Families, Grandparents, and Supporters,

One of the most powerful aspects of our community is its global reach. Every month, we connect with new families from across the world—families who, despite being separated by thousands of miles, share the same challenges, hopes, and determination to fight for a better future reminding us that no one is alone in this journey.

As we continue building these connections, we also take important steps toward treatments. With multiple KCNT1-targeted therapies in preclinical development, the reality of clinical trials is getting closer. We know that navigating this process will be complex, and we are committed to making sure families everywhere—no matter where they live—have access to the information and resources they need when the time comes.

Thank you for being part of this growing, global movement, and because of your support, **hope is no longer just on the horizon—it's getting closer every day.**

With gratitude and hope,
The KCNT1 Epilepsy Foundation Team

Mark Your Calendars

June 13th: In-person family conference in Philadelphia - Register

June 14th: Million Dollar Bike Ride (MDBR) – Sign up or Donate

Grandparents Meet Up – May 18th - Be sure to share this with your beloved grandparents! Register

We Want to Hear From You
Have you ever noticed a positive change in your child — in motor skills, communication, behavior, or seizures — after starting a new medication? We're collecting **anonymous, non-research feedback** to help guide future study planning and support programs. It only takes a few minutes, and your insight could help shape what comes next for our community.

Click for 2 minute Survey: How Quickly Do you See Changes?

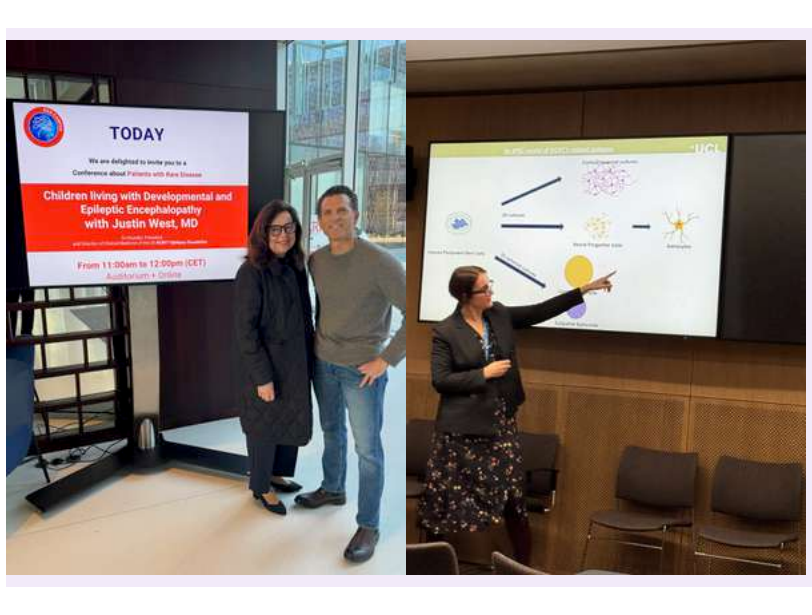
COMMUNITY NEWS

On the Road Again: Family Visits & Pharma Meetings

Co-founder, Justin West, has been traveling internationally, **engaging with our families and strengthening relationships with pharmaceutical partners**. In the UK, families convened to hear about the work being conducted at the UCL Zayed Center for Rare Diseases in Children by our scientific advisory board member, Dr. Amy McTague, and grant recipient, Dr. Raj Karda, who is researching gene editing approaches for KCNT1. Additionally, he met with over a dozen families in France alongside our scientific advisory board member, Dr. Rima Nabbout. Several families volunteered to support our mission of developing new treatments for children. These personal connections reinforce our mission, ensure that family voices remain central to decision-making, and drive progress with industry leaders dedicated to treatments and cures, including UCB and Servier.

One mom said: *"This meeting gave me hope that I did not have for my daughter who has just turned 5. It's great to see how things have moved on for such a rare disease. It's an opportunity. We'll see what the future holds. Thank you to all those involved in this progress."*

The meetings provided an opportunity to observe the efforts being invested in drug development by our pharmaceutical partners and to share patient experiences and therapeutic goals for our children. If you attended the events, please take our survey!



"We are fortunate to have teams that value our input and insights, and we appreciate the chance to influence trial designs to better address the needs of our community."

~ Justin West, MD

Census Count: The Numbers are In

A huge **thank you** to all the families who have joined our community! As of **February 28**, we've reached **521 families**, and in **March**, we welcomed **12 more**—that's nearly one new family every other day! But we know there are still families out there who haven't found us yet.

You can help by:

- **Welcoming new families**

- **Encouraging others to sign up** for our contact list

- **Connecting families** to their Foundation Ambassador (list coming soon!)

- **Sharing our mission** with your network

When families join, they gain access to support, shared wisdom, research updates, and a welcoming, understanding community. Let's keep growing—**together we are stronger**.

Connect the Dots: Create Your Free CRID.org Number

We're asking all KCNT1 families to create a **CRID.org number** — a free, unique research ID that helps link your child's data across multiple studies.

Right now, KCNT1 research is happening in different countries and databases. Without a shared ID, valuable data can stay siloed, duplicated, or disconnected. A CRID allows us to **connect studies later** — creating a more complete picture of KCNT1 and accelerating progress.

It's quick, free, and completely in your control. Keep your number somewhere safe — we'll ask for it when our new patient registry launches later this year.

Get yours today at www.crid.org

Let's make every study count — together.

Upcoming Conference in Philadelphia: Register ASAP! See You There!

Last year's family conference in Philadelphia was a fantastic success, filled with meaningful connections and a fun bike ride the next morning. We can't wait to do it all over again! Registration is now open on our website https://kcnt1epilepsy.org/philly-conference , and we're able to offer travel assistance for those who need assistance to join us. The application is here https://forms.office.com/r/x049XP8pXH

Please let us know if you'll be there—we're excited to meet more families and advocates in person and share inspiring moments together. Watch the video of Kristy and Catherine's heartfelt testimonials!

Why Attend? Watch parent testimonials!

Riding for Research! Million Dollar Bike Ride Fundraiser

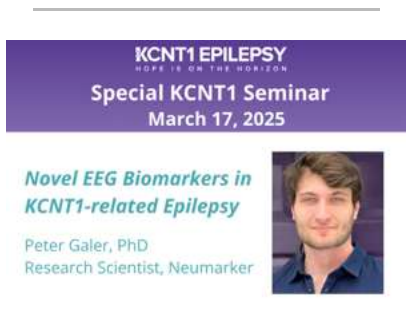
We are preparing for this year's Million Dollar Bike Ride (MDBR), and early indications suggest another strong turnout! Participation enables critical research grants. This event provides an opportunity to collaborate with Penn Medicine and the Orphan Disease Center to raise funds for KCNT1 Research. Participation in this event has funded gene editing research at UCL London, a medical records study at Children's Hospital of Philadelphia (CHOP) that supports clinical trials, and most recently, funded a lab at University of California at Davis using a new mouse model to test sleep and KCNT1. Although Penn is unable to provide a matching grant, we aim to raise $25,000 to support a research project.

How can you help?

Sign up to attend and fundraise

Share a link to our team donation page with your friends and family

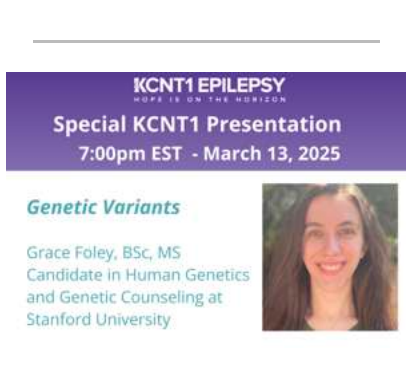
Share our social media posts within your network to increase awareness and support!



Finding Clues in Brainwaves: KCNT1 Biomarker Research

Dr. Peter Galer recently shared his groundbreaking research on identifying unique EEG (brainwave) patterns in KCNT1-related epilepsy. Using advanced technology like machine learning, his work aims to find biomarkers—measurable signals in the brain—that could help track disease progression and treatment effectiveness.

While still early, this research is a critical step toward improving diagnosis and future clinical trials. Watch the full presentation on our YouTube channel to learn more about this important work!

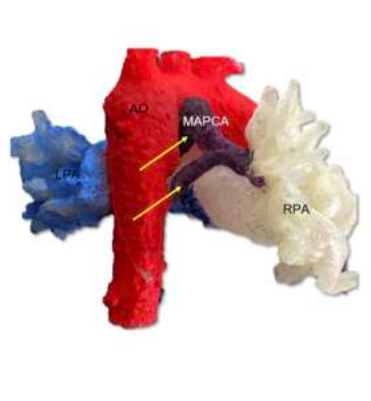


Genetics Presentation

Grace Foley, our Stanford Genetic Counseling Intern, recently led an informative session on **genetic variants**—what they are, how they occur, and why they matter in genetic counseling. She provided an accessible overview of how genetic differences can influence traits and health, making this complex topic easier to understand for families.

One key topic she covered was **variants of uncertain significance (VUS)**—genetic changes that are detected through testing but whose impact on health is not yet fully understood. Grace explained how these variants are classified, what testing methods are used to analyze them, and how they can sometimes be **reclassified over time** as more research becomes available. Understanding these updates can be important for families navigating genetic testing results.

If you missed the session, don't worry! Watch on YouTube or **download the handout here** for a summary of the key takeaways and learn more about the evolving field of genetic counseling.



Clinical Guidelines & MAPCA Initiative

The foundation and our medical advisory team are working to develop **clinical guidelines** for KCNT1 care, and are moving forward with a **MAPCA working group**. These efforts are central to improving diagnosis, care, and long-term outcomes for our children.

Understanding Clinical Trials

What Can Cause a Clinical Trial to Be Put on Hold?

Understanding the clinical trial process can help families feel more prepared and informed. In the early phases of a trial, the primary goal is to assess safety. Even a single unexpected or serious side effect (called an "adverse event") can lead to delays or pauses in the study. Other factors—like not having enough participants enrolled—can also cause a trial to be put on hold.

We know many of you have been waiting a long time for KCNT1-specific treatments and have expressed interest in participating in trials. Right now we are aware of three companies planning to apply for clinical trials in 2025. Stay tuned -- you will be the first to know when these get approved and announced! So, how will you know if your child might qualify for a clinical trial when the time comes? The federal regulators and the companies leading these trials will share the final eligibility criteria once they're confirmed. However, some common factors that **may be considered** include:

- Age

- Genetic confirmation of KCNT1

- Developmental milestones

- Number of seizures per week or month

- Current anti-seizure medications

While we wait, it's a great time to start talking with your healthcare providers. Ask them: **"What can we do now to be ready for clinical trials?"**

We're committed to keeping you informed and supported every step of the way. Be sure to stay tuned—an upcoming schedule of educational webinars will be released soon!

Watch this video to learn more about clinical trials!

Funded Research

Big News: New KCNT1 Research Projects Coming Soon!

We're excited to share that several **new KCNT1-focused research projects** are moving forward—with official announcements coming soon!

We are incredibly **grateful to have been chosen as a partner by CURE Epilepsy**, the leading nonprofit fully committed to epilepsy research. Together, we are **co-funding a promising translational research project** aimed at developing potential treatments for KCNT1-related epilepsy. This project will also explore overlaps with another epilepsy-related gene, expanding the potential impact.

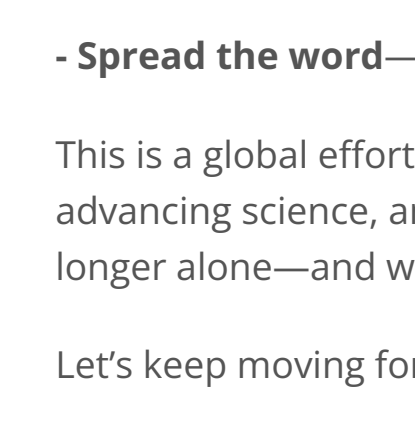
In addition, we're supporting a **separate gene editing project** at a major **children's hospital in the Midwest**, focused on precision strategies to correct KCNT1 mutations.

These projects—and more that are currently in development—are made possible through the incredible **support of our KCNT1 community**. Friends, families, and generous family foundations are helping fund this vital work through **gifts and fundraising efforts**.

Together, we are advancing science, hope, and the search for a better future for all those affected by KCNT1 epilepsy.

Stay tuned—exciting updates are just around the corner!

Advocacy News



Advocacy in Action: Scarlett Goes to Capitol Hill

16-year-old, Scarlett represented our KCNT1 community on **Capitol Hill**, sharing her family's journey and championing the need for rare disease funding and policy support.

Her story touched the hearts of many and underscored the importance of ongoing advocacy efforts. We're so proud of her voice and courage! You can hear her message to legislators here.

With Gratitude and Hope for What's Ahead

As we reflect on the progress we're making—through research, growing connections, and new families joining us—we want to say a heartfelt **thank you**. None of this would be possible without the incredible support, generosity, and passion of **you—our KCNT1 community**.

Whether you've donated, shared your story, welcomed a new family, or simply stayed connected—you're part of this movement. And there are many ways to get involved:

- **Fundraise or donate** to support research and family programs.
(PayPal Giving Fund is available in many countries—an easy way to give!)

- Help us grow our international presence—we're expanding our **Ambassador Program** and looking for families to help build bridges across countries.

- Stay connected and informed—clinical trials are coming, and now is the time to talk with your doctors about readiness and what to expect.

- Spread the word—share our mission with friends, colleagues, and care teams.

This is a global effort, and every voice matters. Together, we are raising awareness, advancing science, and building a future where families affected by KCNT1 are no longer alone—and where effective treatments are within reach.

Let's keep moving forward—**united, informed, and ready.**

With deep gratitude,
The KCNT1 Epilepsy Foundation Team

Continue Your Support

Together we can do this!

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

KCNT1 EPILEPSY
HOPE IS ON THE HORIZON