

# MAKING HOPE A REALITY

NEWS & UPDATES  
MAY 2025

**KCNT1 EPILEPSY**  
HOPE IS ON THE HORIZON



Spring is a season of growth—and our KCNT1 community is no exception. This month brings powerful signs of progress: from growing research partnerships to heartfelt gatherings that remind us we're not alone in this journey.

In this issue, you'll find new opportunities to connect, support, and stay informed—whether you're a parent navigating care, a grandparent offering love, or a supporter pushing science forward. We're excited to share what's unfolding and what lies ahead.

Thank you for being part of this strong and hopeful community.

With appreciation,  
**The KCNT1 Epilepsy Foundation Team**

## Mark Your Calendars

**Grandparents Meet Up – May 18th - [Register](#)**

**June 13th:** In-person family conference in Philadelphia - [Register](#)

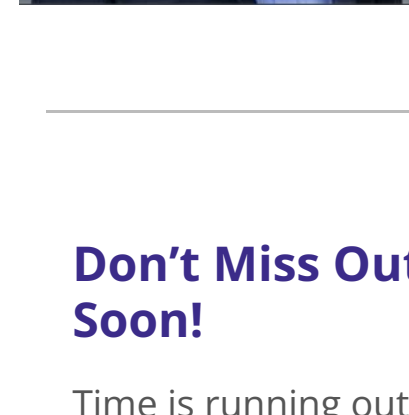
**June 14th:** Million Dollar Bike Ride (MDBR) - [Sign up or Donate](#)

## COMMUNITY NEWS

### Welcoming a New Voice to Our Board: Dr. Dewey McLin

We're thrilled to welcome Dr. Dewey McLin to the KCNT1 Epilepsy Foundation's Board of Directors. With over 20 years of experience in rare epilepsy, Dr. McLin played a key role in launching Epidiolex — the first FDA-approved cannabinoid treatment for childhood epilepsy. His background in both startup and established pharma companies, plus recent work on DEE-focused treatments, brings invaluable insight to our mission.

As KCNT1 research gains momentum, Dr. McLin's leadership will help guide our advocacy, partnerships, and push for faster treatments.



"I'm excited to join such a passionate and mission-driven organization," said Dr. McLin. "Having supported families impacted by rare epilepsies in my past roles, I'm deeply committed to helping bridge science and strategy as this field enters a promising new chapter."

~ Dewey McLin, PhD

### Don't Miss Out — Conference & MDBR Registration Closing Soon!

Time is running out to register for our KCNT1 Family & Research [Conference](#) and to sign up for the Million Dollar Bike Ride (MDBR)! These two incredible events unite our community to connect, learn, and push KCNT1 research forward.

**Need help covering some costs?**  
We've got you covered — a simple [application](#) for financial travel assistance is available, but the deadline is **May 11th**, so act fast!

**Riding for Research!**  
The MDBR is more than a bike ride — it's a critical fundraiser that's powered KCNT1 studies at UCL London, CHOP, and UC Davis. This year, we're aiming to raise \$30,000 to fund another groundbreaking project.


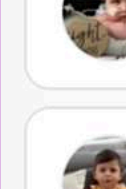


Huge shoutout to the four incredible teams who've already raised **\$13,431** — we see you, and we know more teams will be showing up soon.

**Here's how you can help -- even if you can't attend:**

- Fundraise or donate to [Team KCNT1](#)
- Share our [team page](#) and social media posts with your friends and network

Together, let's make every mile and every dollar count for KCNT1 research!

**Team Members** 17

NAME
 Sydney Phillips
 SARAH DRISLANE
 Catherine Grieco
 Rotem Miller

**\$13,431**  
RAISED OF \$30,000

**Team KCNT1**

[Register](#) [Donate](#)

## Calling All KCNT1 Grandparents!

We're excited to welcome you to our second *Grandparents Meetup* — a warm, supportive Zoom gathering just for grandparents in the KCNT1 community.

**Saturday, May 18th at 3:00 PM Eastern**  
**Online via Zoom**

[Register here](#)

Moderated by Steve Crooks, proud grandfather of Emerson, this meet-up is a chance to connect, share experiences, celebrate your grandchildren, and build community. Whether you're a first-timer or returning, we'd love to see you there.

*Zoom's built-in language translation is available — making it easier for everyone to participate and feel included.* If you'd like to organize your own grandparents meet-up in your country, we can help!

Let's grow this community of care — one grandparent at a time.

## Special Announcement: October is KCNT1 Awareness Month

We're proud to announce that we have chosen October to be KCNT1 Awareness Month — a time dedicated to shining a light on the families, researchers, and advocates working to change the future for children affected by KCNT1-related disorders. We chose October because it leads into National Epilepsy Awareness Month and gives us the chance to spotlight our rare community, raise awareness, and build momentum for research and support. This fall, we invite you to help us make our first KCNT1 Awareness Month unforgettable.

We're putting together a KCNT1 Awareness Month **volunteer crew**—a team of parents, families, and friends who want to help shape what October looks like. You bring the ideas, and we'll help with tools and support. Possibilities include:

- Hosting a local walk, run, or roll
- Coordinating a community fundraiser
- Organizing a Remembrance Day to honor the lives we've lost

Taking on a light advocacy project, like requesting a local or state proclamation

There's no minimum time commitment, and you don't need event experience—we'll provide templates, tools, and a fundraising platform if you'd like to host something.

Want to join the crew or share an idea? Fill out our [volunteer interest form!](#)

**Let's make October a month of hope, connection, and impact for all families affected by KCNT1.**

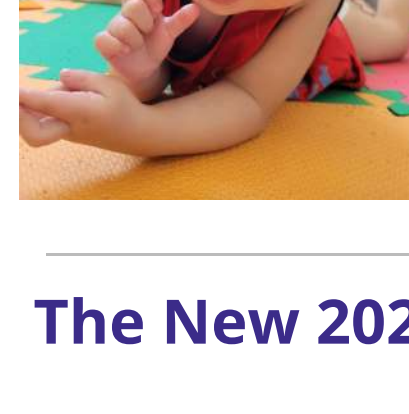
## Show Us Your Warriors!

We're putting out a fresh call for photos and videos of your amazing KCNT1 warriors. Many of our current visuals are several years old — and we'd love to spotlight the children and families at the heart of this community today.

Whether it's a big milestone, a quiet moment, or a candid slice of daily life, your images help bring our mission to life across social media, fundraising, and storytelling.

**Want to share?**

Just fill out our photo release [form](#). Once we receive it, we'll reach out with the best way to submit your files privately and securely.



We're also subscribing to a new video platform soon to make it easier for families to record and share their stories and hopes. More details coming soon!

Let's show the world the faces we fight for — every story matters.

## The New 2025 Seizure Names—What Parents Really Need to Know

The International League Against Epilepsy (ILAE) is the global body that sets the scientific "rules of the road" for classifying, diagnosing and treating epilepsy. Its position papers shape everything from FDA trial endpoints to the wording on your child's clinic note. When the ILAE updates the language, neurologists, researchers and insurance forms follow suit.

*In April 2025, the ILAE published the first overhaul of seizure terminology in seven years.*

**What's changed?**

Doctors now describe seizures with **short three-letter codes** (like **FPC** or **FIC**) instead of long phrases.

A brand-new code, **GNM** (generalized negative myoclonus), covers very brief "floppy-drop" events some KCNT1 kids have.

Extra descriptors (motor, autonomic, sleep-related) let doctors be more precise without changing the core code.

**Why learn them?**

**Speedier care:** When you use the same code your neurologist does, they can adjust meds faster.

**Trial matching:** Upcoming KCNT1 studies will screen by these codes—knowing them keeps you trial-ready.

**Clean paperwork:** Insurance, school forms, and EMRs are switching to the new wording; fluency prevents delays.

**Clear parent-to-parent chats:** Consistent labels make forum posts and diary swaps easier to compare.

*(For the full Z1-type hierarchy see the ILAE's open-access [paper](#).)*

Print our [one-page key](#) of ILAE 2025 codes and keep it on the fridge. The sooner the whole care circle adopts the same language, the easier it is to spot patterns—and move us all closer to targeted treatments.

## Oops! Correction: Connect the Dots: Create Your Free CRID Number

In our last newsletter, we included an incorrect link to create a unique ID for research. Apologies for the mix-up!

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

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

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 <https://thecrid.org>

Let's make every study count — together.



**Help Advance KCNT1 Research: Refresh Your Citizen Health Account**

If you're a parent using Citizen to share your child's medical records, thank you — your participation is making a real impact. By securely connecting electronic medical records (EMRs) through Citizen, you're helping researchers better understand the progression of KCNT1-related disorders and identify new treatment pathways.

Citizen starts by collecting a snapshot of available data, but **it's crucial to log back in and refresh your account periodically.**

This allows newer medical records — such as recent visits, hospital stays, or tests — to be added. More up-to-date data means stronger research insights.

If you haven't logged in for a while, please take a few minutes to check your account **update or refresh** your child's medical records. If you live in the US, please [sign up](#) today!

Every update helps move KCNT1 research forward!

## KCNT1 Clinical Trials: What's Happening Behind the Scenes

Right now, several companies are actively developing their clinical trial plans and preparing to submit IND (Investigational New Drug) applications to the FDA. Once submitted, the FDA has a short window to review and either approve the application or request changes. Once approved, that's when real trial planning kicks into high gear.

We want to extend a heartfelt thank you to the parents who have participated in focus groups with pharmaceutical companies — your insights are helping ensure that upcoming trials are as **accessible, understandable, and family-centered as possible.**

**Clinical Trial Education - Coming Soon**

To help you feel more confident and informed, we're working with industry experts to create a series of educational modules you can watch at your convenience. These will break down the clinical trial process, explain common terms, and walk you through what to expect. Stay tuned — they're coming soon

## KCNT1 Science on the Move!

Behind the scenes, there's a lot brewing — and it's all aimed at better care and faster breakthroughs for KCNT1.

Across the globe, working groups of dedicated clinicians are coming together to explore clinical guidelines tailored specifically for KCNT1-related disorders. Others are digging into potential overlaps between KCNT1 and other genes or conditions — a key step toward smarter diagnoses and more targeted treatments.

And yes, we're even teaming up with a lab to investigate an unexpected but promising lead: **spider venom** as a possible pathway to a whole new kind of therapeutic.

It's an exciting time for KCNT1 science — stay tuned for more updates!

## Scientific Roundtable May 22

We're excited to invite for our next Spring Scientific Roundtable meeting, where researchers share quick, engaging updates on their KCNT1-related work in lightning-round style. Some may be invited back for longer talks or even apply for research grants! Parents are welcome—just be sure to [register](#) to attend! Past presentations can be viewed on our [YouTube](#) channel.

## We Are Stronger Together

As we look at the momentum building—from promising science to stronger family connections—we're reminded that real change happens because of *you*. Every shared story, every step forward, and every act of connection brings us closer to better treatments—and no family walking this path alone.

Whether you're riding, fundraising, joining a webinar, or simply staying informed—you are part of something powerful.

We hope to see you in Philadelphia this June—for the Family & Research Conference and the Million Dollar Bike Ride. There's no substitute for coming together in person, and we can't wait to share that experience with you.

[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



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