KCNT1 EPILEPSY
HOPE IS ON THE HORIZON

News & Updates

August 2024

Dear friends and families,

We hope you and your families have enjoyed a peaceful and restorative summer. As we transition into a new season, we're excited to bring you highlights from the past month, including our deeply meaningful support groups for bereaved caregivers and a unique program for the siblings. These initiatives play an essential role in our mission, offering comfort and connection to families.

None of this would be possible without the unwavering support of our incredible community. Your involvement helps us provide these essential services, and together, we're making a real difference. We are particularly grateful to the Wheeler family for creating *Sydney's Hope Fund*, to provide support for our family programs.

As we look ahead, hope is on the horizon. We'll also be sharing details about upcoming events, opportunities to participate in research, and the latest news on research funding. We're honored to share the positive impact these programs and initiatives have made, and we hope you'll join us in continuing to support our community.

The KCNT1 Foundation Team

✅ Mark Your Calendars ✅

Sept 17th 6pm Eastern

KCNT1 Pathway to Trials: Empowering Families for a Cure
Join us for a KCNT1 community webinar to learn more about how we can get prepared for clinical trials.

Register

Research News

KCNT1 Seed Grant Award

By Ali Rosenberg, PhD, Scientific Outreach Officer

This year we kicked off our first-ever KCNT1 Seed Grant Award, which gives $30,000 to help support important research into KCNT1-related epilepsy. This grant was set up to encourage researchers to start new projects or continue their current ones. We received nine excellent applications from scientists all over the world!

To choose the best project, we used two steps:

Our Scientific Advisory Board (SAB) looked at each application carefully. They checked how important and useful the research would be, whether it was doable, and if it could get long-term funding. They really focused on what would make the most difference for people affected by KCNT1.

We also had help from our KCNT1 Community Reviewers, a group of volunteers who joined us through a Facebook survey. We met with the reviewers to talk about each grant application. They helped us understand how each research project would matter to the KCNT1 community. Their efforts are critical in incorporating the patient and caregiver voice into how we as a Foundation choose what science to support.

Both our SAB and Community Reviewers were crucial in making sure we picked the right research to support, combining scientific expertise with input from our community.

We are thankful to our SAB and community members for their insights and efforts, and we will announce the winner of our inaugural Seed Grant soon!

Community News

570! Our Community is Growing Stronger

By Megan Wright, Parent Liaison, Mother of Lexi

We are excited to welcome new parents, grandparents, and loved ones to the KCNT1 community. A KCNT1 diagnosis is a pivotal point in your child's life, as well as your own. Although the journey is difficult and painful, we hope you take solace in knowing that you never have to walk alone. Our community is growing in numbers and strength with every passing month - a community of love and support for all families across the spectrum of KCNT1-related epilepsies and health conditions.

As you may be aware, we have been working very hard to capture true patient numbers within the KCNT1 community. (Thank you to those who responded to our FB messenger notes and signed up for our Family Contact list!) Dedicated efforts throughout the summer has provided some incredible results: **we now have identified 570 families across more than 50 countries**. These new families in our contact list include recently diagnosed families, families who have been living with KCNT1 for many years, and a whole variety of phenotypes and medical conditions. One KCNT1 warrior is 50 years old!

We are so proud to be uniting KCNT1 families across the spectrum and the globe, and are looking forward to all the ways these connections will move our community and families forward for generations to come. If you know KCNT1 families who are not part of our community, encourage them to sign up here. THANK YOU for being here!

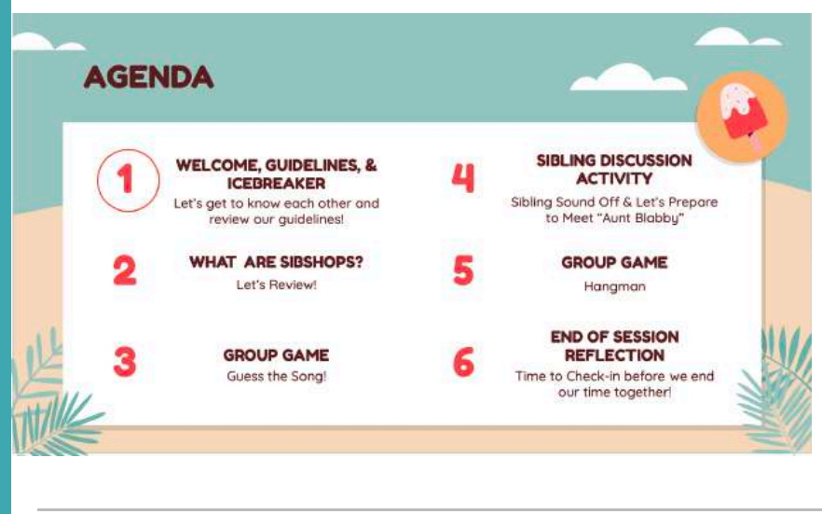
Bereaved Caregiver Sessions with Brad Thompson

Over two days, some of our bereaved caregivers took part in helpful sessions led by grief counselor Brad Thompson, focusing on understanding the complex feelings of grief and learning self-compassion. Brad explained the ongoing nature of grief and emphasized finding hope and meaning after losing someone.We are planning to have these meetings every three months, so please look out for the schedule.
We encourage bereaved families to stay involved by sharing their insights in our Facebook group or by helping others as support specialists and ambassadors. It was particularly special to have two bereaved families at our in-person conference in Philadelphia. Their involvement made the event more meaningful, and we hope to keep growing this supportive community together.

Sibling Circle Meeting Recap: Fun and Friendship

Our Sibling Circle is really taking off, and the kids are loving it! This program is all about giving siblings a chance to meet others who get what it's like to have a brother or sister with special needs. It's a place where they can share their stories and not feel alone.
At our latest meeting, led by the energetic Jessica, kids of all ages came together online. They started by introducing themselves with fun facts, which helped everyone feel more connected. The main part of the meeting, called "Sibling Sharing: Unique Relationships and Connections," let each kid talk about their siblings and the special bond they share. The kids play interactive games and talk about the good and tough parts of having a sibling with special needs. The mood was upbeat and supportive, with everyone showing a lot of understanding and care for each other.
We'd love to see more families join in! It's a great way for your kids to find friends and support in a group that really understands. The Sibling Circle isn't just a meeting—it's a community where kids learn and grow together. Come check it out and see the magic happen!

Next meeting: October 13th 2pm EST


AGENDA

1. WELCOME, GUIDELINES, & ICEBREAKER
   Let's get to know each other and review our guidelines!
2. WHAT ARE SIBSHOPS?
   Let's Review!
3. GROUP GAME
   Guess the Song!
4. SIBLING DISCUSSION ACTIVITY
   Sibling Sound Off & Let's Prepare to Meet "Aunt Blabby"
5. GROUP GAME
   Hangman
6. END OF SESSION REFLECTION
   Time to Check-in before we end our time together!

Reserve your Sibling Circle seat!

Celebrating Our Fifth Year:
An Interview with Co-Founder Samantha MacMechan

As we celebrate our fifth anniversary, we're excited to share a special interview with Samantha MacMechan, a mom and one of our founders. Samantha talks about her journey after her daughter Charlotte was diagnosed with KCNT1-related epilepsy. At first, Samantha felt overwhelmed but she turned her challenge into action by helping start the KCNT1 Epilepsy Foundation with other parents. Her skills in business really helped set up and push forward the foundation's big projects, like a detailed study on the disease and a meeting with the FDA.

Samantha highlights the strength and uplifting spirit of the KCNT1 community, explaining how these experiences have changed her life and way of thinking.

For more insights from Samantha's interview click here.

Your Voice Matters

Join Our Research Efforts

In our ongoing efforts to deepen our understanding the spectrum of KCNT1-related conditions and develop more effective treatments, we invite you to participate in our research studies. This can include sharing data from medical records, surveys, sharing your experiences in a parent panel discussion, or through donations of blood or tissue samples.

In the coming months we will be announcing surveys you can participate in, places you can donate blood, and will announce a new international KCNT1 Carrier Registry.

Citizen Health – Analyzing the Patterns in Medical Records and Genetic Tests

As many of you know, our warriors' medical records and genetic data can provide valuable insights into how KCNT1-related conditions manifest and progress so many of you have created a Citizen account. (Citizen Health was formerly Ciitizen/Invitae) Analyzing patterns can help us identify effective treatments and improve quality of life for our kids. So, if you live in the U.S., please join the 62 other families who have already enrolled and started providing valuable information to study! Bereaved families in the US also have the opportunity to share their warriors' medical records and help generations to come.

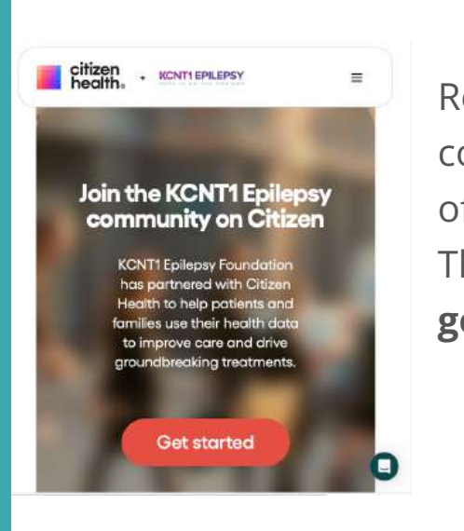
So far 62 of you have joined!

Our goal is 100!

This will give us more valuable data to analyze.

If you need help signing up, we have office hours on Mondays at 10am Pacific time. Schedule a meeting here.

Currently, Citizen Health can only curate records from U.S.-based medical institutions, but soon hope to expand to Canada and Australia.


citizen health • KCNT1 EPILEPSY

Join the KCNT1 Epilepsy community on Citizen

KCNT1 Epilepsy Foundation has partnered with Citizen Health to help patients and families use their health data to improve care and drive groundbreaking treatments.

Get started

Remember, your voice truly matters in this journey. By contributing to research, you're making a difference in the lives of many and helping pave the way for future advancements. Thank you for your support and participation! **Let's reach our goal of 100!**

Enroll in Citizen Health

Helping Us Find Answers: Options for Blood and Tissue Donation

There are several ways you and your family can actively contribute to advancing our understanding of KCNT1. By sharing genetic test results here, participating in surveys and studies, joining Citizen and our patient registry, and even donating biological samples like urine, blood, or tissue during medical procedures, you make a valuable contribution to future discoveries. Bereaved families can also participate in meaningful ways.

To help us coordinate these contributions, we've set up an interest form. This form lets you express your willingness to share health data, donate biological samples, and provide important EEG and genetic information, either now or in the future. Filling out this form doesn't commit you to anything—it simply helps us plan and makes things easier during challenging times. We handle these sensitive decisions with utmost care in partnership with COMBINEDBrain.

If you're interested in making a difference, please consider filling out the form. Your participation could lead to crucial scientific breakthroughs. You can find options for tissue donations for research on the form as well.

Your participation could lead to significant breakthroughs in how we understand, treat, and manage KCNT1.

New! Autosomal Dominant Sleep-Related Hypermotor Epilepsy (ADSHE) Handout for Clinicians

With almost 50 families with ADSHE, we're excited to announce a new resource for parents—a comprehensive handout to share with clinicians. This handout is designed to enhance communication between families and healthcare providers, ensuring a deeper understanding and better management of ADSHE.

In addition, we ar**e planning a family meetup for ADSHE or those who fit within this spectrum.** This gathering will connect you with leading researchers to share your experiences, which will help shape the direction of a longitudinal study for our new patient registry. To participate, **please fill out our interest form**. We will send a scheduling poll to finalize the meeting time based on your availability. Your insights are invaluable in advancing our understanding and treatment of ADSHE.
https://forms.office.com/r/qTPiBHQWnF

Coming Soon: Patient Assistance Fund

We are thrilled to announce the upcoming launch of our new Patient Assistance Fund (PAF), a significant step forward in supporting the families we serve. Thanks to the incredible generosity of our donors during Giving Tuesday 2023 and the foundational support from Sydney's Hope Fund, we will soon be able to offer financial assistance to those in need.

This new fund will provide up to $1,000 per family to help cover medical and related expenses. The assistance will be available on a first-come, first-served basis until the annual fund is depleted each year. Our goal is to alleviate some of the financial burdens that families face, making it easier for them to focus on care and healing.

We are also seeking volunteers to join the review committee for this fund. Importantly, the review process will be conducted anonymously; committee members will not know the names of the applicants to ensure fairness and impartiality. This role offers a unique opportunity to directly impact the lives of families navigating health challenges, and if you are interested in contributing your time and insight, please consider joining us in this important work.

Stay tuned for more details on how to apply for the fund and how to join the review committee. We are excited to bring this additional support to our community and extend our heartfelt thanks to everyone who contributed to making this possible.

Additionally, for those who may need further support, you can find many other financial assistance programs here. This resource is designed to help you find additional aid that may be available to you.

Fundraising News & Inspiration

Family fundraisers play an important role in supporting our mission to discover new treatments and provide support to families. Plus they can be fun and allow people to feel good by supporting an important cause! Angie in Canada is stirring up support in a delicious way—she's hosting a Pampered Chef party where a portion of the proceeds will go to the Foundation. Now that's cooking up some fun for a great cause!

Thanks to the generosity of our community, we are able to push forward in our quest for solutions that make a real difference.

We encourage everyone to consider hosting a fundraiser. Our new Fundraising Toolkit provides ideas, guidelines, and legal agreements to ensure your event is safe and successful. Plus, we're here to help with custom graphics and more to make your fundraiser stand out.

Your efforts not only raise essential funds but also bring us closer as a community committed to a common cause. Every fundraiser adds a vital layer of support and gets us one step closer to our goals. Join us in making a significant impact! There are a few going on right now!

Broward Motorsports Miami Fundraiser

A huge thank you to the Miller, Stanley, and Sousa families for revving up support at Broward Motorsports' Customer Appreciation Day! Their mini fundraiser was a great family meetup that spread awareness and raised funds—doubled by the generous matching from Broward Motorsports. Your efforts are truly driving change in our community!

The Greenblott's Annual Birthday Fundraiser

The first fundraiser for KCNT1 was hosted by the Susan and Seth Greenblott, the founders of our foundation, and we're thrilled that this tradition continues.

We're deeply grateful to all the original supporters who helped launch the foundation five years ago with their incredible support for Lucy on her birthday. Your contributions have played a crucial role in getting us to where we are today.

We hope everyone has a fantastic time at the BBQ! Thank you for being part of this journey with us! Happy 6th Birthday, Lucy!

Arpin Strong Charity Golf Event in Bellingham, MA

We're thrilled to share that we've been chosen again this year as one of the beneficiaries of the Arpin Strong Charity Golf Tournament! We ask that you follow Arpin Strong and like their posts and express your gratitude. There's still time to sign up a team or attend the event to represent our community and show our gratitude. We also still need donations of items and corporate sponsors to make this event a success. **We are looking for volunteers to represent the KCNT1 community at this event.**

For more details and to get involved, please check out this link.
https://arpin-strong.org/arpin-strong-golf-tournament-2024-info/

WE CAN DO THIS TOGETHER

Your dedication makes all the difference. Let's work together to create a brighter future for those affected by KCNT1. We are truly grateful for your unwavering support! Email us if you have questions!

Donate Today

Our Contact Information
{{Organization Name}}
{{Organization Address}}
{{Organization Phone}}
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Looking for something?
Check out our Linktree list of links!
https://linktr.ee/kcnt1