KCNT1 EPILEPSY
HOPE IS ON THE HORIZON

Uniting for KCNT1 Solutions

May 2024

Dear KCNT1 Families,

We reached a milestone for the KCNT1 community: Recently the Foundation, Dr Bearden and some of our KCNT1 families met with the FDA in a Patient Listening session to share with them the needs for new treatments. This was a private 90-minute session for families to share their experiences in caring for loved ones with KCNT1 related epilepsy and neurological disorders.

We extend our sincere appreciation to the families who graciously dedicated their time to prepare for and their effort to participate in the FDA Listening Session: Julie and Jared Schiller, Erna Glisan, Samantha MacMechan, Preston McIntosh, Lorena and Alvaro Avonce, Heather and Brian Atkinson and Jacalyn Kerr. We appreciate the courage and dedication it took to represent the collective voice of our community.

For those unfamiliar with the purpose of such meetings, the FDA listening session serves as a forum for caregivers and foundations to engage directly with regulatory authorities, providing crucial insights into patient needs and preferences. It helps pave the way for informed decision-making when they have applications for clinical trials for KCNT1.

While acknowledging that many more of you would have liked to attend, please know there will be many opportunities for you to share your voice – **because all your voices matter.** You would all be proud of your fellow-parents who presented their experiences and perspectives to the FDA. They represented all of you! And their contributions were instrumental in beginning a relationship with the regulatory agencies and shaping a meaningful dialogue surrounding the development of new treatments.

The significance of this meeting cannot be overstated. By sharing firsthand experiences and perspectives, our families have played an integral role in advancing the development and accessibility of novel therapies.

Once again, we extend our deepest gratitude to each and every family who participated in the FDA listening session. Your dedication and advocacy are invaluable assets to our community and the broader healthcare landscape.

The KCNT1 Foundation Team

✅ Mark Your Calendars ✅

Sibling Circle
Sunday, **June 23** 2:00 EST
Siblings ages 5 and older

Sign up for Sibling Circle

Bereaved Parent Meetup
May 22nd 10:00 Eastern

Join us for a virtual gathering of parents with understanding hearts and shared experiences. If you've experienced the loss of a child, we extend a compassionate invitation to our upcoming meetup. Our moderators will be Megan Murray and Jenny Park, two moms who are well-loved by this community.
RSVP to join us for an evening of connection and comfort.

Sign up for Bereaved Parent Meetup

There is Still Time to Register for the Family Conference on June 7 in Philadelphia

Family Conference at Children's of Philadelphia
Meet with clinicians from the CHOP team, engage with pharmaceutical representatives to share your invaluable perspectives, meet Dr. Bearden, and connect with other families facing similar journeys. We have also arranged for optional clinical appointments with clinicians at CHOP. If you are interested, pre-register now for clinic appointments with neurology, genetic counseling, and physical therapy. We are working on special arrangements for those coming from outside the US and don't have insurance. International families can work out details with the CHOP International office. Contact us for more info.

Don't miss out on this incredible opportunity! Registration is required for the conference, and pre-authorization is necessary for clinic appointments. Details are available on our website. Complete our Parent Assistance Fund Application to apply for funds to offset your hotel costs. Register today and mark your calendars for an enriching experience ahead!

Saturday, June 8th

Million Dollar Bike Ride, Philadelphia
If you are in town for the conference, stay for the morning to cheer on TEAM KCNT1 -- no need to register if you are not riding, but do you if you plan to participate in the one mile walk or volunteer. You can also sign up to fundraise virtually to support the team, or host an event in your hometown! The event concludes by 4pm. Find more info here.

Help your fellow families reach their fundraising goals and help us get to $30,000. Copy this link and share with your friends and family!

Learn more about Conference

Learn More about MDBR

We are grateful for our conference sponsors!

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Your Voice Matters

Caregiver Survey - What's Disruptive

Thank you to the 39 caregivers who completed this survey. We will now have KCNT1 featured in a paper at the American Epilepsy Society meeting in December! Your participation helped to educate and make more aware of KCNT1!

I'm a new Text block ready for your content.


Parent Communication and Sibling Knowledge of Neurogenetic Conditions

Have you discussed your child's diagnosis with their siblings?

What difficult questions have siblings asked?

Who?
- Parents of a child diagnosed with a neurogenetic condition and
- Siblings age 7-17 years old

What?
First, parents will fill out a short survey, and immediately after the sibling will fill out a survey.

Objective
We hope this study will
- lead to the creation of new resources for siblings.
- inform healthcare providers about sibling needs.

Survey QR code

Questions:
Email: abigail.turnwald@cchmc.org

Version 1.0 March 4th, 2024

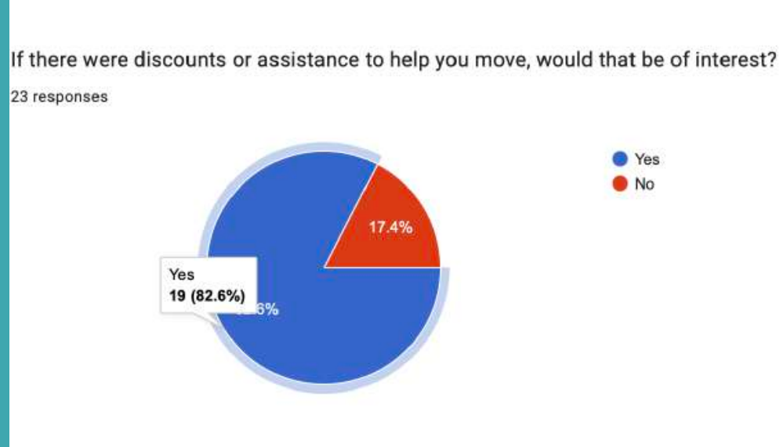
Sibling Survey

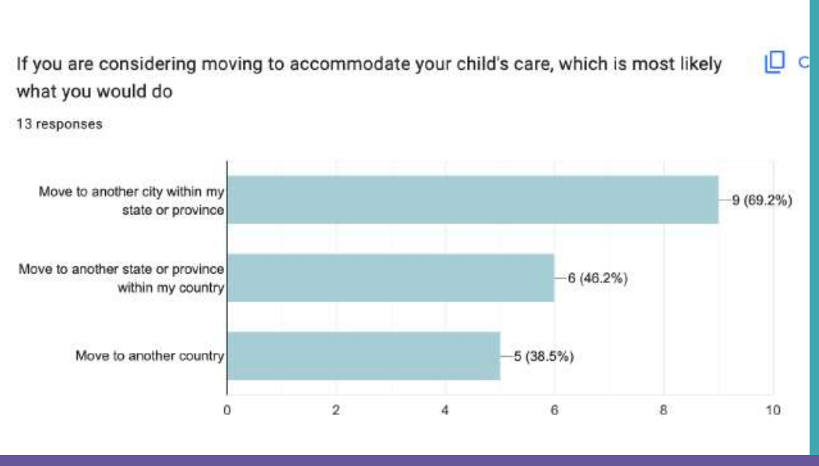
Parents and a Child 7-17 needed to understand sibling needs!

We have a chance to participate in a survey from the Cincinatti Children's Hospital to help us determine what sibling resources are needed! The survey begins with the caregiver portion, then a non-affected sibling ages 7-17 takes the second portion of the survey. You can read more about it here, or go directly to the survey here.

Moving/Relocation Survey

Thanks to the 29 families who completed our relocation survey. Nearly half of you who responded have already relocated to be able to accommodate a wheelchair or other medical needs. Of those who are considering moving, most would move within their state or province and 5 said they would consider moving to another country. When asked about moving for the purposes of being able to participate in a clinical trial for a KCNT1 treatment, 10 said they would or might consider moving to be closer to a clinical trial. And most of you indicated you would consider relocating if there was assistance available.


If there were discounts or assistance to help you move, would that be of interest?
23 responses

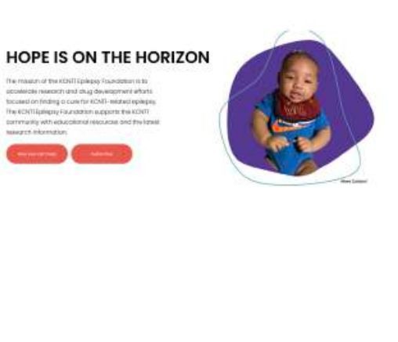

If you are considering moving to accommodate your child's care, which is most likely what you would do
13 responses

SHARE YOUR STORY

Sharing your story helps others understand the challenges and successes you've had on your journey. These stories can be used to raise awareness and also help people understand and relate to what you're going through.

We can share these stories with researchers who work in labs, and the FDA, so they can better understand how this disease affects real children and real families. We'd like to invite you to create a short video using the link provided or schedule an interview with our foundation. Your story can inspire, educate, and have a lasting impact. Click here to record your video.

Fun Stuff



Introducing our Website Warrior of the Month

Welcome to our new initiative, "Warrior of the Month"! We're excited to announce that starting this month, we'll be featuring a different warrior on the cover photo of our website each month. Our warriors embody strength, resilience, and courage in their own unique ways. Be sure to tune in to see if your warrior is the Warrior of the Month! (Birthday Crew members and those who have already provided photos will automatically be entered.) Sign up and submit photos here!

Join our Birthday Crew & Photo Gallery

Make your child's special day truly unforgettable by becoming a part of our Birthday Crew! Sign up now to ensure your child's birthday receives the spotlight it deserves. Simply complete the permission form and send 3-4 adorable photos of your little one to Shane@kcnt1epilepsy.org.

Don't miss out on the opportunity to have a dedicated Facebook and Instagram post created in celebration of your child's birthday month. Let's come together to make their day even more extraordinary! Don't wait any longer – sign up today!

And why not take it a step further? Transform your own birthday into a meaningful fundraiser! Share your dedicated post and let your loved ones contribute to a cause that's close to your heart. Whether it's supporting a charity or lending a helping hand to those in need, we're here to support you every step of the way. Reach out to us if you need any assistance or guidance. Let's make your birthday count!

It's' Our 5 Year Anniversary

Can you believe it has been five years since the formation of our foundation? How many of you attended the first ever KCNT1 scientific meeting in Baltimore in January of 2020? From the humble beginnings of just one company working on a treatment, we've grown to over a dozen teams working on treatments! This incredible progress gives us real hope for the future. While it is cause for celebration, there's still work to be done to transition these treatments into clinical settings. Nonetheless, we take pride in our organized community and the many firsts we continue to achieve as we expand. Join us as we reflect on our journey and recognize the steps forward we've taken together. If you're interested in contributing to our ongoing efforts, including planning for our fifth-anniversary campaign, please don't hesitate to reach out via email. Let's continue our mission with determination and purpose.

Other Happenings

FUNDRAISING NEWS

Complete Our Report Card

So far, 13 parents have completed our survey to provided us some feedback on our efforts. As a nonprofit we have a duty to use our time and donations effectively to ensure we are marching towards our mission and your feedback can help guide us. Click here!

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

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

{{Unsubscribe}}

Looking for something?
Check out our Linktree list of links!
https://linktr.ee/kcnt1