KCNT1 EPILEPSY
HOPE IS ON THE HORIZON

Uniting for KCNT1 Solutions

April 2024

Dear friends and families,

Happy Spring! Please take a moment to review the important updates below. Your continued engagement and support mean the world to us! Thank you for staying connected and being a vital part of our KCNT1 community.

In this issue you will find updates and reminders of ongoing programs we are participating in to build our path to new treatments. Let's dive in!

~The KCNT1 Epilepsy Foundation Team

✅ Mark Your Calendars ✅

Sibling Circle
Sunday, April 21 2:00 EST
Siblings ages 5 and older

Sign up for Sibling Circle

Bereaved Parent Meetup
Saturday, April 20th 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. In this safe space, bereaved parents come together to listen, share, and find solace in the company of those who understand. Let's support one another on this journey of healing. Our moderators will be Megan Murray and Jenny Park, two moms who are well-loved by this community. RSVP to join us for a morning of connection and comfort.

Sign up for Bereaved Parent Meetup

June 7 & 8 Join us in Philadelphia for two days of fun!

Day 1: Family Conference at Children's of Philadelphia, Friday, June 7
We're thrilled to invite you to our inaugural in-person family conference! What can you anticipate? Meet with clinicians from the esteemed CHOP team, engage with pharmaceutical representatives and scientists firsthand 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.

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!

Day 2: Million Dollar Bike Ride, Philadelphia, Saturday, June 8
There are so many ways to participate virtually or in person! Join us in Philly on the lawn to cheer on TEAM KCNT1, sign up to fundraise and ride, participate in the one mile walk or volunteer. 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.

We are grateful for the families who have signed up to fundraise: the Stanley, Wrights, Welch, Garlewicz , Rosenberg and Drislane --- and more every day!! You can share their links and help us fund KCNT1 research! Donate to your favorite team captain here!

Learn more about Conference

Learn More about MDBR

We are grateful for our conference sponsors!

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The Importance of Data to Get Us to Clinical Trials

Do you envision a brighter future for your child? Are you eager for scientists and pharmaceutical companies to invest in finding treatments for our disease? If so, we need your help to make our data accessible to them!

By signing up for a Ciitizen account, U.S. families can contribute to these vital efforts. Robust data is essential before we can participate in clinical trials. Your participation will allow medical data from our warriors to be compared with that of other KCNT1 warriors, enabling researchers to identify trends and determine what treatments work best.

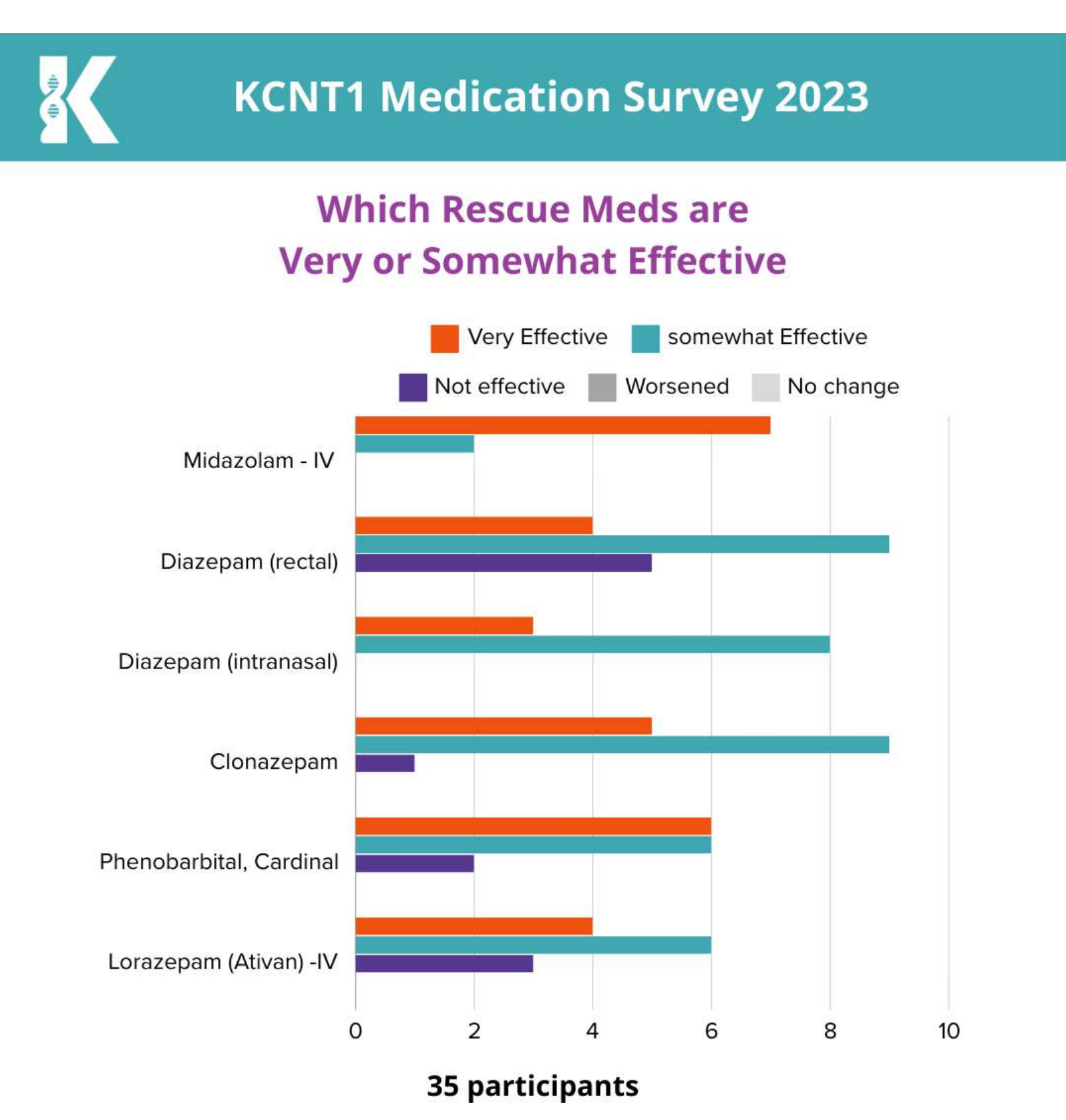
Together, let's empower our community and pave the way for advancements in research and treatments. Sign up for a Ciitizen account today and play a crucial role in shaping a better future for all those affected by KCNT1-related conditions. Currently Ciitizen accounts are available to those in the U.S, including our angel warriors! Tech support is available if you need it!

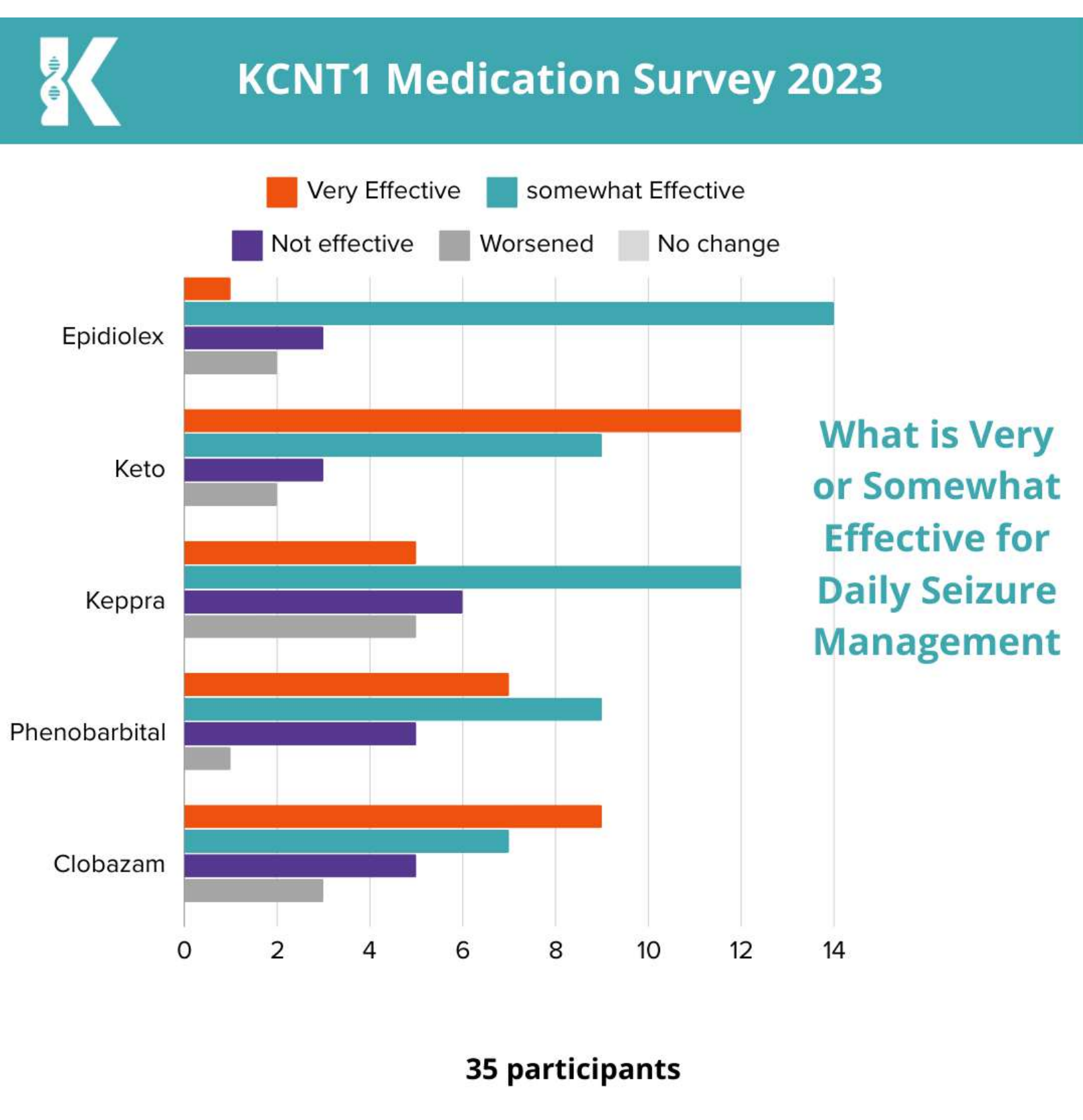
Enroll in Ciitizen

Insights from Your Surveys in the Registry

As many of you are aware, unfortunately, our patient KCNT1 registry hosting company Luna has ceased all operations. We are seeking a new technology platform to host our international registry and facilitate our own studies. We understand that many of you have graciously completed surveys for our registry, and we want to express our gratitude for your participation. Despite this setback, we are committed to leveraging the valuable data collected through the registry to further our understanding of KCNT1-related conditions by publishing it and presenting it at conferences.

In the meantime, we'd like to share some insights gleaned from the medication survey that 35 of you completed. Your top medications/diet for daily seizure management were ketogenic diet, Levetiracetam (Keppra), Phenobarbital, Clobazam (Onfi, Frisium) and Epidiolx. The most effective rescue medications can be seen in the graph below. Is this consistent with your experience? When we relaunch a new registry we look forward to many more families participating for even better data!





Your Voice Matters

Rare epilepsy families are invited to participate in a research survey to
SHARE YOUR INSIGHTS

QUALITY OF LIFE IMPACTS OF RARE EPILEPSY AFFECTING PATIENT AND FAMILY LIFE

Click QR code to launch survey

Each rare epilepsy family's situation and experiences of living with a rare epilepsy are unique, that's why we want to hear from YOU!

Make sure your voice is heard!

Dravet Syndrome Foundation
LGS FOUNDATION LENNOX-GASTAUT SYNDROME
ucb Inspired by patients. Driven by science.

Caregiver Survey
Defining What is Disruptive to You?

Each of your family's situation and experiences of living with KCNT1-related epilepsy is unique. Help us understand and define what 'normal' and 'disruptive' means to each family's quality of life as it relates to their loved one's activities of daily living, communication, behavior, sleep, and seizures. It should take no more than 10-15 minutes. T**he survey will only be open for participation through the end of April.**

This research survey was designed by the Lennox-Gastaut Syndrome (LGS) Foundation, the Dravet Foundation, and UCB (a pharmaceutical company committed to making a difference for individuals with epilepsy) to understand the daily challenges faced by families living with epilepsy. The results will be presented at the American Epilepsy Society's annual meeting in December, but we need 50 responses by the end of April to be include. Your participation can ensure that KCNT1 is represented in the data! Click Here to get started!

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

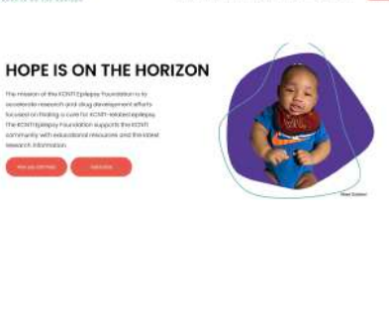
Have you moved to seek better care? To accommodate a wheelchair? We're eager to hear more about your experience. Currently, we're collaborating with a moving company to identify ways they can better support families like yours. Your insights can help us tailor their services to meet your specific needs. Take survey here!

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

This month we sent our Scientific Outreach Officer, Dr. Ali Rosenberg, to Boston for the Milken Institute's "Research Partnership Maturity Model Interactive Workshop." The goal of the workshop was to offer perspective from experienced foundation leaders, group discussion, and exercises aimed at understanding our collective assets, capabilities, and research capacity within the KCNT1 Foundation, and to chart a pathway forward for the Foundation's growth. Learning from other organization's generous experience, Ali brings back new insights in strategy and planning, attracting and sustaining research partners and funding, and providing a greater impact for our patient and caregiver community.

FDA Patient Listening Session

Seven KCNT1 families, Dr. Bearden, and representatives from our foundation will soon be meeting virtually with the FDA in a Patient Listening Session. This session provides a valuable glimpse into the lives of our families, shedding light on the unique challenges and experiences we face daily.

Such engagements are crucial as they enable regulatory authorities like the FDA to better understand the real-life impact of medical conditions and treatments. By sharing our stories, we contribute to shaping policies and decisions that can positively affect the lives of countless individuals and families in the future.

We're grateful for the opportunity to advocate for our community and look forward to continued collaboration with regulatory agencies to ensure that KCNT1 patient perspectives remain at the forefront of healthcare discussions.

FUNDRAISING NEWS

Thank you so much to all the families who've hosted Facebook fundraisers, bake sales, and even lacrosse games! Your help has made a big difference for us and even caught the eye of Family Foundations.

If you're a student and want to do your own fundraiser, check out Warrior Aunt Kimmy's tips here!

We can keep making our community better together.

Complete Our Report Card

Please take a moment to give 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
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Looking for something?
Check out our Linktree list of links!
https://linktr.ee/kcnt1