

KCNT1 EPILEPSY

HOPE IS ON THE HORIZON



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GUIDE TO COMMUNITY FUNDRAISING

You're About to Make a Real Impact for Good!

By fundraising for the KCNT1 Epilepsy Foundation, you become part of a committed community working to unite and support individuals affected by KCNT1 gene variants. Together, we are making a meaningful impact on the lives of those living with this rare condition.

Through fundraising, you make it possible to accelerate research and drug development efforts focused on finding a cure for KCNT1-related epilepsy.

Your commitment to being an advocate for the work of the KCNT1 Epilepsy Foundation helps to ensure that we can be there to support the KCNT1 community with educational resources and the latest research information.



Letter from Co-Founder

As fellow parents and family members navigating the complexities of caring for a loved one with KCNT1-related epilepsy, we know the weight of this journey all too well. When Andrew was diagnosed, our world was turned upside down, filled with uncertainty and fear. I'm sure yours did as well. But as the days turned into months, we also found something incredible—a community of families just like ours, fighting the same battle. We were not alone.

This journey is not one we can walk alone. It takes all of us—parents, friends, extended family, and our broader community—working together to bring about the change our children so desperately need. Every effort, no matter how small, contributes to a larger movement aimed at finding new treatments and ultimately, a cure.

We've been connecting with families across the globe who share our struggle. It's been both heartbreaking and inspiring to see how widespread this condition is, and how many parents are fighting tirelessly for their children. Knowing that we are not alone in this fight gives us strength and hope. Together, we are forming a network of support that crosses borders, cultures, and languages—all united by our shared goal of improving the lives of our children.

This is where you come in. We're asking you to join us in this mission by helping to fundraise for critical research. The enclosed toolkit is designed to make it as easy as possible for you to get involved. Whether you choose to host a small event, reach out to your network, or simply share our story with others, your participation is invaluable. Every dollar raised brings us closer to breakthroughs that could change the course of our children's lives.

This isn't just about raising money—it's about raising awareness, building community, and showing the world that our kids deserve better. It's about standing together as parents who refuse to accept the limitations of this diagnosis. By joining forces, we amplify our voices and make it clear that we are a force to be reckoned with.

We are not alone, and neither are you. Together, we are stronger, and together, we can make a difference.

Thank you for your continued support and for being an essential part of this journey. Let's keep pushing forward, for our kids, for each other, and for the brighter future we know is possible.

With deep gratitude,

Justin West, MD
Father of Andrew | Co-founder



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FAST FACTS



More children are being diagnosed earlier with improved access to genetic testing. Adults who are carriers can have underlying health issues.



Our supporters are funding critical research to help understand KCNT1-related disorders like epilepsy.



Families do not have to feel alone. We work to unite families to support one another and fight for a cure.



Our supporters are investing in a better life and hope for a cure. Research in KCNT1 can have a ripple effect on insights to other brain disorders.

FUNDRAISER STEPS

Here are some steps to follow to help your fundraiser be a success!

1

DECIDE WHAT KIND OF FUNDRAISER SPEAKS TO YOU

Do you have an important celebration or milestone coming up and want people to make a donation in its honor? Or, do you want to hold an event? Decide what type of fundraiser you want to organize that will be special and fun for you.

2

COMPLETE THE MATERIALS

Contact us for assistance in creating a fundraising page and email us for our logo and a donation QR code email: sarah@kcntlpilepsy.org. Don't forget to run the final copy past us for approval.

3

SPREAD THE WORD

Share your fundraiser on your social networks, amplify it amongst friends and colleagues. Email family, friends, colleagues and tell your story. Share why this cause is important to you and why it should be important to them. Don't forget to tap into any company philanthropic match opportunities to maximize your gifts! If it's going to be a "Really Big Show!" contact local media! They LOVE a good community event!

4

THANK THEM

Make sure to thank those who have donated. A personal thank you lets them know they are appreciated and have made a difference.

A close-up photograph of a hand dropping a gold coin into a white piggy bank. The piggy bank has simple black dot eyes and oval nostrils. The background is a soft-focus blue.

FUNDRAISER IDEAS

Fundraisers should be FUN! They are a great chance to mobilize your community to support something meaningful that will make a difference in the lives of others.

Some popular fundraising ideas include:

- Creating and sharing an online fundraiser page that describes your project
- Hosting offline or virtual fundraising events, such as golf tournaments, marathons, car washes, bake sales
- Selling products or services, such as t-shirts, calendars, crafts
- Crowdfunding or peer-to-peer fundraising, where supporters can create their own fundraising pages and share them with their networks
- Upcoming celebrations like birthdays, anniversaries or weddings in lieu of gifts
- Game night with friends
- Dinner party
- Lemonade stand or bake sale
- Bike rides
- Karaoke night
- Yard sale

Frequently Asked Questions

We're here for you to ensure that your fundraiser is as successful as it can be. Below you'll find answers to the most frequently asked questions about fundraising for KCNT1 Epilepsy Foundation.

IS THERE A MINIMUM FUNDRAISING REQUIREMENT? No. There is no minimum requirement to fundraise for KCNT1 Epilepsy Foundation. Every dollar makes a difference!

WHAT IS THE EASIEST WAY TO ACCEPT DONATIONS? The easiest way to handle donations is to leave it to us! Have them scan the QR code or Text to Donate and it will take them directly to our donation form. PayPal Giving Fund, Facebook, Instagram and GoFundMe also work!

ARE DONATIONS TAX- DEDUCTIBLE? All monetary donations are tax-deductible to the extent allowed by law.

WHO SHOULD I MAKE MY CHECK OUT TO? Please make all checks payable to: KCNT1 Epilepsy Foundation Please make sure to state the fundraiser's name in the memo line. For example, please write "KCNT1 John Smith Bake Sale".

WHAT CAN I DO IF A CHECK IS WRITTEN OUT TO ME PERSONALLY? If a donation check has been written out to you personally, you may endorse the back of the check and mail it to the KCNT1 Epilepsy Foundation. Please make sure to state the fundraiser's name in the memo line. For example, please write "KCNT1 John Smith Bake Sale".

WHERE SHOULD I MAIL DONATION CHECKS? Please mail all check donations to: KCNT1 Epilepsy Foundation, 32531 N Scottsdale Rd, Suite 105-530; Scottsdale, AZ 85266 Attn: Community Fundraiser

WHAT IS A TAX ID NUMBER AND HOW CAN I FIND IT? A tax ID number identifies the KCNT1 Epilepsy Foundation as a 501(c)(3) non-profit organization. Many donors will request this number to validate their donation as tax-deductible. The KCNT1 Epilepsy Foundation tax ID number is 84-2748218

WILL YOU SEND A REPRESENTATIVE TO MY EVENT AND / OR PROVIDE VOLUNTEERS? Due to limited resources, we cannot commit Foundation staff or volunteers to events.

HOW DO I HANDLE CASH DONATIONS? We recommend against using mail to send cash donations. If you do collect money, do not deposit any funds collected for KCNT1 Epilepsy Foundation into your own bank account, as this will be considered personal taxable income. Save it up and turn it into a cashier's check, or set up a separate, temporary bank account with the same name as your event.

Do's and Dont's

✓ DO

Say your fundraiser is for the KCNT1 Epilepsy Foundation (KEF), not hosted or run by it.

✓ “All proceeds benefit the KCNT1 Epilepsy Foundation.”

✓ “We’re raising funds to support research and families affected by KCNT1-related epilepsy.”

- Sign and return the Fundraising Agreement. This protects everyone and clarifies responsibilities.
- Use an official KEF fundraising page or QR code.
- Avoid collecting donations yourself if possible. We can set up a secure donation link for you so funds go directly to KEF and donors receive receipts.
- Request and get approval before using the KEF logo or name in print.
- We’re happy to help you design flyers, social posts, or sponsor forms—just send drafts for review.
- Track all donations.
- Use our donation form for any checks or items donated. You must provide documentation for KEF to issue tax receipts.
- Turn in cash donations as a single cashier’s check.
- Do not deposit them in a personal account.
- Feel free to get creative and have fun!
- From lemonade stands to livestreams, every fundraiser makes a difference. We’re here to support your efforts.

✗ DON'T

- Don’t say the event is hosted, sponsored, or organized by KEF.
- Only official KEF events can use this language.
- Don’t use the KEF EIN (tax ID) to open accounts or apply for anything. The EIN is only for donations made through KEF. Using it in other ways puts our nonprofit status at risk.
- Don’t send cash in the mail.
- Convert any physical donations to a cashier’s check or use our donation portal.
- Don’t assume Foundation staff will attend or promote your event.
- We love to cheer you on, but due to limited capacity, we can’t commit to attending or publicizing events.
- Don’t collect donations if you aren’t prepared to track and submit them.
- We must have documentation to provide tax receipts.



Host Name

Address

City

Zip

Phone

Email

Name of
Fundraiser

The KCNT1 Epilepsy Foundation ("KEF") is pleased that you have expressed interest in conducting a fund-raising event to support the purposes of KEF. This letter outlines our understanding in connection with hosting such an event that is not sanctioned by KEF.

You will host a fund-raising event on [date _____] in [location _____] in the nature of a [picnic, bake sale, etc. _____] for purposes of raising awareness about KCNT1 related epilepsy and raising funds for KEF (the "Event").

The KEF office will be happy to fill requests for brochures to be used for your event to raise awareness of KCNT1-related epilepsy.

Donations received by the KEF office will be acknowledged, with proper documentation (backup copies/receipts).

You are solely responsible for complying with national, state, county, and local laws and ordinances regarding your event. You are responsible for all permits, insurance, and other necessary requirements for your event. If you fail to comply with such laws, you hold KEF, its officers, directors, staff and agents harmless from any and all claims and damages arising from such failure to comply.

Any and all details regarding your event (pre, during and post) are your sole responsibility. This event is not sponsored or endorsed by KEF, and KEF disclaims any responsibility or liability associated with this event. You hereby hold KEF, its officers, directors, staff and agents harmless from any and all claims and damages that may arise in connection with this event.

I have read, understand, and agree to the terms and conditions set forth in this letter.

Print Name: _____ Signature: _____ Date: _____

Email a scanned copy of your signed agreement to sarah@kcnt1epilepsy.org or mail your signed agreement to The KCNT1 Epilepsy Foundation 32531 N Scottsdale Rd Ste105-530 Scottsdale AZ 85266

Donations: Contact the KCNT1 Epilepsy Foundation to receive a link to a donation portal. This way you will not be responsible for handling donations and providing receipts. Email Manager@KCNT1epilepsy.org

Notice & Disclaimer Regarding KEF Fundraising: The KCNT1 Epilepsy Foundation is a non-profit organization of families, caregivers and professionals who care about those with KCNT1 epilepsy. KEF reserves the right to deny permission to raise funds for or on behalf of KEF for any lawful reason and refuses to accept responsibility for any funds or fundraising efforts in violation of this policy