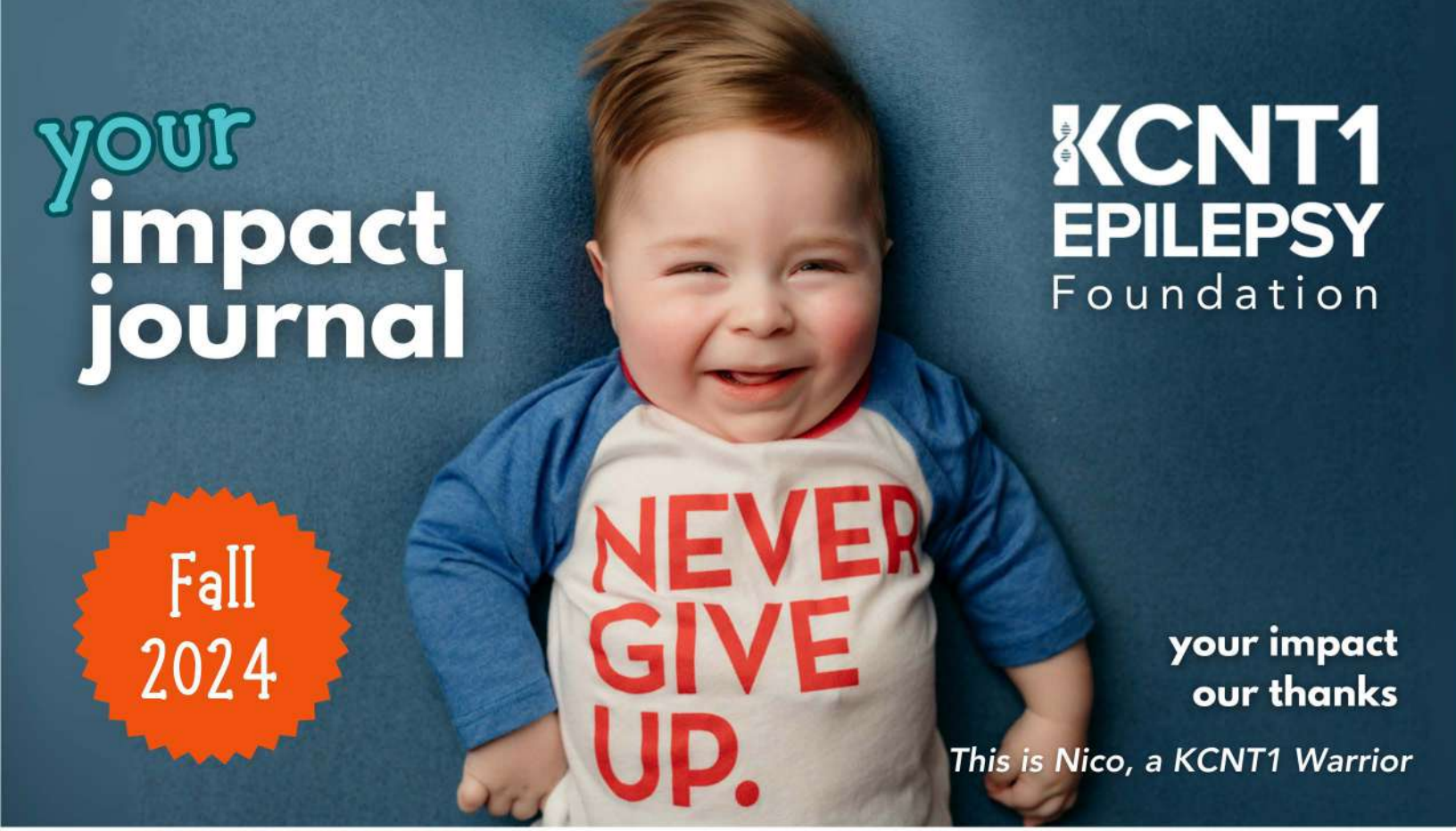


The future of KCNT1 epilepsy research is brighter because of generous people like you!

Meet Brad Bryan, Leading the Charge in KCNT1-related Epilepsy Research

The KCNT1 Epilepsy Foundation is thrilled to introduce Brad Bryan, our Director of Operations, who joined the team in May.

With his extensive background in medical research and a personal dedication to rare diseases, Brad is already making a significant impact in the foundation's mission to find treatments.

Brad's academic and professional background is as impressive as it is diverse. He holds a PhD in Medical Sciences focused on neurobiology, a Master's degree in Biochemistry, and has completed a fellowship at Harvard University. He also has an MBA.

Throughout his career, Brad has focused on rare diseases, tackling some of the most complex and devastatingly uncommon conditions.

One of his proudest achievements was leading a project that repurposed an existing drug to treat angiosarcoma, a rare vascular cancer. The drug, which was already FDA approved for other uses, provided life-saving treatments for some patients.

"*There are still people alive today because of that work*," Brad said, underscoring the potential for similar break-throughs in rare disease research, including for KCNT1-related epilepsy."

Brad with his family. He was a Lieutenant Commander in the Coast Guard, serving from 2008 to 2022.

read more about Brad inside

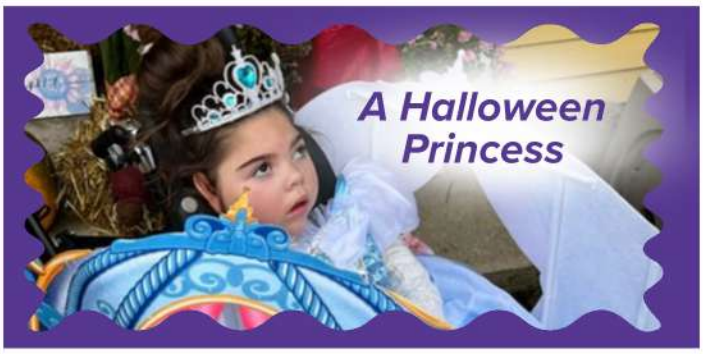
On page 4: how kindness gives hope

Meet Brad Bryan, cont'd

Developing treatments for rare diseases like KCNT1-related epilepsy presents unique challenges. Pharmaceutical companies often hesitate to invest in drugs for small populations, as they aren't as profitable as treatments for more common diseases.

This is where foundations like ours play a crucial role, ***and it's where the support of compassionate people like you becomes invaluable.*** Brad emphasized that research for rare diseases often depends heavily on private funding, and without it advancements simply wouldn't be possible.

One of the key areas of focus for the foundation is exploring drug repurposing. This strategy involves taking drugs that have already been approved for other conditions and testing them for efficacy in treating KCNT1-related epilepsy. By repurposing existing drugs, the foundation can significantly reduce the time and cost involved in bringing new treatments to patients.



It's a path that Brad has walked before in his work with angiosarcoma, and it holds promise for the KCNT1 community as well.

While there are challenges ahead, Brad is optimistic about the progress being made. Although he can't share specifics yet, there are promising clinical trials set to begin in the near future, which could offer new hope for families affected by this devastating disorder.

These trials could include both traditional drugs and cutting-edge genetic therapies that have the potential to address the underlying causes of the disease, rather than just treating the symptoms.

If we can catch KCNT1 early enough and we can get them on genetic therapies... theoretically, you should be able to minimize the developmental problems that happen. And ultimately, give these kids a long, healthy life."

The KCNT1 Epilepsy Foundation is deeply grateful to its generous donors - people like you. Their support not only makes it possible to attract top-tier talent like Brad, but is vital in funding the research, clinical trials, and patient outreach necessary to move the needle forward in the fight against this rare disease. Brad's work, and the work of the foundation as a whole, is directly tied to the kindness of donors like you.

To our donors, Brad has a simple message: *"Thank you. You're making all of this possible. Your support is not just funding research - it's giving hope to families who have nowhere else to turn. Every donation helps us take another step toward a solution, and I'm incredibly grateful for that."*

The KCNT1 Epilepsy Foundation is moving closer to a future where children with KCNT1 epilepsy can live better, healthier lives. Together, we're on the path toward finding life-changing treatments, and we couldn't do it without you.

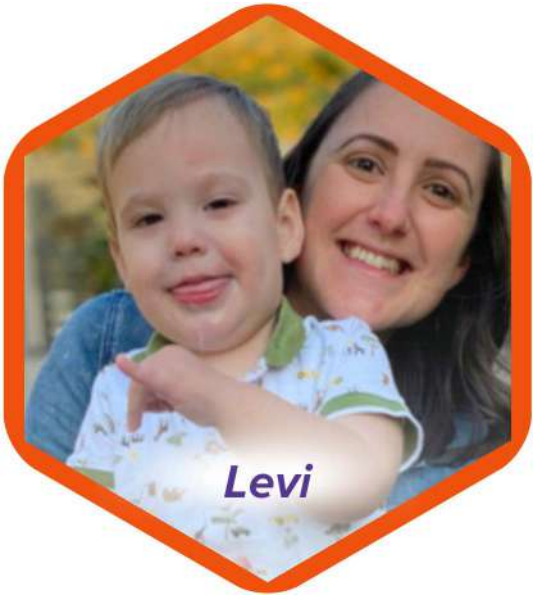
Thank you for being part of this important journey!

"It's not like it might happen. It *will* happen. Are we going to get it here in five years? Are we going to get it here in ten years? Or is it going to take 30 years to get there? I don't know. But we absolutely have the technology to do it."

GROUNDBREAKING RESEARCH IS POSSIBLE!

Click here to donate

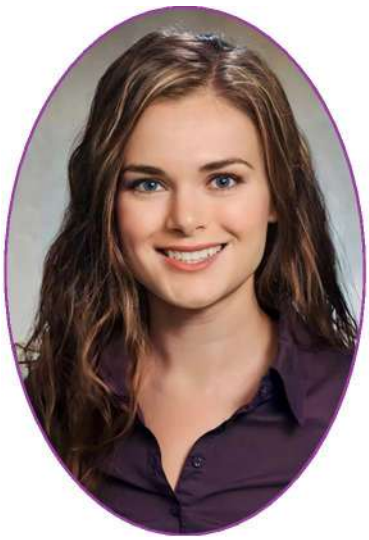
Guiding families through clinical trials: gifts in action



The kindness of donors is giving families hope and confidence as we approach an exciting new milestone. With clinical trials on the horizon, we're creating easy-to-understand materials and hosting webinars to guide families in making the best decisions for their children.

Families will feel informed, supported, and empowered as we move closer to life-changing treatments. *Our donors are making a real difference, and together, we're giving these families the hope they deserve.*

Faster approvals and better trials



Dr. Jillian McKee, MD, PhD, specializes in epilepsy and neurogenetics, focusing on groundbreaking research for KCNT1-related disorders.

We're thrilled to announce that our 2024 seed grant has been awarded to Dr. Jillian McKee at the Children's Hospital of Philadelphia!

Dr. McKee's groundbreaking project will gather essential information about how KCNT1 epilepsy progresses over time. This "natural history" data is key to designing better clinical trials, which could lead to faster drug approvals - sometimes even without the need for a placebo group.

Dr. McKee's study will analyze symptoms, medications, and genetic factors, helping doctors choose the best treatments for those with KCNT1 epilepsy. Her work could also help predict outcomes for families, providing hope and clarity for the future.

Donor generosity is making this critical research possible, bringing us closer to more effective treatments and brighter futures for children with KCNT1-related disorders.

Thank you!

In Jacalyn's words

"Because KCNT1 is so rare, we are fighting the unknown and every day isn't promised with Ember. I would 100% consider a drug trial. These children deserve a better life."

I have an amazing three-year old little girl named Ember. I had a beautiful pregnancy and a beautiful birth. She was developing typically and everything was fine until she was nine months old. That's when she had her first seizure.

She was having up to 50 seizures a day. Just after her first birthday we got the devastating, devastating diagnosis of KCNT1.

We spent 85% of our time those first few months in the hospital with unmanageable seizures. Over the next 10 months, I saw my beautiful 18 month old turned back into a newborn. At three, she is unable to even sit unaided. She is unable to eat orally. She's unable to talk, she's unable to walk, and she is unable to interact as a typical 3-year-old because of KCNT1.

She has trouble swallowing. She has chronic pneumonia that causes her lungs to collapse. On a "good day", she has 15 seizures. On a bad day, we lose count. There's nothing worse than seeing my child sick. The relentless seizures make all her other problems worse.

But she loves her nails being painted. She loves her hair being done. She loves being cuddled. She smiles when she likes something and gives the "sassy eye" when she doesn't. She loves being treated like a normal three-year-old.

She loves being loved.