RESEARCHING FOR A CURE 2024-2025

CURE EPILEPSY

> Being a CURE Epilepsy Champion is a powerful title for our family. We are Ant's Arrows, walking forward with him in life, as we designate our fundraising efforts to CURE Epilepsy. Especially with recent cuts to federal investment in medical research, we know that the funds we raise in Anthony's name can supplement important epilepsy research and protect hard-fought progress towards cures. If we cure epilepsy, we end SUDEP.”
>
> –BOBBY, AUSTIN, AND LISA MAFFIE
> Dad, brother, and mom to Anthony 'Ant' Maffie,
> who passed of SUDEP in 2019

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MESSAGE FROM THE CEO

PROTECTING PROGRESS IN A TIME OF UNCERTAINTY

Dear friend,

Simply put, thank you. Everything we accomplished this year—each cutting-edge project funded, every educational resource developed, all of the inspiring community events held—was made possible by **you**.

There are significant headwinds facing the entire medical research community, but before I share more about that with you, I'd love for us to take a moment to celebrate what we've accomplished together this year—as a community and as an organization. Some highlights in this report include:

- The convening of a successful SUDEP Risk Assessment and Prevention workshop and institution of a new team science SUDEP grant to further advance practical risk assessment tools
- CURE Epilepsy-funded research on drug repurposing that is now on the brink of clinical trials in people with acquired epilepsy
- The launch of our Community Enrichment Program in partnership with UCB and the addition of an amazing woman living with epilepsy to our staff
- The reintroduction of the National Plan for Epilepsy to Congress by a broad coalition of nonprofit organizations followed by coordinated, powerful government advocacy visits

We hope you take pride in all that you've enabled us to do! We are especially grateful now, given the challenges that lie ahead.

We have been disheartened by the news of stalled NIH grants and dramatic proposed funding cuts over the past months and have deep concerns about what that means for our progress towards cures. In our many conversations with university researchers, we continue to hear that those most affected by the uncertainty and change are early-career investigators. Universities are downsizing or eliminating PhD programs, leaving people to look for jobs abroad or abandon research careers altogether. The next generation of scientists will help get us to new treatments and cures, and we must invest in and sustain this critical bench of researchers.

CURE Epilepsy has a unique role to play in the epilepsy research ecosystem. Our funding often acts as seed money, helping investigators test bold ideas and gather the data they need to get larger government grants. The proposed budget cuts the NIH by 40%, meaning that promising research will be left unfunded. We have always been a nimble and agile organization, able to flex as times change. As a first step in protecting scientific progress, our board has approved a plan to fund targeted bridge grants for research at risk due to shrinking NIH budgets, and we hope to share more with you in the coming months.

There is a saying that crisis can be clarifying. Recently we've been powerfully reminded why our mission matters more than ever. The compassion and generosity of our community—and the strength of our united voices—have never been more evident. While the consequences of recent federal actions are deeply concerning, I remain confident in our vision, our collective power, and our ability to drive toward cures. The epilepsy field has some of the most dedicated researchers, clinicians, parents, and advocacy groups out there, and we advance forward with a common goal.

Thank you for your commitment to CURE Epilepsy. Thank you for your generosity, your hope, and your action. While the future of federally-funded biomedical research is unclear, I truly believe that, with the unwavering support of our committed and resilient community, we have what it takes to meet the moment. **Together, we can preserve yesterday's progress and fuel tomorrow's discoveries.**

With gratitude,

Beth Lewin Dean

Advocating for Epilepsy Research

Over the past year we visited Capitol Hill several times to advocate for increased federal funding of epilepsy research, meeting with key legislators. We joined other advocacy organizations at the National Epilepsy Walk on the National Mall and added our name to sign-on letters. We attended innumerable meetings as leaders on the National Plan for Epilepsy Committee (NPEC), the Epilepsy Leadership Council (ELC), and many other coalitions. Sustained collaboration across the epilepsy space will be key to the continued progress of epilepsy research.

Make a Difference!
Your gift helps sustain work toward cutting-edge treatments and disease-modifying therapies

LATEST CURE EPILEPSY GRANTEES

The following list highlights 2024 awardees and their project objectives.

CATALYST AWARD

Lori Isom, PhD
University of Michigan
Develop a gene replacement therapy for SCN1B–related Dravet syndrome as proof-of-concept for first in human testing.

Henrik Klitgaard, PhD and Janine Erler, PhD
NEUmiRNA Therapeutics
Propel an antisense oligonucleotide (ASO) therapy with curative potential (NMT.001) to the clinic by developing patient stratification and efficacy biomarkers needed for clinical trials.

THE SCIENCE YOU FUNDED THIS YEAR

30 active grants under management

$5.2M in program investments

2 scientific publications accepted from CURE Epilepsy staff

RARE EPILEPSY PARTNERSHIP AWARD

Nael Nadif Kasri, PhD
Radboud University Medical Center
Study the complex role of neuron-microglia interactions associated with mutations in the EHMT1 gene and establish a platform for the identification of novel therapeutic compounds or repurposed drugs to treat seizures in Kleefstra syndrome.

Co-funded in partnership with IDEFINE The Kleefstra Syndrome Foundation

Berrak Ugur, PhD
Yale University
Use cellular and organoid models to uncover the specific role of the FAM177A1 gene in brain development and understand how its dysfunction leads to disorders, with the aim of moving toward personalized therapies.

Co-funded in partnership with FAM177A1 RESEARCH FUND

Luis Williams, PhD
Quiver Bioscience
Test the effects of antisense oligonucleotides (ASOs) that target each gene in cellular models of KCNT1– and SCN8A–related epilepsies and evaluate one possible opportunity for therapeutically linking these two developmental and epileptic encephalopathies (DEEs).

Co-funded in partnership with KCNT1 EPILEPSY HOPE IS ON THE HORIZON

CURE EPILEPSY AWARD

Jordan Farrell, PhD
Boston Children's Hospital
Test whether a clinically-relevant pharmacological approach related to endocannabinoid levels can address epilepsy in a fundamentally new way.

Heather Mefford, MD, PhD
St. Jude Children's Research Hospital
Using genetic methods, increase ubiquitin-like modifier activating enzyme 5 (UBA5) protein levels in brain organoids as a potential approach to treating UBA5-related epilepsy.

In partnership with

RAIDEN SCIENCE FOUNDATION

Learn about the inspiration behind this research and how organoids are enabling breakthroughs across the field

Cameron Metcalf, PhD and Mingnan Chen, PhD
University of Utah
Target specific immune cell types as a proof-of-concept approach to prevent seizures and/or reduce the condition's severity in a model of infection-mediated temporal lobe epilepsy.

Avtar Roopra, PhD
University of Wisconsin-Madison
Study longer-term protective effects of a repurposed FDA-approved drug (tofacitinib) shown to profoundly reduce seizures and improve memory and cognition in a mouse model of epilepsy.

> We are incredibly excited to fund this newest set of grants! The breadth of innovative ideas that will help us understand the causes of epilepsy and explore potential new treatments and cures is inspiring. From novel organoid models of rare epilepsies to the repurposing of an arthritis drug for acquired epilepsy, our grantees are pushing the boundaries of their respective areas of expertise."
>
> –DR. LAURA LUBBERS
> CURE Epilepsy Chief Scientific Officer

TAKING FLIGHT AWARD

Michael-John Dolan, PhD
Trinity College Dublin
Develop a better understanding of how the brain and body's immune cells interact during the development of epilepsy, providing a foundation for future studies of brain inflammation and immune responses in epilepsy.

Lauren Lau, PhD
Massachusetts General Hospital
Use cutting-edge, high-resolution imaging techniques to study patterns of neuronal activity to understand the relationship between abnormal electrical activity on EEGs and the onset of seizures in temporal lobe epilepsy, potentially finding new targets for therapies.

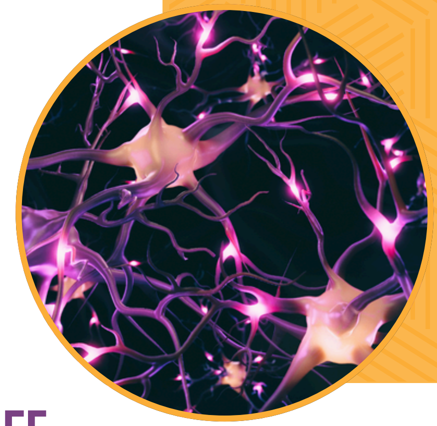
Colin McCrimmon, MD, PhD
University of California, Los Angeles
Use brain organoids to provide insight into how potential therapies can affect network architecture and potentially guide the development of targeted therapies for DEE13, a severe epilepsy caused by variants in the SCN8A gene.

> My career goal is to combine research into the mechanisms underlying epilepsy along with biomarkers for prognostication and treatment-responsiveness with clinical care for patients with epilepsy. By pairing the results from models of epilepsy with clinical data from patients, I plan to seamlessly intertwine my clinical practice and research endeavors, and hope to improve our understanding of epilepsy disorders and inform future care for our patients."

James Neimeyer, PhD
Cornell University
Study how seizure activity spreads outside of the seizure onset zone, potentially identifying new targets for therapeutic intervention and improving surgical outcomes.

Refer to our Grants Awarded webpage to learn more about these projects

BRAIN, HEAL THYSELF



REGENERATIVE MEDICINE OFFERS NEW HOPE FOR LASTING SEIZURE RELIEF FOR DRUG-RESISTANT EPILEPSY

For some, having their brain injected with new brain cells may seem outrageous, but for Annette Adkins the procedure was a welcome development.

“Knowing how much of my life has been taken away by illness, I was ready for anything,” she says. Adkins developed epilepsy in 2014 when she was 45 years old. The frequency and severity of her seizures eventually forced her to stop driving and ended her career as a pharmacist.

Adkins’ ready-for-anything attitude included participation in a clinical trial for a novel therapy based on regenerative medicine. **A merger of life sciences and engineering, regenerative medicine aims to heal damaged human organs using components found in the organ itself.** For epilepsy, this means introducing engineered cells or genes into the brain, where they are incorporated into existing brain tissue to promote recovery.[1] Unlike current treatments that quiet seizure-generating regions with drugs or surgery to kill or remove hyperactive cells, regenerative therapies enlist the brain’s natural biological processes to enhance its ability to suppress seizures, in effect training the brain to fix itself.

One of the first two people to be enrolled in a clinical trial of this cell therapy, **Adkins received cells grown in the lab derived from human stem cells by Neurona Therapeutics.** These cells are designed to inhibit electrical activity in the brain, and since receiving these extra cells through a brain surgery—but not a tissue destructive one like laser ablation or brain resection—Adkins has been seizure-free for over a year.

“I’m really grateful to have been given the opportunity to help other people to know that there’s hope,” she says.

Two paths to healing

Though regenerative medicine is relatively new, the U.S. FDA has already approved some therapies under its umbrella. For example, the treatment Carticel repairs knee cartilage by growing new cartilage cells from a tiny sample taken from a patient’s healthy cartilage. These cells are then reintroduced to the ailing joint to promote regeneration. Other approaches include lab-grown replacement parts (such as human skin cells that help heal ulcers), 3D bioprinted blood vessels, or sheets of cells to repair a cornea. So far for epilepsy, regenerative medicine encompasses two approaches. One is cell therapies like the one Adkins received, in which inhibitory cells are grown in the lab from human stem cells. When implanted into the brain, the cells make connections with other neurons, quieting the hyperactive ones and leading to seizure suppression.[2] Preliminary results of the trial Adkins participated in show that the cell therapy, called NRTX-1001, is safe, well-tolerated, and drastically reduces seizure frequency, while preserving brain tissue and function.[3] NRTX-1001 will advance to a Phase 3 study this year, enrolling adults with drug-resistant mesial temporal lobe epilepsy.[4]

The second type of regenerative medicine for epilepsy is gene therapy, which can treat some epilepsies caused by genetic mutations. For example, damaging variants to the STXBP1 gene reduce the amount of STXBP1 protein in the brain, resulting in severe, early onset epilepsy. With CURE Epilepsy funding, Dr. Mingshan Xue showed that adding back a working copy of the STXBP1 gene reduces seizures in animal models.[5]

Now, Capsida Biotherapeutics has developed a gene therapy called CAP-002 to deliver a replacement STXBP1 gene into the brain with a single-dose intravenous infusion.[6] Upon entering brain cells, the replacement gene is made into healthy STXBP1 protein by the cell’s own machinery.[7] CAP-002 is slated to start clinical trials this year.

Funding the future

Luckily, regenerative medicine approaches may prove effective in other types of epilepsy. For example, CURE Epilepsy is funding multiple projects to investigate how to add working gene copies back into the brain. CURE Epilepsy has also funded cell therapy research, including another type of inhibitory cell therapy derived from cells grown in the lab and aimed at treating intractable epilepsy.

Regenerative medicine may very well catapult us into the next generation of treatment advances and cures for epilepsy. As innovations advance, more and more patients may have the chance to be part of medical progress, both for themselves and the good of others: “It’s worth your while to go for it and be seizure-free,” Adkins says of participating in the trial. “I really believe every one of us deserves that opportunity.”

Article citations and a *Seizing Life* interview with Annette Adkins are available online

RESEARCH BRIEFS

EXCITING NEWS FROM ACROSS THE EPILEPSY RESEARCH FIELD

KCNA1 Gene Plays Key Role in Sudden Unexpected Death in Epilepsy (SUDEP)

Building on studies performed with CURE Epilepsy funding, Dr. Edward Glasscock and colleagues recently demonstrated premature death in epilepsy in a mouse model lacking a specific gene called KCNA1 that makes a potassium channel and is important for neuronal activity. During monitoring, they captured one SUDEP event, a rare phenomenon and a unique opportunity to gain insights into the underlying biology of SUDEP. They observed a generalized tonic-clonic seizure that initiated respiratory dysfunction culminating in cardiorespiratory failure. In addition, they observed that cardiorespiratory abnormalities were common during non-fatal seizures but mostly absent during interictal periods, implying ictal, not interictal, cardiorespiratory impairment as a more reliable indicator of SUDEP risk.

uniQure Gene Therapy in Trials for Refractory Mesial Temporal Lobe Epilepsy

Nearly one-third of people experiencing focal onset seizures do not respond to currently available treatments and are left with limited therapeutic options. Temporal lobe epilepsy (TLE) is the most common form of focal epilepsy, with mesial TLE accounting for a majority of the cases. uniQure's gene therapy candidate, AMT-260, has the potential to be a transformative, single administration treatment option for people with TLE. AMT-260 is designed to reduce the production of a particular receptor responsible for generating unwanted electric currents in the brain and causing seizures. CURE Epilepsy grantees Drs. Pavel Klein and Ellen Bubrick are site leads for the current Phase I/IIa clinical trial, which is expected to be completed in mid-2027.

Focused Ultrasound for Epilepsy Clinical Trial Begins in Australia

Focused ultrasound is a noninvasive therapeutic technology being tested across many disorders. The technology uses ultrasonic energy to modulate or remove tissue deep in the body without incisions or radiation. The fundamental principle is analogous to using a magnifying glass to focus beams of sunlight on a single point to burn a hole in a leaf. A device from NaviFUS uses real-time neuronavigation guidance to direct focused ultrasound energy precisely and noninvasively through the skull to select brain tissues without surgery. In a new trial in patients with drug-resistant epilepsy led by Dr. Terry O'Brien, up to 18 participants will undergo low-intensity focused ultrasound to generate neuromodulation effects to areas deep in the brain called the hippocampi that are associated with seizures. The goal is to decrease the number of seizures. In the U.S., CURE Epilepsy is funding Dr. Ellen Bubrick at Brigham and Women's Hospital to explore the use of focused ultrasound in epilepsy in a different pilot clinical study.

Childhood Epilepsy Linked to Later Memory Disorders

CURE Epilepsy grantees Drs. Bruce Hermann and Matti Sillanpää's work studying a unique patient cohort since the 1960s continues to provide learnings on the long-term outcomes of childhood epilepsy. Their team recently demonstrated that individuals who had childhood epilepsy have an increased accumulation of brain amyloid—abnormal protein deposits—later in life (around 60-65 years old), potentially predisposing them to late-onset brain amyloid disorders, such as Alzheimer's disease.

More News
Get these research briefs all year long

TOGETHER IN COMMUNITY

HIGHLIGHTS FROM OUR CHAMPIONS

The strength, love, and determination of our families, supporters, and Champions across the country bring our mission to life. We're so grateful to our Champions, who tirelessly work to raise funds for research. Together, we're creating a network of hope, resilience, and connection.

CURE Epilepsy's Run/Walk Series—Seany's Shuffle

The CURE Epilepsy Run/Walk Series is a network of regional fun runs and walks hosted each year around the U.S. Board member Maureen Flood Rabus held the inaugural Seany's Shuffle on November 17, 2024 in Lakewood Ranch, FL to honor her six-year-old son Sean, who was diagnosed with infantile spasms at seven months old and has a rare genetic disease called Menkes that is the underlying trigger for his epilepsy. The event raised nearly $50,000 and had over 100 participants in its first year!

Team CURE Epilepsy at the NYC Marathon

Team CURE Epilepsy participants of all skill levels run, bike, swim, and climb in the name of epilepsy research. Longtime supporter Elvin Angulo ran the NYC Marathon on November 3, 2024 and raised over $10,000 for CURE Epilepsy to honor his daughter Vera's epilepsy journey. Elvin's wife Cindy supports CURE Epilepsy through her annual corporate fundraiser at Salesforce, and she—along with Vera and son Kai—cheered Elvin on as he well-surpassed his finish time goal for his first marathon!

Champions Challenge Winners Rosini Family at Epilepsy Awareness Day at Disneyland (EADDL)

Our Champions program offers individuals the opportunity to host grassroots fundraising events that honor a loved one impacted by epilepsy. The Rosini family, 2023 Champions Challenge winners, enjoyed a special trip to EADDL in November 2024. Jessica and Chris Rosini host a wide variety of DOMinate Epilepsy Champion events, from school fundraisers to Purple Day-inspired events, in Pennsylvania in honor of their son Dominic, who has Doose syndrome.

CURE Epilepsy Community Enrichment Program Intern

With generous support from UCB, Ohio Champion and epilepsy warrior Channing Seideman has been interning at CURE Epilepsy for the past year. The Community Enrichment Program was created to enrich the lives of those living with epilepsy through experience, education, and empowerment, specifically by providing skills needed to gain meaningful professional employment, while also expanding CURE Epilepsy's capacity.

Watch Channing's spotlight video

FUELED BY LOVE, DRIVEN BY PURPOSE

THE SIEGELS' FIGHT FOR A CURE

For nearly 30 years, Lisa and Randy Siegel have built a beautiful life for their children filled with love, success, and connection. Their daughter, Becca, is a remarkable woman who delights in writing letters to pen pals, enthusiastically enjoys musical theater, and befriends every dog in her neighborhood.

Becca also has epilepsy and suffers daily seizures that have delayed her development and prevented her from living independently. With the threat of a drop seizure striking without warning, Lisa or Randy need to always walk arm-in-arm with Becca. Like so many families affected by epilepsy, the Siegels have spent decades looking for relief for their daughter. They've tried over 30 medications, participated in clinical trials, and traveled to epilepsy centers across the nation.

"Epilepsy is the defining challenge of our lives," Randy shares. "In every other way, our family is incredibly fortunate. But when it comes to Becca's seizures, we've failed to find answers—and that's devastating."

The Siegels have been champions of CURE Epilepsy since the early days, when the organiation was a small network of parents determined to find answers for their children. They have supported the organization and epilepsy community not just financially, but with time and community building. Randy served as a CURE Epilepsy board member from 2007-2013 and helped the organization get key national exposure in Parade Magazine in 2009. Still today, at the end of business meetings that are unrelated to epilepsy, someone will ask, "Hey, Randy, do you have a second?" Invariably, it will be someone new to the world of epilepsy looking for guidance and reassurance. Randy says that he always sends them to CURE Epilepsy's website, so that they can find out more about epilepsy, research treatment options, find helpful resources, and most importantly, learn that they are not alone in this fight.

Lisa and Randy are inspired by the progress CURE Epilepsy has driven in understanding and treating epilepsy—but they know there is still much more work to be done to get seizure relief for everyone. "As much as we've accomplished at CURE Epilepsy," Lisa says, "there are still millions of people like Becca who are suffering every day. Now more than ever, we have to double down."

And doubling down is exactly what they are doing. To accelerate progress and support the millions of people worldwide struggling to find seizure control, like Becca, the Siegels are committing a major gift to CURE Epilepsy that will help fund the next wave of promising science.

"There is real momentum in science right now," Randy says. "Our understanding of the brain is growing. Our tools are better. We're closer to better treatments and, someday, a cure. But we have to keep going."

Hope and fear walk hand in hand for families like the Siegels. The happiness of another birthday highlights developmental milestones missed. The joy Becca gets from her service dog, Camden, exists alongside the anxiety that he'll signal a seizure is happening. The hope of a new treatment is tempered by the fear of new side effects. Every day brings risk and uncertainty. But in research, in community, and in CURE Epilepsy, the Siegels have found reasons to believe in a better tomorrow.

> When we give, it's because we believe in CURE Epilepsy's mission to drive science toward a cure. It's personal. It's urgent. And it gives us hope."
>
> —LISA SIEGEL

KEY CONVENINGS

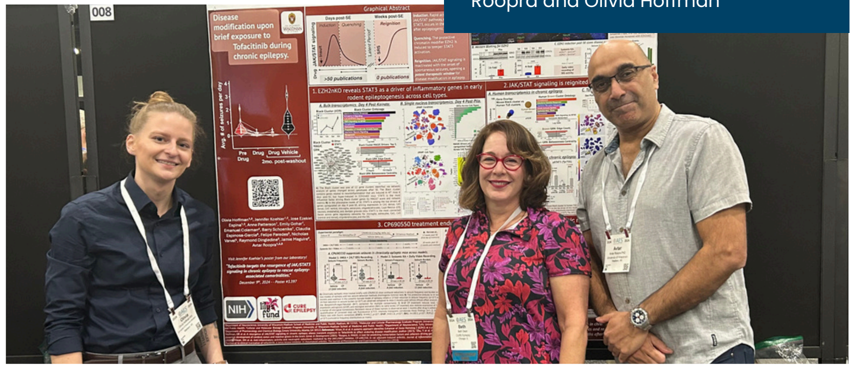
NOTES FROM THE FIELD

CURE Epilepsy has always been a funder, a convener, and a doer. Collaborating with scientists, coalition partners, and community members builds bridges and fosters innovation. Over the past year, donor investment has helped facilitate the exchange of ideas across numerous meetings and events, including:

American Epilepsy Society (AES) 2024 Conference

- Fourteen poster presentations featuring CURE Epilepsy-funded work
- More than 200 researchers in attendance at the CURE Epilepsy reception
- CURE Epilepsy leadership team presentations for Infantile Spasms Action Network (ISAN) and Rare Epilepsy Network (REN) gatherings

Chief Scientific Officer Dr. Laura Lubbers speaking on standardized data collection in SUDEP models at the Partners Against Mortality in Epilepsy (PAME) meeting



CEO Beth Dean with University of Wisconsin grantees Drs. Avtar Roopra and Olivia Hoffman

February 2024 *Seizing Life* guest and Harvard neurologist Dr. Daniel Goldenholz

Researchers enjoying the cocktail hour

SUDEP Risk Assessment and Prevention Workshop

Date: October 2024

Location: New York City, Ovid Therapeutics offices

Partners: Epilepsy Foundation & Cameron Boyce Foundation

Participants: 20+ researchers and families, including Maria Teresa Ioannou from the Joanna Sophia Foundation, who opened the meeting with the personal story of her daughter Joanna

Goal: Identify additional factors that may contribute to SUDEP risk and discuss the development of a risk assessment tool for the community

Outcomes: New team science grant opportunity to fund additional clinical SUDEP research (projects starting Spring 2026)

Scientific Salons Across the Country

Rare Epilepsy Partnership grantee Dr. Jillian McKee of CHOP spoke to CURE Epilepsy supporters at board member Matthew Schneider's Maryland home during a June 2024 scientific salon. Dr. Walter Koroshetz, NINDS Director (pictured below, left), was in attendance and added to the robust discussion.

Thanks to the work of supporter Francesca Calloway (pictured below, right), 90 guests gathered at the Jonathan Club in Los Angeles in September 2024 to learn more about CURE Epilepsy and hear from *Taking Flight* grantee Dr. Ranmal Samarasinghe of UCLA.

CURE EPILEPSY IN NEW YORK

$300,000+ RAISED THROUGH YOUR GENEROSITY

CURE EPILEPSY TAKES MANHATTAN

Over the past year, CURE Epilepsy held two successful fundraisers in the city that never sleeps. Guests came together to enjoy entertainment and community, all while raising funds to ensure important research progress continues.

2025

At *CURE Epilepsy Takes Manhattan* in May 2025, Miguel Cervantes and his Broadway friends Tamar Greene, Ginna Clair Masón, and David Josefsberg regaled the audience with intimate, exclusive performances and humorous backstage stories. CURE Epilepsy intern Sasan Korangy (16) also spoke passionately about his mom's epilepsy and the impact it's had on his family.

In November 2024, CURE Epilepsy held an intimate and interactive conversation about the intersection of the arts and neuroscience. Grammy-winning opera singer and National Medal of Arts recipient Renée Fleming spoke with board member and USA Today bestselling author Kelly Cervantes. They were joined on stage by music therapy pioneer Dr. Connie Tomaino and epileptologist Dr. Alan Ettinger.

2024

Check out our event calendar for all our upcoming events

CURE EPILEPSY CORPORATE CARES

CONVERSATIONS ABOUT RESEARCH IN EPILEPSY AND SEIZURES (CARES)

CURE Epilepsy Corporate CARES virtual events are hosted by companies who strive to welcome diverse perspectives into the workplace. They feature leading epilepsy experts from around the country and are typically initiated by a company staff member who is touched by epilepsy. CARES events help leaders and colleagues be more aware of the challenges of epilepsy and triumphs of research. Past events have been hosted by Salesforce, ComEd, and Cisco.

servicenow. JOHNS HOPKINS MEDICINE

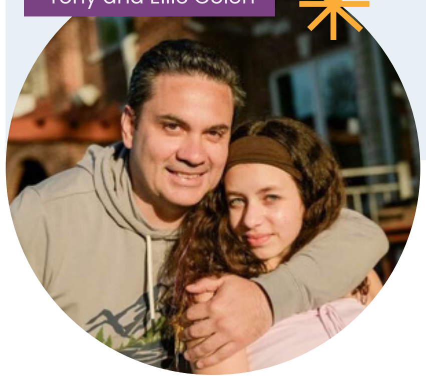
In May 2025, ServiceNow SVP Tony Colon and Johns Hopkins Medicine neurologist Dr. Babitha Haridas hosted an incredible virtual event for employees, several of whom shared their connections to epilepsy and engaged in a thoughtful conversation with colleagues. Attendees learned about seizure first aid, the latest treatment options, family impact, and CURE Epilepsy's mission.

Interested in hosting a CARES event with your company? Contact Alysha.Biehl@cureepilepsy.org.

Making it Personal

Tony's daughter Ellie began having seizures just before her fourth birthday. While her epilepsy diagnosis came quickly, resolving her seizures has been a multi-year journey. Since 2014, Tony and his wife, CURE Epilepsy board member Irina Colon, have been relentless in their pursuit of relief, management, and ultimately a cure for Ellie, all while being passionate champions of and fundraisers for CURE Epilepsy's mission.

Tony and Ellie Colon



> It was incredibly meaningful for me to get to share Ellie's story with professional colleagues during the CURE Epilepsy CARES event. There are not always natural opportunities to discuss our family's epilepsy journey with coworkers, but if people don't know about Ellie, they don't know about a big piece of who I am and what drives me each and every day. It was great to be able to help educate ServiceNow staff about epilepsy and CURE Epilepsy's mission."
>
> –TONY COLON
> Senior Vice President/General Manager, Customer Success Product & Strategy, ServiceNow

OUR ORGANIZATION

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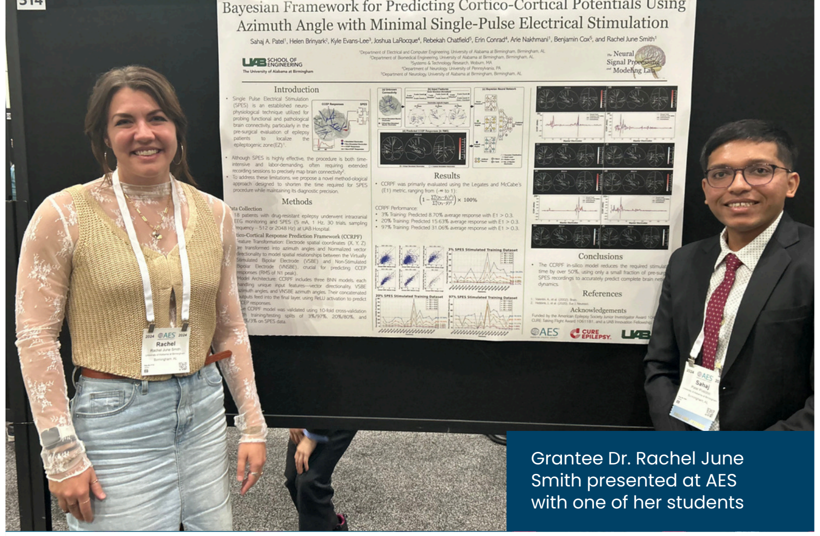
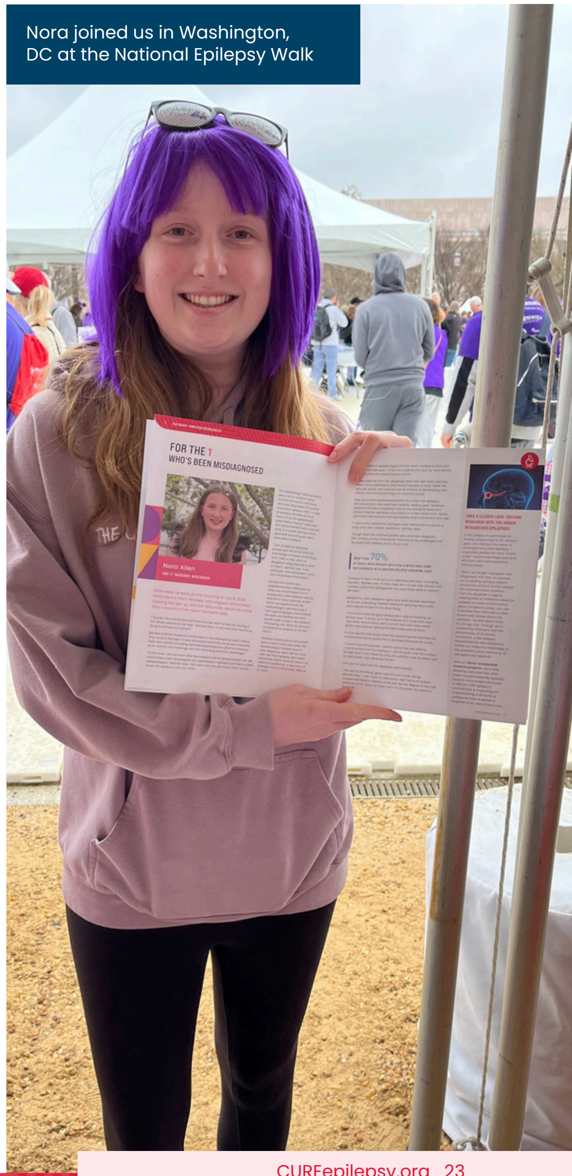
See our donor honor roll and a digital version of this report



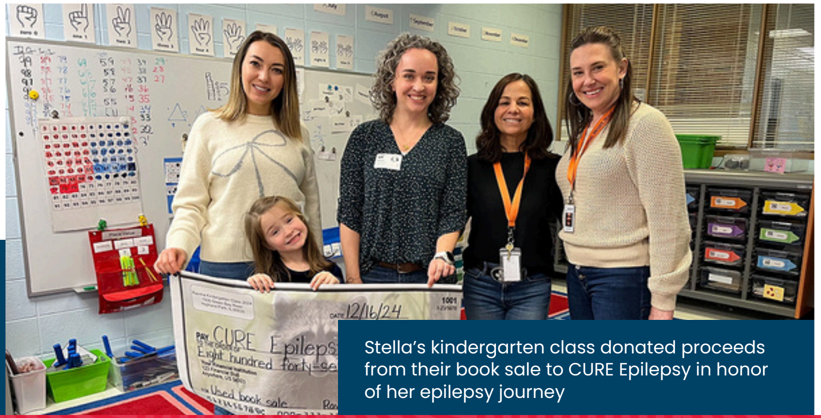
Grantee Dr. Rachel June Smith presented at AES with one of her students

UMES Strides Against Epilepsy—our longest running Champion event

'Tri-Dadletes' Quentin, Chris, and Dario competed in Maine in honor of their daughters with epilepsy



Nora joined us in Washington, DC at the National Epilepsy Walk



Stella's kindergarten class donated proceeds from their book sale to CURE Epilepsy in honor of her epilepsy journey