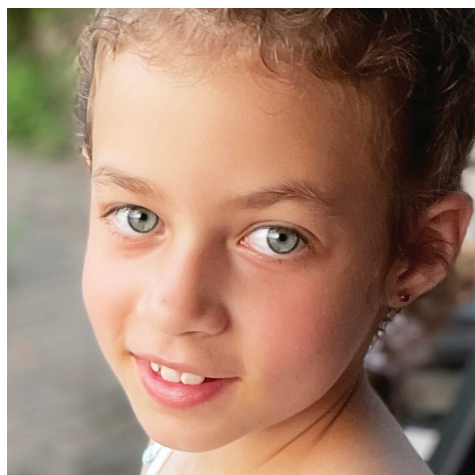




# RESEARCHING TO CURE EPILEPSY

FALL 2021





**BETH LEWIN DEAN**  
Chief Executive Officer  
CURE Epilepsy

## Scientific research is our greatest hope for discovering cures for epilepsy.

In the past, I have written and spoken about the challenges that the pandemic has created for the research community. One of the less tangible impacts that we have experienced has been on our overall ability to conduct scientific exchange. We have all become masters of Zoom, but it is so much more challenging to exchange ideas, brainstorm new approaches, or bounce ideas off colleagues in a virtual setting. That is why we are so excited to attend this year's annual American Epilepsy Society meeting in person in December, where we will share ideas and dream of possibilities that will move our understanding of epilepsy forward. Thousands of healthcare professionals and researchers focused on epilepsy will gather to share best practices and breakthrough research, learn about new scientific findings, and exchange ideas with colleagues from all over the world.

We've spent over 20 years solely focused on epilepsy research because we understand the challenges that our community faces when living with epilepsy and loving people who live with epilepsy. We know that epilepsy is a heterogeneous disorder; it affects each member of our community differently. We research to find cures for all types of epilepsy and for all who are impacted: those who are seizure-free with medication and devices, those who are mildly impacted, and those who are profoundly impacted. Our vision of a world without epilepsy is what drives us every day.

This year, we're proud to have made incredible strides in several areas to advance our vision. In this issue of **Researching to CURE Epilepsy**, you'll find the latest discoveries, partnerships, and people who've made extraordinary breakthroughs in epilepsy research, as well as those living with epilepsy who've deeply inspired us to continue our important work. Read on for:

- **The latest from the Epilepsy Genetics Initiative**, a database created by CURE Epilepsy, in partnership with the National Institute of Neurological Disorders and Stroke, to hold the genetic data of people with epilepsy and be made available for research.
- **Progress from the Post-Traumatic Epilepsy Initiative**, a program created by a grant from the Department of Defense Traumatic Brain Injury and Psychological Health Research Program.
- **A donor spotlight on Kate Neale Cooper**, who has donated to CURE Epilepsy for over a decade and shares her story as a parent to a daughter with epilepsy.

We're thrilled to share our latest report with you. Thank you for your support as we work toward our shared vision of a world without epilepsy.

With continued gratitude,

Beth Lewin Dean  
Chief Executive Officer, CURE Epilepsy



# THE LATEST FROM THE EPILEPSY GENETICS INITIATIVE



DID YOU KNOW THAT

**2** OUT OF **3**

PEOPLE WITH EPILEPSY  
DON'T KNOW THE CAUSE  
OF THEIR CONDITION?

WE'RE AIMING  
TO CHANGE THAT.

The Epilepsy Genetics Initiative (EGI) is a database created by CURE Epilepsy, in partnership with the National Institute of Neurological Disorders and Stroke (NINDS), to better understand the genetic causes of epilepsy and improve how we prevent, diagnose, and treat this devastating disease.

EGI collects the genetic (exome) data of people with epilepsy, analyzing each participant's data automatically every six months. These analyses have revealed new or modified diagnoses for dozens of patients, while also uncovering new genes associated with epilepsy, such as PPP3CA. The data from EGI are furthering cutting-edge research and supporting the development of promising epilepsy treatments, including therapies for Dravet syndrome and Lennox-Gastaut syndrome.

Launched in April 2015, this initiative has been possible thanks to the generous support of the John and Barbara Vogelstein Foundation.

# OUR LATEST EGI FINDINGS

**364**  
PATIENTS

**364 patients** who did not have a clear genetic diagnosis on a clinical whole-exome sequencing (WES) test were enrolled into EGI.

**34**  
PATIENTS

EGI has provided new or modified genetic diagnoses for a total of **34 patients**.

**10**  
CASES

In **10 cases**, the EGI team confirmed that a variant identified on the initial clinical WES report was responsible for all or some of the patients' seizure types.

**18**  
GENES

The Columbia University EGI team identified **18 genes** that they concluded had strong evidence of causation but could not yet be linked to the patient's epilepsy. We will continue to monitor these genes over time.

The preliminary data suggest that, despite negative clinical WES, patients with epilepsy may still carry damaging variants in genes not yet associated with disease, and their data should be reanalyzed as the genetic architecture of epilepsy is further untangled.

## WHAT'S NEXT FOR EGI?

Nearly 1,000 patients and their family members consented to having their data made available for researchers via the National Institutes of Health (NIH) Database of Genotypes and Phenotypes. This international research tool allows researchers to download large data sets for comparative analysis and further research. Investigators at Columbia University also created a search browser that allows researchers to simply find the different variants identified within EGI. Even if patients

didn't receive a diagnosis from EGI, their data continues to be valuable to further epilepsy research as we work to unlock the genetic secrets of epilepsy.

In addition, the Lennox-Gastaut Syndrome Foundation (LGSF) provided funding for WES for 63 individuals (a combination of patients with LGS and their parents). Potential findings from this work are being confirmed, and we're eager to learn about any potential advancements from this important work.

“

**EGI is a powerful research tool established on behalf of the broader epilepsy community.”**

DAVID GOLDSTEIN, PHD  
EGI PRINCIPAL INVESTIGATOR  
INSTITUTE OF GENOMIC MEDICINE  
COLUMBIA UNIVERSITY





CURE EPILEPSY IS RESEARCHING FOR...

## ELLIE

When Irina and Tony Colon's daughter, Ellie, was 3 years old, they noticed she was having what Irina described as "brain freezes." Looking back now, they realize these were Ellie's first seizures. When she had her first tonic-clonic seizure several months later, their pediatric neurologist said it could just be a one-off, but it wasn't. The Colons made an appointment for Ellie to get an electroencephalogram (EEG), but the seizures began happening more frequently leading up to the test. During one incident, Ellie's seizure was so severe that the Colons immediately went to the emergency room. The pediatric neurologist at the hospital told them definitively, "Ellie has epilepsy."

Ellie's seizures were treated with Keppra, and it appeared that her seizures were under control for almost two years. However, an overnight EEG revealed that she was still having ongoing seizures while she was sleeping. The Colons tried several medications to address the nighttime seizure activity, but the seizures only intensified and Ellie developed severe rashes as a side effect. The Colons sought a second opinion with a pediatric neurologist who diagnosed Ellie with Doose syndrome and prescribed the modified Atkins diet (MAD) to supplement her medications. Although the diet helped in reducing Ellie's seizures, the Colons knew it wasn't a cure for their daughter. Their physician suggested they run the epilepsy genetics panel, which revealed that Ellie had a genetic mutation in the FASN gene that could be causing her epilepsy.

Tony and Irina chose to become involved with CURE Epilepsy to help support research in epilepsy genetics, so families like theirs can get answers. Advancements in genetic testing and the development of databases, such as the Epilepsy Genetics Initiative, have helped researchers learn a great deal more about how a single gene may be associated with multiple forms of epilepsy. Though there are still many unknowns about the role of genetics in epilepsy, these tests and databases can help advance progress toward treatments and, ultimately, a cure.

### WHAT IS DOOSE ("DOHS-AH") SYNDROME?

- Doose is a rare childhood epilepsy that usually begins between ages 1 and 5.
- Doose is also known as Myoclonic Astatic Epilepsy (MAE).
- Doose symptoms include generalized seizures, such as drop seizures, staring spells (absence seizures), and myoclonic jerks.
- Doose has common treatment options, including antiepileptic drugs, dietary treatments, and sometimes even surgery.
- The prognosis for Doose can vary widely depending on the individual, with many becoming seizure-free or controlled through medication.



# THE LASTING IMPACT OF CURE EPILEPSY FUNDING: A FORMER GRANTEE'S RESEARCH BREAKTHROUGHS



In 2011, Dr. Brian Litt of the University of Pennsylvania received a CURE Epilepsy grant, generously supported by the Julie's Hope Award, to break new ground in the field of implantable devices to detect and treat epilepsy. With this funding, Dr. Litt and his coworkers developed an implantable brain device to map, analyze, and control epileptic networks on a much finer scale than previously possible for individuals with treatment-resistant epilepsy.

Funding from Dr. Litt's CURE Epilepsy grant allowed him to continue researching and building active electronics on this device, which had never been done in brain implants before. As a result of that work, Dr. Litt recently received the prestigious National Institutes of Health Director's Award, which will provide \$5.6 million over the next 5 years to develop next-generation brain-computer interfaces. He plans to focus next on developing algorithms that adjust automatically to brain states and can query or answer questions from the user, especially when the device detects subclinical spikes.

These advancements wouldn't have been possible without the initial funding from CURE Epilepsy, which provided Dr. Litt and his team with the flexibility they needed to take risks and make tremendous progress on their devices. This support gave the team time to experiment for the advancement of science and, ultimately, to enhance the lives of people living with epilepsy.

"I can't tell you how grateful I am to the organization and the donors," Dr. Litt says. "Probably the biggest impact of CURE Epilepsy is that the organization spends its dollars wisely. CURE Epilepsy invests in the people as well as the science."

Dr. Litt's unique position as a member of both the Departments of Neurology and Bioengineering enabled him to foster collaboration and further accelerate science through his work, establishing a new generation of scientists and flexible electronics. He is proud to have trained many of his students to think about epilepsy and their impact on creating a potential cure.

"Getting the result is just one piece of the research puzzle," Dr. Litt says. "But what's even more important is getting a lot of smart young people to think about epilepsy and work on it, so you build this critical mass and this community."

We are looking forward to seeing how Dr. Litt's research will continue to benefit our community.

“

**Research is incremental. It builds on itself over time, and what is today's novel discovery or novel device becomes tomorrow's historical foundation for some breakthrough that happens later.”**

BRIAN LITT, MD  
PROFESSOR OF NEUROLOGY AND  
BIOENGINEERING AND DIRECTOR OF  
THE CENTER FOR NEUROENGINEERING  
AND THERAPEUTICS AT THE  
UNIVERSITY OF PENNSYLVANIA



Watch a conversation with Dr. Litt as he discusses his latest research progress on the road to curing epilepsy.





CURE EPILEPSY IS RESEARCHING FOR...

## DANIEL

In May 2005, Daniel Allbeck was 22 years old and weeks away from finishing his junior year at the University of California, Riverside. Then he had his first seizures, a series of tonic-clonic episodes that landed him in the hospital for a week and changed the course of his life. He was diagnosed with epilepsy.

After his initial struggles to control his seizures, Daniel was able to find a combination of medications that worked for him. With his seizures under control, he finished college and joined the Peace Corps. He was all set to go to Africa when the seizures returned and interrupted his plans. Unable to travel abroad with the Peace Corps, Daniel put this setback behind him and decided to pursue his dream of becoming a science teacher. Unfortunately, this career path was also put on hold due to his frequent, ongoing seizures in and out of the classroom.

Throughout these challenges, Daniel's family stood alongside him, providing support, navigating the complex healthcare system, researching treatment options, and advocating for Daniel. It was this unrelenting search for answers that brought the Allbecks directly to CURE Epilepsy. Daniel's parents, Paula and David, began volunteering at events, including CURE Epilepsy's Day of Science (now called CURE Epilepsy CARES), a forum where physicians specializing in epilepsy share recent advances and answer questions from people with epilepsy and their loved ones. During one such event, the Allbecks made a discovery that gave them so much hope: Daniel might be a candidate for resective surgery to reduce his seizure frequency. The Allbeck family consulted with a doctor specializing in epilepsy surgery, who confirmed the good news.

In March 2021, Daniel underwent successful resective surgery. Though he continues to take antiepileptic drugs, he no longer experiences tonic-clonic seizures. Daniel is hopeful and once again on track to realizing his dream of becoming a teacher, just like his parents.

“

**There is so much more to understand about epilepsy, and I still have so many questions. The research that CURE Epilepsy funds brings us all closer to answers.”**

DANIEL ALLBECK



**HEAR DANIEL  
SHARE HIS STORY**

Tune in as Daniel describes his experience with epilepsy on the Nov. 17 episode of *Seizing Life*®. [CUREepilepsy.org/seizing-life](https://CUREepilepsy.org/seizing-life)



# LEADING THE EPILEPSY RESEARCH COMMUNITY

This year, CURE Epilepsy has worked to accelerate epilepsy research by funding scientific grants for epilepsy researchers, advocating for more governmental funding for epilepsy research, and sharing our Post-Traumatic Epilepsy (PTE) Initiative's team science approach to researching PTE, a condition that remains underreported and underinvestigated.



## WHAT IS POST-TRAUMATIC EPILEPSY?

PTE is a type of epilepsy that can develop in the weeks, months, or even years following a traumatic brain injury (TBI). Any type of TBI — whether a mild, repeated TBI, such as a concussion, or a severe TBI, such as a penetrating brain injury — can increase a person's risk for developing PTE.

PTE is a particularly challenging form of epilepsy for many reasons: It is hard to predict who will develop PTE after a TBI; there is no way to prevent the development of PTE; and treatments may be only partially effective and can have severe side effects. We at CURE Epilepsy believe that, through research, we can find a way to predict and prevent PTE.

## CURE EPILEPSY'S POST-TRAUMATIC EPILEPSY INITIATIVE

Our PTE Initiative, a program created by a \$10 million grant from the Department of Defense Traumatic Brain Injury and Psychological Health Research Program, characterizes and identifies biomarkers for PTE in both preclinical and clinical populations. Our PTE Initiative investigators have taken diverse and innovative approaches to tackling this problem, with the mission of eventually being able to predict and prevent the development of epilepsy after TBI.

PTE REPRESENTS

5%

OF ALL EPILEPSIES

## SUPPORTING THE DEFENSE HEALTH RESEARCH CONSORTIUM

CURE Epilepsy is proud to be a member of the Defense Health Research Consortium (DHRC). The DHRC was formally established in 2014 to bring together the diverse community of patient advocacy organizations, medical provider groups, veterans organizations, research advocacy groups, and private sector interests — all with the single purpose of protecting and preserving funding for the Congressionally Directed Medical Research Programs (CDMRPs) at the Department of Defense.

Since the DHRC was founded, the overall funding level for the CDMRP has doubled from approximately \$600 million to more than \$1.2 billion – in no small measure due to the advocacy of the DHRC and its members. The DHRC has also worked to defeat legislative measures that would have terminated many of the CDMRP programs or severely restricted the kinds of research funded by the program.



Defense Health Research Consortium

These programs include:

- Epilepsy Research Program (CURE Epilepsy's founder, Susan Axelrod, helped establish this program many years ago)
- TBI and Psychological Health Research Program (this program funds CURE Epilepsy's PTE Initiative)
- Tuberous Sclerosis Complex Research Program

## NATIONAL NEUROTRAUMA SOCIETY 2021

The CURE Epilepsy PTE Initiative team presented their progress in a special symposium at the National Neurotrauma Society Meeting. This meeting focused on accelerating TBI research by bringing together clinicians, basic science researchers, and individuals who have been impacted by TBI to share their personal stories, research findings, and ideas with the goal of influencing the care and cure of neurotrauma victims. During the symposium, PTE Initiative investigators discussed their multidisciplinary and translational approaches to studying PTE, including candidate biomarker discovery and insights into mechanisms underlying its development.

CURE Epilepsy's PTE Initiative addresses individuals – both civilian and military – who have been affected by TBI that has resulted in PTE. PTE is a debilitating complication of TBI, causing chronic morbidity and representing 5% of all epilepsies. Due to the nature of their work, military service members may be especially susceptible to PTE. **Over 400,000 U.S. military personnel were diagnosed with TBI from 2010–2019 and are at risk for PTE. Iraq and Afghanistan war veterans with TBI were almost 19 times more likely to develop epilepsy than veterans without TBI.** The risk of PTE is not limited to veterans; anyone who sustains a TBI – for example, by accidental fall, motor vehicle accident, or sports-related injury – is at greater risk for developing PTE.

“

**The importance of epilepsy research is especially timely because so many of our soldiers experiencing traumatic brain injury have an increased probability of developing epilepsy as a result of the trauma to their brains.”**

SUSAN AXELROD  
FOUNDER OF CURE EPILEPSY

# MEET OUR NEWEST CURE EPILEPSY CATALYST AWARDEES

**CURE Epilepsy has been instrumental in shifting the focus of epilepsy research from managing seizures and side effects to understanding its causes.** Over the last two decades, we've awarded 270+ grants for epilepsy research in 17 countries worldwide.

We created the Catalyst Award in response to additional needs in the research community, since projects often lack the funding to transition research findings into curative therapies. Meet the most recent recipients of the Catalyst Award.



**RUTH WESTENBROEK, PHD**

UNIVERSITY OF WASHINGTON  
SEATTLE, WA

JUNE 1, 2021 - MAY 31, 2023

## ABOUT

Dr. Westenbroek has extensive experience with the localization and imaging of voltage-gated sodium and voltage-gated calcium channels in a wide variety of tissues. Recently, she was the senior author on a successful investigation into the therapeutic efficacy of cannabidiol in treating seizures associated with Dravet syndrome (DS), a study that was partially funded by CURE Epilepsy.

## RESEARCH EXPERTISE

Dr. Westenbroek's work on voltage-gated sodium channels contributed to the generation and characterization of a mouse model of DS. Using this precision medicine tool, she has been working with a range of collaborators to identify potential therapeutics to combat the symptoms of DS.

## CATALYST GOAL

With this grant, Dr. Westenbroek will further her research on DS. Dr. Westenbroek's lab plans to test newly developed inhibitors that act on sodium channels called Nav1.6 and Nav1.2. Her team will test these drugs for efficacy on specific symptoms of DS, such as thermally induced seizures, spontaneous seizures, and premature death. If these findings are validated, they could transform the treatment of pediatric epilepsies by fueling the development of improved therapeutic strategies to control intractable seizures.





## RODRIGO GUTIERREZ-QUINTANA, MVZ, MS

UNIVERSITY OF GLASGOW  
GLASGOW, SCOTLAND

JANUARY 1, 2022 - DECEMBER 31, 2023

### ABOUT

Dr. Gutierrez-Quintana is a board-certified veterinary neurologist who strongly believes in clinical research for the benefit of patients. His research interests are canine and feline neurological conditions, with a focus on epilepsy, brain tumors, autoimmune encephalitis, neurodegenerative disorders, and congenital malformations.

### RESEARCH EXPERTISE

Dr. Gutierrez-Quintana has participated in characterizing the phenotype and genotype of multiple neurodegenerative diseases and congenital malformations. Recently, he started a doctorate degree looking at the effects of radiation in combination with other drugs on normal brain tissue.

### CATALYST GOAL

Dr. Gutierrez-Quintana's team previously found that, in brain tissue from people with temporal lobe epilepsy, there was a consistent increase in the level of one of these molecules called microRNA-134. The team developed an inhibitor of microRNA-134, called Ant-134, that has been shown to have potent and long-lasting anticonvulsant effects in numerous rodent models after a single dose.

His team will now test the effects of Ant-134 in dogs with naturally occurring drug-resistant epilepsy, an important step toward translating their findings into treatments for humans. If successful, this project will pave the way for human clinical trials for a treatment that has the potential of providing long-lasting seizure control after a single dose and may even cure some forms of epilepsy.

## ROBERT WITHROW WIER CHALLENGE GRANT: YOU MADE IT HAPPEN!

More than 200 new and returning donors gave a total of \$250,324 to help us reach our goal for the Robert Withrow Wier Challenge Grant. These donations helped to make the Catalyst Award program possible, funding our first two projects led by Dr. Detlev Boison at Rutgers University and Dr. James McNamara at Duke University.

Many thanks to each and every donor who made the decision to increase their gift or make their first gift. This incredible research is only happening because of you. Thank you!

# 209

NEW DONORS

# \$250,324

DONATED

# 1 MATCH

OF \$250,000

# 2 CATALYST

AWARDS

# 4 YEARS

OF RESEARCH BRINGING US  
ONE STEP CLOSER TO A CURE

# RESEARCH ADVANCES DISCOVERY. DISCOVERIES CREATE BREAKTHROUGHS. BREAKTHROUGHS LEAD TO A CURE.

## Announcing Our 2021 CURE Epilepsy Taking Flight Grantees

CURE Epilepsy's Taking Flight Award promotes the careers of young epilepsy researchers, allowing them to develop a research focus independent of their mentor. The award grants up to \$100,000 for one year.



**RINA ZELMANN, PHD**

MASSACHUSETTS GENERAL HOSPITAL

OCTOBER 1, 2021 - SEPTEMBER 30, 2022

### REALITY

Identification of individuals at risk of developing epilepsy remains a major challenge. If we could predict who will develop epilepsy after a first seizure or brain injury, treatment could start earlier, and prognoses might improve.

### RESEARCH

High-frequency oscillations (HFOs), a type of electrical activity in the brain, could be used to identify brain regions responsible for seizure generation. This could possibly predict the development of epilepsy, since HFOs are hard to detect on the scalp. Dr. Zelmann proposes to generate HFOs by repeated stimulations, allowing for easier detection of HFOs on the scalp and potentially leading to an easy test to predict epilepsy in outpatient clinics.



**ANA BEATRIZ DEPAULA-SILVA, PHD**

UNIVERSITY OF UTAH

NOVEMBER 1, 2021 - OCTOBER 31, 2022

### REALITY

Inflammation caused by viral infection of the central nervous system is associated with seizures and epilepsy, but how inflammation can lead to seizures is not fully understood.

### RESEARCH

In this viral infection model of epilepsy, Dr. DePaula-Silva will aim to identify specific gut bacterial populations and molecules produced by the bacteria that can protect animals from seizure development. If successful, the knowledge obtained from this study will allow for the development of novel therapies, including modification of gut microbiota or of specific molecules, to treat and possibly cure seizures and epilepsy.



**JOANNA MATTIS, MD, PHD**

UNIVERSITY OF PENNSYLVANIA

SEPTEMBER 1, 2021 - AUGUST 31, 2022

### REALITY

A seizure is a sudden burst of uncontrolled electric disturbance in the brain. So, how do seizures start? This fundamental question remains unanswered despite decades of research.

### RESEARCH

Dr. Mattis will study neuromodulatory neurons, which are “master regulators” that control many functions in the brain. These neurons are located deep within the brain but connect with seizure-prone brain regions. Dr. Mattis will test whether these neurons coordinate the transition between normal brain activity and seizures, and whether activating these neurons can be therapeutic in epilepsy.

## CURE EPILEPSY IS RESEARCHING FOR...

# ALEX

Alex Heldman was a typical 19-year-old college sophomore who was on vacation with his family when he experienced a throbbing headache. His family rushed Alex to the emergency room after the throbbing in his head persisted. At the hospital, Alex had his first seizure. The hospital released Alex, but he continued to have nonstop seizures, known as status epilepticus.

Alex was later diagnosed with a form of acquired epilepsy caused by a viral infection that reached his brain. The resulting injury to his brain forced Alex to be put into a coma, since his seizures could not be controlled and his life was in danger. We now know that what Alex experienced is called New Onset Refractory Status Epilepticus (NORSE). NORSE is just beginning to be understood, and it is unclear – for Alex and others with NORSE – whether the illness preceding it is a viral infection or an autoimmune response.

After six agonizing months for the Heldman family, Alex woke from his coma, but he was left with nerve damage so severe that he was unable to walk. Today, his seizures are controlled by numerous medications that have significant side effects. Alex’s experience with NORSE, and his ongoing struggle with seizures and their side effects, illustrate the need for the important research that CURE Epilepsy supports. Through our continued commitment to epilepsy research, we hope to gain a deeper understanding of why and how people develop epilepsy in the first place so that we can find a cure.



“

Even if a cure would affect only a small percentage of the many kinds of epilepsies, it would allow people to recognize that this incredibly complex and distressing problem has a light at the end of the tunnel.”

PAUL HELDMAN

ALEX’S FATHER, FORMER CURE EPILEPSY BOARD MEMBER



# DONOR SPOTLIGHT

## KATE NEALE COOPER

MOTHER TO VIRGINIA, WHO RECENTLY COMPLETED HER THIRD BRAIN SURGERY AND REMAINS SEIZURE FREE.

After years of being frustrated with medications that failed to help her daughter Virginia, Kate was determined that research had to be the key to a cure for epilepsy. For more than a decade, Kate has supported CURE Epilepsy every year, whether running a 24-hour race, participating in our virtual event, or making a year-end gift.

### Can you tell us about Virginia's diagnosis and the treatment options you pursued prior to surgery?

We went to several hospitals, had several tests done, and whatever they tried didn't work. So we'd gear up to go somewhere new and transfer all of Virginia's medical records to a new place — once again full of hope — only to be told that there's nothing they can do, even after trying many, many different medications; I lost count after eight. In an attempt to pinpoint the location of her seizures, the doctors even tried implanting electrodes into her brain, but that didn't work. Her doctors said deep brain stimulation was the best they could do for Virginia. I knew that wouldn't stop the seizures, only reduce the risk of death, and my gut told me there had to be something better out there. So I kept looking.

### HELP FUND MORE RESEARCH!

During this season of giving, we hope you will join Kate and make your year-end gift to CURE Epilepsy. Visit [CUREepilepsy.org/2021fall](https://CUREepilepsy.org/2021fall) or use the enclosed response card.



KATE AND VIRGINIA RUNNING FOR CURE EPILEPSY IN 2014

Despite hearing discouraging information about the difficulty of the ketogenic diet, I knew it was even more difficult not to try everything I could for Virginia. The diet actually provided her with some limited reprieve from her seizures, but ultimately they came back. I wish I had done it years earlier because, when combined with the right medications, research suggests that the younger the patient is, the more likely the ketogenic diet will work.

Finally, and thanks to my network of CURE Epilepsy friends, I found Dr. M. Scott Perry at Cook Children's Hospital in Texas. We went to visit, and after one night of observations, the staff there informed me that 'we can help her.' They enrolled Virginia in a new research study that combined another diagnostic surgery with advanced brain imaging techniques. Through this combination, the team was able to do what no other doctors could do before: pinpoint exactly where the seizures were coming from. With that information, they could do a minimally invasive laser ablation. She was discharged from the hospital after surgery and hasn't had another seizure.

### What led you to decide that surgery would be the best option for Virginia?

For years and years, we were told that surgery was not an option for Virginia. Surgery sounds like such a big deal and there's so much misinformation in the media. We have a ton of educating to do about how safe and non-invasive surgery can be, especially for small children. The combination of advanced imaging tools and electroencephalography options will allow us to find that more people are surgical candidates much sooner. We need to move people with epilepsy down that



path faster because imaging and data processing is so far beyond what it was when my daughter was first diagnosed.

**You participated in the 200-mile Ragnar Relay Race to raise money for CURE Epilepsy. What inspired you to get involved?**

I started running for my own mental health and for a break from everything and to take care of myself. So many of my friends felt powerless and wanted to help, and contributing to our Violet Femmes team in the Ragnar Relay Race race was something they could do whether they wanted to run, raise awareness, or give. I would run with my CURE Epilepsy shirt and people would say, 'Awesome cause! I'm going to give!' You know the more we talk about CURE Epilepsy, the more awareness there is, and the more we can close the funding gap to eventually cure epilepsy.

**How do you think the research that CURE Epilepsy funds can help Virginia and people like her?**

Epilepsy is tragically underfunded. The lack of conversation around epilepsy and the lack of funding go hand in hand. Most research is funded through the government, which has very strict criteria. CURE Epilepsy has more flexibility in terms of identifying studies that are very cutting-edge but may not meet all the federal guidelines. Seventy percent of people don't know what is causing their epilepsy and a third cannot achieve seizure freedom with medications. That's not good enough. Virginia failed more than eight medications, and that's not including all the ones to counteract the side effects of the antiepileptics. We simply need more advances and options.

**Virginia recently started her freshman year of college away from home. What has that experience been like for her?**

Virginia is living away from home and is attending college, which is a major milestone that we never would've imagined prior to her surgery. She is currently studying culture and media studies, and loves being in a big city and being independent. I admire Virginia's bravery, curiosity, and compassion, and I can't wait to see what she does and where she goes. I want to know that I've done everything I could to keep my daughter alive and living a full life, and CURE Epilepsy helped me do that.



“  
The lack of  
conversation  
around epilepsy  
and the lack of  
funding go hand  
in hand.”

KATE NEALE COOPER





# THE NEXT AGENTS OF CHANGE IN EPILEPSY: CURE EPILEPSY'S SCHOLARSHIP RECIPIENTS

CURE Epilepsy's Education Enrichment Fund Scholarship supports students living with epilepsy, their family members, or their caregivers as they pursue their education. Made possible by the generous funding of Greenwich Biosciences, CURE Epilepsy scholars receive a one-time scholarship (up to \$5,000) to support their coursework and prepare them to be agents of change in the epilepsy community.

**AUBREY BROWN** | SAGINAW VALLEY STATE UNIVERSITY, UNIVERSITY CENTER, MI

Aubrey is proud of embracing her epilepsy. She was accepted into Saginaw Valley State University's College of Education program and hopes to work with children with learning disabilities because she struggled with her own epilepsy-related learning disabilities in school.

**MARJORIE FITZSIMMONS** | UNIVERSITY OF SOUTH FLORIDA MORSANI COLLEGE OF MEDICINE, TAMPA, FL

Marjorie was in a car accident that resulted in a traumatic brain injury, which evolved into generalized seizures and led her to learn more about epilepsy. This scholarship will support Marjorie's goal of becoming a physician and bettering the lives of individuals like her who are living with life-changing medical conditions.

**RACHEL HAUBERT** | CLARKE UNIVERSITY, DUBUQUE, IA

Rachel's sister Maddie was diagnosed with Sturge-Weber syndrome, which caused an abnormality on Maddie's brain and resulted in epileptic seizures. Inspired by her sister, Rachel's goal is to earn a Doctorate of Physical Therapy and use her expertise to assist those recovering physically from epileptic injuries and improve their overall quality of life.

**KIARA MOWAT** | MCMASTER UNIVERSITY, HAMILTON, CANADA

Kiara experienced her first tonic-clonic seizure when she was in 9th grade and was eventually diagnosed with juvenile myoclonic epilepsy, which led her to learning more about epilepsy. After completing her degree in the Justice, Political Philosophy & Law program, Kiara plans on becoming a lawyer to further advocate for doctors, researchers, and people living with epilepsy.







**OLIVER KILMARTIN** | UNIVERSITY COLLEGE DUBLIN, DUBLIN, IRELAND

Oliver was diagnosed with epilepsy when he was 11 years old. His desire for patients to have free access to healthcare, housing, and education in Ireland is a driving force for him to study law. Oliver believes that, with a law degree, he can help individuals by working on important cases and setting precedents to further identify, protect, and vindicate people's rights.



**KATHERINE LONERGAN** | SIMMONS UNIVERSITY, BOSTON, MA

Katherine developed epilepsy as a child and sought answers at her local library, where she found that many medical texts on epilepsy were written by and for people like her. Katherine graduated from Wellesley College and has enrolled in the Masters of Library and Information Science program at Simmons University, where she hopes to continue the cycle by assisting others in gaining access to reliable resources about epilepsy.



**RACHEL MCKELVEY** | LESLEY UNIVERSITY, CAMBRIDGE, MA

When Rachel's sister Ava was diagnosed with epilepsy, Rachel became determined to advocate for people with disabilities. Rachel, who has autism, began creating comics to illustrate what it feels like to be a person with a disability trying to navigate the world, and what others can do to be helpful. Rachel plans on pursuing a bachelor's degree in animation to continue advocating for people with disabilities through her art.



**RACHEL MILLER** | UNIVERSITY OF MICHIGAN, ANN ARBOR, MI

Rachel's brother Steven was diagnosed with epilepsy when he was 5. This led Rachel to explore links between the brain and epilepsy more deeply. Rachel has been accepted to the Loddenkemper Pediatric Epilepsy Research Internship, where she will gain a better understanding of epilepsy in the search for a cure, and actively contribute to research that improves the lives of patients with epilepsy.



**GWYNETH ROBINS** | UNIVERSITY OF MINNESOTA, ST. PAUL, MN

Gwyneth's brother Mitchell has had autism and epilepsy since he was 4. Mitchell's diagnosis led Gwyneth to study neuroscience in college and set a career goal to attend medical school and become a neurologist. She is excited to enter the field of neurology and is hoping to develop treatments in her neuroscience classes that she can pass along to her future patients.



**KIRSTON ZANDWYK** | CONESTOGA COLLEGE, KITCHENER, CANADA

As a foster parent to medically complex children, Kirston has cared for several children with epilepsy. She is currently the proud mom to a son with medically complex, drug-resistant epilepsy. Kirston is enrolled in pre-health sciences, and her dream is to become a registered nurse so she can help bring coordinated care to rural communities near her through a satellite office.

# CONNECTING THE EPILEPSY COMMUNITY THROUGH VIRTUAL EDUCATION

## PURPLE DAY® AROUND THE WORLD



This past spring, CURE Epilepsy joined the epilepsy community as we came together online for Anita Kaufmann Foundation's annual Purple Day® Around the World 2021 Virtual Epilepsy Education Conference.

CURE Epilepsy presented a video, "A Clinical Trials Overview: Incorporating the Patient Voice," on the first day of the conference with speakers Dr. M. Scott Perry, Medical Director of Neurology at Cook Children's in Texas, and Hillary Savoie, writer, rare disease advocate, and a mother of a determined little girl named Esme. They discussed patient participation in epilepsy clinical trials. In addition to determining the safety and efficacy of new epilepsy drugs, clinical trials can also help determine new ways to detect seizures, prevent seizures, and even improve the quality of life for people with epilepsy. Watch the video via the QR code to learn more about clinical trials.



Watch the recording  
of CURE Epilepsy's  
Purple Day® presentation.

### WANT TO JOIN A CLINICAL TRIAL?

To find a comprehensive list of clinical trials, visit [CUREepilepsy.org/for-patients/clinical-trials](https://CUREepilepsy.org/for-patients/clinical-trials) for the National Institutes of Health and U.S. National Library's online clinical trial database.

# WATCH OUR LATEST WEBINARS

Epilepsy affects groups of people in different ways, from women and siblings to older adults. CURE Epilepsy's webinars provide education and information to empower people with epilepsy and their loved ones.



## **WOMEN'S HEALTH: COMPLEX INTERACTIONS OF EPILEPSY, MEDICATIONS, AND HORMONES**

Dr. Page B. Pennell is a Professor of Neurology at Harvard Medical School, Vice-Chair of Academic Affairs in the Department of Neurology, and Director of Research for the Division of Epilepsy at Brigham and Women's Hospital, with a secondary appointment in the Division of Women's Health. She discussed how epilepsy and antiseizure medications can affect hormones and reproductive health, how sex steroid hormones can affect antiseizure medications and seizure control, and how the menopausal transition can affect epilepsy.



## **AGING AND EPILEPSY: CONSEQUENCES AND COMORBIDITIES TO CONSIDER IN OLDER INDIVIDUALS**

Dr. Alice Lam, an Assistant Professor of Neurology at Harvard Medical School and the Massachusetts General Hospital, discussed the relationship between epilepsy, dementia, and stroke. She also spoke about specific strategies that people with epilepsy can implement to reduce their risk for these conditions.



## **SIBLINGS AND SEVERE CHILDHOOD EPILEPSY: THE IMPACT OF SEIZURES ON THE FAMILY'S MENTAL HEALTH**

Dr. Kelly Knupp, Associate Professor of Pediatrics and Neurology at the University of Colorado and CURE Epilepsy Scientific Advisory Council member, discussed The Siblings Voices Study. The study included siblings in a variety of age ranges and was created to help families understand more about the impact of having a sibling with severe epilepsy. Dr. Knupp discussed some of the key research findings from the study, including some strategies to help improve the mental well-being and social development of siblings, as well as resources that are available for families.

You can watch these webinars and more by visiting  
[CUREepilepsy.org/webinars](https://CUREepilepsy.org/webinars).



## **SEIZING LIFE®, A CURE EPILEPSY PODCAST AND VIDEOCAST**

In this series, Kelly Cervantes, the host and current CURE Epilepsy Board Chair, inspires empathy, offers helpful stories, and provides hope as we search for a cure for epilepsy. Listen as guests share stories and insights on living with and battling epilepsy.

### **FEATURED EPISODES**

#### **FROM EPILEPSY RESEARCHER TO EPILEPSY PATIENT: A NEW PERSPECTIVE**

In this episode, we spoke with Dr. Steve White, a professor and Chair of the Department of Pharmacy at the University of Washington, epilepsy researcher for over 40 years, former CURE Epilepsy grant recipient, current member of the organization's Scientific Advisory Board, and an epilepsy patient, having experienced his first seizure in 2010.

#### **RAISING A CHILD WITH BOTH AUTISM AND EPILEPSY**

In this episode, we spoke with Liane Kupferberg Carter, an author, journalist, and mother. Liane's son Mickey was diagnosed with autism at 5 years old, and several years later, received an additional epilepsy diagnosis. Liane discusses her family's difficult and frustrating journey.

[CUREepilepsy.org/seizing-life](https://CUREepilepsy.org/seizing-life)





## TEAM CURE EPILEPSY

### RUN FOR RESEARCH

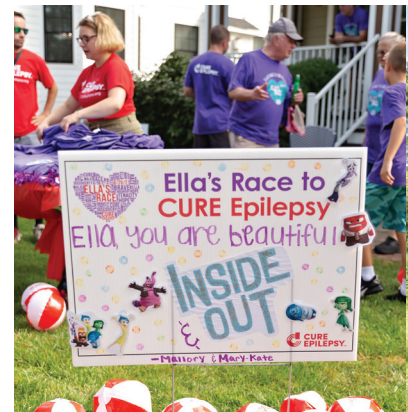
Earlier this year, we brought runners together virtually in the first ever Team CURE Epilepsy Run for Research. Each participant ran 26.2 miles throughout the week as an ode to the 1 in 26 Americans living with epilepsy. This fall, Team CURE Epilepsy is being represented in marathons across the country. Connect with Team CURE Epilepsy runners around the world by using the hashtag #TeamCUREepilepsy when you post pictures on social media.

If you're interested in running for Team CURE Epilepsy, please contact us at [events@cureepilepsy.org](mailto:events@cureepilepsy.org).

## CURE CHAMPIONS

### ELLA'S RACE

Ella, an 11-year-old who has severe epilepsy, walked a one-mile route on August 29. To recognize the 1 in 26 Americans who will develop epilepsy in their lifetime, Ella and her family placed signs every 26 feet along the route in their neighborhood. Their aim is to find a novel treatment for Ella and people like her to become seizure-free. Ella and her family will donate all of the proceeds from Ella's Race to CURE Epilepsy, where they volunteer and where her parents, Blake and Shalee, have both served on the board.







## JASON'S 100-MILE RUN

On September 17, Jason set out to run a 100-mile ultramarathon through the rugged terrain of Georgia to raise funding and awareness for CURE Epilepsy in memory of his dear friends' daughter, Adelaide Cervantes. Earlier, during his training, he ran 26 miles and dedicated each mile to a certain individual impacted by epilepsy, and for the 1 in 26 Americans diagnosed with epilepsy in their lifetime.

## COMMISH GOLF OPEN

The Commish Golf Open in Maryland is an annual golf event in memory of Donny and Mary Nichols, specifically honoring their grandson Aidan who was diagnosed with epilepsy at the age of 5. This year marked the 3rd annual event and was particularly meaningful since Aidan lost his battle with epilepsy in January 2021 at the age of 16.

## HONEYDEW FUNDRAISER

Over the summer, the Maffie family partnered with a local Massachusetts company, HoneyDew, to raise funds in memory of Anthony Maffie. Anthony, a 22-year-old aspiring nurse, passed away from SUDEP two years ago, and his family is dedicated to raising funds for CURE Epilepsy to advance SUDEP research.

## BIG 10 VS. SEC COMPETITION FOR A CURE

The 2nd annual fundraiser, hosted by the Chalfant family in South Carolina, encourages individuals to engage with epilepsy facts and statistics posted on social media, with more points awarded for increased engagement. This friendly competition also allows participants to show off their school pride while raising funds for epilepsy research.



## GET YOUR CURE EPILEPSY SWAG!



In late 2021, CURE Epilepsy will be opening an online store. We'll be offering CURE Epilepsy branded tees, pullovers, hoodies, water bottles, totes, and much more! Show your CURE Epilepsy pride and gift it to others this holiday season.







## JOEY'S SONG EVENT AND AUCTION: A GREAT TIME FOR A GREAT CAUSE

On January 8, 2022, Joey's Song Benefit Concert will take place live at the Sylvee Theatre in Madison, WI. For those who can't join in person, the show will be available online throughout the world. The event brings together Grammy award-winners, Top 40 hitmakers, and rock 'n' roll Hall of Famers for an evening of inspiration and celebration. CURE Epilepsy will once again be one of the primary beneficiaries of the event. Joey's Song will also be hosting an online auction with signed guitars, travel experiences, and more, with all of the proceeds from the auction going to CURE Epilepsy.

Since its founding in 2010, Joey's Song and Auction has helped raise over \$500,000 for epilepsy research and programmed services for children with special needs. The event honors Joey Gomoll, who passed away from a rare form of epilepsy on March 30, 2010, just shy of his 5th birthday.

Buy tickets, bid on an auction item, and learn more about the event by visiting [joeyssong.org](http://joeyssong.org).



**OVER 3.4 MILLION AMERICANS  
AND 65 MILLION PEOPLE WORLDWIDE  
CURRENTLY LIVE WITH EPILEPSY.**

Help us continue to advance science toward a cure for future generations.



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[CUREpilepsy.org/2021fall](https://CUREpilepsy.org/2021fall)



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