



# RESEARCHING TO CURE EPILEPSY

FALL 2020



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



# THE EPILEPSY COMMUNITY IS A COMMUNITY THAT KNOWS CHALLENGE.

In the face of a global pandemic, we're experiencing more challenges than ever before. Paused research. Major shifts in medical care. Increased health risks. Feelings of isolation, fear, and anxiety.

## **BUT WE'RE ALSO A COMMUNITY THAT RISES ABOVE CHALLENGES.**

That's CURE Epilepsy's commitment to you – that we will remain steadfast in our mission to find a cure by identifying and funding the most innovative research in the epilepsy space.

In this issue, you'll read about our new continuity fund, fueled by the Cotton family who rushed to support researchers with projects stalled because of pandemic funding shifts. You'll also learn about our new COVID-19 online hub, filled with educational resources on how the virus impacts epilepsy patients.

We're all learning how to live in a new normal, but while much has changed, living with epilepsy has not. For those impacted by epilepsy every day, I hope you'll find inspiration in this issue and feel our relentless commitment to a cure. Your stories of living with epilepsy motivate us and serve as powerful reminders that this disease must be stopped.

Our work to fund epilepsy research is made possible because of our generous donors who believe in a world without epilepsy. When it became clear that we would have to postpone or cancel fundraising events to keep our community safe, you responded with creativity and passion that led to reimagined activities to support our mission. We have been amazed by the dedication of all of our donors, especially our CURE Epilepsy Champions who brainstormed new ways to bring together their communities to raise funds for research.

A pandemic is our latest challenge to finding a cure, but it's a challenge we'll overcome. We will protect the progress we've made and drive for future discoveries. Thank you for being our partner in hope as we work to end epilepsy.

A handwritten signature in black ink, appearing to read 'Beth Lewin Dean'.

Beth Lewin Dean  
Chief Executive Officer, CURE Epilepsy



## NEW NAME, SAME VISION

We've always been an organization at the forefront of change and innovation. In line with this commitment, we recently updated our organizational branding to state our mission more directly. Changing our name and logo from CURE (Citizens United for Research in Epilepsy) to CURE Epilepsy reinforces to our community and beyond that we're laser-focused on finding a cure to end epilepsy.

# BRIDGING A CRITICAL RESEARCH GAP: INTRODUCING THE **CURE EPILEPSY CATALYST** AWARD

At CURE Epilepsy, we recently expanded our research approach to dedicate funding to translational research projects. The new award, **CURE Epilepsy Catalyst**, is a funding program that supports the next step of research findings – enabling the science from successful basic research studies to translate into potential new treatments for epilepsy.

This bold new initiative reflects our unrelenting mission to find a cure for epilepsy through research. Over the last two decades, we've funded more than 240 grants in 15 countries to better understand the causes of epilepsy and uncover new therapies.

Through their work, our grantees have shifted the focus of epilepsy research from managing symptoms to identifying underlying causes of epilepsy. This successful shift now allows us to evolve our funding to accelerate the development of new, transformative therapies.

Catalyst fills a need identified during our work with current grantees. Many projects lack the funding needed to transition basic research findings to curative therapies. By funding projects through the Catalyst award, CURE Epilepsy can offer new opportunities and hope for the epilepsy community.

CURE Epilepsy will award funding in stages based on results-driven milestones. As studies show progress, projects will continue to receive funding, up to a maximum of \$250,000. A successful outcome could allow the project to move into subsequent stages of development, including clinical trials, bringing us one step closer to a cure.

## MEET OUR FIRST GRANTEE



### DR. DETLEV BOISON

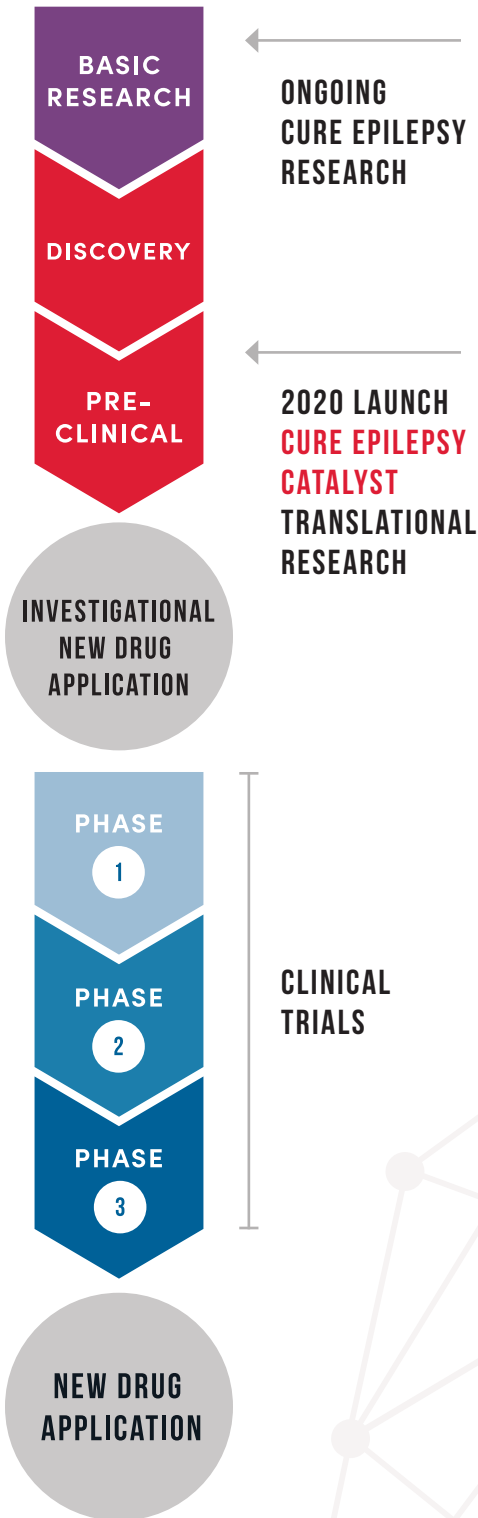
RUTGERS UNIVERSITY

A previous CURE Epilepsy grantee, Dr. Boison has spent his 25-year career studying ways to prevent and treat epilepsy. During that time, he and his team discovered that some people develop epilepsy when a substance in the brain called adenosine (ADO) decreases.

Dr. Boison will use the Catalyst award to build on prior CURE Epilepsy-funded work, which demonstrated it's possible to increase ADO levels with a drug that blocks the enzyme responsible for reducing it. The team's goal is to optimize and test this drug's potential to prevent epilepsy in the hopes of creating new treatment options for patients.

# ONE STEP CLOSER TO A CURE

Bringing a new epilepsy drug to patients involves numerous steps. **CURE Epilepsy Catalyst** provides funding for a later phase of research than our previous work, accelerating progress toward a cure.



# MAKE A GIFT, UNLOCK ONE MORE



## \$250,000

Your support to jumpstart **CURE Epilepsy Catalyst** will now make an even bigger difference. To encourage new gifts, a generous donor has established the **Robert Withrow Wier Challenge Grant**. This grant of \$250,000 will only be given as CURE Epilepsy raises the same amount in new or increased commitments.

By making a new or increased gift to CURE Epilepsy today, you can help us achieve our goal of funding two Catalyst grants to translate basic research into potential new epilepsy treatments. For more information or to make your gift, visit [CUREepilepsy.org/donate/2020fall](https://CUREepilepsy.org/donate/2020fall) or contact **Alysha Biehl** at (312) 589-5578 or [alysha.biehl@CUREepilepsy.org](mailto:alysha.biehl@CUREepilepsy.org).

# EPILEPSY HAS NOT STOPPED. NEITHER HAS CURE EPILEPSY RESEARCH.

In the midst of a massive healthcare crisis, epilepsy research is more vulnerable than ever. Researchers are experiencing delays because of mandatory time away from their labs and additional costs for personal protective equipment and other materials. **Recognizing this need, we're proud to establish the CURE Epilepsy Research Continuity Fund (CERCF) with generous funding from the Cotton family, in honor of Vivian Cotton.**

CERCF provides financial relief to epilepsy researchers whose work has been impacted by COVID-19. With a goal to keep epilepsy research moving forward during these unprecedented times, CERCF reimburses up to \$15,000 of research-related expenses incurred because of institutional shutdowns, including salaries for lab staff, PPE equipment and supplies, and expired laboratory supplies.



## RESEARCH IMPACTS DURING COVID-19

When COVID-19 first forced many academic institutions to close temporarily, our immediate concern was the progress of epilepsy-related research projects.

We anticipate that continued restrictions experienced by researchers will impact progress on epilepsy research in 2021.

As the nonprofit leader in epilepsy research, we are committed to filling as many funding gaps as possible.

CURE EPILEPSY IS RESEARCHING FOR...

# VIVIAN



Vivan Cotton was always a fighter. Born at 27 weeks, Vivian experienced brain trauma because of her premature birth, and developed hydrocephalus which required the surgical implantation of a shunt. As a side effect of the trauma and treatment, Vivian also developed epilepsy.

The Cottons sought out a variety of treatments to control Vivian's seizures, experiencing success with the ketogenic diet. But a pancreatitis diagnosis and complications from her shunt required more surgery, forcing her to discontinue the diet. Her seizures returned and her hospital stays escalated.

At 18 months old, Vivian passed away. After her passing, Vivian's parents, Lisa and Michael, vowed to continue fighting for a cure to help other families struggling with epilepsy.

“

We look to researchers to help us solve this complex illness. It is their hard work and dedication that has made breakthroughs in medicine and forged the trail of discovery so that others may follow. We will continue to support research that will help fuel discoveries in Vivian's memory.”

LISA COTTON, VIVIAN'S MOTHER

# RESEARCHING FOR NEW DISCOVERIES

## ANNOUNCING OUR NEW CURE EPILEPSY GRANTEES

### AES/CURE EPILEPSY RESEARCH & TRAINING FELLOWSHIP FOR CLINICIANS

\$50,000 FOR ONE YEAR, FUNDED 50% BY CURE EPILEPSY



**JAMES GUGGER, MD, PHARM D**  
UNIVERSITY OF PENNSYLVANIA

#### THE REALITY

Some people develop epilepsy after a traumatic brain injury (TBI) while others do not. If researchers could determine what causes – or who is most likely to develop – epilepsy after trauma, we may be able to prevent it from developing in the first place.

#### THE RESEARCH

Dr. Gugger's project works to better understand why some people develop epilepsy after a TBI. By using diffusion tensor imaging – a special brain scan – Dr. Gugger will investigate if changes in the brain's wiring, the amount of water in the brain, or brain inflammation are associated with the development of epilepsy following a brain injury.

#### WORKING TO

identify why some people develop epilepsy after a TBI and who is at a higher risk

#### WORKING FOR ALEC

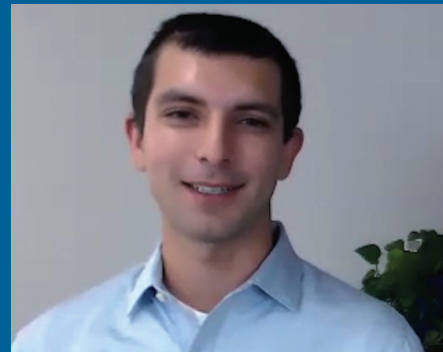
# \$70 MILLION +

TO DATE, CURE EPILEPSY HAS RAISED  
MORE THAN \$70 MILLION FOR EPILEPSY  
RESEARCH FUNDING.



CURE EPILEPSY IS RESEARCHING FOR...

# ALEC



Injured in a military training accident, former Marine Alec suffered extensive damage to his hand and a concussion. Unknown to his doctors, Alec had brain damage that led to a tonic-clonic seizure. Nearly two more years, and another tonic-clonic seizure, passed before Alec received his post-traumatic epilepsy diagnosis. He continues to explore treatments to make him seizure-free, and live as independently as possible.



You can't do this alone... You have to take a slower pace. Everything is achievable just at the right speeds and with the right support system."

ALEC

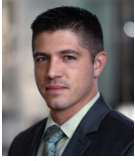


Listen as Alec and his mother recount his journey from injury to PTE diagnosis, how his seizures changed his life, and his drive to maintain independence.

[CUREpilepsy.org/seizing-life/the-invisible-consequences-of-traumatic-brain-injury](https://CUREpilepsy.org/seizing-life/the-invisible-consequences-of-traumatic-brain-injury)

# TAKING FLIGHT AWARD GRANTEES

\$100,000 FOR ONE YEAR



**CHRIS MCGRAW, MD, PHD**  
MASSACHUSETTS GENERAL HOSPITAL

## THE REALITY

Despite advancements in antiepileptic drugs (AED), one-third of epilepsy patients are unable to control their epilepsy with medication – one of the greatest therapeutic challenges in the field today.

## THE RESEARCH

Using a zebrafish model, Dr. McGraw is developing a system that integrates genetic engineering advances with non-invasive neural activity monitoring to enable a rapid screen for genes that enhance seizure resistance. His goal is to identify genes that are seizure-resistant in an animal model, allowing these genes and their protein products to serve as targets for the next generation of AEDs in human patients.

## WORKING TO

**identify more effective AEDs that have fewer side effects**

## WORKING FOR REAGAN

CURE EPILEPSY IS RESEARCHING FOR...

# REAGAN



When her daughter was 16 months old, Erin heard the words no parent wants to hear: “Your child had a seizure.” Four months later, another seizure followed, and a hospital stay confirmed two diagnoses – epilepsy and cerebral palsy. For more than five years, Reagan and her family wrestled with different medications, trying to identify a combination that left Reagan both seizure-free and without side effects. Now on the medical ketogenic diet, Reagan maintains good seizure control and her attention to tasks has increased, along with some of the other skills she had lost.

“

Thinking back to that Mom [after the diagnosis] who was scared and wondered what this would mean for her then 2-year-old, I would tell her that epilepsy is a part of Reagan, but it does not define her.”

ERIN, REAGAN'S MOM



**ANKIT KHAMBHATI, PHD**  
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

**THE REALITY**

For patients with drug-resistant, focal-onset seizures, treatment was often limited to the removal of epileptic brain tissue. Now, an emerging therapy – neurostimulation – offers hope. Chronically implantable devices deliver electrical pulses that prevent seizures from occurring, but their efficacy is modest – reducing approximately 60% of a patient’s seizures.

**THE RESEARCH**

Dr. Khambhati and his research team aim to optimize faster and more effective stimulation-based control of seizures. Using high-density direct brain recordings and stimulation technology, they will work to separate control points in the human epileptic brain. These studies will yield a detailed map between patterns of stimulation and epileptic network response, helping to better calibrate devices for more effective control of a patient’s seizure-generating network.

**WORKING TO**

**unlock the full potential of neurostimulation as a transformative therapy**

**WORKING FOR ROB**

**CURE EPILEPSY IS RESEARCHING FOR...**

**ROB**

Rob first experienced seizures in high school, but was afraid to come forward to his loved ones or medical professionals. Shortly after high school, he sought medical care and received an epilepsy diagnosis. As part of his treatment, Rob had four epilepsy surgeries in the hopes of stopping his seizures, including implanting a NeuroPace device on each side of his brain. Since having these devices implanted, Rob has only had one seizure.



I wish people were more aware of how big of an impact it [epilepsy] can have on your life, whether or not they see you have a seizure.”

ROB



# DONOR SPOTLIGHT



## BARBI BUCHANAN

MONTHLY DONOR TO CURE EPILEPSY SINCE 2015

Barbi Buchanan was inspired to become a monthly donor to CURE Epilepsy following her daughter Bryn's diagnosis at 12 years old. A few years later, her family was dealt another blow when Barbi was diagnosed with treatment-resistant epilepsy at age 58. Although her symptoms are not as severe as Bryn's, she lives every day with the lifestyle changes brought on by epilepsy. Here, Barbi shares her story and why she's committed to supporting CURE Epilepsy to fuel progress toward a cure.

### How has your experience as a patient and a parent shaped your perspective on epilepsy?

Like any parent, I worry most about my child. John and I have adjusted to what we call an alternate universe of parenthood. We've realized Bryn's life journey might change.

It is important to us that she experience life fully, with our support. That means allowing her to ski or horseback ride

or travel – activities that parents don't typically try to restrain. Today she's independent, but there's not a day that I don't worry about her.

Having epilepsy myself helps me better understand what Bryn goes through and her limitations. My independence continues to waver as my health changes. I was finally able to drive about three years ago, after being seizure-free for two years. Then this July, I started having seizures again.

“

Donating to CURE Epilepsy is our family's way of directly funding a cure and supporting our epilepsy community.... I've experienced caring for a child and supporting a young adult with epilepsy firsthand, and this disease must be stopped.”

BARBI BUCHANAN



## BE LIKE BARBI AND SUPPORT US MONTHLY!

When you become a monthly donor like Barbi, you sustain CURE Epilepsy's work to fund critical research in pursuit of our shared vision: a world without epilepsy. You can make your gift on a credit card or from a checking account by visiting [CUREepilepsy.org/donate/2020fall](https://CUREepilepsy.org/donate/2020fall). Questions? Email us at [info@CUREepilepsy.org](mailto:info@CUREepilepsy.org).

 **Make it monthly!**

### Why did you first give to CURE Epilepsy? And as a monthly donor, why do you keep giving?

Donating to CURE Epilepsy is our family's way of directly funding a cure and supporting our epilepsy community. Epilepsy seems to strike our most vulnerable – our children – most often. I've experienced caring for a child and supporting a young adult with epilepsy firsthand, and this disease must be stopped.

### What part of CURE Epilepsy's work inspires you most?

Researching for a cure is my quick answer. But I think raising awareness about epilepsy is also critical to the day-to-day lives of those of us with epilepsy. When we received Bryn's diagnosis, we knew nothing about it. Was it curable? Was it like MS? What would her life look like? We had to find our own information and community around this disease. Now, I never shy away from speaking about epilepsy.

### What message about epilepsy would you share with others?

I would start by saying that epilepsy kills. This disease needs to be taken seriously by patients and caregivers, and also by those in positions of influence who can move us closer to a cure.

But I'd also tell patients that epilepsy doesn't have to be a death sentence. For many, treatment, lifestyle changes, and careful monitoring will lead to a full life. It's a different life than we imagined, but it's a happy one.



**BRYN BUCHANAN**

# SUPPORTING OUR COMMUNITY DURING COVID-19

“In the face of the coronavirus pandemic, much of what we are dealing with today reminds me of my family’s personal journey with epilepsy. We lived in the face of something over which we had little or no control. **We craved answers that didn’t exist.**”

SUSAN AXELROD  
CURE EPILEPSY FOUNDER

As many of us adapt to constant change under COVID-19, this historic season is especially hard for people with epilepsy. How we live, how we work, how we socialize, and how we view the future has been forever changed. And the medical community has had to make significant shifts in how it offers care to all patients, including those with chronic conditions.

Recognizing our community’s need for additional support, CURE Epilepsy has developed a COVID-19 and Epilepsy online resource hub for patients and caregivers. This hub is a one-stop destination for answers about how the virus impacts those living with epilepsy.

## FEATURED RESOURCES

### FREQUENTLY ASKED QUESTIONS

with information about any increased risks for epilepsy patients and continuing medical care during COVID-19

### LIVE STREAMS WITH MEDICAL PROFESSIONALS

about how COVID-19 may impact individuals with epilepsy

### PODCASTS

on parenting a special needs child during a pandemic and living with tuberous sclerosis complex (TSC) during COVID-19

### A GUIDE TO VIRTUAL HEALTHCARE VISITS

as many providers moved to telehealth appointments to minimize patient exposure

### STATEMENTS FROM OUR CEO AND OUR FOUNDER

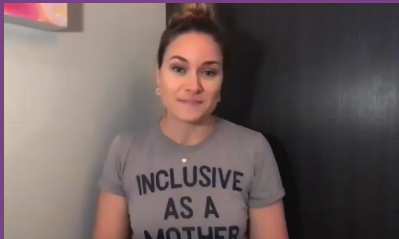
about CURE Epilepsy’s continued commitment to our mission, despite the challenges presented by the pandemic

# WHAT WE KNOW ABOUT EPILEPSY AND COVID-19

- Individuals with epilepsy who don't have additional health issues are not at a greater risk of contracting COVID-19 compared with the general population.
- People with epilepsy are considered high-risk if they also have diseases restricting mobility, respiratory conditions, diabetes mellitus, hypertension, severe heart disease, or impaired immune function.
- Patients on immunosuppressive therapies, such as ACTH (Acthar®), steroids, and CellCept®, are also at an increased risk.
- Researchers have stated that, when infected, people with epilepsy may experience altered seizure frequency associated with fever or more severe seizures.

**FOR MORE INFORMATION**  
explore CURE Epilepsy's  
COVID-19 Resource Hub  
at [CUREepilepsy.org/  
for-patients](https://CUREepilepsy.org/for-patients).

## HONORING THE PATIENT EXPERIENCE: *SEIZING LIFE*® PODCAST TALKS EPILEPSY IN THE EVERYDAY



Hosted by CURE Epilepsy board member Kelly Cervantes, our *Seizing Life* podcast and videocast offers insights and gives hope as we search for a cure. Honesty and transparency are core values for *Seizing Life*, even when that means tackling tough issues. As our country continues to grapple with issues of race and inequality, we dedicated a podcast to looking at how these issues intersect with Black families living with epilepsy.

In episode 45, Kelly speaks with mother and advocate Sherri Brady. At 3 years old, her daughter Lauren was diagnosed with Rett syndrome. For the past 20 years, Sherri has been her daughter's healthcare champion, navigating Lauren's care in a system that has implicit bias.

“ As the parent of a child with a disability that happens to also be Black, the challenges we face are multiplied. I've seen and must be constantly mindful of the statistics showing the health disparities due to race to ensure that Lauren gets the care she needs – because not receiving a treatment or necessary medication could very well be life or death for her.”

SHERRI, LAUREN'S MOM

Check out the full series at  
[CUREepilepsy.org/seizing-life](https://CUREepilepsy.org/seizing-life)

# WEBINARS TO WATCH:

## CURE EPILEPSY PRESENTS THE LEADERS IN EPILEPSY RESEARCH WEBINAR SERIES

Our webinar series showcases epilepsy experts discussing cutting-edge research and discoveries, and the most advanced treatments. Available on our website, these free webinars are designed for the epilepsy community at large to make scientific discoveries more tangible.



### TRANSFORMING DATA INTO SEIZURE CONTROL WITH LEARNING HEALTHCARE SYSTEMS

DR. ZACH GRINSPAN  
WEILL CORNELL MEDICINE

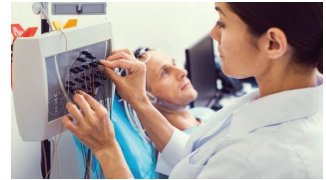
Learning healthcare systems is a method of improving clinical outcomes by collecting and analyzing anonymized electronic health data. Highly collaborative, this approach brings together patients, caregivers, doctors and researchers to globally improve care by changing medical practices. In this webinar, the Pediatric Epilepsy Learning Healthcare System's leading researcher, Dr. Zach Grinspan, discusses its progress and potential impact.



### THE EPILEPSY-AUTISM CONNECTION: RESEARCH, DIAGNOSIS, AND TREATMENT

DR. JAMIE CAPAL  
CINCINNATI CHILDREN'S  
HOSPITAL MEDICAL CENTER

It is estimated that more than 30% of people with epilepsy also meet the diagnostic criteria for autism.<sup>1</sup> This webinar features physician and autism expert Dr. Jamie Capal as she discusses the leading theories on the connection between autism and epilepsy. She also reviews the most common seizure types in people with autism and what current research reveals as to why so many children with autism develop epilepsy.



### THE ABCS OF EEGS: AN EVOLVING TOOL FOR EPILEPSY DIAGNOSIS

DR. DAVID BURDETTE  
SPECTRUM HEALTH  
MEDICAL GROUP

An electroencephalogram – better known as an EEG – is a test that records electrical brain patterns from the scalp. Critical for the diagnosis of many neurological conditions, EEG technology continues to advance, benefiting the epilepsy community with more accurate results. This webinar, led by Dr. David Burdette, discusses these benefits and highlights the role EEG and other neuroimaging tools play in the future of epilepsy diagnosis and seizure localization.

<sup>1</sup> Spence, S., Schneider, M. The Role of Epilepsy and Epileptiform EEGs in Autism Spectrum Disorders. *Pediatr Res* 65, 599–606 (2009). <https://doi.org/10.1203/PDR.0b013e31819e7168>.



REGISTER FOR OUR  
LIVE WEBINARS AT  
[CUREepilepsy.org/webinars](https://www.cureepilepsy.org/webinars)

### COMING THIS FALL

#### BREATHING AND SUDEP: RESEARCH & THE INFLUENCE OF SEIZURES ON THE RESPIRATORY SYSTEM

Revealing how respiratory health impacts seizure severity and what this means in the time of COVID-19

#### DISPARITIES IN EPILEPSY: OVERCOMING BARRIERS TO IMPROVE CARE AND TREATMENT OUTCOMES

Exploring how your education, occupation, income, and where you live impacts your access to accurate diagnosis and quality care



# SUPPORTING THE NEXT GENERATION OF ADVOCATES

CURE Epilepsy's Education Enrichment Fund Scholarship supports students living with epilepsy, their family members, or caregivers as they pursue their education. With funding from 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. This year's class of scholars aspire to many noble professions, but most importantly, they are all aspiring advocates.



**LOGAN DREW**  
THOMAS MORE UNIVERSITY

A committed soccer player, Logan feared that his epilepsy diagnosis in high school would halt his soccer career. Working with a psychologist allowed him to accept his diagnosis and see himself as a role model for other young athletes – all while continuing to play soccer and making captain of his team. This mental health work, plus a passion for helping others, drew Logan to study psychology. He hopes to use his psychology degree to serve not only epilepsy patients, but anyone who feels like a medical condition is holding them back from living a full life.

“ My current studies in engineering and future ambitions to go to medical school will equip me with a unique perspective and the right tools to understand epilepsy, develop better devices for patients, and ultimately treatments to improve patient outcomes.”

NATHAN BLISS



**NATHAN BLISS**  
TEXAS A&M UNIVERSITY

Nathan's older brother, Charles, lives with autism, a rare genetic disorder, and daily seizures caused by Lennox-Gastaut syndrome. Caring for Charles, and being involved with his team of specialists, ignited Nathan's interest in medicine. Nathan is studying to become a physician-researcher, with the goal of turning scientific discoveries into treatments that work for patients.



**CALISTA DAWN HALL**  
WHITWORTH UNIVERSITY

Growing up with absence seizures and bone weakness, Calista experienced many challenges. Now seizure-free due to an antiseizure medication, she sees these hardships as a blessing that helped her find her calling: pediatric medicine. Thanks to the excellent care she received at Seattle Children's Hospital, Calista is pursuing a health sciences degree and plans to work as a physician assistant, providing comfort and healing to pediatric patients and their families.



**KRISTEN HARRISON**  
VANDERBILT UNIVERSITY

Kristen is quick to say that epilepsy doesn't define her. Despite having daily absence seizures and facing discrimination because of her disability, Kristen graduated summa cum laude with her nursing degree. She is now pursuing graduate work to become a nurse practitioner to better the lives of children with epilepsy. In addition to her medical pursuits, Kristen volunteers at a summer camp for kids with epilepsy, where she encourages campers to dream big despite their diagnoses.



**MADISON LEE INTEMANN**  
UNIVERSITY OF GEORGIA

Madison's younger brother, Brady, was diagnosed with a condition that causes low energy levels and Lennox-Gastaut syndrome. Madison cares for Brady alongside her family, helping him with everyday functions and preparing formula for his G-tube feedings. Brady's condition sparked Madison's curiosity in biomedical research, even encouraging her to take career and technical education (CTE) courses in the biomedical field during high school. She plans to become a researcher, studying neurological conditions and driving science toward cures.

“ I hope to one day work in a state-of-the-art lab where I can study diseases and disorders, including epilepsy, with the intention of finding a cure.”

**MADISON LEE INTEMANN**



**GABRIELLA JOSEPH**  
COLUMBIA UNIVERSITY

Diagnosed at age 3, Gabriella takes seizure medications as part of her daily routine. She says she has an insider's perspective of living with a chronic condition – a perspective that she used to advance her career in neuroscience. After managing a genetic study and being named on two projects presented at a national conference, her interest shifted to how insurance policies can best accommodate chronically ill underprivileged populations. Gabriella is pursuing her master's degree in public health to improve healthcare access in the epilepsy community and beyond.

“ By expanding my specialized knowledge of how health policy affects epilepsy patients, I can research how to deliver quality healthcare at lower costs to them.”

**GABRIELLA JOSEPH**



**MARIA E. SHERIDAN**  
VANDERBILT UNIVERSITY

Maria is a competitive swimmer, but one who has to wear a pink swim cap, identifying her medical condition in case she has a seizure in the water. Her sister also lives with epilepsy, and Maria's family experienced firsthand the devastating toll healthcare expenses can take on a family's financial security. After studying sociology, global health, and markets and management at Duke University, Maria is now earning her master's degree in public health at Vanderbilt University in hopes of learning how to expand medical access for all.



**TREVOR PHILLIPS**  
KIRKWOOD COMMUNITY COLLEGE

In addition to living with seizures, Trevor struggles with anxiety and depression – mental health challenges all too familiar to epilepsy patients. But Trevor turned his negative experiences into learning opportunities for others, preparing and presenting an epilepsy training to student leaders at his high school. He also represented his home state of Iowa in Washington, D.C., sharing his epilepsy story in an effort to raise \$11.5 million in Centers for Disease Control and Prevention funding for epilepsy research and support programs. Trevor is attending college to become an electroneurodiagnostic technician, a career in which he will interact with and inspire other epilepsy patients.

“ Even though epilepsy has been a very difficult challenge for me and my family, it has shaped me into someone who wants to make a difference in the world.”

TREVOR PHILLIPS



**MADelyn ROSE SAMUEL**  
EAST TENNESSEE  
STATE UNIVERSITY

Straight-A student Madelyn experienced more than 15 tonic-clonic seizures her sophomore year of high school, forever changing her brain. After many months of tutoring, she regained what she had lost, now with her “new brain.” She’s using her experience to teach others about epilepsy, SUDEP, and seizure first aid. She’s also pursuing a rehabilitative health sciences degree with a neurology/neuroplasticity focus. Since there is no cure for epilepsy (yet!), it’s her goal to help rehabilitate others and give them hope of living in a new normal.

“ Epilepsy has made me realize I am a leader, I have a voice, I can handle anything that comes my way, and I should always look for the blessings.”

MADelyn ROSE SAMUEL

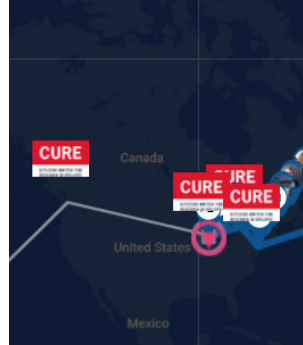
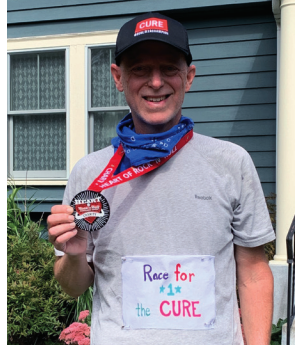


**LINDSAY ROSE SLEDGE**  
WESTERN NEW MEXICO UNIVERSITY

A single mom of three girls, two of whom have special needs, Lindsay personifies resilience. Her daughter Paloma’s treatment for Dravet syndrome includes medical cannabis oil, which her school would not allow her to use in the building. Lindsay responded by helping to create a law that would allow students who need this life-saving treatment to use it in school. The many social workers who have supported her along the way inspired Lindsay to pursue her master’s degree in social work.

“ Being a caretaker of a child with epilepsy is heartbreaking and the hardest thing I’ve ever done. I want to help other families who are walking this same path.”

LINDSAY ROSE SLEDGE



# COMING TOGETHER TO CURE EPILEPSY



## ELLA'S MILE

To understand someone, you're supposed to walk a mile in their shoes. Ella – a 10-year-old with severe epilepsy – challenges her community to walk that mile each year. Although Ella and her family walked alone this year because of social distancing, countless supporters and fans lined the sidewalk to cheer her on along the route.

**TOTAL RAISED - \$60,000**





## VIRTUAL SCAVENGER HUNT

After COVID-19 forced the cancellation of the Team CURE Epilepsy endurance races, CURE Epilepsy got creative, planning a virtual challenge to both engage and educate the epilepsy community. Each person or team aimed to reach 260,000 steps – honoring the 1 in 26 Americans who will develop epilepsy in their lifetime.

**55 PEOPLE PARTICIPATED**

**MORE THAN 14 MILLION  
STEPS LOGGED**

**\$12,000 RAISED  
TO CURE EPILEPSY**



## CURE EPILEPSY CHAMPION EVENTS

From distance-approved races and virtual runs to lemonade stands and even a horse show, our CURE Epilepsy Champions continue to use their passions to lead events that raise awareness and funds for epilepsy research.



CURE EPILEPSY IS RESEARCHING FOR...

# CHANNING



Channing's passion for horses began at 5 years old, but by age 9, she had traded her saddle for seizures. Diagnosed with juvenile myoclonic epilepsy, she was told it would be too difficult for her to ride again. She decided to fight, not only to ride again but to be an advocate for others with epilepsy. Now a CURE Epilepsy Champion, Channing hosts her annual "Dressage for a Cause" to benefit our organization.

Held each year at a world-class equine facility, this fundraiser is an exhibition that showcases artful horse riding. In 2019, the event raised nearly \$6,000, but Channing and her family fear that COVID-19 could impact their donations this year. Not one to back down from a challenge, Channing's mom started growing purple carrots in her garden with one goal in mind: to sell them for a cure! Donors can also sponsor purple carrots for the horses participating in the dressage show.

“

Hold on tight to what you love, and never let go of the reins. Don't let epilepsy win.”

CHANNING

# RESEARCHING TO CURE EPILEPSY

FALL 2020

## LEADING WITH PURPOSE

Innovation and determination take leadership, especially during a time of uncertainty. We would like to publicly thank our 2020 Board of Directors and Scientific Advisory Council members for their unwavering support and perseverance this year. Their leadership guides and strengthens our organization, advancing our mission until there is a cure.

### 2020 BOARD OF DIRECTORS

Stacey Pigott, *Board Chair*

Kelly Cervantes, *Chair-Elect*

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### 2020 SCIENTIFIC ADVISORY COUNCIL

Dr. James Cloyd

Dr. Kelly Knupp

Dr. Daniel Lowenstein

Dr. Eric Marsh

Dr. Manisha Patel

Dr. Vicky Whittemore

**IN UNCERTAIN TIMES, WE HOLD  
FAST TO WHAT WE KNOW –  
AND WE KNOW THERE'S A CURE  
FOR EPILEPSY.**

**Your partnership makes it possible for us to drive  
research forward and imagine a life without seizures.**

**Thank you for your support.**



[CUREEPILEPSY.ORG/DONATE/2020FALL](https://cureepilepsy.org/donate/2020fall)

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