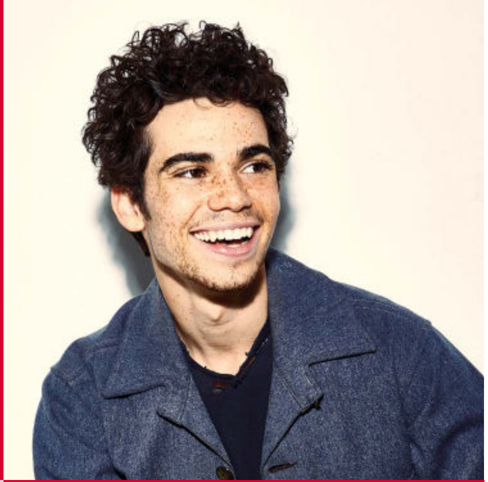
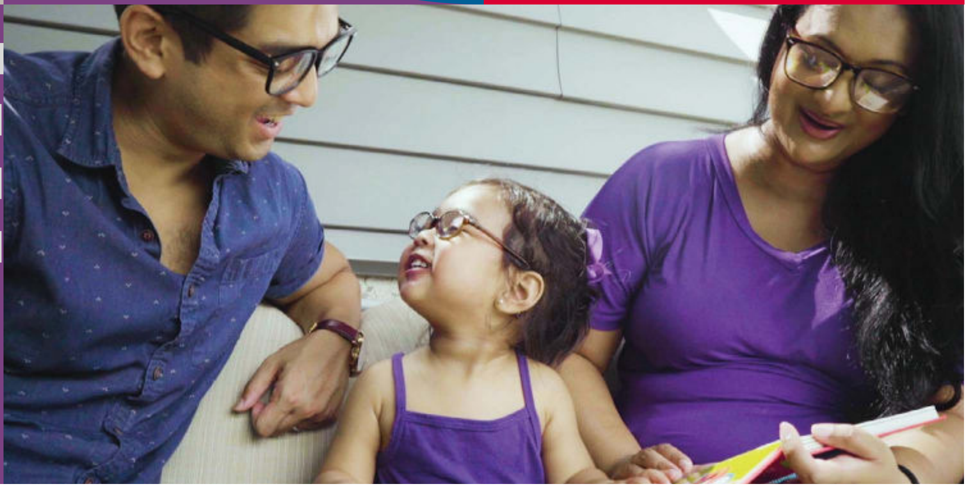
CURE EPILEPSY™

RESEARCHING TO CURE EPILEPSY

SPRING 2021





SCIENCE MATTERS AND RESEARCH SAVES LIVES.

We've experienced these truths through COVID-19, and we'll continue to pursue them within the epilepsy community until there is a cure.

BETH LEWIN DEAN
Chief Executive Officer
CURE Epilepsy

Even as we continue to battle this pandemic, I am grateful to see science at work, research that continues to make a difference, and vaccine discoveries to potentially end a global health crisis.

I have seen this same dedication in our epilepsy research community. Our incredible team of researchers continue to persevere through a pandemic, understanding that theirs is a mission that must not be stopped.

At CURE Epilepsy, we match this determination by remaining steadfast in our support of finding a cure. Recognizing that we are a critical source of funding for our community, we have continued fundraising and awarding grants to accelerate epilepsy research. And when other funding sources were cut because of COVID-19, we created our new Continuity Fund to fill financial gaps for epilepsy researchers.

As you explore this report, I hope you'll celebrate our community's progress in a pandemic. For many of us, life has felt on hold as we distance, quarantine, and limit our exposure, but we've proven that epilepsy research is a priority. We work every day for our loved ones who can't escape this devastating disease, giving them hope with each new discovery, clinical trial, and treatment.

To further increase the reach of our research, we are proud to announce a new strategic partner in the fight to end epilepsy. Founded in 1966, Epilepsy Canada shares in our commitment to advance epilepsy research to find a cure. By partnering together, we will have more opportunities to identify and fund cutting-edge research from around the world. We will also create efficiencies and strategically target our financial resources for greater impact.

In a challenging year, you showed us unwavering support, allowing us to continue leading critical research for the epilepsy community. Please know that the new discoveries, partnerships, grants, and opportunities we celebrate in this issue are possible because of you. Because we can count on you, our community can count on us to find a cure.

With continued gratitude,

Beth

Beth Lewin Dean
Chief Executive Officer, CURE Epilepsy

Our spring issue highlights our many donors, volunteers, and researchers who give generously and work tirelessly because they believe in a cure. One of these leaders is Stacey Pigott, 2020-2021 Chair of CURE Epilepsy's Board of Directors.

STACEY PIGOTT

CHAIR, CURE EPILEPSY BOARD OF DIRECTORS

> "We all know the total loss of control you have when you have a loved one with epilepsy. Having an outlet where you can make a difference helps to give you a little bit of control in an uncontrollable situation."
>
> STACEY PIGOTT

Stacey is a committed CURE Epilepsy volunteer, having served in various roles for more than 10 years with the organization. She is currently Chair of the CURE Epilepsy Board of Directors. In addition to her leadership positions, Stacey co-founded "Rock the Block for Pediatric Epilepsy Research" with former CURE Epilepsy board member Kathy Dodd and has successfully hosted personal fundraisers to help sponsor five CURE Epilepsy Pediatric Awards for research.

Stacey and her husband John are inspired by their son Evan who was diagnosed with electrical status epilepticus in sleep (ESES) when he was 4 years old. As Evan matured he outgrew his epilepsy and now lives seizure-free. Even though Evan no longer experiences seizures, his family - including brother Henry and sister Ava - remains committed to finding a cure. Stacey's commitment to finding a cure has only grown stronger and more urgent as her father has recently been diagnosed with temporal lobe epilepsy, one of many older adults newly diagnosed with epilepsy in the U.S. each year.

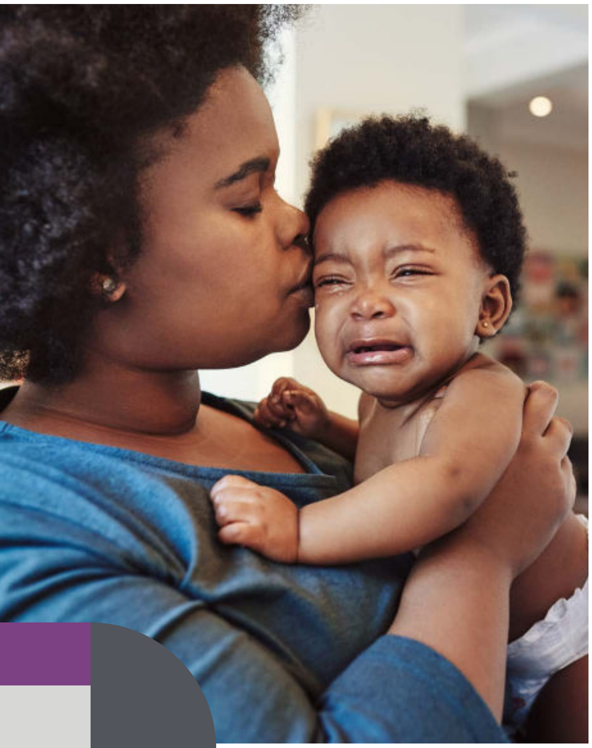
NEW APPROACH, NEW BREAKTHROUGHS

INITIATIVE ACCELERATES INFANTILE SPASMS RESEARCH

Often called little seizures with big consequences, infantile spasms (IS) are subtle seizures that occur in a baby's first year of life - a time when brain development is most critical. The neurological effects of IS can be severe, often causing cognitive and developmental delays.

Because these spasms do not look like traditional seizures, primary care physicians and pediatricians can find it challenging to diagnose IS. This often means that effective treatment for affected children is delayed, which can have dire consequences. And for those that are diagnosed accurately, many do not respond to treatment or have adverse side effects.

UNDERSTANDING INFANTILE SPASMS



AFFECTS
1 IN 2,000
CHILDREN[1,2]

DISCOVERED NEARLY
200 YEARS AGO
BY DR. WILLIAM JAMES WEST

TYPICALLY BEGINS BETWEEN
2 TO 12 MONTHS
OLD AND PEAKS AROUND
4 TO 8 MONTHS OLD[3]

ALSO KNOWN AS
WEST SYNDROME

NOT WELL-UNDERSTOOD
AND TREATMENT IS OFTEN
INEFFECTIVE

SEIZURES ARE
SUBTLE,
OFTEN RESEMBLING A JERK,
REFLEX, OR HEAD BOB

KNOW THE SIGNS

View this video to understand what signs to look for in a baby experiencing infantile spasms.

CUREepilepsy.org/infantile-spasms-video

---

[1] Riikonen R. Epidemiological data of West syndrome in Finland. Brain Dev. 2001; 23: 539– 541.

[2] Ludvigsson P, Ólafsson E, Sigurðardóttir S, et al. Epidemiologic features of infantile spasms in Iceland. Epilepsia. 1994; 35: 802– 805.

[3] Hrachovy R. West's syndrome (infantile spasm). Clinical description and diagnosis. Adv Exp Med Biol. 2002;497:33–50.

INFANTILE SPASMS: A MEDICAL EMERGENCY

- Early diagnosis and treatment is critical.
- Many primary care doctors and parents are not familiar with IS signs and symptoms.
- Current standard treatment is a hormone (ACTH, prednisone) or anti-seizure medication (vigabatrin).
- Not all children with IS will respond to treatment. There is no reliable way of predicting who will respond favorably.

TEAMING UP FOR INFANTILE SPASMS RESEARCH

With $4 million in funding, CURE Epilepsy launched the Infantile Spasms Initiative in 2013 as the first team science approach in the epilepsy research community. The initiative brought together eight researchers from different institutions to work as a team and study the pathology of infantile spasms.

WHAT IS TEAM SCIENCE?

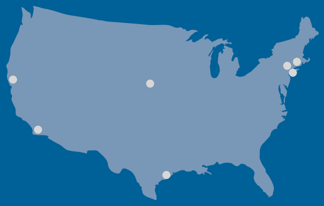
Team science is a research approach that involves a multidisciplinary, multi-scientist team working together to accelerate the research process.

Operating in different labs, these scientists share data, preliminary research findings, and learnings in real time.

Scientists are encouraged to collaborate, rather than isolate.

Key benefits include the rapid dissemination of results among teams, cross-fertilization of ideas between basic research scientists and clinicians, and mentoring of junior researchers.

Confronting IS was a daunting assignment. The mechanisms of the disorder are not understood, and research to find an effective treatment has been slow. That's where the IS Initiative filled a significant research gap. Collectively, the IS research team studied the basic biology of IS, searched for biomarkers and drug targets, and tested potential treatments.



MEET OUR INFANTILE SPASMS TEAM

CHRIS DULLA, PHD
Tufts University

ARISTEA GALANOPOULOU, MD, PHD
Albert Einstein College of Medicine

JEFF NOEBELS, MD, PHD
Baylor College of Medicine

DOUG NORDLI, MD
University of Chicago (formerly at Children's Hospital of Los Angeles)

MANISHA PATEL, PHD
University of Colorado Denver

ELLIOTT SHERR, MD, PHD
University of California San Francisco

JOHN SWANN, PHD
Baylor College of Medicine

LIBOR VELISEK, MD, PHD
New York Medical College

TUNE INTO OUR SEIZING LIFE® PODCAST on identifying and responding to infantile spasms – our most-viewed episode ever.

CUREepilepsy.org/seizinglife

WORKING TOGETHER TO CURE INFANTILE SPASMS

One of the CURE Epilepsy IS Initiative's research groups, led by Dr. John Swann at the Baylor College of Medicine, focused its efforts on discovering novel drug targets and better treatment strategies to stop the spasms and the associated developmental delays.

The team identified that treatment with (1-3) IGF-1, a derivative of the growth hormone insulin-like growth factor 1 (IGF-1), reduced the spasms and irregular brain wave pattern in an animal model. Adding this compound to vigabatrin, an FDA-approved IS treatment, reduced the dose of vigabatrin required to eliminate the spasms. Diminishing the dosage also decreased the risk of serious side effects, including the potential for irreversible peripheral vision loss.

The Swann lab patented this combination treatment and used the discovery to obtain two National Institutes of Health (NIH) grants. One of these grants, totaling approximately $350,000 over five years, will investigate the molecular basis for the combination therapy. Through the second grant, the team will work to establish a specific IS rodent model for identifying more effective, less toxic therapies.

Through work partially funded by CURE Epilepsy's IS Initiative, Dr. Swann's team also identified the specific cell type and its location (the frontal lobe of the brain) where severe epileptic spasms often begin, revealing that brain activity immediately before epileptic spasms closely resembles a phase of the sleep cycle. These discoveries highlight potential avenues to prevent these spasms from occurring in future patients.

KEY IMPACTS FROM THE INFANTILE SPASMS INITIATIVE:

DISCOVERED A POTENTIAL TREATMENT AND ACQUIRED A PATENT

to reduce spasms and decrease side effects

IDENTIFIED THE CELL TYPE

and location where severe spasms start

REVEALED THAT BRAIN ACTIVITY

prior to spasms resembles a sleep cycle phase

PUBLISHED 19 PAPERS

as a team to share new knowledge with other researchers in the field

SECURED 3 NIH GRANTS

as a team, with more than $4.4 million in total expected funding

RAISING AWARENESS TO STOP INFANTILE SPASMS

CURE Epilepsy is a proud member of the Infantile Spasms Action Network – a collaborative network of organizations raising awareness around IS.

SHAPING THE FUTURE OF RESEARCH ACROSS THE EPILEPSIES

Today, CURE Epilepsy's IS Initiative continues to impact the larger epilepsy community. The IS Initiative marked the beginning of CURE Epilepsy's team science approach – a groundbreaking method that we now use to accelerate research in other focus areas.

In fact, this approach was key to receiving a $10 million grant from the Department of Defense to launch the CURE Epilepsy Post-Traumatic Epilepsy (PTE) Initiative. With this funding and through a team science approach, we will improve methods of studying PTE, develop biomarkers, and understand predictive risk factors. This research will lay the groundwork for the creation of novel therapies to prevent the development of PTE.

> "CURE Epilepsy is a beacon in the epilepsy research community. [They] are very innovative in that they rely on scientists and patients to decide where they invest their money. And that agility and ability to adapt to the biggest, most exciting opportunity is what really makes them different."
>
> CHRIS DULLA, PHD, ASSOCIATE PROFESSOR OF NEUROSCIENCE AT TUFTS UNIVERSITY AND A RESEARCHER FOR THE IS INITIATIVE

CURE EPILEPSY IS RESEARCHING FOR

Hadley

Hadley was a miracle baby from the start. Born three months before her due date, she spent 91 days in the newborn intensive care unit fighting to go home to her loving family.

At 5 months old, Hadley began another fight. After feeding Hadley a bottle, her mom Erin watched as she repeatedly rolled her eyes back, threw her hands in the air, and cried. Suspecting a seizure, Erin filmed the episode and showed it to her pediatrician who immediately referred her to Nationwide Children's Hospital's emergency department where Hadley was diagnosed with IS during an EEG.

Every time Hadley has a spasm, she experiences brain damage, critically affecting her development. Now almost 3 years old, she cannot stand independently, walk, or talk.

In 2020, Hadley had brain surgery. While the surgery did not cure Hadley of epilepsy, it did give back her smile, laugh, and skills she had lost. It also gave her family hope that she can work toward bigger developmental goals.

> "I don't know why this happened to Hadley and to our family. And, I don't know when this will end, if ever, but I do know we have to keep fighting for Hadley and for her future."
>
> ERIN, HADLEY'S MOM

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

Announcing Our New CURE Epilepsy Research Grantees

True to our mission to end epilepsy, we are the only U.S. nonprofit laser-focused on funding research to find a cure for epilepsy. Even during uncertain times, we are a constant support for the epilepsy research community. Learn more about the research funded by CURE Epilepsy and the hope it offers to those who need it most.

MECHANISMS OF EPILEPSY

MARK BENNETT, PHD

THE WALTER AND ELIZA HALL INSTITUTE OF MEDICAL RESEARCH, AUSTRALIA

TAKING FLIGHT AWARD

REALITY

Genetic factors can impact a person's risk of developing epilepsy.

DISCOVERY

"Repeat expansions" are genetic changes that occur when repeated segments of DNA are copied many times, in error, within the DNA sequence. Research has linked these expansions to neurological disorders, including epilepsy.

OPPORTUNITY

Dr. Bennett will analyze data from one of the largest genetic studies of epilepsy and aim to discover repeat expansions linked with epilepsy. This research will provide new insights into the genetic causes of epilepsy, which he hopes will lead to better treatment options.

CURE EPILEPSY GRANTS

TAKING FLIGHT AWARD

Promotes the careers of young epilepsy researchers, allowing them to develop a research focus independent of their mentor; grant is up to $100,000 for 1 year

CURE EPILEPSY AWARD

Provides up to $250,000 over 2 years for researchers focused on the basic mechanisms of epilepsy, acquired epilepsies, pediatric epilepsies, SUDEP, treatment-resistant epilepsies and sleep and epilepsy

CATALYST AWARD

Accelerates research by helping transition basic research findings to curative therapies; awards up to $250,000 over 2 years

RANMAL SAMARASINGHE, MD, PHD

UNIVERSITY OF CALIFORNIA
LOS ANGELES

TAKING FLIGHT AWARD

REALITY

Researchers can develop and utilize human brain organoids - 3D brain-like structures made from human cells - to enhance our understanding and treatment of epilepsy.

DISCOVERY

Dr. Samarasinghe previously made brain organoids from the cells of patients with severe epilepsy because of a mutation in the SCN8A gene. He developed these organoids to model different regions of the human brain and observed unique patterns of neuronal activity.

OPPORTUNITY

Building off of his previous research, Dr. Samarasinghe will work to uncover the cellular changes that account for these differences in neuronal activity and will use the organoids as a model to test anti-seizure medications.

CURE EPILEPSY IS RESEARCHING FOR

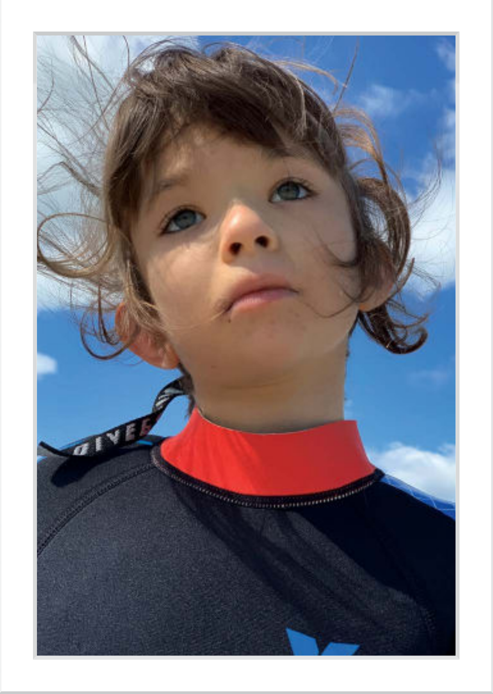
Esmé

From birth, Esmé's parents knew her life would not be typical. Born limp and not breathing well, she experienced cardiac and respiratory arrest at just 3 months old.

By 8 months old, she had what her family suspects was her first seizure. With "normal" EEG tests, many doctors dismissed an epilepsy diagnosis, until one physician discovered that her seizures were so deep in her brain that even EEGs could not detect them. Her diagnosis now includes gene mutations PCDH19, SCN8A (referenced in Dr. Samarasinghe's research overview above), TBL1XR1, and MAP3K7.

Almost one and a half years after Esmé's first seizure she was diagnosed with PCDH19, a rare epilepsy syndrome. Esmé is a medical mystery, complicated by the likelihood of additional syndromes, but she is also cheerful, determined, and a joy to her family.

> **"I never stop thinking about the many things that could steal her from me — a seizure, a respiratory illness, a drug reaction, a medical mistake. Esmé cannot outrun these risks, even if I carry her."**
>
> HILLARY SAVOIE, ESMÉ'S MOM



MECHANISMS OF EPILEPSY

Read Cameron Boyce's story on pg. 16 and why his family is committed to a cure.

Photo courtesy of Ben Cope

CRISTINA RESCHKE, PHD

RCSI UNIVERSITY OF MEDICINE
AND HEALTH SCIENCES

CURE EPILEPSY'S CAMERON BOYCE TAKING FLIGHT AWARD

REALITY

The body, including its development and everyday functions, often follows 24-hour cycles called circadian rhythms. Currently, it is unknown if genetic mechanisms that control the body's natural rhythms affect how the brain develops epilepsy.

DISCOVERY

There is increasing evidence that seizures in some people occur in predictable patterns potentially related to circadian rhythms.

OPPORTUNITY

In this project generously funded by The Cameron Boyce Foundation, Dr. Reschke will study how disruption of circadian rhythms could affect gene expression during epileptogenesis. She will also develop a gene therapy approach to restore proper function of a central gene involved in regulating circadian rhythms.

Finally, Dr. Reschke will explore whether "adjusting the clocks" represents a potential approach for disease modification by testing the gene therapy in mice with drug-resistant epilepsy. Together, these findings will explore an important potential mechanism influencing epilepsy development.

SUDDEN UNEXPECTED DEATH IN EPILEPSY (SUDEP)

CHRISTINA GROSS, PHD

CINCINNATI CHILDREN'S HOSPITAL

CURE EPILEPSY AWARD

STEVEN CRONE, PHD

CINCINNATI CHILDREN'S HOSPITAL

CURE EPILEPSY AWARD

REALITY

SUDEP affects 1 in 1,000 people with epilepsy each year, but the causes are not fully understood.

DISCOVERY

Leading SUDEP research points to breathing abnormalities as a potential cause of death.

OPPORTUNITY

Dr. Gross and Dr. Crone will use mouse models to test if alterations in a specific genetic pathway in cells, called the PI3K/mTOR pathway, lead to breathing abnormalities and ultimately SUDEP. They will also test whether blocking this pathway with a specific inhibitor reduces SUDEP risk factors. The PI3K/mTOR pathway is often altered in epilepsy, so studying this in relation to SUDEP could be the first step toward a novel treatment.

NURIA LACUEY-LECUMBERRI, MD, PHD

MCGOVERN MEDICAL SCHOOL,
THE UNIVERSITY OF TEXAS HEALTH SCIENCE CENTER AT HOUSTON

CURE EPILEPSY AWARD

REALITY

There are currently no technologies or devices available for directly preventing death in patients at high risk for SUDEP.

DISCOVERY

SUDEP usually occurs in patients with frequent convulsive seizures because of seizure-induced breathing failure.

OPPORTUNITY

The goal of Dr. Lacuey-Lecumberri's project is to improve the overall understanding of breathing control by identifying those brain areas most important for breathing function. After identifying these areas, Dr. Lacuey-Lecumberri will work to develop neurostimulation techniques that can be used to prevent seizure-induced breathing failure. She hopes to pave the way for the creation of deep brain stimulation devices for breathing rescue as a targeted SUDEP prevention strategy.

IAN WENKER, PHD

UNIVERSITY OF VIRGINIA

TAKING FLIGHT AWARD

REALITY

There is increasing evidence that respiratory arrest is the primary cause of death for many cases of SUDEP.

DISCOVERY

In a novel mouse model of SUDEP, Dr. Wenker found that death due to respiratory arrest often occurs during the tonic phase of seizures.

OPPORTUNITY

Dr. Wenker hypothesizes that breathing recovery is possible once tonic activity subsides. During his study, he will activate specific neuronal populations of the brainstem to recover breathing. This research will provide insight into how the brain's control of breathing is altered during seizures, in the hope of identifying therapeutic targets for SUDEP.

CURE EPILEPSY IS RESEARCHING FOR

Alexander

Alexander's fiancée was the first to notice his seizures. A Class A truck driver, he came home one day unaware of his surroundings and not making sense. His doctor assumed exhaustion and prescribed time off of work.

Alexander went back to work, only to have his symptoms reoccur. After a 48-hour EEG, he was diagnosed with epilepsy at 26 years old – one day before his wedding.

With his wife's support, he was determined to regain his health. He made major lifestyle changes, including adopting the ketogenic diet, regular exercise, and healthy sleep habits.

Although he still struggles with epilepsy, his seizures are less frequent and smaller. He did have a major seizure the day of his daughter's birth, but he continues to diligently manage his health for both himself and his family.

> "I have not given up hope that they will find a cure for epilepsy. I want you to know that because you have epilepsy, your life is not over. You can have a normal life, and you are not alone in this."
>
> ALEXANDER

TREATMENT-RESISTANT EPILEPSY

JAMES O. McNAMARA, MD

DUKE UNIVERSITY

CATALYST AWARD

REALITY

Temporal Lobe Epilepsy (TLE) is a common form of epilepsy, with approximately 35% of patients having recurrent seizures despite treatment.

DISCOVERY

Dr. McNamara and other researchers previously discovered that proteins in the brain called BDNF and TrkB play an important role in the development of TLE in animal models. Dr. McNamara's team also found that BDNF/TrkB can cause epileptogenesis (the process of developing epilepsy in the brain) through activation of another protein called PLCgamma1. This led to their discovery of a novel peptide, pY816, which blocks the activation of PLCgamma1 and prevents epileptogenesis in animal models.

OPPORTUNITY

The goal of Dr. McNamara's translational research project is to conduct key studies to advance pY816 to human clinical trials, ultimately developing a novel therapy for drug-resistant TLE. Specifically, the team will determine how to reliably detect pY816 in the blood of treated animals and the best dose which causes minimal toxicity in the animals.

EDILBERTO AMORIM DE CERQUEIRA, MD

UNIVERSITY OF CALIFORNIA SAN FRANCISCO

TAKING FLIGHT AWARD

REALITY

For patients with acquired epilepsy, it's still unpredictable as to who will benefit from early medication and which treatments are most effective.

DISCOVERY

Acute brain injury from trauma, stroke, or a lack of brain oxygenation are among the most common causes of acquired epilepsy in adults and children worldwide.

OPPORTUNITY

Dr. Amorim's research uses non-invasive brain monitoring with EEG to predict, prevent, and treat seizures in critically ill patients. He is designing algorithms that can determine seizure risk after acute brain injury, as well as measure the individual's response to antiepileptic drugs. Dr. Amorim hopes that this data-driven approach to seizure physiology will lead the way to personalized treatments to prevent epilepsy development after acute brain injury.

CURE EPILEPSY IS RESEARCHING FOR

Stephen

Stephen had his first seizure when he was 2 years old, a result of brain inflammation from a case of German measles. His diagnosis was absence epilepsy, which contributed to challenges at school. After seeing a neurologist, Stephen improved with treatment, becoming a straight-A student.

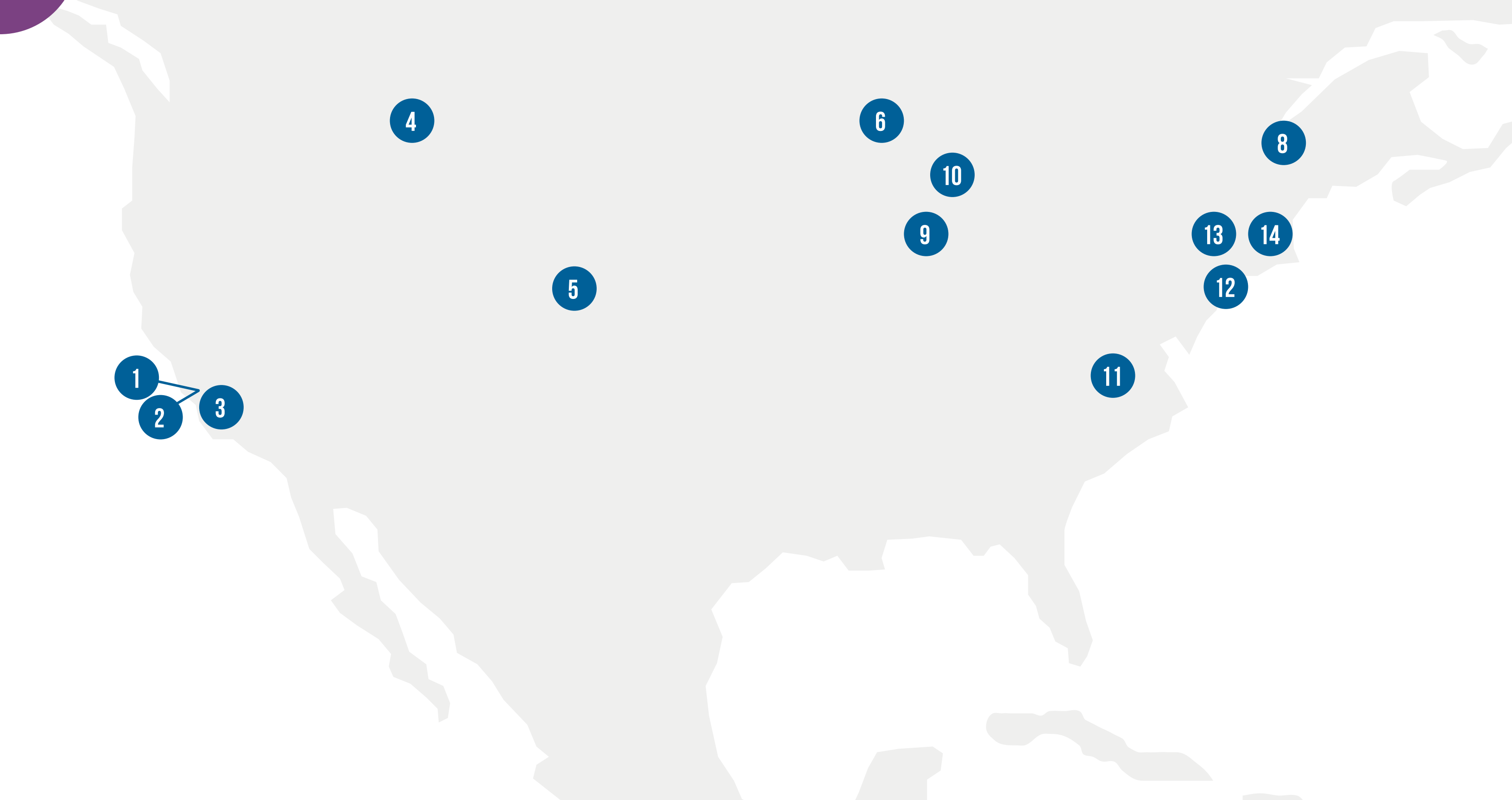
However, in his teen years, Stephen suffered a traumatic brain injury and started having tonic-clonic seizures. After many falls, injuries, and hospital stays, he finally gained seizure control.

With his health more stabilized, he studied the culinary arts and hospitality in college, while also serving as the president of the Students with Disabilities Club.

Stephen now uses his baking skills to raise donations and awareness for the epilepsy community. He created the Stephen Piorkowski Scholarship for Epilepsy to give college financial assistance to those affected by epilepsy.

RESPONDING TO RESEARCH NEEDS

CURE EPILEPSY CREATES CONTINUITY FUND FOR RESEARCH IMPACTED BY THE PANDEMIC



1

ADAM NUMIS, MD

UNIVERSITY OF CALIFORNIA SAN FRANCISCO

Evaluating the Role of Inflammation in Neonatal Epileptogenesis

2

LAKSHMI SUBRAMANIAN, PHD

UNIVERSITY OF CALIFORNIA SAN FRANCISCO

Transcriptomic Diversity of Cell Types in Cortical Malformations

3

JULIET KNOWLES, MD, PHD

STANFORD UNIVERSITY

Abnormal Myelin in Absence Epilepsy: Cause and Functional Impact

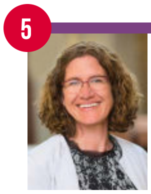
4

BRAXTON NORWOOD, PHD

EXPESICOR NEUROSCIENCE RESEARCH

Modeling Drug-Refractory Epilepsy with the KaL Method

5



HEIDI GRABENSTATTER, PHD

UNIVERSITY OF COLORADO BOULDER

AMPK and Cardiac Dysfunction in Chronic Epilepsy: A Prognostic Indicator of SUDEP Risk

6

BRUCE HERMANN, PHD

UNIVERSITY OF WISCONSIN-MADISON

Brain Aging in Persons with Childhood Onset Epilepsy: A Population Based Investigation II

FAMILY'S GENEROSITY PROTECTS THE PROGRESS OF EPILEPSY RESEARCH

Since the start of the pandemic, epilepsy researchers have faced unanticipated challenges that have threatened the progress of their research. Recognizing these needs early on, our nimble organizational model and generous donors allowed us to act quickly. In partnership with the Cotton family, and in memory of Vivian Cotton, we launched the CURE Epilepsy Research Continuity Fund to support critical research projects impacted by COVID-19.

The CURE Epilepsy Research Continuity Fund provided grants of up to $15,000 to each researcher to cover unexpected costs from the pandemic. These extra expenses could include rebuilding reagents for interrupted experiments, additional salaries to cover employee time, increased costs to comply with COVID-19 health and safety requirements, and funding cuts.

Launched in the fall of 2020, the fund has already benefited 14 research projects, allowing the continuation of vital epilepsy research around the world.

7

JUAN ENCINAS, PHD

ACHUCARRO BASQUE CENTER FOR NEUROSCIENCE

Reactive Neurogenesis and Gliosis in a Model of Generalized Infant Epilepsy

7

8

AMANDA HERNAN, PHD

UNIVERSITY OF VERMONT STATE AND AGRICULTURAL COLLEGE

Mechanisms for Improving Cognitive Outcome in Pediatric Epilepsy with ACTH

9

CATHERINE CHRISTIAN-HINMAN, PHD

UNIVERSITY OF ILLINOIS AT URBANA-CHAMPAIGN

Neural and Pituitary Mechanisms Linking Epilepsy to Co-Morbid Reproductive Endocrine Dysfunction

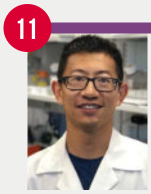
10

JEFF LOEB, MD, PHD

UNIVERSITY OF ILLINOIS CHICAGO

Targeting Epileptogenic Effects of Subarachnoid Blood in TBI

11

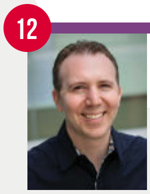


BIN GU, PHD

UNIVERSITY OF NORTH CAROLINA AT CHAPEL HILL

Identification of Pathophysiological and Genetic Mechanisms of SUDEP Using an Innovative Genetic Reference Population of Collaborative Cross Mice

12



TRISTAN SHUMAN, PHD

ICAHN SCHOOL OF MEDICINE AT MOUNT SINAI

Closed-Loop Resynchronization of Epileptic Circuits

13

JASON GERRARD, MD, PHD

YALE UNIVERSITY

Neuromodulation to Restore Conscious Decision-Making During Seizures

14

CHRIS DULLA, PHD

TUFTS UNIVERSITY

Predicting Post-Traumatic Epilepsy Using Transparent, Stretchable Multielectrode Arrays and Simultaneous Glutamate Imaging

Photo courtesy of Storm Santos

THE BOYCES BELIEVE IN A WORLD WITHOUT EPILEPSY

They shared their son with the world. Now they're sharing his legacy.

Cameron Boyce started acting as a child, scoring significant roles in everything from music videos and films to a Disney Channel series. A beloved actor, his death – confirmed as Sudden Unexpected Death in Epilepsy (SUDEP) – shocked his family, friends, and fans. The world continues to mourn his talent and the kindness and personality he showed on-screen and in person.

Today, Cameron's parents, Libby and Victor, continue the humanitarian efforts he started as a young actor with a powerful voice. Through The Cameron Boyce Foundation, the Boyces are committed to ending SUDEP by raising awareness and funding research. Learn why they've chosen to partner with CURE Epilepsy to drive research forward.

You've often said that Cameron didn't let epilepsy define his life. Did you or Cameron know about SUDEP and the impact it could have on the life of anyone with epilepsy?

VICTOR: The short answer is no. The first time I heard SUDEP mentioned was when the coroner told me that it caused Cameron's passing. We were completely blindsided.

LIBBY: When we were told he passed away, we immediately knew it was a seizure. We had worried that he might choke in his sleep or fall out of the bed and hit his head, but we had no clue about SUDEP.

How do you raise awareness about SUDEP without instilling fear in those living with epilepsy?

LIBBY: When Cameron was diagnosed, we were given no tools on how to manage epilepsy. Now, we believe it is a physician's responsibility to give someone resources to understand what the disease is and what lifestyle changes need to be made. We don't believe that doctors need to be fatalistic, but they have an obligation to communicate how serious the disease is to reduce certain risks.

The Cameron Boyce Foundation supports a number of worthy causes, including curing epilepsy. Why did you choose to partner with CURE Epilepsy?

LIBBY: We decided to form a foundation within hours of Cameron's passing, and we knew epilepsy would be a focus area. We didn't know the world of epilepsy, and a mutual friend connected us to [CURE Epilepsy founder] Susan Axelrod. As we got to know CURE Epilepsy, we recognized the organization as a leader in epilepsy research, truly at the forefront of finding a cure.

What breakthroughs do you believe are possible in epilepsy research?

LIBBY: We believe a cure is possible, and we want to make sure more attention is paid to the disease. It's the most common neurological disease that we talk about the least. Why? What is the stigma about? By accelerating research, we can get people closer to living normal lives without worrying about dying from a seizure.

Your foundation is funding CURE Epilepsy's Cameron Boyce Taking Flight Award, supporting the research of Dr. Cristina Reschke. What do you think of the work so far?

LIBBY: Dr. Reschke's work studies a body's natural rhythms as a potential connection to seizure patterns. When we heard this, that word – rhythm – jumped out because it really complemented Cameron's essence. He used rhythm to memorize lines and to perform as a dancer.

We also appreciate that Dr. Reschke is a young, female researcher who is known for over-delivering. Even as a child, she was innovative, creative, and pursued her dreams. Cameron would have loved her for it.

Our epilepsy community understands the pain of lives cut short. What would you say to those who have lost loved ones to this devastating disease?

VICTOR: Everyone's situation is different, and everyone's grief is different. Cameron's memory is a blessing – I try to focus on the positive moments I had with my son, not what was taken away.

We're not immune from tragedy. If it can happen to us, it can happen to anyone. But, we don't want SUDEP to impact another family, especially when a cure is possible. We're making our voice heard through the platform we have, and we believe everyone has a platform that they can use to get us closer to a cure.

HONOR A LOVED ONE BY FINDING A CURE

CURE Epilepsy shares in the pain of losing a loved one to epilepsy. We feel privileged that many families choose to honor their loved ones with gifts to CURE Epilepsy. Knowing this, we are driven every day in our relentless pursuit of a cure. To make a gift in memory or honor of someone, please visit **CUREepilepsy.org/2021spring.**

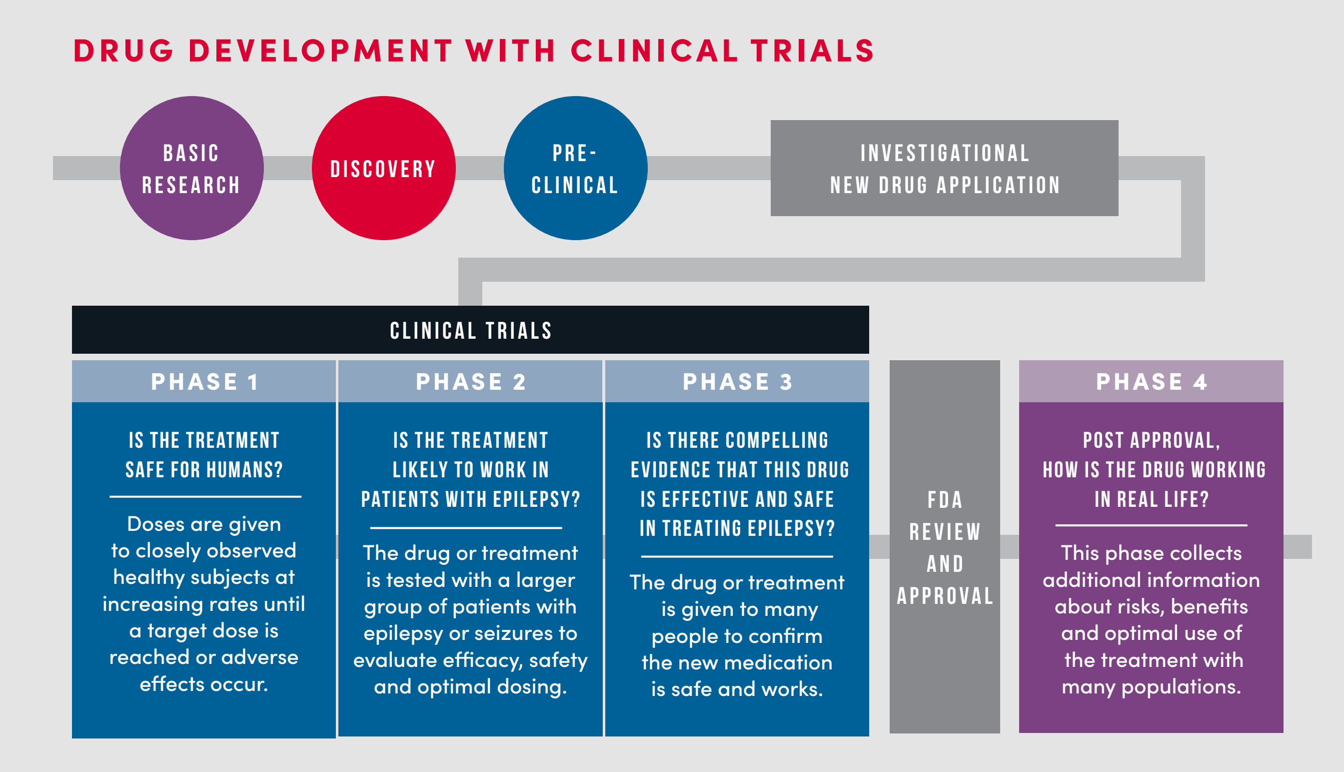
Photo courtesy of Ben Cope

> **"We're lucky to work with CURE Epilepsy. When we first started, we didn't know how we could make an impact. Because of working with CURE Epilepsy and others, we now believe we can make a difference. We encourage people to keep donating – there are brilliant people that are working very hard to end epilepsy."**
>
> **VICTOR BOYCE**

DOING YOUR RESEARCH

IS A CLINICAL TRIAL RIGHT FOR YOU OR YOUR LOVED ONE?

Clinical trials are essential research steps to advance new treatments toward Federal Drug Administration (FDA) review and approval. Unlike research conducted in laboratory settings with animal models, clinical trials include human volunteers who help establish a treatment's safety and effectiveness. The FDA requires that drug companies evaluate potential therapies in clinical trials before they're approved for the public.



DRUG DEVELOPMENT WITH CLINICAL TRIALS

PHASE 1

IS THE TREATMENT SAFE FOR HUMANS?

Doses are given to closely observed healthy subjects at increasing rates until a target dose is reached or adverse effects occur.

PHASE 2

IS THE TREATMENT LIKELY TO WORK IN PATIENTS WITH EPILEPSY?

The drug or treatment is tested with a larger group of patients with epilepsy or seizures to evaluate efficacy, safety and optimal dosing.

PHASE 3

IS THERE COMPELLING EVIDENCE THAT THIS DRUG IS EFFECTIVE AND SAFE IN TREATING EPILEPSY?

The drug or treatment is given to many people to confirm the new medication is safe and works.

PHASE 4

POST APPROVAL, HOW IS THE DRUG WORKING IN REAL LIFE?

This phase collects additional information about risks, benefits and optimal use of the treatment with many populations.

Clinical trials require both healthy volunteers and volunteers with the illness that the new drug will treat. Researchers choose participants based on varying eligibility requirements, including age, gender, type and stage of a disease, previous treatment history, and other medical conditions.

Clinical trials can offer benefits including access to new (and free) medical treatments and expert medical care at leading healthcare facilities. Trial participation is also a tangible way to contribute to medical research that may save lives in the future.

Understanding the risks of clinical trials should be an important part of your decision to participate. Risks could include ineffective or placebo treatment, unpleasant or serious side effects, and the inconvenience of additional treatments and hospital visits for study.

To find a comprehensive list of clinical trials, visit **ClinicalTrials.gov** – the National Institutes of Health and U.S. National Library's online clinical trial database. Through this site, you may search for "epilepsy" in the condition or disease field, as well as search by seizure type or the name of the investigational treatment.

QUESTIONS TO ASK WHEN CONSIDERING A CLINICAL TRIAL

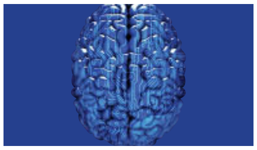
- What is the purpose of the study?
- What is the control for the study?
- How will the study affect my current treatment regimen?
- What do we already know about the medications that are being tested?
- How long will the trial last and where will it take place?
- How often do I need to come to the clinic for the trial?
- What will happen during trial-related visits? What tests are required?
- How are the costs for the study covered?
- What happens if I stop participating in the trial?
- Is long-term follow-up care part of the trial?
- If this drug works for my seizures, can I continue taking it even after the trial ends?

WEBINARS TO WATCH

CURE Epilepsy breaks down cutting-edge research and discoveries in free webinars designed to make scientific discoveries more understandable for the epilepsy community as a whole. Visit **CUREepilepsy.org/webinars** for past episodes or to sign up for live webinars.

ANTIEPILEPTIC DRUG RESEARCH

With approximately one-third of people with epilepsy resistant to current treatment options, it is critical to understand new therapies, their benefits, and potential side effects.



CENOBAMATE: A NEW TREATMENT OPTION FOR PARTIAL-ONSET (FOCAL) SEIZURES

DR. MICHAEL SPERLING,
THOMAS JEFFERSON UNIVERSITY

FENFLURAMINE FOR DRAVET: AN OLD DRUG WITH A NEW PURPOSE

DR. JOSEPH SULLIVAN,
UNIVERSITY OF CALIFORNIA SAN FRANCISCO PEDIATRIC EPILEPSY CENTER

DISPARITIES IN EPILEPSY CARE

Increasing awareness of the social factors that influence epilepsy diagnosis and care is the first step toward eliminating inequities and improving outcomes for all people living with the disease.

OVERCOMING BARRIERS TO IMPROVE CARE AND TREATMENT OUTCOMES

DR. MAGDALENA SZAFLARSKI,
UNIVERSITY OF ALABAMA AT BIRMINGHAM

SOCIAL & ECONOMIC EFFECTS OF EPILEPSY IN SUB-SAHARAN AFRICA

DR. GRETCHEN L. BIRBECK,
UNIVERSITY OF ROCHESTER

SHARING KNOWLEDGE TO ACCELERATE RESEARCH

Through our leadership role in the epilepsy community, we participate in and host a number of events and activities to share knowledge about the disease and emerging treatments.

Just two years after our founding in 1998, CURE Epilepsy established our leadership role by helping launch the first Curing the Epilepsies Conference with its targeted mission: to talk about a cure for epilepsy, not just treatments. This conference, hosted by the National Institute of Neurological Disorders and Stroke (NINDS), only occurs every seven years on average and has helped develop specific benchmarks and new strategies for epilepsy research.

Over the last three years, CURE Epilepsy actively contributed to review and revision of the epilepsy research priorities that guide the nation's scientists. This process culminated in January at the 2021 Curing the Epilepsies Conference. This year's program focused on transformative research priorities, and each session began with a patient story to highlight the personal impact of epilepsy. CURE Epilepsy's Chief Scientific Officer Dr. Laura Lubbers shared her sister Ellyn's experience living with the disease, and advocated for a collaborative research infrastructure that accelerates research-based learnings to clinical practice.

CONNECTING WITH OUR RESEARCH COMMUNITY

FRONTIERS IN RESEARCH SEMINAR SERIES

CURE Epilepsy hosts this regular seminar series with generous support from the Nussenbaum-Vogelstein family. The series' goal is to help educate and expose young scientists to leading epilepsy research. Although these seminars typically occur in person at leading research facilities, we now host them virtually due to the pandemic.

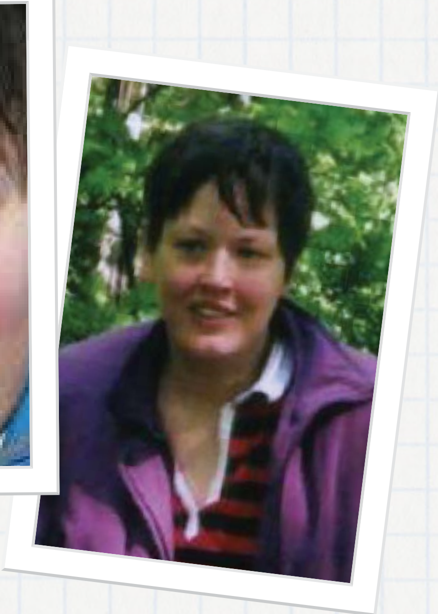
AES ANNUAL MEETING

The American Epilepsy Society offers the most extensive epilepsy education and scientific exchange in the field through its annual meeting in December. After moving the event online, more than 4,500 people participated in sessions, exhibits, posters and virtual networking booths. CURE Epilepsy founder Susan Axelrod helped to host the CURE Epilepsy booth.

PAME MEETING

This year, Partners Against Mortality In Epilepsy (PAME) hosted its annual meeting as an extension of AES. Many CURE Epilepsy grantees presented at the 2020 meeting, and Libby and Victor Boyce of The Cameron Boyce Foundation, a generous supporter of CURE Epilepsy, were keynote speakers. CURE Epilepsy was an initial organizer for PAME and continues to be involved today.

Dr. Laura Lubbers, CURE Epilepsy's Chief Scientific Officer, has dedicated her life to researching neurological disorders, inspired by her sister Ellyn. She shares Ellyn's story to show the personal side of epilepsy research and remind us of the many families counting on a cure.



CURE EPILEPSY IS RESEARCHING FOR

Ellyn

> "Our strategy was to wait and hope and deal with the consequences."
>
> DR. LAURA LUBBERS, ELLYN'S SISTER

Ellyn experienced her first seizure at 3 months old and subsequently had innumerable partial complex (now called focal aware) seizures. Eventually, Ellyn was diagnosed with a genetic disorder called tuberous sclerosis complex (TSC), but even with a diagnosis, her treatment options remained limited. The numerous medications used to treat the symptoms of TSC, particularly her seizures, negatively impacted her psyche and bone health. In addition, she suffered many injuries during seizures, including falls that broke her wrist and hip.

As the pandemic initially gripped our country, Ellyn contracted COVID-19 and was slow to recover. Although the reason is unclear, her seizures changed from partial complex to status epilepticus. In June 2020, she was transported to a major medical center and put into a coma to stop the seizures. Ellyn eventually recovered enough to be transferred to a rehabilitation facility, but her health deteriorated and she passed away in September.

Her family often thinks of what could have been done differently to manage her medical condition. They are quick to recognize the hard work of Ellyn's medical team, but also strongly advocate for more treatment options so others don't have to suffer as Ellyn did.

UNITE to CURE Epilepsy

TENACITY. DISCOVERY. HOPE.

SEPTEMBER 24, 2020

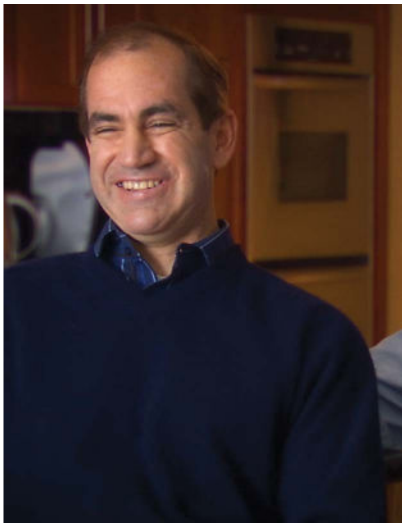
During this special evening, we gathered together virtually to hear inspirational stories; learn about encouraging new research; enjoy performances from global superstars; and, most importantly, raise critical research funds. Special guests included country music star Eric Church, Rock & Roll Hall of Fame inductee Nils Lofgren, actor Miguel Cervantes, and CNN Chief Medical Correspondent Dr. Sanjay Gupta.

$1.84 MILLION RAISED

DONORS FROM 42 STATES

MORE THAN 7,000 VIRTUAL ATTENDEES

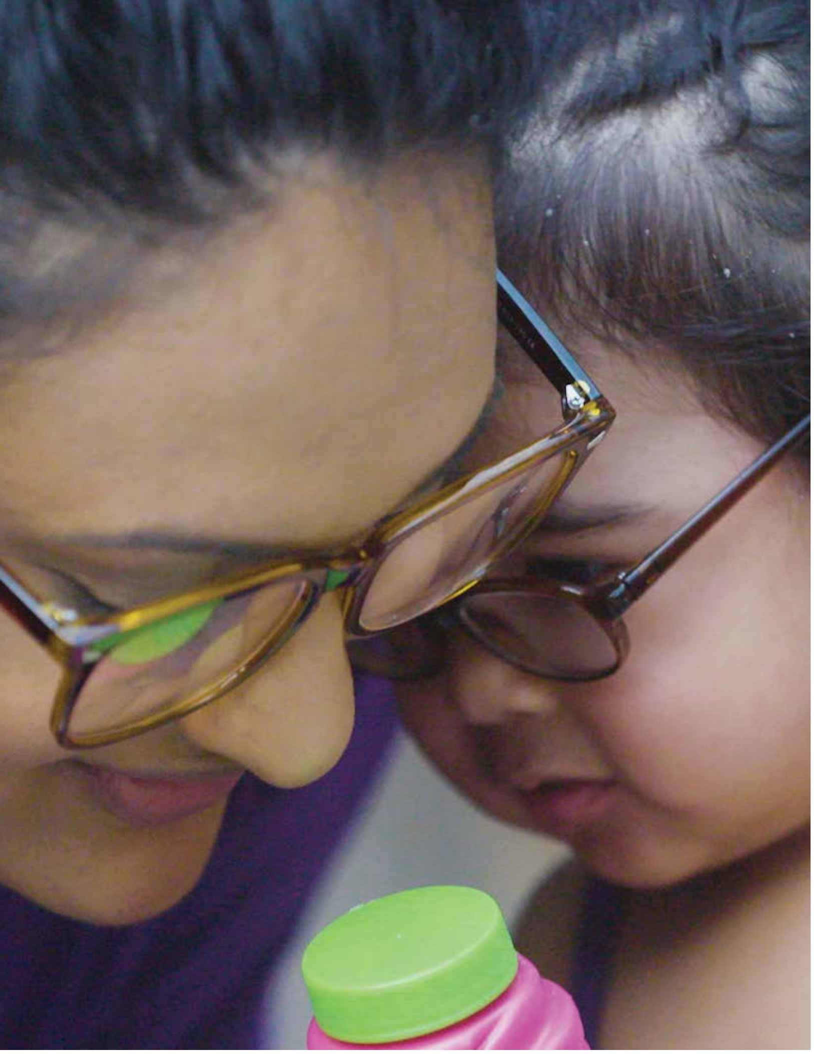
OUR LARGEST EVENT TO DATE



CURE EPILEPSY WEEK

SEPTEMBER 21-25, 2020

Leading up to Unite to CURE Epilepsy, we hosted a week of virtual activities to shine a light on innovative epilepsy research projects. In addition, we shared stories of people helped by groundbreaking research and how we can continue to drive science forward.



SOCIALLY DISTANCED, BUT COMMITTED TO CURING EPILEPSY TOGETHER

For more than a year, we've adapted our CURE Epilepsy events and activities to be virtual, including our largest fundraiser of the year. Although we can't be together in person, you continue to show up in big ways. Thank you for sharing in our mission, supporting our community, and fueling our hope.

Photos from left to right:

Sanjay Gupta, CNN Chief Medical Correspondent

Susan Axelrod, CURE Epilepsy Founder

Mike Barnicle, event host and contributor to MSNBC's Morning Joe with his wife Anne Finucane, Bank of America Vice Chairman

Cindy and Vera Angulo

Eric Church, award-winning country music star

Michael Platt, teenage culinary entrepreneur living with epilepsy

Miguel Cervantes, Broadway's "Hamilton"

The late Phil Doran, Jr. and the late Phil Doran, Sr.

Kelly Cervantes, CURE Epilepsy Board Chair-Elect

Nils Lofgren, Rock & Roll Hall of Fame inductee

Lauren Schrero with her husband Adam Levy, co-founders of the Nora Project

CHAMPIONING OUR CAUSE

Even in the midst of a pandemic, CURE Epilepsy Champions showed their commitment to a cure. While some Champion events were postponed for safety reasons, other activities persevered with creativity and careful planning. Large or small, every generous act increased support for our community.

ANNUAL EVENT ADAPTS TO PANDEMIC

$4,800+ RAISED

On November 7, 2020, CURE Epilepsy supporters saddled up to enjoy artful horse riding. COVID-19 challenged Champion Channing and her family to brainstorm ways to supplement donations lost due to the reduced number of event attendees. Channing's mom responded by growing purple carrots in her garden and encouraging donors to sponsor purple carrot "goody bags" for participating horses.

CHAMPIONS LAUNCH NEW EVENT WITH POWERFUL PURPOSE

$5,600+ RAISED

The Powers family wouldn't let a pandemic stop their drive for a cure. The family launched PowerUp for CURE in honor of their son Jack, challenging their friends and family to participate in an outdoor activity while pledging donations to CURE Epilepsy.

$240,000

RAISED BY OUR 2020 CHAMPIONS

MORE THAN TWO TAKING FLIGHT AWARDS

CHAMPION FIGHTS FOR A CURE IN HOLIDAY CARD

$10,000+ RAISED

Champion Elissa Moore added a special message in her family's 2020 holiday card. During this season of giving, Elissa asked those who received her holiday card to consider donating to CURE Epilepsy in honor of her son's epilepsy fight. More than 40 supporters responded, praising Cormac's strength and courageous journey toward being seizure free.

BECOME A CURE EPILEPSY CHAMPION

Becoming a CURE Epilepsy Champion is easier than you think. Check out some of our fundraiser types below to get you started:

CREATE A DIY EVENT	**Host a community 5K, golf event, virtual yoga class, or livestream an event - get creative!**
CELEBRATE A LIFE EVENT	**Celebrate a birthday, recognize an anniversary, or remember a loved one – no event setup required!**
SUPPORT A CURE EPILEPSY EVENT	**Join Team CURE Epilepsy or fundraise around our annual Unite to CURE Epilepsy benefit.**

Still not sure where to start? Contact our dedicated staff at **(312) 255-1801** or **events@CUREepilepsy.org.**

TEAM CURE EPILEPSY

As we look ahead to the latter half of 2021, we are hopeful that our Team CURE Epilepsy events will occur safely in person. Please save the date for the below marathons and consider teaming up with CURE Epilepsy so we can outrun epilepsy. Not a runner? Join the Team by volunteering at one of these events.

OCTOBER 10, 2021: **Bank of America Chicago Marathon**

NOVEMBER 7, 2021: **TCS New York City Marathon**

NOVEMBER 7, 2021: **Los Angeles Marathon and the Charity Challenge 13.1**

NOVEMBER 28, 2021: **Amica Insurance Seattle Marathon and Half Marathon**

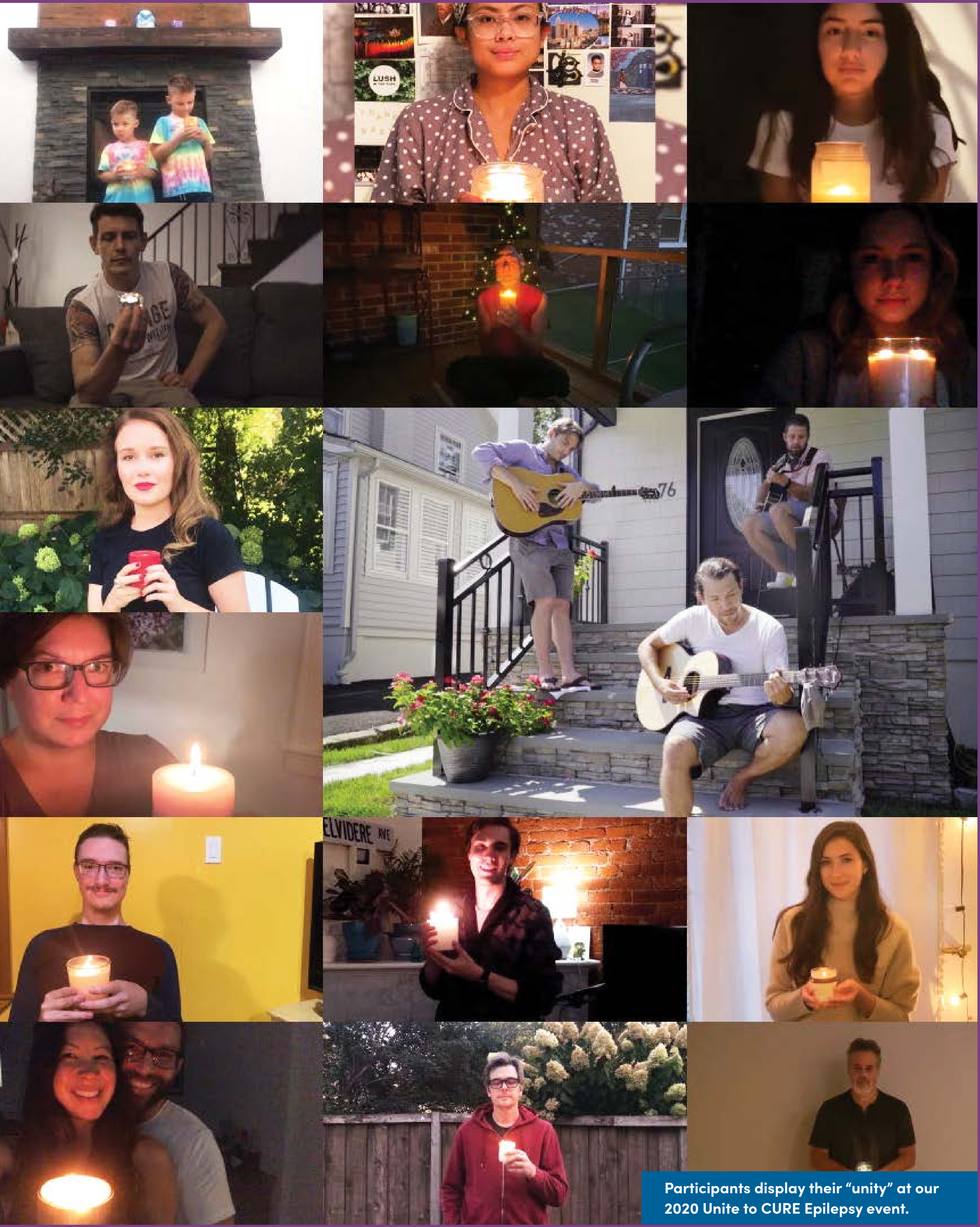
2020 DONOR HONOR ROLL

We are profoundly grateful to the thousands of individuals and organizations who, with a gift to CURE Epilepsy, helped advance epilepsy research and our mission to find a cure. While space limits us to print only some of these donors, our gratitude is limitless. Thank you.

The following reflects donors who gave $500 or more between January 1 - December 31, 2020. We have made every effort to ensure the accuracy of this report. If your name has been omitted or misprinted, please accept our sincere apologies and notify the CURE Epilepsy staff at **info@CUREepilepsy.org** or **(312) 255-1801.**

To make a donation:

CUREepilepsy.org/2021spring



Participants display their "unity" at our 2020 Unite to CURE Epilepsy event.

$100,000–$249,999

Anonymous
The Cameron Boyce Foundation
Debra Cafaro and Terrance Livingston
Lisa and Michael Cotton
Shery Cotton
Greenwich Biosciences
Grosvenor Capital Management
Ann G. and James B. Ritchey Foundation

$50,000–$99,999

Bank of America
Bloomberg Philanthropies
The Kenneth C. Griffin Charitable Fund
Ravichandran Foundation
Select Equity Group Foundation
Glen and Patricia Tullman

$25,000–$49,999

Alexandria Real Estate Equities, Inc.
Anonymous
Susan and Stephen Austin
Susan and David Axelrod
Ellen Benninghoven and Michael Schafer
Kimberly Borden
Eileen and Jack Connors
Crown Family Philanthropies
The Shurl and Kay Curci Foundation
Development Specialists, Inc.
Anne Finucane and Mike Barnicle
Matthew and Carrie Garman
Jerome Foundation
Carol Jones and Thomas Hynes
Michele and Howard Kessler
Deborah Kirshner and Paul Heldman
Kivvit
Mass General Brigham
Isaiah Stone Foundation
Suffolk Cares Foundation
The Pritzker Traubert Foundation
UCB, Inc.
Ventas
Wachtell, Lipton, Rosen & Katz

$10,000–$24,999

AKPD Message and Media LLC
Anonymous
Anonymous Fund at East Texas Communities Foundation
Sarah and Paul Auvil
Barack Ferrazzano Kirschbaum & Nagelberg LLP
Louann Benbow
Joel and Lisa Benenson Foundation
Bergstein Family Foundation
Nancy Calcagnini
Liane Kupferberg Carter and Marc Carter
Cisco
Clayco
Lucy and Brian Conboy
Dara and John Corkery
Nancy and Sean Cotton
Cozen O'Connor
Shalee and Blake Cunneen
CVS Corporation
John Del Cecato
The Driscoll Foundation as recommended by Elizabeth and Edwin Hlavka
Eisai Inc.
Howard Gottlieb
Karen and Larry Grisolano
Julia and Albert Hofeld
Estate of Karen Jo Haldeman
Celia and Daniel Huber
The Estate of John and Mildred Winchell Hubiak in memory of Christopher Donalty
Irish Woods Foundation
Jenner & Block LLP
Lois and Aaron Johnson
Barbara Kelly
Kirkland & Ellis LLP
Burks Lapham
The Steve Mason Family
McKinsey & Company
Randy Mehrberg and Michele Schara
Suzu and David Neithercut
Neurelis
Cheri and James Niewiara
Evelyn Nussenbaum and Fred Vogelstein
Mariana and Joe Parke
Stacey and John Pigott
PNC Bank
Judy Pomeranz
Richard and Linda Price
J.B. and M.K. Pritzker
John Ray
Molly Reinhart
Lori Rotskoff and Michael Canter
Kathryn Ruemmler
SK Life Science Inc.
Sunshine Foundation
The University of Chicago
White Family Fund

$5,000–$9,999

Anonymous
Ann and Doug Benschoter
David Binder Research
BNY Mellon Wealth Management
Conagra Brands
Kate and Matthew Cooper
Traci DeAngelis
Ellen and Scott Diamond
Mary I. Doran
Rahm and Amy Emanuel
Theo Epstein
Kay and Karl Fricke
Alan and Virginia George
Robert and Mary Catherine Gibbs
Gibi ASMR
Dema Hadi
Linda Kaplan and The Wiliam and Mildred Kaplan Foundation
Gardiner and Nick Lapham
Estate of Glenn F. Leiter
Evelyn Lincourt Charitable Fund
Cory and Debbie Lipoff
Barrington Lopez
Daina Lyons and Forrest Claypool
Kathleen and Doug Martin
Kathy and John McKenna
Mesirow Financial
The Oak Foundation
Osprey Foundation
Jim and Margie Pines
Anna and Raymond Pitera
Polly and Kenneth Rattner
Paula Robinson-Doyle and James Doyle
Jennifer and Jeffrey Robinson

The Roche Family Foundation, Inc.
Irene Rosenfeld and Richard Illgen
Bettylu and Paul Saltzman
SC Benjamin Foundation
Christina and Zac Schneider
Matthew and Marjorie Schneider
Schuler Family Foundation
Kristin and Andrew Seaborg
Lisa and Randy Siegel
Richard Silveria
Andrea and Martin Singer
Julie and Dave Stout
Television Bureau of Advertising Inc.
The Walsh Foundation; Patti and Dan Walsh
Frederick and Cate Waddell
Angela Byrd and Eric Weil
White & Case LLP
Whitten Newman Family
Connie Wishner
Tom and Heather Wurzer
Zogenix, Inc.

$2,500–$4,999

Loretta and Walter Anderson
Cindy and Elvin Angulo
Anonymous
The Apple Lane Foundation
Jeffrey Boutilier
Cordeck
Sara and David DeCoste
Nicholas DeVore
Julia and Richard Diasio
Kathy and Bob Dodd
Stacy Dodd
Alison Donalty and Chris Hampson
Jeanne and Barry Donalty
Joanna Edgell
Erin and Justin Foley
Russell Fradin
Albert and Suzanne Friedman
Mary and Gene Gager
Jackie and Al George
Susan Graham
Kim and Alan Hartman
Henry's Heroes Foundation Inc.
Vicki Heyman and the Honorable Bruce Heyman
James Horvitz
Susan and Jules Kaufman
Katie Kitchen and Paul Kovach
Radha Krishnan
Donna La Pietra and Bill Kurtis
Toby and Greg Lewis
Cecil and Karen Loyd
Andrea Mathews
McCullough Family Foundation
Hanne and John Messerich
Matthew and Elissa Moore
Alyson and Patrick Nash
Lee and Herman Ostrow Family Foundation
Michele and Mark Patterson
Rebecca Anhang Price and Matthew Price
Julie and Robert Ramirez
Caroline and Dierk Reuter
Fred and Kathleen Robinson
Rush University Medical Center
Rob Saltiel
Sidley Austin LLP
Erik Smith and Edith Gregson
Katharine and Edwin Smith
Alan Solow and Andrea Lavin Solow
Chris and Carl Stamp
Storment Family Fund
Vicki Taylor-Roskopf
Ren and Suzanne Umeda

$1,000–$2,499

Nilesh Acharya
Matt Acuna
Ahee Jewelers
Craig and Heidi Albert
Paula and David Allbeck
Ethan Axelrod and Jenna Kalin
Lisa and Timothy Bazemore
Terry Behrle-Mohs and Richard Mohs
Cheryl Beil
Mark Bisnow
Barbara Brackenridge
Linda Burtwistle
Sally and John Cardamone
Steven Casey
Bette and Bruce Cerf Hill
Chicago White Sox
Michael and Jane Clark
Patrick and Suzanne Coffey
Cheryl and Russell Cohen
Eileen Cohen
Patricia Collins and Gordon Greenberg
Denise and Vincent Comparato
Catherine and Joe Conti
Sarah and William Cool
Laura Coulter and David Reifman
Stella and Roger Craig
Mary Louise Crane-Ryan
Elizabeth and Jim Cross Bridges
Pat and James Cunneen
The Cupid Chase
Karen Daly
Nancy-Ann DeParle
Yssa DeWoody
Carl Donnelly
Kelly Dougherty
Jillian Dryfoos
Michael and Marty Dwyer
Emeritus, Ltd.
Carla and Ed Engelbrecht
Epilepsy Alliance Louisiana
John and Sally Filan
Julia Filan
Veronica Finkel
Cherissa Fischer
Sharon Flaim
Lynn Fleisher and John Roberts
Sarah and Fred Flosi
The Fountainhead Group
Mary Fox
Alan Frankel
Mary Frey and William Bennett
Jennifer and Kenneth Fruehauf
Kathryn Furman
Marilynn and Patrick Gardner
Lois and Dennis Gates
Janice Gault
Roger Gay
Edward Gelles
Caren Gerszberg
Lisi and Rob Gheewalla
Sherina Girardi

Cindy and Brian Gorczynski
Jane Greenfield
Terri and Gary Grefer
Carolyn Grisko
Lisa Gustavson
Hakluyt & Company (North America) Ltd
Deborah and James Hardin
Kimberly Hare
Joan W. Harris Charitable Fund
Michelle and John Hart
Erica Hawthorne
Marilyn Hayden
Anne and Robert Hendrix
Nora Hennessy
Kay Henrichs
Karen and Mark Hermelin
Kathleen Hickey
Lynne and Bill Higgins
Raymond Hirsch
Hobbs Family
Hoerr Schaudt Landscape Architects
Rabbi Lawrence Hoffman
Barbara Hoggan
Terry Hong
Katherine and Kevin Hooper
Elizabeth and Christopher Huff
John Huguenard
Janet and David Hyland
Mickey and Lorraine Jaffe
Ann and John Jentz
Sheri and Mark Jessell
Edward Johnson
Kathy and Arthur Judd
Kaplan Rosenow Family Foundation
Jessica and Glen Kaufman
Barb Keller
Melinda and Walter Kelly
Robert and Susan Kelly
Deborah Kiley
Howard and Claudia Koh
Cathy Kopf
Paul and Nancy Kurland
Lanin Family Fund
David and Erin Laslow
David and Laura Laslow
Bill Lauzon
Legacy Wealth Management Group of Wells Fargo
Mary and Larry Liebscher
Jeffrey Loeb
Jacqueline Logan and Whitney Magruder
Mr. and Mrs. Barry Long
Laura Lubbers and Trent Buck
Susan and John Lynch
Christine Madden
Martin and Francesca Marciniak
Marino Chrysler Jeep Dodge
Donald and Kim Matthews
McMullen and Kime Family Charitable Fund
Mercedes-Benz of Des Moines
Krysia and Michael Miller
Janice and Ken Milnes
Mode Project
Cecilia Molick Nish and Jim Molick
Stephen Moore
David Morrisey
Kathleen and John Morrissey
Jane Moses
Caroline Moyer
Katherine and James Mutchnik
Beth and Mark Myers
Sara and Patrick Nash
Kristin and Mark Nelson
John and Stephanie Nish
Nonnina
Maureen O’Connor
Dorothy Osborn
Kelley and Sean Owen
PJ Panganiban
Deborah Peacock and Nathan Korn
Peter Perkins
Pledgeling Foundation
Mary and Walter Pratt
Melissa and Steve Quick
Joanne Radice-Rahaim
Richard and Alba Raskin
Priscilla and Russell Rose
Benjamin Ross
Laura and David Ross
Mary Kay and Raymond Rossi
Barbara Rothway
Dr. and Mrs. Kenneth Rotskoff
Liz & Jason Roudabush
Paul and Ann Rutecki
Lori Sapio
Martha Sayre
Darrell Scherbarth
Robin Schirmer and John Bouman
Susan and James Schneider
School District of Greenfield
Gene Schoon
Marty and Jamie Schrero
Schultz Controls Inc.
The Sexton Family Foundation
Carol and John Showel
Julie and Brian Sikkema
Jacob Silver
Richard and Karen Solle Foundation
Marilyn and Julius Sparacino
Ann and Christopher Stack
Cynthia Stack
Scott Stackman
Paige Stephan
Erica and Jed Stern
Linda and Donald Stewart
John Stubbs
Nancy and Stephen Summers
Eileen and Thomas Sutula
Lauren Swager
Robert and Kim Swidler
SynergEyes Cares
Susan and Dit Talley
Chris Thome and Colleen Kenyon
Joseph and Margaret Tilson
Mike Turner
Brian Tweedie
Mandy and William Vadbunker
Polly and Dan VanderWoude
Robert Vanecko
Mike Vihon
Medita Vucic
Bruce Watrous
Barbara Weade and Michael Goc
Bruce and Suzette Wedel
Sanford Weinstein
Travis Wellman
John and Holly Whetstone
Vera Whipple
Whiskey River Charitable Foundation
Laura and Bruce White
Steve and Kathryn White
Wendy and Scott Whittaker
Seth and Deb Wohlberg
Ann Wolf

$500–$999

Cara Abercrombie and David Freccia
Donald Abrams
Michael Abrams
Debbie and Carl Adams
Megan Allen
Allied Mineral Products
Dorothy Granata Amado and Mitchell Amado
Mary Anglin
Anonymous (8)
C. Kent Argenta
Philip Askenazy and Wendy Hansen
John and Regina Balzano
Lindsey Barile
John Becker and Karen Smith Fund
Karen and Erik Berkman
Ellen Berne and Paul Needle
Adam and Suzy Biehl
Mary and Bill Boehler
Helen Boen
Patricia Brady and Robert Smith
Nancy Brandon
Debbie and Tim Braxmeyer
Miriam Buckley
Gary Cadez
Michael Caprile
Kelly and Miguel Cervantes
CEU Technologies, Inc.
Daniel Chang
Stefanie and Chase Chavin
City Kids Inc.
CJR Foundation, Inc.
Kathryn Celeste Coats
Donna and Dennis Coggins
Jonathan Cohen
Paul Cohen
Kara Conry
Richard Cooper
Pam and John Cullerton
Jack Cunneen
Douglas and Meghan Dahl
Beth and Michael Dean
June and Stan Dean
Jennifer DeBower
David and Elizabeth DeBruin
Matthew Decker
Judith Desenis and E. Scott Peterson
Jane and John DeWitt
John and Jennifer Doran
Dean and Sarah Duncan
Douglas Dybzinski
Bryan Engler
Jackie and Bogdan Ewendt
Daniel Fallon
Jeff and Jana Fillbach
Izabela Fitts
Charlotte Ford
Jason Foster
Carol and C. Bernard Fulp
George Furtado
Gamma Sigma Sigma of UTK
Bonnie Garrick
Lily and Roberto Garza
Suzanne Gaumond
Mary and Pasquale Genco
Elizabeth Gerard
Valerie and Joseph Golbus
Gary and Bonnie Goldberg
Joseph Goodman
Stephen Graf
Bonnie and Robert Graham
Eliana Green
Patricia and Rich Green
Barbara and Fred Greenstein
Michael and Nettie Greenstein
Cecilia Griffin
Jason Griffin
Sandra and Jonathan Grindlay
Constance and E. Wayne Grogan
Eric Gunzelman
Marjorie Halperin and Alan Robinson
James Colin Harding
Patricia and Paul Hartnett
Lauren and Scott Henkin Fund of the Jewish Communal Fund
Aaron Hopewell
Howard Horton
Thomas and Nancy Hughes
Marnie and Chuck Hulan
Diane Huntley
Rich and Virginia Hyland
Infuse Hospitality
Martha Jacob and Richard Campbell
James Jalbert
Shannon Janney
Ellie and Glenn Johnson
Katsy and Beth Johnson
Cynthia and Jean Joho
Fred Juengling
Stacy Kanter and Eric Kornblau
Anne and Jeffrey Katz
Katie Keenan
Connie and Bruce Kinnison
Henrik Klitgaard
Jeff Knupp
Phyllis and David Kupperman
Diane and Nicholas Lahowchic
Roderick Landreth
Jennifer Lattner
Jay and Ruth Lenrow
Jodie Levin-Epstein
Nathan Little
Lesley Lloyd
James and Rose Loesher
Greg Long
Stephanie Lowell and Gregg Duthaler
Daniel Lowenstein
Lynne Manna-Fisher and Scott Fisher
David Mark and Jean D'Amico
Cameron Martin
Reynold Martin
Stephanie Martin
Kevin McAnneny
Donna McCaffrey
Alexie and Bobbi McCarthy
Abbie McConnell
Pamela McIntyre
Peggy and Mike Meagher
Sandra and Andrew Merrill
Carole and Jude Metcalfe
Deborah and Jeremy Michaels
Laura and Charles Miller
Angie and Dave Mimms
Paolo Morante and Brigid Doherty
Jon Morris
Mary Morrissey
Harold and Carole Moskowitz
Susan and Gene Myers
Barbara Napoli
Patrick and Sara Nash
Linda Nolten
Douglas and Joanne Nordli
Roy O'Neil

Veronica and Billy Ocasio,
National Puerto Rican Museum

Eleanor and Allan Odden

Susan Olsen

OneHope Foundation

Pacers Sports and Entertainment

Thomas and Deborah Page

Francesca Passudetti and
Martin Marciniak

Polly Piland

Joyce Plyler and Mark Horoschak

Karin Popkin

Sean Power

Kelly Powers

Richard Prager

Harrison Price

Joan and David Pritchard

Anne Quinn

Donald Raab

Patti and Kenneth Raskin

Debra Rigney-Hays

Heidi Robbins

Judy and James Roediger

Vickie Rooda

Jessica Rosini

Kenny Jacob Rudin Memorial Foundation

Leslie Rutkowski

Biff Ruttenberg and Gwen Callans

Paul Sabini

Christine Salmi

Phillip and Christiane Salvador

Julie and Bob Sauer

Vicki and Allen Saxon

Margaret Scanlan Brown

Jennifer and Joshua Schafer

Jan Schakowsky and Robert Creamer

Diane Scherbarth

Natali Scherbarth

Erin Scherbinske

Robert and Nancy Sheets

Emily Sheridan

Lynn Shesser and Gary Falk

David Simmons

Carmen and John Skilton

Carol Slazyk

Mark Slevin

Cathleen and Michael Smith

Douglas Smith

Mary Smith

Ashley Smithson

Daryl Spencer

Lolita and Mark Spiro

Joseph and Augusta Stanislaw

Donald Taylor

Patricia and Donald Taylor

Jeff and Bonnie Tobias

Thomas Tobin

Caryl Kawalsky Uzelac and Nikola Uzelac

Ronald and Leona Van Den Bussche

Vocatura, Spagnuolo & Company, PC

Richard L. and Lois S. Werner
Family Foundation

D Fonde and J Steven Werts

Gail Wheeler

Stephanie and Thomas Winter

Jori and Michael Witt

Sharon and Lawrence Wsol

Luda Sorin, MD and Kevin Yuda

Joan Zajeski

The Zealous Root

Maureen and Peter Zeller

Corinne Zola

James Zouras

CURE EPILEPSY CHAMPIONS

Our Champions are grassroots fundraisers that help us raise critical research funds and bring awareness to epilepsy.

Cindy and Elvin Angulo

Beth Arrigo

Alana Caraciollo

Jeff Cismesia

Megan Cullen

Shalee Cunneen

@DarkBlade

@DarthMathis

Sam DeCaprio

Carl Donnelly

Douglas Dybzinski

Mary Fox

Mara G

Gamma Sigma Sigma of UTK

Nichole Greaves

Michael Greenstein

Mikki Lewis

Erin Monast

Elissa Moore

Amelia Murray

Lauren Nathan

Jason O'Malley

The Power Family

Jessica Rossini and Beth Scolis

Jenna Rummelhart

Kellie Sadens

Kendra Scott

Channing Seiderman and Kelly Hall

Jenna Skinner

@Th3BlueRose

Christina Vilardi

THANK YOU VOLUNTEERS

The work of CURE Epilepsy would not be possible without all of our volunteers. We thank each of you, including those who serve on our committees.

CURE EPILEPSY BOARD OF DIRECTORS

Michael Axelrod
Ann Benschoter, MBA*
Kimberly Borden, MBA
Kelly Cervantes
Gary Collins
Lisa Cotton
Blake Cunneen, MBA
Marilynn Kelly Gardner
Carrie Garman
Brian Gorczynski, MBA
Celia Huber, MBA*
Kathy McKenna, MBA
Stacey Pigott, MA
David Reifman, JD, MA

CURE EPILEPSY SCIENTIFIC ADVISORY COUNCIL

Angélique Bordey, PhD
Yale University School of Medicine

James Cloyd, PharmD
University of Minnesota

Kelly Knupp, MD
University of Colorado
Anschutz Medical Campus

Daniel Lowenstein, MD
University of California San Francisco

Eric Marsh, MD, PhD
University of Pennsylvania

Manisha Patel, PhD*
University of Colorado Anschutz
Medical Campus

H. Steve White, PhD
University of Washington

Vicky Whittemore, PhD
NINDS Program Director

CURE EPILEPSY SCIENTIFIC GRANT REVIEWERS

External research professionals kindly volunteer their time and expertise to ensure the science we fund has the highest potential impact in the epilepsy community. We do not list their names to maintain the integrity of our grant review process.

CURE EPILEPSY LAY REVIEW COUNCIL

Members of the Lay Review Council dedicate their time to ensure a patient voice and lay perspective in our efforts to fund the best science. We do not list their names to maintain the integrity of our grant review process.

* Term ended in 2020

CURE EPILEPSY COMMUNITY ADVISORY COMMITTEE (CECAC)

CECAC members are directly connected to the epilepsy community as both patients and caregivers and help us reflect the community's voice in all that we do – including strategic planning, educational programs, fundraising and awareness events, communication strategies, and much more.

Cindy Y. Angulo
Elizabeth Cross Bridges
Kate Cooper
Princess Costello
Erin Earnest
Katie Eberspacher
Angie M. Froehlich
Carrie Garman
Christin Godale
Joanne L. Guthrie-Gard
Kelly J. Hall
Melanie Karlberg
Jessica Kaufman
Andy McGinn
Sandra Merrill
Jessica Rosini
Jenna Rummelhart
Kellie Sadens
Elizabeth Scolis
Rob Seiderman

NEW YORK FRIENDS OF CURE EPILEPSY

The New York Friends of CURE Epilepsy are a group of dedicated volunteers committed to advancing the mission of CURE Epilepsy through their awareness and fundraising efforts in the New York area.

Liane Kupferberg Carter
Kelly Cervantes
Jeanne Donalty
Alison Donalty
Susan Kaufman
Sandra Merrill
Julie Ramirez
Dianne Raso
Lori Rotskoff
Lisa Siegel
Caryl Kawalsky Uzelac
Polly VanderWoude
Connie Wishner

Cover photo of Cameron Boyce courtesy of Storm Santos

WE FIGHT TO END EPILEPSY EVERY DAY BECAUSE 3 MILLION ADULTS AND NEARLY 500,000 CHILDREN IN THE U.S. LIVE WITH EPILEPSY EVERY DAY.

Help us to continue to make progress toward a cure.

MAKE A GIFT

CUREepilepsy.org/2021spring

FOLLOW US ON SOCIAL MEDIA

BECOME A CURE EPILEPSY CHAMPION

LEARN MORE ABOUT EPILEPSY

CUREepilepsy.org/webinars
CUREepilepsy.org/seizing-life

CURE EPILEPSY™

CUREEPILEPSY.ORG/2021SPRING

CURE EPILEPSY
420 N. WABASH AVENUE, SUITE 650
CHICAGO, ILLINOIS 60611

(312) 255-1801
(844) 231-2873