CURE EPILEPSY 25 years

Inspiring Hope. Delivering Impact.

25 YEARS OF

RESEARCHING TO CURE EPILEPSY

CURE EPILEPSY BEGAN 25 YEARS AGO WITH A DREAM:

A WORLD WITHOUT EPILEPSY.

BETH LEWIN DEAN
Chief Executive Officer
CURE Epilepsy

In that world, no child or adult would know what it's like to be wracked with unpredictable and untreatable seizures, and their loved ones would never know the fear of waiting – waiting for a seizure to take hold, to pass, to reappear. We don't live in that world – yet. **But I have confidence it is our organization that is eventually going to make that dream a reality.**

Twenty-five years ago, Susan Axelrod and other parents sat around a kitchen table desperate for answers for their children. Though the ultimate goal of a cure is still in front of us, the founders could not have imagined how much progress CURE Epilepsy would make in the fight to change the conversation to be about more than living well with epilepsy by funding research for a cure.

CURE Epilepsy's progress has not been made in a vacuum; it has been accomplished through the work of so many people: researchers, clinicians, donors, volunteers, community members, board of directors, and staff. The work is diverse, but the themes are the same: **leadership, collaboration, and innovation.**

WE ARE LEADERS. CURE Epilepsy co-founded important agenda-setting organizations such as the Epilepsy Leadership Council (ELC) and Partners Against Mortality in Epilepsy (PAME). We help shape the conversation on federal research spending through our relationship with National Institute of Neurological Disorders and Stroke (NINDS). We are the leading private funder of epilepsy research in the United States, and our initiatives help the epilepsy community keep the pulse on up-and-coming research directions.

WE ARE COLLABORATORS. We introduced the concept of team science to the field of epilepsy research. Partnering with other epilepsy organizations, academic centers, and the government, we share data for the common good. And people living with epilepsy are at the center of both our grantmaking process and organization as a whole, ensuring our research is always patient-focused.

WE ARE INNOVATORS. Our grants fund cutting-edge science and nurture young investigators, helping seed methods and data that lead to exponentially larger government grants. Our researchers' breakthroughs in Sudden Unexpected Death in Epilepsy (SUDEP) and Infantile Spasms (IS) have been truly paradigm-shifting. We look at not just curing epilepsy, but stopping it before it starts, and our priority is always to push the limit of what is possible.

This issue of **ReSearching** to CURE Epilepsy is as much a celebration of our first 25 years as it is a promise for our next 25. **We are and will continue to be leaders, collaborators, and innovators, because we know that it will take all three to eliminate epilepsy.** CURE Epilepsy's commitment is to forge ahead – to keep making it possible for the best researchers to pursue the best science, so that a seizure free world becomes our reality.

Whether you've been with CURE Epilepsy since the beginning or you've joined our community recently, know that your support in the fight against epilepsy matters. Where there is research, there is hope.

With much gratitude,

Beth

Beth Lewin Dean

“It always impressed me and touched my heart that Susan took a genuine interest in every family struggling with epilepsy. Susan and CURE Epilepsy have been an important psychological and emotional anchor for me and my family for the last 15 years.”

ROBIN STERN
NYC FRIEND OF CURE EPILEPSY
PARENT TO SCOTT, DIAGNOSED AT 20
NOW 36 LIVING WELL WITH EPILEPSY

“I first became aware of CURE Epilepsy in 2000 when I heard Susan Axelrod speak at the first White House-initiated Conference on Curing the Epilepsies. I will never forget her passionate call to action that challenged each of us in the research community to think beyond symptomatic treatment of epilepsy and look to the day when a cure might be possible.”

STEVE WHITE, PHD
PROFESSOR OF PHARMACY AND CO-DIRECTOR OF THE CENTER FOR EPILEPSY DRUG DISCOVERY, UNIVERSITY OF WASHINGTON, FORMER RESEARCH ADVISOR TO CURE EPILEPSY

FOUNDER’S SPOTLIGHT

SUSAN AXELROD

SCAN TO SHARE HOW SUSAN OR CURE EPILEPSY HAS IMPACTED YOUR LIFE.

“We’ve made so much progress since Susan founded CURE Epilepsy, but there’s still so much more to do for future generations. I just wish there were more options besides removing part of my daughter’s brain. I’m not sure where we’d be without Susan sitting down 25 years ago and realizing that living with epilepsy is not good enough. We’d certainly be lost.”

NORA HENNESSY
MOM TO CATHERINE, DIAGNOSED AGE 20 MONTHS NOW 6 YEARS OLD

“Twenty five years ago, I witnessed the birth of CURE Epilepsy as parents came together in their frustration over the inability to stop their children’s seizures. It was this frustration that drove Susan Axelrod and others to champion foundational research into the causes of epilepsy that would open the door for discoveries leading to better treatments and cures.”

MICHAEL SMITH, MD
DIRECTOR OF THE EPILEPSY CENTER, RUSH UNIVERSITY MEDICAL CENTER, FOUNDING BOARD MEMBER OF CURE EPILEPSY

“Cures are out there, and CURE Epilepsy is determined to find them. I have faith it will be because of leaders like Susan Axelrod. Susan inspires hope in me and all the people she touches. Susan, thank you for making our family’s epilepsy journey a little easier by being a true leader, a friend, the energy force behind CURE Epilepsy, and for spearheading the research that will one day lead to a cure.”

PHIL EMERY
FORMER CURE EPILEPSY BOARD MEMBER AND CHICAGO BEARS GM, PROUD FATHER TO DAUGHTER APRIL, DIAGNOSED AT AGE 7 AND NOW AGE 39

25 YEARS OF

DELIVERING IMPACT

1998

CURE Epilepsy is founded by Susan Axelrod and other parents desperate for answers to help their children impacted by epilepsy. The pioneers had a goal: to find a cure for this devastating disorder.

2002

CURE Epilepsy takes up research in acquired epilepsy by funding Dr. Annamaria Vezzani to study the role inflammation may play in epilepsy.

2005

To increase SUDEP awareness in the medical community, CURE Epilepsy and the American Epilepsy Society (AES) co-host the first SUDEP workshop at the annual AES meeting.

Before CURE Epilepsy's involvement, research gaps kept physicians from informing patients and caregivers about SUDEP. This workshop is a step toward broader information sharing and patient education.

2000

CURE Epilepsy is instrumental in establishing the first ever Curing the Epilepsies Conference by the National Institute of Neurological Disorders and Stroke (NINDS). This is the first time NINDS holds a conference about curing epilepsy.

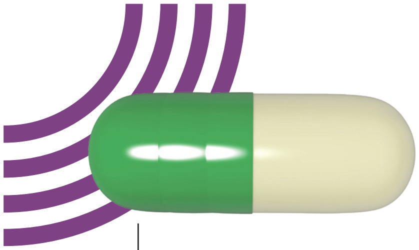
CURE Epilepsy funds its first two grants. These grants are the first of over 285 innovative projects CURE Epilepsy has funded in 18 countries since its inception.

2004

CURE Epilepsy's Sudden Unexpected Death in Epilepsy (SUDEP) Initiative breaks new ground as the first private research program dedicated to investigating SUDEP and its prevention.

SUDEP occurs when a seemingly healthy person with epilepsy dies for no known reason and is one of the most devastating possible consequences of epilepsy.

Friend of CURE Epilepsy Jeanne Donalty is key in driving this initiative after her son Christopher passed away due to SUDEP at the age of 20.



2006

A CURE Epilepsy-funded study provides evidence that Prozac® (fluoxetine) can reduce respiratory arrest in SUDEP-prone mice, paving the way for further research in this field by Dr. Carl Faingold and others.

CURE Epilepsy grantee Dr. Walter St. John shows that seizures can profoundly depress respiratory function in an animal model of epilepsy and potentially account for SUDEP.

2007

CURE Epilepsy starts its first multi-year, multi-investigator research program with funding from the Department of Defense to study Post-Traumatic Epilepsy (PTE).

This initial funding paves the way for future Congressionally Directed Medical Research Program Funds to be directed toward understanding PTE and its impact on veterans and civilians.

In addition to head injury, acquired epilepsy can also be linked to infections of the brain, an area that CURE Epilepsy has invested in.

2010

CURE Epilepsy is instrumental in creating the Interagency Collaborative to Advance Research in Epilepsy (ICARE). Led by NINDS, these annual meetings bring together government agencies, researchers, and patient advocates to discuss the state of epilepsy research, community needs, recent advances, and research grants.

CURE Epilepsy partners with NINDS to develop the Centers Without Walls (CWOW) concept.

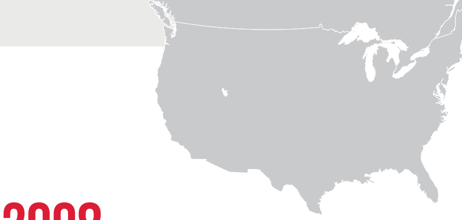
These centers promote collaboration and speed up the pace of epilepsy research.

2012

The Partners Against Mortality in Epilepsy (PAME) meeting is established with help from CURE Epilepsy. PAME's goal is to create broader SUDEP awareness by bringing together doctors, researchers, families, and advocates.

CURE Epilepsy plays a key role in publishing the first report on the prevalence of epilepsy, Epilepsy Across the Spectrum: Promoting Health and Understanding. Over 25 institutions came together to craft this now essential reading.

NIH National Institute of Neurological Disorders and Stroke



2008

CURE Epilepsy drives collaboration with NINDS to host the first scientific conference focused on SUDEP.

2009

SUDEP registries are established in the US and Canada thanks, in part, to funding from CURE Epilepsy.

CURE Epilepsy has since supported and advocated for other national registries for SUDEP.

2011

CURE Epilepsy grantee, Dr. Scott Baraban, establishes zebrafish as a new animal model for testing antiseizure medications. He subsequently discovers two FDA-approved drugs that could potentially reduce seizures in children with Dravet syndrome.

2014

The groundbreaking CURE Epilepsy Infantile Spasms Initiative begins, bringing an innovative team science approach to epilepsy research.

This multi-disciplinary approach is later applied to PTE research and helped secure funding from the Department of Defense in the following year.

NINDS works with CURE Epilepsy to establish a SUDEP CWOW, committing to fund $27.6 million in research over 5 years. This is the largest federal investment in SUDEP to date.

2015

CURE Epilepsy launches the Epilepsy Genetics Initiative (EGI), which connects patient data to physicians and researchers around the world.

Thirteen years after her first CURE Epilepsy funded project, Dr. Annamaria Vezzani discovers that the HMGB1 protein may be a biomarker of epileptogenesis in acquired epilepsy. CURE Epilepsy continues to fund grants exploring the protein's role in epilepsy development, prevention, and treatment, including research by Dr. Jin Xiaoming.

2016

EGI identifies a variant in the PPP3CA gene as a cause of epilepsy, giving physicians a new genetic cause to consider when diagnosing patients.

2017

A less invasive, more accurate method of recording electrical activity in the brain is developed thanks to CURE Epilepsy funding.

Dr. Flavia Vitale develops this diagnostic tool as a CURE Epilepsy Taking Flight grantee, kicking off her promising career.

CURE Epilepsy awards the first grants to study the interaction between sleep and epilepsy.

2019

CURE Epilepsy funds two additional research projects as part of the PTE initiative.

2020

CURE Epilepsy Catalyst, a new grant mechanism funding translational research, is introduced and awards its first two grants.

2021

The Cameron Boyce Foundation (CBF) establishes an enduring partnership with CURE Epilepsy by funding its second grant. The CURE Epilepsy CBF SUDEP Research Grant is awarded to Dr. David Auerbach to further our understanding of SUDEP.

EGI
EPILEPSY
GENETICS
INITIATIVE
A Signature Program of CURE

REN

2015

CURE Epilepsy and Illinois Senator Dick Durbin advocate to establish the Epilepsy Research Program at the Department of Defense. Congress directs $1.5 million toward studying PTE – funding that grew to $12 million annually in 2023.

CURE Epilepsy's PTE Initiative is awarded a five year, $10 million grant by the Department of Defense to study PTE using a team science approach.

2018

CURE Epilepsy grantee Dr. Annapurna Poduri discovers a link between an epilepsy gene and Sudden Infant Death Syndrome (SIDS), making the case for researching epilepsy genes as a cause of sudden death even in the absence of an epilepsy diagnosis.

2022

CURE Epilepsy partners with rare epilepsy organizations to build their research priorities and programs and jointly fund research to develop critical knowledge and cures for rare epilepsies.

2023

CURE Epilepsy is awarded a $1.29 million grant and launches the PTE Astrocyte Biomarker Initiative, which will use a team science approach to study potential biomarkers for PTE development, focusing on the role of a brain cell known as an astrocyte.

AS WE CELEBRATE 25 YEARS OF LEADING, COLLABORATING, AND INNOVATING, OUR COMMITMENT TO CURING EPILEPSY IS STRONGER THAN EVER.

Ella and Shalee Cunneen at the 2022 Ella's Race to CURE Epilepsy

WE ARE LEADERS

CURE Epilepsy began because a group of parents dreamed of a future when their children would no longer be impacted by epilepsy. Their unwavering pursuit of better – better research, better treatment, better outcomes – set the vision for CURE Epilepsy and our belief that managing epilepsy's symptoms isn't enough.

Today, we're the leading non-governmental funder of epilepsy research in the world. But 25 years ago, we were a small, passionate group of people who dared to believe that a cure was possible. All these years later, our unrelenting focus has opened doors to more: more research that advances our understanding of the disease, more awareness and funding, and more progress toward a world without epilepsy.

IN 25 YEARS OF RESEARCH, CURE EPILEPSY HAS:

AWARDED

285+ GRANTS

IN 18 COUNTRIES WORLDWIDE

RAISED

$90,000,000+

TO FIND A CURE

LEAVE YOUR MARK ON OUR NEXT 25 YEARS

Beth Dean (CEO), 2007 Grantee Anne Anderson, MD, and Susan Axelrod

HOW WE LEAD

1998

Susan Axelrod and other parents found CURE Epilepsy as they desperately search for answers to help their children and others impacted by epilepsy.

2000

CURE Epilepsy partners with the National Institute of Neurological Disorders and Stroke (NINDS) to launch the Curing the Epilepsies Conference.

LEADERS

WHO DEFINED THE RESEARCH AGENDA FOR THE EPILEPSY COMMUNITY

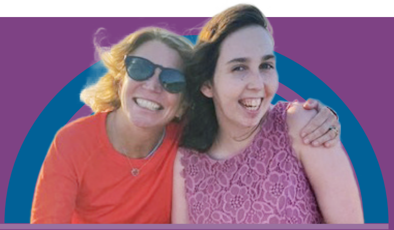
Our vision is simple: a world without epilepsy. But getting there requires a strategic balance of research, funding, and community.

In our first 25 years, we've brought together researchers, elevated awareness, secured funding, and increased our commitment for the cures. When all of these forces work together, breakthroughs happen.

And while we've witnessed many of those breakthroughs over the last two and a half decades, people like Stacy Dodd remind us that we cannot stop until we find cures.

RESEARCHING FOR…

Stacy



In February 1999, Stacy cried out. Her parents found her limp and moaning. They gave her Tylenol, thinking she was getting sick. By noon that day, Stacy had been rushed to the hospital with a seizure that lasted 45 minutes. She was just 7 months old.

In the years since, Stacy has had over a thousand seizures, sometimes over a hundred in one day. Her parents searched for answers until 2007, when she was diagnosed with Dravet syndrome, a progressive form of epilepsy defined by severe and uncontrolled seizures and developmental delays. Stacy and her parents have yet to find a medication that fully controls her seizures.

Stacy is why we fund research. Our unwavering focus is how we will find a solution that can help Stacy and people like her live seizure-free.

"We will never give up. And our work will not be done until we have helped find a cure for epilepsy." – Bob and Kathy Dodd

> "I've been caring for patients and doing research in pediatric epilepsy for most of the past 30 years. During that time, I've seen an incredible transformation in pediatric epilepsy, and I credit CURE Epilepsy for being one of the major driving forces in that transformation.
>
> DOUGLAS NORDLI, MD,
> PROFESSOR AND CHIEF OF CHILD
> NEUROLOGY AT UNIVERSITY OF CHICAGO

2005

CURE Epilepsy encourages information-sharing between physicians and patients at the first SUDEP Workshop at the American Epilepsy Society.

2008

CURE Epilepsy drives collaboration with NINDS to host the first scientific SUDEP conference.

2009

SUDEP registries are established in the US and Canada, thanks in part to funding by CURE Epilepsy.

LEADERS

WHO ADAPTED GRANTMAKING TO KEEP UP WITH THE LATEST SCIENCE

Everything we do is focused on making a difference in the lives of people with epilepsy and their loved ones – but that difference depends on continued progress toward a cure.

As our understanding of epilepsy has evolved, so has the research landscape. Our grant mechanisms are designed to drive scientific progress by expanding both the types of epilepsy we research and how that research happens.

CATALYST AWARD

As one of our first Catalyst grantees, Dr. James O. McNamara, and his team built on their work from a previous CURE Epilepsy grant to investigate a novel peptide, pY816, that may prevent the development of Temporal Lobe Epilepsy (TLE), a common form of epilepsy marked by recurring seizures. Dr. McNamara is now working to develop pY816 as a novel therapy for drug-resistant TLE. Dr. McNamara's work is generously supported by the Robert Withrow Wier Fund.

> “The resources and flexibility afforded by the CURE Epilepsy Catalyst program enable researchers an opportunity to jump-start the long, complex path from lab discovery to clinic. The design and implementation of this program will reap rich dividends for the field.
>
> JAMES MCNAMARA, MD,
> DUKE SCHOOL OF MEDICINE
> DISTINGUISHED PROFESSOR IN
> NEUROSCIENCE, FIRST CATALYST AWARDEE

SLEEP & EPILEPSY AWARD

Many people with treatment-resistant epilepsy also experience sleep disruptions, a connection that was once overlooked. The CURE Epilepsy Sleep & Epilepsy Award, funded by the BAND Foundation, supported research like that of Dr. Franck Kalume. In 2017, he received a grant to study environmental factors that impact sleep and may increase SUDEP risk.

Dr. Kalume discovered that even small changes in eating and exercise improved sleep quality and reduced seizures in mice with similarities to Dravet syndrome, laying the groundwork for future interventions that might reduce the risk of – and even prevent – SUDEP.

HOW WE LEAD

2010

CURE Epilepsy partners with NINDS to develop the Centers Without Walls concept to speed up the pace of epilepsy research through collaboration.

2012

CURE Epilepsy and 25 fellow institutions publish a landmark epilepsy report, “Epilepsy Across the Spectrum: Promoting Health and Understanding.”

RARE EPILEPSY PARTNERSHIP AWARD

Rare diseases are those that impact fewer than 200,000 people in the United States. Many epilepsies are rare or even ultra-rare and were only identified within the past five to ten years. People impacted by these epilepsies are still awaiting answers, which is why we've partnered with several rare epilepsy organizations to co-fund one-year, $100,000 grants for research into rare epilepsies. Through these grants, researchers will develop:

- Rare epilepsy-specific cellular and animal models
- Novel assays and techniques to accelerate rare epilepsy research
- Research tools and data collection platforms that lead to a better understanding of rare epilepsies

Our inaugural funding cycle of this award is made possible by the Robert Withrow Wier Fund.

RESEARCH CONTINUITY FUND

Our research community faced many challenges during the pandemic, many of which stopped research programs in their tracks. We swiftly responded by providing $15,000 to researchers through the Research Continuity Fund, made possible by the generous support of the Cotton Family, in memory of Vivian Cotton. This helped grantees cover costs that would have otherwise inhibited their research, including the increased cost to comply with COVID-19 health and safety standards in their labs.

OUR 2022 RARE EPILEPSY PARTNERS

SCN8A EPILEPSY
The Cute Syndrome© FOUNDATION
www.TheCuteSyndrome.com

Dup15q Alliance
FOR 15Q 11.2-13.1 MULTIPLICATIONS

KDVS
Koolen-de Vries Syndrome Foundation

2012

CURE Epilepsy helps establish the Partners Against Mortality in Epilepsy conference to drive understanding and awareness of epilepsy-related mortality, including SUDEP, within the epilepsy community.

2014

NINDS, with the encouragement of CURE Epilepsy, establishes a SUDEP Center Without Walls to fund $27.6 million in research over 5 years — the largest federal SUDEP investment to date.

LEADERS

WHO HAVE TRANSFORMED OUR UNDERSTANDING OF EPILEPSY

Epilepsy has no borders. Approximately 65 million people around the world are affected by epilepsy, all of whom deserve freedom from seizures, from side effects, from stigma, and from discrimination.

In our 25 years, we've funded research that pushes the boundaries on what we know about epilepsy so that millions of people and their caregivers can finally live without worry about when a seizure will strike.

Left to Right: Cameron Boyce, Andriana, Joanna Sophia, and Isobella Ioannou, Jeanne Donalty

RESEARCH SPOTLIGHT: SUDEP

Sudden Unexpected Death in Epilepsy (SUDEP) occurs when a seemingly healthy person with epilepsy dies for no known reason. More than 3,000 children and adults with epilepsy die of SUDEP every year, but many more deaths are believed to go unreported.

Thanks to the determination of volunteers like Jeanne Donalty, who lost her son Christopher to SUDEP, we launched the first-ever private research program in 2004 to investigate SUDEP and its prevention. Twenty years later, dedicated partners like the Cameron Boyce Foundation, the Joanna Sophia Foundation, and HOPE4SUDEP.org, organizations founded by families who lost a loved one to SUDEP, continue to fund research that pushes our understanding of SUDEP forward as we get ever closer to preventing it.

AWARDED
$5.6 MILLION FOR
39 SUDEP PROJECTS TO DATE

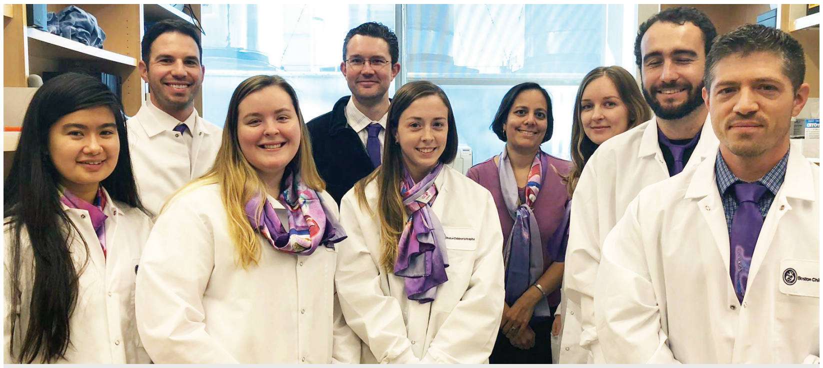
HOW WE LEAD

2017

CURE Epilepsy awards the first grants to study the interaction between sleep and epilepsy.

2018

CURE Epilepsy grantee Dr. Annapurna Poduri discovers a link between an epilepsy gene and Sudden Infant Death Syndrome (SIDS) — spurring research into epilepsy genes as a cause of sudden death.


Dr. Annapurna Poduri and the Boston Children's Epilepsy Genetics Team

RESEARCH BREAKTHROUGHS

A POTENTIAL GENETIC LINK BETWEEN EPILEPSY AND SUDDEN DEATH IN CHILDREN

In 2017, we awarded Dr. Annapurna Poduri at Boston Children's Hospital with the CURE Epilepsy Award, generously funded by the Isaiah Stone Foundation. One year later, Dr. Poduri and her team found a potential genetic link between epilepsy and sudden death – a link that could catalyze future research to understand the possible causes and prevention of sudden deaths.

FIRST REGISTRY SHOWS SUDEP MORE COMMON IN CHILDREN THAN PREVIOUSLY THOUGHT

SUDEP accounts for 34% of all sudden deaths in children with epilepsy – yet no registry previously existed to help better understand the risk factors and causes of SUDEP. As part of our SUDEP Initiative supported by the Henry Lapham Memorial Award, Dr. Elizabeth Donner created one in 2009 to collect SUDEP data across Canada. Registry data shows that 1.11 of 1,000 children with epilepsy die suddenly each year – four times higher than previous estimates.

PEOPLE WITH EPILEPSY SHOW SIGNS OF ACCELERATED BRAIN AGING

Little is known about how brain function may change as people with epilepsy age. In 2013, Drs. Bruce Hermann and Matti Sillanpää used a $50,000 CURE Epilepsy grant to conduct a population-based study of individuals 55 years after their epilepsy diagnosis. They discovered signs of accelerated brain aging and identified the risk factors that predict problematic brain aging outcomes – both of which highlight the need for expanded treatment options and seizure control.

LEADING THE RESEARCH CONVERSATION

CURING THE EPILEPSIES CONFERENCE

Since 2000, we've collaborated with the National Institute of Neurological Disorders and Stroke (NINDS) to host this federal conference focused on finding cures by furthering our understanding of epilepsy and prioritizing a research strategy that puts patients first.

CENTERS WITHOUT WALLS

In 2010, we inspired the creation of the Centers Without Walls concept in partnership with NINDS to fill research gaps through team science. Centers Without Walls promotes collaborative research and encourages data-sharing between researchers and institutions.

PARTNERS AGAINST MORTALITY IN EPILEPSY (PAME)

In 2012, CURE Epilepsy helped to found PAME, a multi-stakeholder conference to make progress on research to prevent deaths related to epilepsy, including those from suicide, status epilepticus, and SUDEP.

2020

CURE Epilepsy introduces the Catalyst Award, a new grant funding translational research to convert scientific breakthroughs into new treatment options.

2022

CURE Epilepsy partners with rare epilepsy organizations to jointly fund research into epilepsies affecting fewer than 200,000 people.

WE ARE COLLABORATORS

Over the past 25 years, CURE Epilepsy has blazed a trail toward the cure. But we haven't done it alone. Collaboration has been in our DNA from the start, when a small group of parents banded together to support each other in the quest to eliminate epilepsy.

Ever since, we've walked in their footsteps, uniting both the patient and scientific community to learn more about the epilepsy research we've already done, raise funds to support the epilepsy research to come, and, ultimately, empower epilepsy investigators to make a difference for future generations of people with epilepsy.

THEN:

3 FOUNDING MOTHERS

NOW:

290+ PRIMARY INVESTIGATORS FUNDED

1000+ GRASSROOTS FUNDRAISERS

100,000+ MEMBERS OF OUR ONLINE COMMUNITY

LEAVE YOUR
MARK ON OUR
NEXT 25 YEARS

Kelly, Miguel, Jackson, and Adelaide Cervantes

HOW WE COLLABORATE

2000

CURE Epilepsy funds its first two grants – the first of over 285 innovative projects we've funded in 18 countries since inception.

2007

CURE Epilepsy launches its work on PTE through a grant from the federal government. The Department of Defense funding paves the way for future PTE research.

COLLABORATORS

WHO UNLEASHED THE POWER OF TEAM SCIENCE

A breakthrough for one is a breakthrough for all. When researchers and institutions work together and share their findings, they make it possible for multiple projects to work in tandem to advance science beyond the bounds of a single research initiative.

That's why we don't just fund research. We facilitate the collaboration it takes to translate scientific findings into life-changing policies, practices, and treatments.

COLLABORATING FOR THE CURE

INFANTILE SPASMS INITIATIVE

Infantile spasms (IS) cause clusters of short seizures and an irregular pattern of brain activity in babies. The seizures are so subtle that they're difficult to diagnose; they also have far-reaching consequences and are challenging to treat. In response, we launched the first-ever team science approach in the epilepsy research community, called the Infantile Spasms Initiative.

Eight research teams from different institutions worked together to study the pathology of IS by examining its basic underlying biology, biomarkers, and novel drug targets – all of which help advance the science for potential new treatments for some of epilepsy's youngest patients.

THE INFANTILE SPASMS INITIATIVE PUBLISHED

19 TEAM PAPERS

TO SHARE FINDINGS WITH FELLOW RESEARCHERS

SECURED

$4.4 MILLION IN FUNDING FROM

THE NATIONAL INSTITUTES OF HEALTH

POST-TRAUMATIC EPILEPSY INITIATIVE

Post-traumatic epilepsy (PTE) is unpredictable. It's a recurrent seizure disorder that occurs after a traumatic brain injury (TBI). But it can take weeks or months for seizures to appear, and there's still no way to prevent the condition.

With $10 million in funding from the Department of Defense, the PTE Initiative is leveraging a multi-center, multi-investigator research team to make a difference for people with PTE. Its work is allowing us to understand biomarkers that could reveal who will develop PTE after TBI, laying the groundwork for the creation of novel therapies for PTE.

POST-TRAUMATIC EPILEPSY ASTROCYTE BIOMARKER INITIATIVE

Through this initiative, CURE Epilepsy will build on the work of our PTE Initiative to examine how star-shaped cells in the central nervous system called astrocytes contribute to the transition from TBI to PTE. We hope to better understand how PTE develops following TBI, advance PTE research, and eventually make it possible to identify PTE risk factors and develop preventative therapies and treatments.

2010

CURE Epilepsy is instrumental in creating the Interagency Collaborative to Advance Research in Epilepsy (ICARE) with NINDS to discuss the state of epilepsy research.

2014

The groundbreaking CURE Epilepsy Infantile Spasms Initiative begins, bringing an innovative team science model to epilepsy research.

COLLABORATORS

WHO PUT PATIENTS AT THE CENTER OF THE GRANTMAKING PROCESS

People with epilepsy are the reason why we research, why we advocate, and why we strive to represent the voices of people with epilepsy in our work and the work of the community.

Our grant review process is rigorous as well as collaborative, gathering input both from scientific experts and members of our lived-experience community. When we leverage both professional expertise and real-world experience, we identify research that has the potential to reach out of the lab and into the lives of people with epilepsy.

RESEARCHING FOR…

Serafina

Some time around her birth, Serafina had a stroke that would impact her life in ways even her doctors could not have predicted.

At just seven months old, Serafina developed infantile spasms. Steroids treated her seizures at first, but that didn't last. Once she turned four, her seizures became harder to stop. Nothing helped – not higher dosages of medications, not new medications, not specialists or sub-specialists, not even specialized epilepsy centers.

Two years and three brain surgeries later, Serafina is currently seizure free, but her parents are still committed to advancing research for the cure. They dream of a day when no child or parent experiences the fear and heartache they have due to epilepsy.

The most important thing for my family moving forward is research. While this surgery has worked so far for Serafina, there are many, many kids who don't even have a surgical option. Those kids need our help."
– Francesca Calloway

> “As a parent of a patient with treatment resistant epilepsy, I feel it is important as a lay reviewer to emphasize to the scientific board CURE's research mission of funding novel, innovative research grants. It is the success and the knowledge acquired with these cutting edge projects that lead to larger scaled basic and clinical research, greatly amplifying the effectiveness of the research dollars we have invested.
>
> **JAMES SCHNEIDER,**
> **PROUD PARENT OF JULIE (38),**
> **FUNDER OF JULIE'S HOPE AWARD**
> **(2007, 2011, 2013, 2016)**

HOW WE COLLABORATE

2015

The Department of Defense awards CURE Epilepsy a 5-year, $10 million grant for its team science PTE Initiative, which seeks to develop new research models and biomarkers.

2015

CURE Epilepsy launches the Epilepsy Genetics Initiative to deepen our understanding of genetic causes of epilepsy by sharing epilepsy genetic data from around the world.

COLLABORATORS

WHO ACCELERATED EPILEPSY RESEARCH THROUGH DATA SHARING

Nearly 50% of people with epilepsy don't know the cause. And while research into epilepsy genetics is rapidly evolving, it advances faster when researchers and their findings come together.

As often as we're funding research, we're also looking for opportunities to compound that research – to see how data from around the world may be more meaningful together than it was apart.

EPILEPSY GENETICS INITIATIVE

With funding from the John and Barbara Vogelstein Foundation, the Epilepsy Genetics Initiative (EGI) created a database that holds genetic (whole exome sequence) data so people with epilepsy can understand the cause of their epilepsy.

From 2015 to 2020, people with epilepsy who had their whole exomes sequenced in a diagnostic lab but didn't receive a diagnosis could submit their data to EGI. The anonymized data was analyzed every six months and will continue to be analyzed by researchers around the world so we can continue to advance the study of epilepsy genetics and, one day, develop customized treatments for epilepsy syndromes based on the gene involved.

1,108 PATIENTS AND FAMILY MEMBERS ENROLLED IN EGI AT THE END OF THE STUDY

364 PATIENTS IN EGI DID NOT HAVE A CLEAR DIAGNOSIS

34 PATIENTS FOR WHOM EGI HAS PROVIDED NEW OR MODIFIED GENETIC DIAGNOSES

RESEARCHING FOR…

Joey

Joey Gomoll would have turned 18 in April 2023. Instead, April marked 13 years since he died after battling Dravet syndrome, a rare form of epilepsy that comes with persistent, uncontrollable seizures.

His parents, Mike and Nory, remember him as a fun, music and dance-loving kid. Every year, they honor that memory through Joey's Song, a benefit concert and celebration that raises funds for critical epilepsy research.

Joey may be gone, but his parents remain committed to finding a cure so that no one else has to experience the grief that they did.

"Our goal is to help the next family. Someday they're going to find a cure for Dravet's, and you will never convince me that our contributions didn't buy the test tube that was used to unlock the cure." – Mike Gomoll

2016

EGI uses its database to identify a variant in the PPP3CA gene as a cause of epilepsy, giving physicians a new genetic cause to consider.

2018

CURE Epilepsy catalyzes the PTE Initiative by funding four promising multi-investigator, multi-center research projects.

2019

Researchers continue to collaborate through the PTE Initiative with two additional research projects funded by CURE Epilepsy.

WE ARE
INNOVATORS

Innovation is multi-faceted. It challenges scientists to think about epilepsy in new and exploratory ways, while urging us to deliver funding that makes innovation possible. But it's also about evolving the mechanisms that surround epilepsy – research, diagnosis, and treatment – so that innovation doesn't end with the science but goes on to benefit people with epilepsy.

In our first 25 years, we've driven change by establishing grants that encourage young investigators to join our field and by funding novel ideas so researchers can generate the data they need to secure even larger grants. It is through these approaches that we'll achieve breakthroughs and, eventually, find a cure.

50

EARLY INVESTIGATORS FUNDED THROUGH 2022

$4,975,000

IN FUNDING AWARDED TO EARLY INVESTIGATORS THROUGH 2022

LEAVE YOUR
MARK ON OUR
NEXT 25 YEARS

CURE Epilepsy Grantees Alica Goldman, MD, PhD and Jeff Noebels, MD, PhD

HOW WE INNOVATE

2002	2004
CURE Epilepsy takes up research in acquired epilepsy by funding Dr. Annamaria Vezzani to study the role inflammation may play in epilepsy.	CURE Epilepsy's SUDEP Initiative breaks new ground as the first private research program dedicated to investigating SUDEP and its prevention.

INNOVATORS

WHO LAUNCHED A NEW GENERATION OF RESEARCHERS

Paradigm-shifting epilepsy research depends on young investigators. But they can't pursue their careers or their groundbreaking ideas without funding. Our epilepsy grants attract young investigators to the field, helping them build careers centered around epilepsy.

We introduced the Taking Flight Award in 2011 to support early-career scientists as they pursue ideas that can make real change for people with epilepsy. Many of these investigators go on to secure larger grants from other funders including the federal government, make significant contributions to the understanding of epilepsy, and return to mentor the next generation of researchers.

NEW INSIGHTS INTO THE PROGRESSION OF EPILEPSY

When seizures develop, it changes the brain's white matter, which is the densely packed collection of axons (nerve fibers) and the myelin sheath that both insulates them and helps them transmit electrical signals.

Dr. Juliet Knowles used funding from her Taking Flight Award, made possible by the Ravichandran Foundation, to demonstrate that a change in myelin accompanied absence seizures in animal models. Dr. Knowles discovered:

- Abnormal brain activity during absence seizures may lead to changes in myelination.
- The changes in myelin may, in turn, lead to seizure progression.
- Future studies could investigate whether preventing changes in myelin could effectively treat some forms of epilepsy, like Lennox-Gastaut syndrome (LGS), where seizures typically increase despite treatment.

With a $250,000 CURE Epilepsy Award funded by the Isaiah Stone Foundation, Dr. Knowles and her team will build on their findings to study therapeutic interventions in a model of LGS.

RESEARCHING FOR…

Adam

Years ago, Sara Todd returned from a run to hear her husband say into the phone, "OK, he's breathing now." Adam had experienced his first seizure.

He had another seizure a week later and was diagnosed with epilepsy. A more specific diagnosis followed: LGS, an epilepsy syndrome that leads to developmental and/or intellectual delay.

Adam is now 24 years old. Though Adam has faced many challenges, he also lives a full life, attending a day habilitation program and playing softball with his peers.

Because of research, Adam and his family now know the cause of his LGS: a rare genetic mutation. They still hope that more research — like Dr. Knowles' — will deliver life-changing discoveries to Adam and patients like him.

2006

CURE Epilepsy grantee Dr. Walter St. John shows seizures can depress respiratory function in an animal model of epilepsy and may account for SUDEP.

2006

A CURE Epilepsy-funded study by Dr. Carl Faingold suggests that Prozac® (fluoxetine) can reduce respiratory arrest in SUDEP-prone mice, leading to continued research by Dr. Faingold and others.

INNOVATORS

WHO CHAMPIONED RESEARCH THAT COULD PREVENT EPILEPSY

What if we could stop epilepsy before it starts? What if millions of people with epilepsy and their families around the world never felt the devastating impact of unpredictable and incurable seizures?

CURE Epilepsy has worked toward that world for the past 25 years. As important as it is to cure epilepsy in patients who are already affected, we also need to find ways to prevent epilepsy before it develops – which could spare millions of people from ever experiencing a seizure.

KEY DISCOVERIES

STOPPING ACQUIRED EPILEPSY BEFORE IT STARTS

Our novel epilepsy research has an unrelenting focus on acquired epilepsy and finding a biomarker that can indicate whether a person is likely to develop seizures. CURE Epilepsy researcher Dr. Annamaria Vezzani and her team found one: HMGB1, a protein the brain releases in response to injuries, trauma, or infections, such as those that might lead to epilepsy.

Using an animal model of brain injury and epilepsy, Dr. Vezzani found that high HMGB1 levels might be measured as a sign of impending epilepsy. How might that stop epilepsy? Dr. Vezzani also discovered a combination of drugs that prevented the increase of HMGB1 levels, delayed the onset of epilepsy, blocked the progression of the disease, and eliminated impairments in memory.

PREDICTING ACQUIRED EPILEPSY FOLLOWING A BRAIN INFECTION

Individuals who contract cerebral malaria are at an increased risk of developing epilepsy, but there are no methods to predict or prevent it. CURE Epilepsy grantees Dr. Bruce Gluckman and Dr. Steven Schiff discovered that in a mouse model of malaria-induced epilepsy, mice that developed epilepsy experienced abnormal brain activity immediately followed by abnormal heart activity — a potential biomarker for epileptogenesis. This discovery may lead to the prevention of not only post-malarial epilepsy, but other forms of brain injury-induced epilepsy.

> “We sought to create the first animal model of post-malarial epilepsy with the support we received from CURE Epilepsy. Such an experimental platform now gives us the potential framework to study better ways of preventing the development of epilepsy in children with malaria, which would have a very substantial impact on millions of children worldwide.
>
> STEVEN SCHIFF, MD, PHD,
> VICE CHAIR FOR GLOBAL HEALTH
> IN NEUROSURGERY, YALE UNIVERSITY
> SCHOOL OF MEDICINE

HOW WE INNOVATE

2007

CURE Epilepsy researchers Drs. Steve White and Robert Fujinami discover that inflammation in the brain can cause infections that are a risk factor for acquired epilepsy.

2011

With CURE Epilepsy funding, Dr. Scott Baraban develops a new animal model – Zebrafish – to discover two FDA-approved drugs that could potentially reduce seizures in Dravet syndrome.

INNOVATORS

WHO DROVE THE DEVELOPMENT OF NEW EPILEPSY TREATMENTS

We know that every seizure damages the brain. As we innovate, we remain laser-focused, both on the cure and on developing treatments that help eliminate seizures and the devastating complications they cause.

While we work aggressively to find cures, we know that each study that we fund moves us one step closer to a world without epilepsy. It's studies like these that build on the first 25 years of CURE Epilepsy and give us confidence in the breakthroughs we'll make in the years to come.

INHIBITING A BRAIN ENZYME PREVENTS THE DEVELOPMENT OF EPILEPSY

"Acquired" epilepsies are those that develop following a severe concussion, brain infection, fever-induced seizure, or stroke. These conditions often lead to epilepsy because brain injuries trigger a series of events that elevate adenosine kinase (ADK) levels. ADK is an enzyme that regulates a naturally-occurring substance called adenosine (ADO) in the brain. ADO reduces neuronal activity in the brain and protects the DNA from changes that can lead to the development of epilepsy. ADK can prevent ADO from doing its job and reducing neuronal activity. Dr. Detlev Boison and his team built on their work from two previous CURE Epilepsy grants from 2009 and 2013 to uncover:

- An ADK inhibitor called 5-ITU increases ADO levels in the brain and prevents seizures — suggesting it could be a preventative treatment for some epilepsies.
- Short-term use of 5-ITU prevents epilepsy from developing 100% of the time in mouse models of acquired epilepsy.

Dr. Boison is now working to optimize and test a disease-modifying therapy suitable for clinical trials, while his groundbreaking work draws attention and funding from across our community.

SINCE 2020, WE'VE LEVERAGED OUR CATALYST AWARD TO DEDICATE:

9 GRANTS

TO SUPPORT TREATMENT-FOCUSED RESEARCH

$1.2 MILLION

IN TOTAL FUNDING FOR TREATMENT-FOCUSED RESEARCH

2015

Dr. Annamaria Vezzani discovers that the HGMB1 protein biomarker may indicate whether a person will develop acquired epilepsy and may be a target for future treatments.

2017

Taking Flight grantee Dr. Flavia Vitale develops a less invasive, more accurate method to diagnose epilepsy by recording electrical activity in critical layers of the brain.

MEET THE FIRST GRANTEES OF OUR NEXT 25 YEARS

We've led, collaborated, and innovated throughout our first 25 years to advance our understanding of epilepsy and inch ever closer to a cure. With our most recent class of grant recipients, we take a step into our next 25 years and toward a world without epilepsy.

CATALYST AWARD

A two-year, $250,000 grant to fund research supporting the nimble development of new transformative therapies.

SANGMI CHUNG, PHD
NEW YORK MEDICAL COLLEGE

iPSC-Derived Hypoimmunogenic Human Migratory Cortical Interneurons To Treat Intractable Epilepsy

Dr. Sangmi Chung's team is advancing the knowledge about how transplanting cortical interneurons suppress seizures and comorbidities in a mouse model of epilepsy. The team will advance this therapy toward clinical applications by studying the minimal dose of cells and the optimal transplantation location in the brain needed for seizure control.

This grant is generously supported by the Robert Withrow Wier Fund.

SHILPA KADAM, PHD
AXONIS THERAPEUTICS, INC.

Preclinical Testing of Oral KCC2-Potentiator Drug AXN-006-01-3 To Rescue Phenobarbital-Resistant Neonatal Seizures

HIE, Hypoxic (lacking oxygen) Ischemic (restricting blood flow) Encephalopathy (affecting brain), is the most common cause of seizures in newborns. Dr. Kadam and her team are studying how a novel antiseizure medication which increases the function of an important brain protein called KCC2 can treat refractory neonatal seizures and prevent epileptogenesis.

This grant is generously supported by the Robert Withrow Wier Fund.

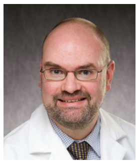
SUZANNE PARADIS, PHD
BRANDEIS UNIVERSITY

A Gene Therapy Approach to Treating Pharmacoresistant Epilepsy

Runaway excitation in neural circuits (sites of cell-cell contact) are a hallmark of seizures. Dr. Paradis and her team are studying a protein called Sema4D (Semaphorin 4D) that rapidly inhibits excitation in the brain. The team will test the safety and efficacy of using gene therapy to deliver Sema4D as a novel and potentially disease-modifying therapy for drug-resistant epilepsy.

CURE EPILEPSY AWARD

A two-year, $250,000 grant to fund scientific advances that have the potential to transform the lives of those affected by epilepsy, with prevention and disease modification as critical goals.



GORDON BUCHANAN, MD, PHD
UNIVERSITY OF IOWA MEDICINE

Nighttime Mechanisms for SUDEP

Emerging data suggest that time of day may play a role in SUDEP, the leading cause of death in people with treatment-resistant epilepsy. Dr. Buchanan's group will examine whether serotonin drives this time of day vulnerability to SUDEP by studying the effect of eliminating the body's 24-hour clock or removing serotonin on the timing of seizure-induced death.

This grant is generously supported by the Joanna Sophia Foundation.

ANNAELLE DEVERGNAS, PHD
EMORY UNIVERSITY

Implication of the Pedunclopontine Nucleus in Comorbid Sleep Disorders

A brain structure called the pedunculopontine nucleus (PPN) is known to control arousal and regulation of rapid eye movement. Dr. Devergnas and her team will study whether frontal lobe seizures disrupt the normal function of the PPN, leading to changes in sleep, and that manipulating PPN activity might restore normal sleep activity.

JULIET KNOWLES, MD, PHD
STANFORD SCHOOL OF MEDICINE

Targeting Maladaptive Myelination in Lennox-Gastaut Syndrome (LGS)

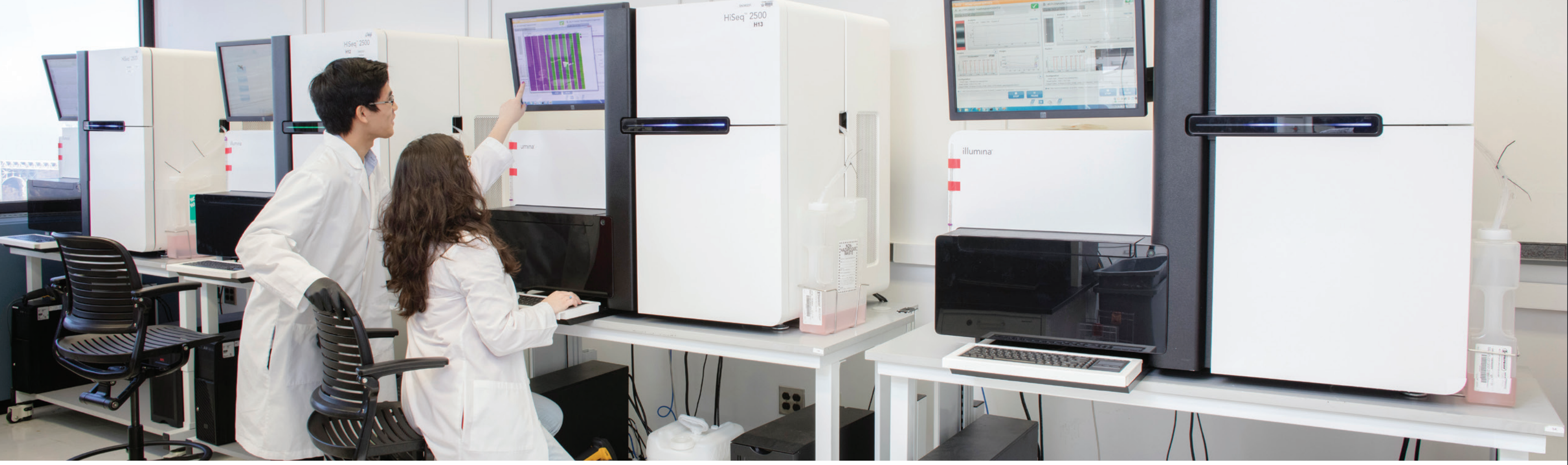
Dr. Juliet Knowles and her team previously demonstrated that a change in the white matter (myelin) of the brain contributed to the progression of typical absence seizures in LGS. For this project, the team will study whether the drug HDACI can prevent myelin changes and seizure progression to help identify a possible therapy for LGS.

This grant is generously supported by the Isaiah Stone Foundation.

MAXIME BAUD, MD, PHD
UNIVERSITY OF BERN

Forecasting Seizure Cycles in People With Genetic Generalized Epilepsy

Recurring and seemingly unpredictable seizures are hallmarks of genetic generalized epilepsies. Dr. Baud's group recently developed a method to accurately forecast seizure risk in focal epilepsy using EEG recordings from implants in the brain. They'll examine whether a similar approach could forecast seizures in genetic generalized epilepsy, which could eventually help people manage their seizures and improve their quality of life.



TAKING FLIGHT AWARD

A one-year, $100,000 grant to promote the careers of young epilepsy investigators to allow them to develop a research focus independent of their mentor(s).

JEFFREY CALHOUN, PHD
NORTHWESTERN UNIVERSITY

Massively Parallel Reporter Assays To Reveal Noncoding Variant Contribution in Epilepsy

The impact of genetic variants in non-coding regions of epilepsy-associated genes is not well studied. Dr. Calhoun will use a new approach to test whether non-coding variants identified in the sodium voltage-gated channel alpha subunit 1 (SCN1A) gene can impact its function and contribute to epilepsy risk and could lead to novel treatments.

This grant is generously supported by the Joseph Gomoll Foundation.

WILLIAM TOBIN, PHD
UNIVERSITY OF VERMONT

Optimizing Precision Treatment Targeting for Genetic Epilepsy

Gain-of-function mutations in the KCNT1 gene, which makes a widely expressed ion channel called a sodium-activated potassium channel, cause severe childhood epilepsies. Using a mouse model of KCNT1 epilepsy, Dr. Tobin and his team will test whether therapies can be improved by restricting them to severely affected cells and brain areas.

This grant is co-funded with the KCNT1 Foundation.

GERBEN VAN HAMEREN, PHD
DALHOUSIE UNIVERSITY

Mitochondria Function as a Target in Post-Traumatic Epilepsy

Traumatic brain injury (TBI) increases the risk of developing post-traumatic epilepsy (PTE). This project will focus on understanding how spreading electrical activity (depolarization) after a TBI can lead to PTE by inducing mitochondrial dysfunction and could define the relationship between the acute spreading of depolarization after TBI and the development of epilepsy later in life.

RARE EPILEPSY PARTNERSHIP AWARD

A one-year, $100,000 grant to support the development of necessary tools, techniques, model systems, and data collection platforms to stimulate research on rare epilepsies.

THESE INAUGURAL AWARDS ARE MADE POSSIBLE THANKS TO THE GENEROUS SUPPORT OF THE ROBERT WITHROW WIER FUND.

HANS VAN BOKHOVEN, PHD
STICHTING RADBOUD UNIVERSITAIR MEDISCH CENTRUM (RADBOUDUMC)

Increasing KANSL1 Expression Through Modulation of Endogenous Anti-Sense RNAs

In Koolen de Vries syndrome (KdVS), the loss of one copy of the KANSL1 gene leads to reduced levels of KANSL1, a protein that supports DNA regulation. Dr. van Bokhoven will restore normal KANSL1 levels by using different genetic techniques to increase the activity of the normal copy of the gene still present in people with KdVS and investigate whether these increased levels can help form normal neural networks.

This grant is co-funded with the KdVS Foundation.

YPE ELGERSMA, PHD
ERASMUS UNIVERSITY MEDICAL CENTER

Characterization of a Novel Dup(Atp10a-Tub5gcp5) 'Dup15q' Mouse Model With Varying Levels of UBE3A

Dup15q syndrome is a neurodevelopmental disorder caused by duplications of a region on chromosome 15, often resulting in intellectual disability and intractable epilepsy. Dr. Elgersma's team proposes to study the interaction and dose effect of these genes to help develop tools for studying the syndrome and testing future therapies.

This grant is co-funded with the dup15q Foundation.

JILLIAN MCKEE, MD, PHD
THE CHILDREN'S HOSPITAL OF PHILADELPHIA

Reconstructing the Longitudinal Disease History in SCN8A-Related Disorders

Genetic mutations in the gene SCN8A can result in early-onset developmental and epileptic encephalopathies. Dr. McKee's team will use electronic medical records (EMR) to identify the SCN8A mutation's previously unknown clinical subgroups, disease courses, and medication responses to improve clinical care, medication choice, and aid in the design of clinical trials and targeted therapies.

This grant is co-funded with the Cute Syndrome Foundation.

25 YEARS OF
INSPIRING HOPE

For however long it takes to find a cure, we'll continue to lead the way. Our promise is not only to deliver impact, but also to inspire hope in the lives of patients and anyone who loves them.

Look back on some of CURE Epilepsy's milestone moments of community, inspiration, and hope we've built since our founding.

2000

CURE Epilepsy hosts its annual benefit. Future benefits welcome speakers and entertainers including Hillary Clinton, President Barack Obama, Paul Simon, Eddie Vedder, Jon Stewart, and many others.

2010

Joey's Song begins as a grassroots $5,000 event to support CURE Epilepsy's research. The event has grown over the years, and proceeds funded a $100,000 grant in 2022.

Long-time supporters Stacey Pigott and Kathy Dodd co-host "Rock the Block," a music-themed Champion fundraiser that raised over $600,000 from 2010-2012.

2011

Jim and Susan Schneider host the first Drive for CURE event, a golf-themed Champion fundraiser that raised nearly $600,000 over 5 years.

2013

University of Maryland Eastern Shore hosted their 10th annual event in 2023, making it the longest-running event in our community-led CURE Epilepsy Champions fundraising program.

2016

Ella's Race to CURE Epilepsy kicks off. This 2.6-mile fun run/walk and silent auction raises both funds and awareness for the millions of people living with epilepsy.

2019

Hamilton Chicago star Michael Cervantes leads Broadway Sings for CURE Epilepsy, a performance from incredible Broadway stars to raise funds for our critical research.

2020

Unite to CURE Epilepsy, a virtual program born out of necessity during the pandemic, connects CURE Epilepsy with the epilepsy community across the country and around the world.

2021

CURE Epilepsy rings the Closing Bell® at the New York Stock Exchange to kick off Epilepsy Awareness Month and announces a $1.8 million investment that will fund nine new research grants to advance the understanding and treatment of epilepsy.

CURE EPILEPSY'S 25TH ANNIVERSARY GALA

As we look excitedly toward the future of epilepsy research, we also want to celebrate the many advancements we've made over the past 25 years and our many supporters who've made them possible.

On May 6, 2023, we gathered to reminisce about the breakthroughs we've made, share the many stories that have inspired our community, and raise funds for critical research that will bring us closer to a cure.

Through the generosity of so many, we were able to surpass our goal of $2 million, raising a record-setting $3.1 million, including a $1 million pledge from Vivian Cotton's "Mimi," to continue to fund groundbreaking epilepsy research.

Some gala moments to remember:

- Susan Axelrod presented the very first Founders Award to the founding Research Chair and long-time epilepsy advocate, Barbara Kelly.
- Parent Nora Hennessey and her child's doctor, Dr. Doug Nordli, sat down for an emotional interview with CNN commentator David Axelrod.
- We looked back on CURE Epilepsy's contributions to the epilepsy community through a video from President Barack Obama, speeches from significant CURE Epilepsy funded researchers, key epilepsy thought leaders, and past performers and speakers, including Carole King.







Row 1: Video message from President Barack Obama; Hannah Whitten, Reggie Whitten, Dr. Crysten Cheatwood, and Emmy Jo Watkins; Susan and Jim Schneider, Bob Dodd, Jeanne and Barry Donalty; CURE Epilepsy Board Chair, Kelly Cervantes. Row 2: Susan Axelrod and Barbara Kelly; Bette Sacks and David Axelrod; CURE Epilepsy CEO, Beth Dean; Miguel Cervantes and Mike Gomoll. Row 3: Stacy and Kathy Dodd. Row 4: Sean Cunneen and Jackson Cervantes; Joe Ferguson, Peter Cunningham, Alexi Giannoulias, and Rob Gamrath; Michelle Marciniak and her daughter; Lisa, Caroline, and Michael Cotton; Gala performers, Fitz and the Tantrums. Row 5: Dr. Doug Nordli, Nora Hennessey, and David Axelrod; Guests of Bronze Sponsor Aura, Inc.



2022

DONOR HONOR ROLL

We are profoundly grateful to the thousands of individuals and organizations who, with a gift to CURE Epilepsy, made it possible for us to lead, innovate, and collaborate for a cure.

While space prevents us from acknowledging every donor here, our gratitude is limitless. Thank you.

The following reflects donors who gave $1,000 or more between January 1 - December 31, 2022. 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.

You can find an expanded version of the 2022 Donor Honor Roll on the CURE Epilepsy website.

LEAVE YOUR MARK ON OUR NEXT 25 YEARS. SCAN THE CODE TO THE LEFT OR VISIT CUREEPILEPSY.ORG/25YEARS TO MAKE A GIFT.

$100,000+

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Cisco
Lisa and Michael Cotton
GCM Grosvenor
The Joseph Gomoll Foundation Inc.
Judy and Scott Leisher
Mugar Foundation
Ravichandran Foundation

Ann G. and James B. Ritchey Foundation

Dianne Raso, Chair of the Ritchey Foundation, saw Susan Axelrod sharing her family's story on TV and was moved. That same day, she met a new neighbor living with epilepsy and had a friend call about a family member having seizures. She was inspired to give through the foundation set up by her uncle and has been giving since 2010.

$50,000-$99,999

BAND Foundation
The Kenneth C. Griffin Charitable Fund
Jazz Pharmaceuticals
SK Life Science Inc.
Isaiah Stone Foundation

$25,000-$49,999

Anonymous
Susan and David Axelrod

Estate of Daniel Benninghoven

Daniel Benninghoven lovingly remembered his son, Cameron — who died of SUDEP — by including CURE Epilepsy in his will. That gift will help further our commitment to funding cutting-edge SUDEP research.

Kimberly Borden
Brackenridge Foundation Inc.
Lindsay and Jon Cotton
The Cornwall Trust
Crown Family Philanthropies
The Shurl and Kay Curci Foundation
Carrie and Matthew Garman
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$10,000-$24,999

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The Driscoll Foundation, as recommended by Elizabeth and Edwin Hlavka
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Popeye's Supplements Aurora
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Julie and Dave Stout
The Strategy Group
Donald Taylor
UFCW Charity Golf Classic, Inc.
The University of Chicago
Ventas, Inc.

Eileen and Thomas Sutula

Dr. Tom Sutula is an epilepsy researcher, and Eileen is an epilepsy advocate. Together, they have been donors to CURE Epilepsy for over 20 years. In addition, they have rallied the local community in Madison, WI, and hosted successful Champions events.

Jason Vicari

Jason's sister has epilepsy. He and his parents, Gary and Amy, honor their sister and daughter by making gifts to CURE Epilepsy and amplifying their impact through their companies' matching gift programs.

The Wintner-Meisel Fund
Ann and Ben Wolf
Robert Zimmer*

$5,000-$9,999

Rebecca Anhang Price and Matthew Price
Aura
Liz and Mike Axelrod
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Kristin Love
Daina Lyons and Forrest Claypool
Courtney and Blake Mackenzie
Barbara Manley
John Marlott

* deceased

Mercedes-Benz of Des Moines

Mesirow

Mesirow has been a proud supporter of CURE Epilepsy since 2002, giving more than $250,000 in corporate sponsorships to events. This incredible support has been made possible by Richard Price and Tom Hynes, executives at Mesirow who both have loved ones affected by epilepsy.

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Julie and Ken Moore
Ruth Mort
Murray & Randy Sawyer Foundation
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Linda Nolten
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The Sexton Family Foundation
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Angela Byrd and Eric Weil
Tom and Heather Wurzer
Samuel Yin

$2,500-$4,999

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Michael Abrams
Alan Adams
Be Your Possible
Terry Behrle-Mohs and Richard Mohs
Jeffrey Boutilier
Carolyn and Larry Conlee
Janet and Michael Cornfeld
Kathy and Bob Dodd
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Joanna Edgell
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Charles and Maureen's son Sean has a rare genetic disorder that caused him to suffer from Infantile Spasms. She has supported CURE Epilepsy through a variety of campaigns, including hosting a birthday fundraiser in his honor, Giving Tuesday, Unite to CURE Epilepsy, and more.

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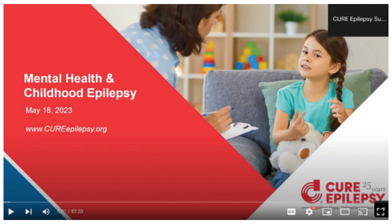
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