



RESEARCHING FOR A CURE

CURE

CITIZENS UNITED FOR
RESEARCH IN EPILEPSY

FALL 2019



CURE IS THE NONPROFIT LEADER IN EPILEPSY RESEARCH

WITH A SINGULAR FOCUS ON PROMOTING
AND FUNDING PATIENT-FOCUSED RESEARCH
TO MOVE US CLOSER TO A CURE.



BETH LEWIN DEAN
Chief Executive Officer of
Citizens United for Research
in Epilepsy (CURE)

A YEAR OF MILESTONES

As we continue on the road to a cure for epilepsy, scientific research is our greatest hope of reaching its triumphant end. And that's where CURE comes in.

As the new CEO of CURE, I'm profoundly honored to carry on the work that began more than 20 years ago with our founder, Susan Axelrod. Frustrated by the inability to protect their children from seizures and treatment side effects, Susan and a small group of parents joined forces to invest in evidence-based research for this often overlooked disease. Today, I'm proud to lead the daily pursuit of our mission: **to find a cure for epilepsy, by promoting and funding patient-focused research.**

All of this work is made possible by our dedicated supporters. Earlier this year, we received a transformational \$2 million gift from Shery and David Cotton and Lisa and Michael Cotton in memory of Lisa and Michael's daughter, Vivian. This gift will fuel a wide range of organizational activities and epilepsy research. We are grateful to the Cottons and so many others who have given their resources, time, and energy in the pursuit of a cure.

We're excited to now share "Researching for a Cure," the first issue of a biannual report detailing our progress toward that goal over the past year. Our Chief Scientific Officer, Dr. Laura Lubbers, is leading an ambitious research program, and we've made strides that include:

UNCOVERING NEW GENETIC
LINKS THAT COULD HELP
PREVENT SUDDEN
UNEXPLAINED DEATH
IN EPILEPSY

LAUNCHING A \$10 MILLION
INITIATIVE TO STUDY AND
DEVELOP BIOMARKERS FOR
POST-TRAUMATIC EPILEPSY

HELPING TO IDENTIFY
GENETIC CAUSES OF
EPILEPSY IN PATIENTS
WHO PREVIOUSLY
COULDN'T BE DIAGNOSED

From our insightful Day of Science conversations across the country to our star-studded Broadway event, you'll also find highlights from the educational programming, community events, and special moments that have defined 2019.

Thank you for believing in us and supporting our efforts to raise awareness, eliminate stigma, and find a cure. Research is what we do best at CURE, and we won't stop until we have answers.

Beth Dean

CEO, Citizens United for Research in Epilepsy

EPILEPSY IS UNRELENTING...

1 IN 26
AMERICANS WILL DEVELOP
EPILEPSY IN THEIR LIFETIME

3.4 M
AMERICANS
HAVE EPILEPSY

65 MILLION
PEOPLE WORLDWIDE ARE
IMPACTED BY EPILEPSY

\$15.5 BILLION
IN EPILEPSY COSTS
IN AMERICA ALONE

3 IN 10 CASES
DON'T RESPOND
TO MEDICATION

20+ YEARS
OF GROUNDBREAKING
RESEARCH AT CURE

\$60,000,000
RAISED BY CURE
FOR RESEARCH

230+ GRANTS
AWARDED BY CURE IN
15 COUNTRIES
WORLDWIDE

...AND SO
ARE WE

CURE FOUNDER SUSAN
AXELROD AND HER
DAUGHTER, LAUREN.

EPILEPSY IMPACTS
MORE PEOPLE THAN

MULTIPLE SCLEROSIS,
CEREBRAL PALSY,
MUSCULAR DYSTROPHY,
AND PARKINSON'S
DISEASE COMBINED,

YET RECEIVES FEWER
FEDERAL DOLLARS
THAN EACH OF THESE DISEASES.

OUR CURE
INVESTIGATORS
SEEK TO:

BETTER
UNDERSTAND THE
BASIC SCIENCE
BEHIND EPILEPSY

FIND A CURE
FOR
EPILEPSY

UNCOVER
PROMISING
THERAPIES

RESEARCHING FOR NEW DISCOVERIES

From uncovering the genetic causes of epilepsy to breakthroughs that could help prevent epilepsy-related deaths, here are just a handful of the highlights from our research over the past year.

UNCOVERING A GENETIC LINK TO SUDEP

THE REALITY

Sudden Unexpected Death in Epilepsy (SUDEP) is **one of the most devastating consequences of epilepsy**, highlighting the need to find meaningful answers for patients and their families.

THE RESEARCH

CURE grantee Dr. Annapurna Poduri of Boston Children's Hospital found a **potential link between SCN1A gene variants and children who died from SIDS** – even those who had never experienced a seizure or showed signs of epilepsy.



THE RESULTS

By identifying a genetic connection to SUDEP, this work lays the foundation for **promising new therapies that can help prevent these tragic deaths**. Dr. Poduri's research was generously supported by the Isaiah Stone Foundation.



A RESEARCHER AT THE INSTITUTE FOR GENOMIC MEDICINE AT COLUMBIA UNIVERSITY, THE HOME OF CURE'S EPILEPSY GENETICS INITIATIVE.

A SUDEP PIONEER

2004 CURE launches the first private SUDEP research program in the U.S.

2005 A CURE grantee establishes respiratory arrest as a leading cause of SUDEP.

2008 Researchers discover a link between epilepsy, cardiac disease, and SUDEP.

2012 CURE helps establish the Partners Against Mortality in Epilepsy conference.

2014 The National Institute of Neurological Disorders and Stroke works with CURE to establish SUDEP as a Center Without Walls topic, the largest federal investment in SUDEP to date.

2016 CURE further invests in SUDEP-related studies by establishing a more targeted research focus, the CURE Sleep and Epilepsy Award.

2019 CURE continues to focus on SUDEP by funding new research grants.

POST-TRAUMATIC EPILEPSY

POST-TRAUMATIC EPILEPSY INITIATIVE

Many of our veterans are coming home with traumatic brain injuries that later lead to epilepsy. In fact, post-traumatic epilepsy accounts for an estimated 20% of all symptomatic epilepsy cases, which can occur following a brain injury whether an individual is in the military or not. With no known ways to predict or prevent post-traumatic epilepsy and limited treatment options available, the need for scientific research is great.

Launched in 2018, this groundbreaking program takes a team science approach to develop new research models and biomarkers and understand risk factors for post-traumatic epilepsy. The ultimate goal? To uncover new ways to predict, prevent, and treat epilepsy for veterans and others who suffer from head injuries.

\$10 MILLION

GRANT FROM THE
U.S. DEPARTMENT OF DEFENSE

40+

COLLABORATORS AROUND THE GLOBE

350,000

U.S. MILITARY PERSONNEL DIAGNOSED
WITH TBI FROM 2000-2018

EPILEPSY AND GENETICS

NEW HOPE FOR UNCONTROLLED CASES

THE REALITY

Reduced activity of a gene called STXBP1 can lead to epileptic encephalopathy, a **group of severe pediatric epilepsies** that often result in treatment-resistant seizures, developmental delays, and intellectual disabilities.

THE RESEARCH

CURE grantee Dr. Mingshan Xue and his team at Baylor College of Medicine discovered that **reducing STXBP1 causes an imbalance between inhibition and excitation in the brain**, resulting in higher anxiety, impaired motor skills, and lower cognitive functioning.



THE RESULTS

By uncovering the brain science behind epileptic encephalopathy, the team aims to develop **effective new therapies for some of the most difficult epilepsy cases.**

Dr. Xue has now received a grant of nearly

\$350,000
FROM THE NATIONAL INSTITUTES OF HEALTH

to continue this work, reinforcing CURE's role in seeding early-stage research that leads to bigger impact.

EPILEPSY GENETICS INITIATIVE

Our genes hold the secrets to treating, preventing, and curing epilepsy once and for all. In partnership with the National Institute for Neurological Disorders and Stroke and funded through the generous support of the John and Barbara Vogelstein Family Foundation, the Epilepsy Genetics Initiative has sought to understand the genetics behind this complex condition.

Since its launch, the initiative has collected and analyzed patients' raw exome data biannually, reporting confirmed results back to patients. This approach has helped to identify underlying genetic causes that can lead to scientific breakthroughs, while also revealing the genetic causes of epilepsy in several patients where genetic testing was previously unsuccessful in identifying a diagnosis.

1,000+

TOTAL ENROLLMENT, INCLUDING
PATIENTS AND FAMILY MEMBERS

13

UNCOVERED GENETIC
CAUSES IN 13 PATIENTS

1

NEW EPILEPSY-RELATED
GENE IDENTIFIED

"The mere mention of your organization's name has changed everything about the way we think about our work. We all appreciate everything CURE does to support research in epilepsy."

JEFFREY L. NOEBELS, M.D., PH.D., BAYLOR COLLEGE OF MEDICINE

Dr. Noebels served as part of CURE's infantile spasms research team, a multidisciplinary initiative that has worked to advance our understanding of this rare and often devastating epilepsy syndrome.



**CAPT. PAT HORAN,
WHO IS LIVING WITH
POST-TRAUMATIC
EPILEPSY AFTER BEING
INJURED IN IRAQ.**



To learn more about our opportunities for researchers, including our "Frontiers in Research" seminar series and CURE-sponsored conferences, visit cureepilepsy.org/for-researchers.

RESEARCHING FOR DEEPER UNDERSTANDING

Through our educational webinars, Day of Science: Epilepsy Conversations, “Seizing Life” podcast, and regular updates from our team, our programming throughout this year has kept patients and families informed and inspired along the journey toward a cure.

“LEADERS IN RESEARCH” WEBINAR SERIES

These virtual, on-demand sessions help the global epilepsy community understand the science behind the search, providing updates on the latest advances in epilepsy research and a deeper dive into specific epilepsy-related topics.

SUPPORTING TOMORROW’S EPILEPSY LEADERS

Through generous funding from Lundbeck, CURE’s Education Enrichment Fund provides a path to become a powerful agent for change in the epilepsy community.

\$150,000 AWARDED TO NEARLY
30 RECIPIENTS TO DATE

10 RECIPIENTS SELECTED
FOR 2019 ACROSS THE
U.S. AND CANADA

A CONVERSATION
ABOUT THE FUTURE OF
EPILEPSY RESEARCH
AT A DAY OF SCIENCE
EVENT HOSTED BY CURE.



TUNE IN TO OUR PODCAST

cureepilepsy.org/seizing-life

Listen in as CURE Board Member and Epilepsy Advocate Kelly Cervantes speaks with guests about their challenges and triumphs living with epilepsy.

DAY OF SCIENCE: EPILEPSY CONVERSATIONS

What would you ask an epilepsy physician if you had the chance? Hosted in locations across the country, our Day of Science events give our community a chance to come together, stay informed on epilepsy, and meet the experts who are tirelessly searching for answers.

5 EVENTS HOSTED OVER THE PAST YEAR

Houston
Boston
Orange County
Miami
Raleigh-Durham



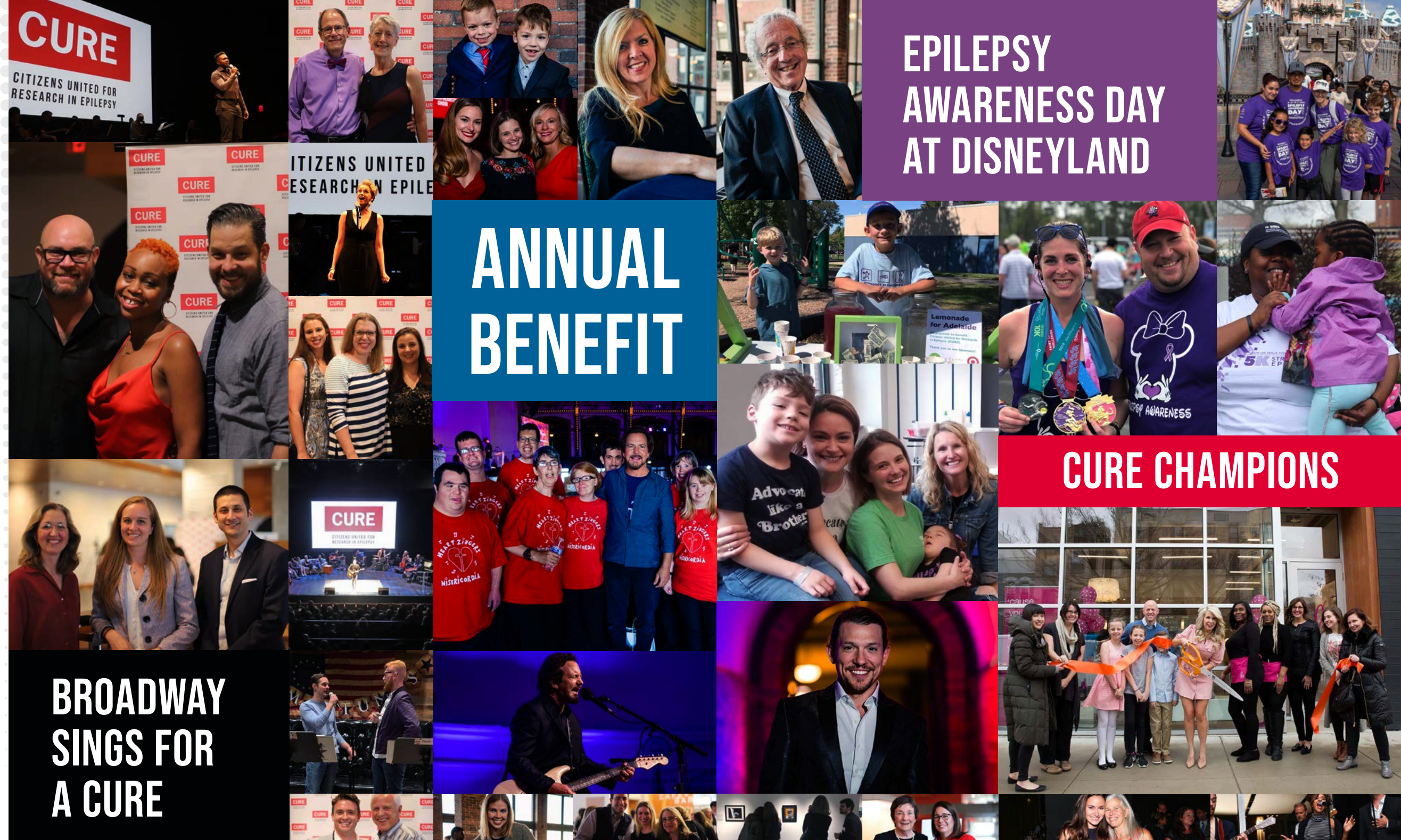
RESEARCHING FOR OUR COMMUNITY

We're humbled by the support of so many who gave, volunteered, and made a difference for CURE this year.

Thank you to our entire community for walking with us along this journey.



Have what it takes to
become a CURE champion?
Learn how to set up your own
fundraiser at [cureepilepsy.org/
curechampions](https://cureepilepsy.org/curechampions).



EPILEPSY
AWARENESS DAY
AT DISNEYLAND

ANNUAL
BENEFIT

CURE CHAMPIONS

BROADWAY
SINGS FOR
A CURE

RESEARCHING FOR...



ISAIAH

“ I have never felt so helpless as when I watched Isaiah’s first seizure.”

C. RENZI STONE, ISAIAH’S FATHER

Several years after Isaiah’s death at 11 months old, new genetic testing revealed he had Dravet Syndrome – a first step toward diagnosing and treating others with this devastating condition.



CAROL

“ For more than 50 years, I kept my struggle with epilepsy hidden until I met other patients and families in the CURE community. Now, I’m working to fight for a cure and to eliminate the stigmas so many of us face.”

CAROL FULP



ELLA

“ I hope one day to not have to count how many days it has been since Ella’s last seizure, to not have to count out 11 pills for her to take with breakfast and then again at dinner, and to not have to count the years she is behind her peers developmentally.”

SHALEE CUNNEEN, ELLA’S MOTHER



JORDAN

“ Thanks to CURE’s Educational Enrichment Fund Scholarship, I’m pursuing a career as a neurologist. My goal is helping others like me who suffer from debilitating neurological disorders to lead better lives.”

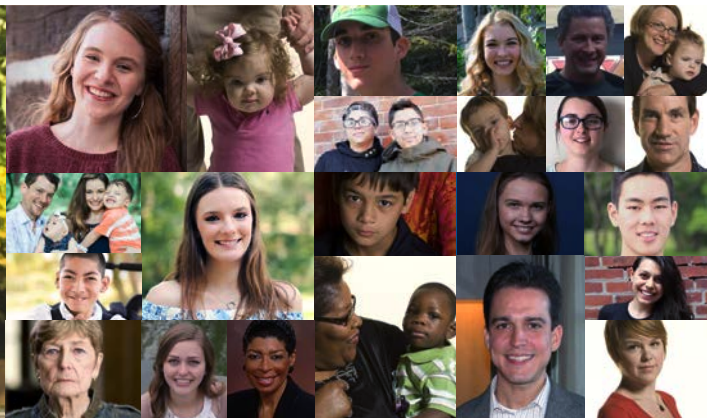
JORDAN KAUFMAN



CAMERON

“ We had never even dreamed that Cameron could die from epilepsy. Cameron is a reminder that the people and families who suffer SUDEP are not just a statistic.”

ELLEN BENNINGHOVEN, CAMERON’S MOTHER



...AND SO MANY MORE.

The road to a cure for epilepsy is long, but we know we can reach our destination with your help. From all of us at CURE, thank you for your support.

To donate to CURE, please use the enclosed envelope or visit cureepilepsy.org/donate.





CUREPILEPSY.ORG

CITIZENS UNITED FOR RESEARCH IN EPILEPSY
430 WEST ERIE STREET, SUITE 210
CHICAGO, ILLINOIS, 60654

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

