



CURE

CITIZENS UNITED FOR
RESEARCH IN EPILEPSY
SPRING 2020

RESEARCHING FOR A CURE





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

EVERY DAY WITH EPILEPSY...

...is an unknown. Some days, life can seem perfectly normal. Other days are filled with seizures and setbacks. Yet every day, our community faces this condition with courage as we continue to search for a cure.

At CURE, we're researching every day for those living with epilepsy. As the only nonprofit organization solely focused on epilepsy research, we've spent the last two decades seeking to understand the underlying causes of this condition, uncover promising therapies, and ultimately find a cure. The road is long, and we get closer with every day, every scientific breakthrough, and every gesture of support from our community.

In this issue of "Researching for a Cure," we share some of the most exciting discoveries that have filled our days over the past few months, including:

**ASSEMBLING A TEAM OF 60+ COLLABORATORS AT INSTITUTIONS
ACROSS THE GLOBE TO RESEARCH HOW TO PREDICT, TREAT,
AND PREVENT POST-TRAUMATIC EPILEPSY**

**UNCOVERING ONE OF THE BIGGEST RISK FACTORS FOR SUDEP –
AS WELL AS RECOMMENDATIONS TO REDUCE THOSE RISKS**

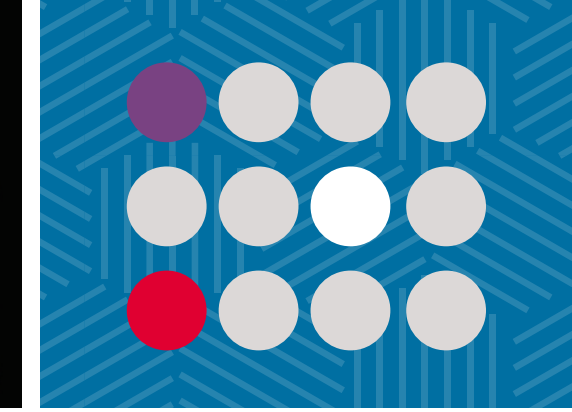
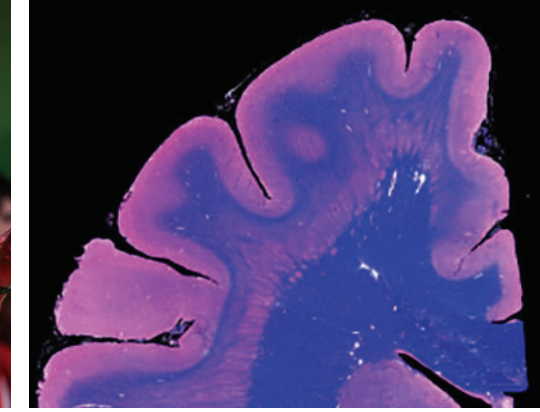
**DEEPENING OUR UNDERSTANDING OF EPILEPSIES CAUSED BY
GRIN GENE MUTATIONS**

You'll also hear inspiring stories from members of our community, including a young college student navigating school and life with epilepsy, and a CURE researcher who revealed his own struggles with epilepsy at a recent CURE event.

Every day, we're researching for you – and we won't stop until we find a cure. Thank you for your support, today and every day.

Beth Lewin Dean

The road is long, and we
get closer with every day,
every scientific breakthrough,
and every gesture of support
from our community.



CURE IS RESEARCHING...

BASIC MECHANISMS OF EPILEPSY

TO UNDERSTAND WHAT CAUSES EPILEPSY AND IDENTIFY WAYS TO STOP IT.

OVER 80%

OF CURE RESEARCH FUNDS INVESTED IN BASIC SCIENCE SINCE 2011

RESEARCH SPOTLIGHT:



Focal cortical dysplasias (FCDs) are a common cause of focal epilepsy, a difficult-to-treat condition that often requires surgery. CURE grantee Dr. Yu Wang and his team used a gene editing technique to develop a groundbreaking animal model of FCD, revealing that an existing therapy may be effective in treating focal epilepsy.

SUDDEN UNEXPLAINED DEATH IN EPILEPSY (SUDEP)

TO PUT AN END TO ONE OF THE MOST DEVASTATING CONSEQUENCES OF EPILEPSY.

20X

PEOPLE WITH EPILEPSY ARE 20X MORE LIKELY TO DIE SUDDENLY THAN THE GENERAL POPULATION¹

OVER \$4 MILLION

IN SUDEP GRANTS AWARDED TO DATE

30+

RESEARCH PROJECTS

¹ Ficker D.M., Sudden unexplained death and injury in epilepsy, *Epilepsia*, 2000; 41(suppl 2):S7–12.

SLEEP AND EPILEPSY

TO UNDERSTAND THE CONNECTION BETWEEN SLEEP AND SEIZURES FOR THOSE LIVING WITH EPILEPSY.

UP TO 25%

OF PATIENTS HAVE PREDOMINANTLY NOCTURNAL SEIZURES²

2017

CURE ESTABLISHES SLEEP AND EPILEPSY AS A KEY RESEARCH PRIORITY, ATTEMPTING TO BETTER UNDERSTAND THE RELATIONSHIP BETWEEN SLEEP AND EPILEPSY IN THE HOPE OF IMPROVED TREATMENT OPTIONS

RESEARCH SPOTLIGHT:



CURE grantee Dr. Judy Liu and her team at Brown University are studying whether seizures are more likely to occur in certain stages of sleep, ultimately leading to a better understanding of sleep and epilepsy and potential new strategies to manage these seizures.

This research was generously funded by the BAND Foundation.

² Carreno M. and Fernandez S., Sleep-Related Epilepsy, *Curr Treat Options Neurol.*, 2010; 18(5):23.

ACQUIRED EPILEPSY

TO HELP PREDICT, PREVENT, AND TREAT EPILEPSY AFTER TRAUMA TO THE BRAIN.

4.2%

OF ALL U.S. TROOPS WHO SERVED FROM 2000 TO 2011 WERE DIAGNOSED WITH A TRAUMATIC BRAIN INJURY, MAKING THEM ESPECIALLY SUSCEPTIBLE TO DEVELOPING POST-TRAUMATIC EPILEPSY³

RESEARCH SPOTLIGHT:

Launched in 2018, CURE's Post-Traumatic Epilepsy Initiative features more than 60 research collaborators working to develop new research models and biomarkers and understand risk factors for this condition.

Learn the latest about the Initiative on page 10.

³ Centers for Disease Control and Prevention, Report to Congress on Traumatic Brain Injury in the United States: Epidemiology and Rehabilitation, National Center for Injury Prevention and Control, Division of Unintentional Injury Prevention, Atlanta, GA, 2015, https://www.cdc.gov/traumaticbraininjury/pdf/TBI_Report_to_Congress_Epi_and_Rehab-a.pdf.

CURE IS RESEARCHING...

PEDIATRIC EPILEPSY

TO HELP CHILDREN ACHIEVE FREEDOM FROM SEIZURES AND LIVE WITHOUT THE FEAR OF EPILEPSY.

FIRST YEAR

NEW CASES OF EPILEPSY ARE MOST COMMON IN CHILDREN, ESPECIALLY IN THE FIRST YEAR OF LIFE ⁴

1 IN 150

CHILDREN 10 YEARS OF AGE OR YOUNGER ARE DIAGNOSED WITH EPILEPSY, MAKING IT ONE OF THE MOST PREVALENT NEUROLOGICAL CONDITIONS IN CHILDREN ⁵

TREATMENT-RESISTANT EPILEPSY

TO PROVIDE ANSWERS FOR THOSE WITH EPILEPSY WHOSE SEIZURES DON'T RESPOND TO TREATMENT.

MORE THAN 1/3

OF PEOPLE WITH EPILEPSY CONTINUE TO EXPERIENCE SEIZURES DESPITE AVAILABLE MEDICATIONS ⁶

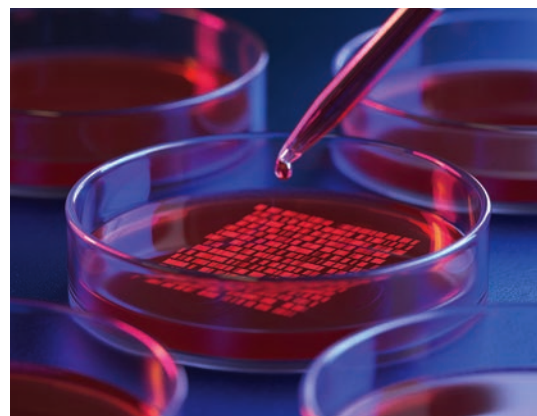
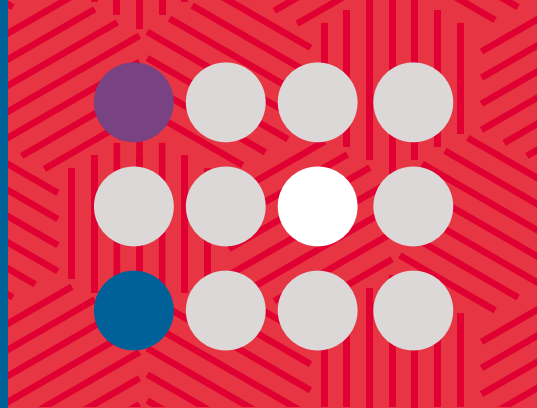
RESEARCH SPOTLIGHT:



A new treatment for Dravet syndrome, a rare and catastrophic form of treatment-resistant epilepsy, could become a reality thanks to research from two CURE grantees in Australia. Dr. Glenn King and Dr. Steven Petrou identified a peptide in spider venom that successfully reduced seizures and mortality in mice experiencing Dravet symptoms.

RESEARCH

Since its inception, CURE has been at the forefront of epilepsy research, raising over \$70 million to fund research and other programs that will lead the way to a cure for epilepsy.



FEATURED RESEARCH:

POST-TRAUMATIC EPILEPSY INITIATIVE

For many U.S. troops, the gravest injuries suffered in combat aren't always the visible ones.

The changing nature of combat has made traumatic brain injury (TBI) a major health concern for service members, both during times of conflict and in daily life. Brought on by blast exposures, vehicle crashes, and other impacts to the head, TBI can increase the chance of developing post-traumatic epilepsy (PTE), a debilitating condition defined by recurrent seizures. Research from the Vietnam, Afghanistan, and Iraq wars has shown sharply increased rates of PTE in troops who sustained TBI.

Research also shows PTE represents approximately 20% of all symptomatic epilepsy cases, occurring among veterans and civilians alike. Currently, there is no way to predict or prevent PTE, and treatment options are often ineffective and can have severe side effects. With hundreds of thousands of service members diagnosed with TBI since 2000, the need for innovation in research is clear.

KEY FACTS

OVER
400,000

U.S. MILITARY PERSONNEL
DIAGNOSED WITH TBI FROM
2000-2019⁷

53%

OF VIETNAM VETERANS
WHO SUFFERED FROM
SEVERE TBI THAT REQUIRED
NEUROSURGERY SUBSEQUENTLY
DEVELOPED EPILEPSY⁸

19X

A GROUP OF AFGHANISTAN AND
IRAQ WAR VETERANS WITH TBI
WERE APPROXIMATELY 19X MORE
LIKELY TO DEVELOP EPILEPSY
THAN THOSE WITHOUT TBI⁹

INSIDE THE INITIATIVE

CURE's newest signature research effort, the Post-Traumatic Epilepsy Initiative, is an ambitious multidisciplinary program that seeks answers for veterans and others affected by this condition. Funded through a \$10 million U.S. Department of Defense grant, the Initiative takes an innovative team science approach to better understand the causes of post-traumatic epilepsy, which may one day support development of new treatments. Through this work, CURE investigators aim to develop:

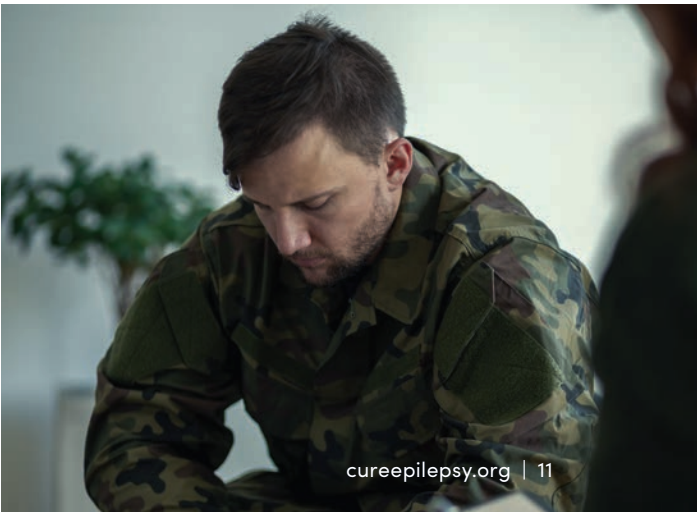
EFFECTIVE NEW MODELS
FOR STUDYING PTE

AND

BIOMARKERS TO IDENTIFY
SOMEONE'S RISK OF
DEVELOPING PTE FOLLOWING
A TBI

THAT LEAD TO

THERAPIES TO PREVENT
OR HALT PTE



⁷ DoD Worldwide Numbers for TBI, Defense and Veterans Brain Injury Center, 2020.

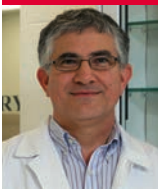
⁸ Salazar A.M. et al., Epilepsy after penetrating head injury. I. Clinical correlates: a report of the Vietnam Head Injury Study, Neurology, 1985; 35(10):1406-1414.

⁹ Pugh M.J. et al., The prevalence of epilepsy and association with traumatic brain injury in veterans of the Afghanistan and Iraq wars., J Head Trauma, 2015; 30(1):29-37.

TAKING ON PTE AS A TEAM

To address this complex issue, the Post-Traumatic Epilepsy Initiative brings together more than 60 researchers from across the globe. The Initiative features six research teams across multiple institutions, each with a specific focus related to TBI and PTE.

Under the oversight of CURE, the Department of Defense, and an external advisory council, the investigators exchange data, materials, and models in real time as they work toward shared goals. This approach allows the Initiative to adapt as researchers share findings, informing the program's overall direction to make the outcomes as impactful as possible. Through collaboration and shared discovery, the Initiative aims to provide results that can improve the lives of people everywhere living with post-traumatic epilepsy.



UNIVERSITY OF ILLINOIS, CHICAGO
PRINCIPAL INVESTIGATOR:
DR. JEFFREY LOEB

Focusing on an animal model as well as humans with subarachnoid hemorrhage, a common type of bleeding following TBI, Dr. Loeb and his team are utilizing EEG and imaging to uncover potential biomarkers for PTE.



UNIVERSITY OF FLORIDA
PRINCIPAL INVESTIGATOR:
DR. KEVIN WANG

Using a mouse model of TBI, Dr. Wang and his team are seeking to uncover the unique chemical and molecular processes that lead to PTE following TBI, offering potential new focus areas and biomarkers for developing treatments.



HARVARD MEDICAL SCHOOL
PRINCIPAL INVESTIGATOR:
DR. KEVIN STALEY

Dr. Staley and his team are exploring changes in the brain's neuronal support system after TBI in a new animal model of PTE as well as in humans with moderate to severe TBI, with the goal of providing new insight into how PTE develops and new methods to identify high-risk patients.



UNIVERSITY OF PENNSYLVANIA
PRINCIPAL INVESTIGATOR:
DR. VICTORIA JOHNSON

Using a novel animal model along with human tissue from those affected by TBI, Dr. Johnson and her team are studying the relationship between the detrimental neural changes that can follow TBI and the development of PTE.



MID-ATLANTIC EPILEPSY AND SLEEP CENTER
PRINCIPAL INVESTIGATOR:
DR. PAVEL KLEIN

Dr. Klein and his team plan to examine a group of patients at high risk for PTE, searching for biomarkers in patients' EEG signatures, MRIs, or blood that can help predict who is at an increased risk of developing this condition.



VIRGINIA TECH
PRINCIPAL INVESTIGATOR:
DR. HARALD SONTHEIMER

In response to the need for additional animal models of PTE, Dr. Sontheimer and his team are investigating the ways TBI leads to PTE in both an established as well as a new mouse model of PTE.

THE POWER OF DATA



In partnership with the University of Southern California's Laboratory for Neuro Imaging, the Post-Traumatic Epilepsy Initiative is creating a database to store team data for cross-comparison and analysis, as well as electronic case report forms with common data elements for clinical and preclinical TBI.

The Initiative is also supporting the International League Against Epilepsy/ American Epilepsy Society Joint Translational Task Force's efforts to develop electronic case report forms containing common data elements for preclinical epilepsy research. Using common elements will help to increase rigor, transparency, and reproducibility in epilepsy research.

MEET THE TEAM

6 RESEARCH TEAMS
60+ COLLABORATORS

RESEARCHER

Q&A DR. H. STEVE WHITE UNIVERSITY OF WASHINGTON



Over the past four decades, Dr. H. Steve White has devoted his career to epilepsy research, with a focus on understanding what causes seizures and ways to mitigate them. Currently the Department of Pharmacy chair at the University of Washington, Dr. White was also CURE's research director from 2011 to 2015 and served on the faculty at the University of Utah for 30 years. In 2010, his interest in epilepsy took a personal turn when he experienced his first seizure. Here, Dr. White shares how his new perspective as a patient has shaped his work and his hopes for the future of epilepsy research.

You've spent nearly 40 years researching epilepsy. What initially drew you to this field of study?

When I began graduate school in 1980, I knew that I wanted to study neuroscience, but I knew very little about epilepsy. However, I soon realized that epilepsy as a field of study was extremely interesting to me, because it provided a window into the complexity of the brain. At the time, the community was learning more and more about the neurobiology of epilepsy and how seizures start and spread. I realized quickly that trying to understand epilepsy at a neurobiological level was both fascinating and important work.

Like many graduate students, my career was shaped early on by my mentor, Dr. Dixon Woodbury, who was passionate about his work to advance a greater understanding of the mechanisms of action of antiseizure drugs and the role of the non-neuronal glial cell in seizure onset and progression. Dr. Woodbury was a strong advocate for his students. At every meeting we attended, he would take me and his other students under his wing and introduce us to the greater epilepsy community. The more scientists and clinicians I met, the more I began to appreciate the passion they had for their work and their patients.

You've played a role in the development of several new antiseizure drugs and served in multiple leadership roles throughout your career. What are your proudest achievements?

First, I want to acknowledge that any achievements that I may have enjoyed have been possible because of the team of dedicated individuals I've been fortunate to work with over the years. Since 1993, the

Anticonvulsant Drug Development Program at the University of Utah has touched all of the new seizure drugs on the market in some way. To know that this work contributed to the clinical advancement of several new antiseizure drugs has been extremely rewarding for the entire team. On a personal note, I think a lot about how our work together over the years has contributed to a better quality of life and seizure control for people living with epilepsy. Being the beneficiary of one of the antiseizure drugs first screened by the University of Utah Program, I am reminded twice daily how modern science and drug discovery can change lives by bringing new therapies to the marketplace. In addition, the team at Utah has been able to advance new animal models for drug screening, work that has impacted how the National Institute of Neurological Disorders and Stroke's Epilepsy Therapy Screening Program evaluates new drugs. I am so pleased to see how this work continues today under the leadership of Dr. Karen Wilcox. I am also so proud of my work with CURE, particularly the Infantile Spasms and Post-Traumatic Epilepsy Initiatives. I have over the years been humbled by the support from the entire CURE family, not only for me but for all people with epilepsy and their families.

After a generalized tonic-clonic seizure in 2010, you were eventually diagnosed with focal epilepsy. How has your diagnosis impacted your personal and professional life?

In that moment, I got my first glimpse into what the lives of 60 million people living with epilepsy must be like on a daily basis. I can honestly say that there's not a day that goes by that I don't think about it, and how

it's impacted me and my family. I remember waking up in the emergency department and being told that I had had a seizure, but not to worry because "everyone gets their first seizure for free." Even though I tried to rationalize the seizure on the basis of sleep deprivation and stress, I knew enough about the disease state to know that no one gets any seizure for free and that there was likely an underlying cause that could not be so easily dismissed. If I have ever wanted to be wrong, it was that night. Unfortunately, shortly after an MRI the next morning, I found myself meeting with the Chief of Neurosurgery at the University of Utah discussing neurosurgery to remove an unidentified mass that the MRI had identified in my brain. When the pathology report suggested that my tumor was a low-grade nonmalignant brain tumor, I realized that I was very fortunate to have incredible access to the healthcare system and the best doctors and health care team at a time when I needed it. That's something I fear doesn't exist for a large percentage of people faced with a similar situation.

You were fortunate to find a treatment that has helped you control your focal seizures. How do you continue to manage your epilepsy day to day?

Eighteen months after the neurosurgery, I started having focal events that were becoming more frequent and longer in duration. In my mind, I realized they were probably focal seizures and I had prepared myself for the diagnosis. No matter how much I had prepared myself, hearing the words "focal epilepsy" was when the full irony of the situation hit home. To think that I now have a diagnosis for a disease that I had studied my entire career, and that I was taking an antiseizure drug that was first screened by the team I directed during my tenure at the University of Utah, has certainly personalized how important science is and that we cannot stop seeking better treatments for this disease.

You publicly announced your epilepsy diagnosis at the American Epilepsy Society (AES) conference last year. What inspired you to share this news with the community?

It was a decision that took me years to make. I remember a conversation with Susan Axelrod and Dr. Dan Lowenstein a number of years earlier about how the landscape for epilepsy research might change if those of us with the disease were able to speak out and take ownership. Easier said than done, I told myself. I, like many others, felt almost paralyzed by the stigma that still exists around epilepsy. I worried about how my friends and colleagues would react. My decision to go public slowly evolved over the last two years. The last two summers, I've been fortunate to travel with a group of 20 to 25 pharmacy students to Ghana on a Global Brigades Medical Mission, where we interviewed a number of people with epilepsy and their caregivers in an effort to understand their needs and how the 85% treatment gap was affecting their

access to healthcare and medications. I wanted to share my story, thinking that in some way it might help ease their pain and anxiety, but I could not find my voice. Long story short, I finally figured out that I could no longer sit silent. I have found great solace in being able to speak openly about what life is like with epilepsy. The diagnosis no longer controls me; I control it by being open with friends, colleagues, and students and there is no longer a reason for me to hide. I've been very lucky, and I hope that my story can drive science and advocacy forward to ultimately help others.

After I shared my story at AES, I was moved by the level of support I received. People kept coming up to me to tell me that they or a child had been personally affected by epilepsy. I couldn't think of a better place to have had that conversation than with the CURE family present. I will always cherish the warmth that I felt, and I will be eternally grateful for the support that was shared with me and my wife, Kathryn, that night.

What are your hopes for the future of epilepsy research?

If I have one big hope, I don't want to be standing here 20 years from now and still not have a cure or a treatment for those patients with treatment-resistant epilepsy. My hope is that we can use the knowledge of an ever-evolving science to finally find that transformative therapy that will someday alter or prevent the development of epilepsy in the susceptible individual. To do that, we need to all be strong advocates for epilepsy research and provide assurance that it is okay to talk about epilepsy.



"Being the beneficiary of one of the antiseizure drugs first screened by the University of Utah Program, I am reminded twice daily how modern science and drug discovery can change lives by bringing new therapies to the marketplace."

DR. H. STEVE WHITE, UNIVERSITY OF WASHINGTON

RESEARCH HIGHLIGHTS

TREATMENT-RESISTANT EPILEPSY

UNCOVERING CONNECTIONS BETWEEN GRIN GENE MUTATIONS AND EPILEPSY

THE REALITY

N-Methy-D-aspartate receptors (NMDA-R) are an essential component of electrical signaling in the brain and have recently been linked to many epilepsies. NMDA-Rs are made up of proteins encoded by the GRIN family of genes. Mutations in GRIN genes can therefore impact how NMDA-R works.

THE RESEARCH

Dr. Stephen Traynelis and his team at Emory University are looking into previously unstudied GRIN gene mutations to see which ones produce a strong overactivation of NMDA-R, making them potential candidates for off-label treatment with drugs that reduce NMDA-R function.⁸ The team has also created a registry where patients with GRIN mutations can sign up to determine if they are good candidates for these off-label treatments.



THE RESULTS

The team plans to evaluate how effective these treatments are for patients, providing clues into whether particular GRIN mutations may be better-suited for these treatments than others. The study is expected to provide data for a clinical trial, which could lead to new therapies for these difficult-to-treat epilepsies.

⁸ Pierson T.M., Yuan H. et. al., Ann Clin Transl Neurol., March 1, 2014;1(3):190-198.



SUDEP

UNCOVERING NEW RISK FACTORS FOR SUDEP

THE REALITY

People living with epilepsy are at higher risk of unexplained death, but the reasons largely remain a mystery. To address this devastating phenomenon, scientists are working to uncover what puts people at greater risk of Sudden Unexplained Death in Epilepsy (SUDEP).

THE RESEARCH

By analyzing the medical records of more than 250 people who died from SUDEP, Dr. Torbjörn Tomson at the Karolinska Institute in Sweden and his team recognized a common thread: generalized tonic-clonic seizures (GTCS). While GTCS was the most important risk factor, the team found that sleeping alone heightened those risks even more.⁹



THE RESULTS

This data confirms previous research showing that unattended generalized tonic-clonic seizures are the biggest risk factor for SUDEP. These findings suggest that improved seizure monitoring devices, sleeping with someone else in the room when possible, and treatments to reduce seizures could all be potentially lifesaving interventions for people with GTCS.

[This research is generously funded by the Leisher Family Award.](#)

⁹ Sveinsson O. et. al., Clinical risk factors in SUDEP: A nationwide population-based case-control study, Neurology, January 28, 2020;94(4):e419-e429.

HOW CAN YOU REDUCE YOUR SUDEP RISK?



CONSIDER NIGHTTIME SUPERVISION OR MONITORING



TAKE MEDICATION AS PRESCRIBED



KEEP A SEIZURE DIARY, AND AVOID SEIZURE TRIGGERS



TAKE CARE OF YOURSELF: EAT WELL, GET ENOUGH REST, AND EXERCISE REGULARLY



KEEP STRESS TO A MINIMUM

WHAT ARE GRIN GENES?

The glutamate ionotropic receptor NMDA type subunit (GRIN) family of genes make proteins that form NMDA-R, an essential component of electrical signaling in the brain. Mutations in these genes can affect how the NMDA-R works, resulting in certain types of epilepsies.

CONGRATULATIONS TO OUR CURE GRANTEES

A life free from seizures is the driving goal of CURE’s epilepsy research program, which supports novel projects with a focus on identifying, preventing, and treating epilepsy. We’re delighted to announce the recipients of our 2019 CURE grants, who join a growing team of investigators around the globe working toward a cure.

CURE EPILEPSY AWARD GRANTEES \$250,000 FOR TWO YEARS

This award reflects CURE’s continued focus on scientific advances that have the potential to truly transform the lives of those affected by epilepsy.



HEATHER MEFFORD, MD, PHD
UNIVERSITY OF WASHINGTON

Dr. Mefford and her team will explore if a process called “abnormal methylation” is a cause of severe pediatric epilepsy syndromes known as developmental and epileptic encephalopathies.



NICHOLAS VARVEL, PHD
EMORY UNIVERSITY

Dr. Varvel and his team will focus on status epilepticus – a neurological emergency with a seizure lasting more than five minutes or when a person doesn’t return to consciousness following multiple seizures. Building on previous findings, the team plans to test an approach to relieve the detrimental effects of these seizures.

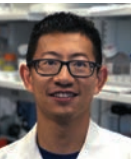


CHRISTOPHER REID, PHD
FLOREY INSTITUTE, AUSTRALIA

Dr. Reid and his team will work to identify key SUDEP risk factors by developing new rodent models that replicate having both epilepsy and a genetic heart abnormality.

TAKING FLIGHT AWARD GRANTEE \$100,000 FOR ONE YEAR

This award seeks to promote the careers of young epilepsy investigators, allowing them to develop a research focus independent of their mentors.



BIN GU, PHD
UNIVERSITY OF NORTH CAROLINA
AT CHAPEL HILL

Dr. Gu and his team plan to use a unique resource – genetically diverse mice – to identify genes that increase susceptibility to SUDEP.

POST-TRAUMATIC EPILEPSY INITIATIVE GRANTEES



PAVEL KLEIN, MD
MID-ATLANTIC EPILEPSY
AND SLEEP CENTER

Dr. Klein and his team plan to address the current inability to predict who will go on to develop PTE following a traumatic brain injury by examining a group of high-risk patients with a greater chance of developing PTE.



JEFFREY LOEB, MD, PHD
UNIVERSITY OF ILLINOIS, CHICAGO

Dr. Loeb and his team are studying subarachnoid hemorrhage, a type of bleeding that commonly occurs following a brain injury and is known to produce seizures. Their goal is to understand and predict who is at risk for developing this condition to identify potential treatment strategies.

Learn more about the Initiative on page 10.

EDUCATION

As the leader in epilepsy research, CURE provides educational insights to empower patients and families as they navigate life with epilepsy.



EPILEPSY EDUCATION FROM EVERY ANGLE

LEADERS IN EPILEPSY RESEARCH WEBINAR SERIES

These webinars dive deep into the latest breakthroughs in diagnosing, treating, and controlling epilepsy, helping patients, families, and caregivers understand the clinical side of this condition. Explore the most innovative developments in epilepsy research today.



EPILEPSY EMERGENCIES AND CURRENT RESCUE MEDICATIONS

DR. KAMIL DETYNIECKI
UNIVERSITY OF MIAMI

DR. NATHAN FOUNTAIN
UNIVERSITY OF VIRGINIA

When a seizure becomes an emergency, rescue medications are a critical lifeline to provide relief and prevent the need for emergency care. In this special two-part webinar, leading experts on this topic explore different types of seizure emergencies, current therapies, and promising research that could lead to new effective rescue medications.



EPILEPSY SURGERY: ADVANCEMENTS, OPTIONS, & CONSIDERATIONS

DR. KATE DAVIS
UNIVERSITY OF PENNSYLVANIA

Surgery can be life-changing for patients with uncontrolled epilepsy. As this area of epilepsy research and treatment evolves, this webinar highlights the types of surgeries currently available to patients, potential risks and benefits, and who is an appropriate candidate for surgery.



EPILEPSY AND DIETARY THERAPIES

DR. JONG RHO
UNIVERSITY OF CALIFORNIA SAN DIEGO

DR. ERIC KOSSOFF
JOHNS HOPKINS CHILDREN'S CENTER

Can changing your diet help control seizures? This webinar discusses dietary therapies from a research and clinical perspective, including the effectiveness of the ketogenic diet and which patients are the best candidates for this type of treatment.





SEIZING LIFE

WANT MORE INSPIRATION?

Check out the full series at cureepilepsy.org/seizing-life



SEIZING LIFE®

The Seizing Life® podcast series chronicles the daily frustrations and triumphs of living with epilepsy, inspiring empathy and providing insight to our community as we search for a cure. Here's a closer look at some of the stories that have touched our lives.

“I really do think we’re changing the conversation from how epilepsy used to be viewed even 10 or 20 years ago.”

NANCY IIDA

TACKLING LIFE WITH PTE AND CTE

MIKE ADAMLE

A former NFL player and broadcaster, Adamle shares his 20-year fight against the effects of post-traumatic epilepsy and how he's working to give hope to others dealing with the condition.

TESTING CAN MAKE A DIFFERENCE

DR. JOHN MILLICHAP, PEDIATRIC EPILEPTOLOGIST,
ANN AND ROBERT H. LURIE CHILDREN'S HOSPITAL OF CHICAGO

With hundreds of epilepsy-related genes, how can you know if you or your child are a candidate for genetic testing? In this episode, Dr. Millichap discusses the basics of epilepsy genetics and the potential power of testing for patients and their families.

YOU'RE NEVER TOO YOUNG TO BE A HERO

HENRY AND NANCY IIDA

After having a seizure in gym class while his classmates watched, Henry Iida knew he wanted to find a way to fight back. With his mother's help, he's raised \$50,000 for epilepsy through Henry's Heroes.

SURVIVING (AND THRIVING) IN COLLEGE WITH EPILEPSY

EVA AND MICHELLE WADZINSKI

College is a big transition for any student – so what's it like for a student living with epilepsy? Eva and her mother, Michelle, share how she's balancing the stresses of college with her condition and strategies that can help make college easier for others with epilepsy.

KNOWING THE SIGNS OF INFANTILE SPASMS

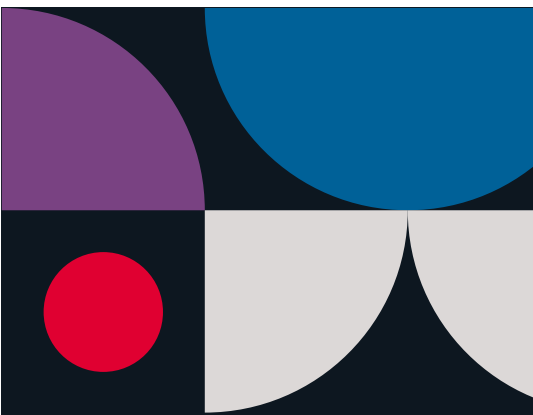
AMY BRIN MILLER, EXECUTIVE DIRECTOR, CHILD NEUROLOGY FOUNDATION

Infantile spasms is a rare and severe form of epilepsy, making swift detection essential to prevent cognitive and developmental delays. In this episode, Miller shares what parents should look for and what to do next if their child has spasms.

EVENTS

From our annual benefit to local block parties and fundraisers, our supporters are making a difference in the search for a cure in so many ways.







AES

EPILEPSY
CONFERENCE



COMING TOGETHER AS A COMMUNITY

We danced and sang. We shared stories of joy and loss. And we walked away energized and hopeful about our shared mission: to find a cure for epilepsy.

Thank you to everyone who's shown up for CURE and the epilepsy community this year. Your support continues to fuel amazing progress in epilepsy research.



\$2 MILLION

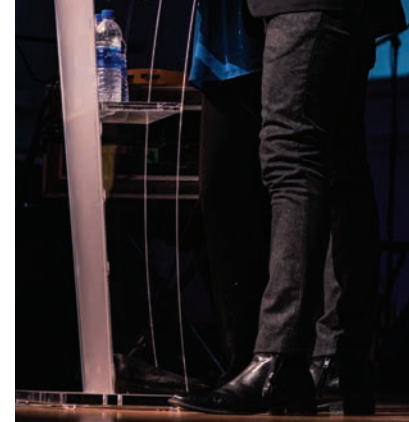
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ANNUAL BENEFIT



EPILEPSY AWARENESS DAY DISNEYLAND



PURPLE DAY





THANK YOU TO OUR CHAMPIONS

Heroes come in all sizes at CURE. Our CURE Champions had their most successful fundraising year ever, raising nearly \$375,000 to advance lifesaving research for epilepsy. Large or small, every gesture of generosity makes a big difference.



WHAT DOES CURE CHAMPIONS SUPPORT?
NEARLY \$375,000 RAISED IN 2019 =
1 CURE EPILEPSY AWARD (\$250,000)
1 TAKING FLIGHT AWARD (\$100,000)

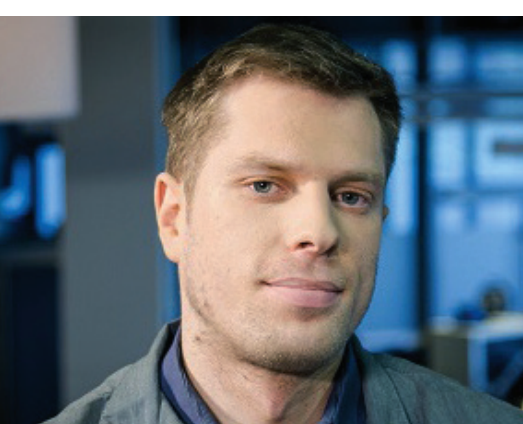
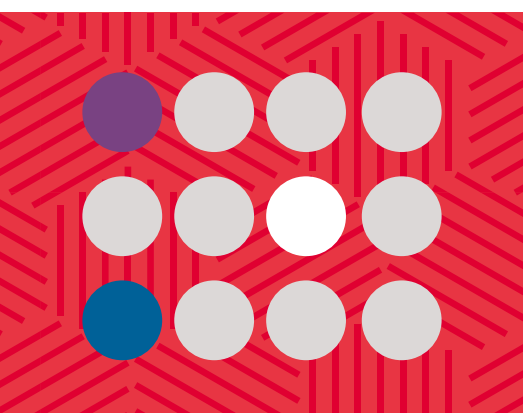




PATIENT STORIES

"We won't stop fighting, advocating, and raising imperative research dollars. Because no family should have to go through this kind of loss, but way too many of us have."

KELLY CERVANTES



CURE IS RESEARCHING FOR...



ADELAIDE

“ I will never stop advocating on [Adelaide’s] behalf, raising awareness and money for research so that families in the future will receive their epilepsy or neuro-degenerative diagnoses along with a treatment plan to full recovery. I promise...that I will fight for science to catch up to the next child, even though it could never catch up to her.”

KELLY CERVANTES,
ADELAIDE’S MOTHER

Adelaide passed away in 2019 from complications from epilepsy, days before her 4th birthday.



VERA

“ While treatment is so helpful, ultimately it doesn’t end our fear or struggle. In fact, the medicine that stopped Vera’s recent seizures has been known to lead to permanent blindness. So medicine in the long run is not ideal. What we need is a cure.”

ELVIN AND CINDY ANGULO,
VERA’S PARENTS

1-year-old Vera has Sturge Weber Syndrome, a rare condition that causes vision issues and epilepsy.



CLARE

“ I’m one of the lucky ones because I finally found a drug that works for my epilepsy. Never finding a proper drug should not be something that happens. Thanks to CURE’s Educational Enrichment Fund scholarship, I plan to major in biological sciences and eventually to help patients as both a clinician and researcher.”

CLARE TYLER

The Educational Enrichment Fund supports students so they can become agents of change in the epilepsy community. Meet all the 2019 scholars at cureepilepsy.org/scholarships.



PAT

“ Pat has tried several medications [for his post-traumatic epilepsy] but continues to suffer from seizures. At this point, I fear our options are running out.”

PATTY HORAN, PAT’S WIFE

Pat developed post-traumatic epilepsy after being shot during a mission in Iraq in 2007. Learn more about CURE’s newest research initiative on post-traumatic epilepsy on page 10.

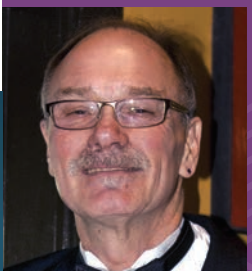


MICHAEL

“ You can’t let the bad times stop you from doing what you love.”

MICHAEL PLATT

14-year-old Michael started cupcake company Michaels Desserts to combat hunger. After an epilepsy diagnosis prevented him from activities like gymnastics and diving, Michael discovered his passion for baking. Watch Michael share his story with David Axelrod at cureepilepsy.org/michaelsdesserts.



AND SO MANY MORE...

At CURE, we’re researching **every day** for those living with epilepsy.

2019 DONOR LIST

We depend on your
support every day.

Every day, we move one step
closer to curing epilepsy –
and we're humbled to have
you with us along the journey.

Thank you for your support.

While space permits us to only list some of
our 4,500+ donors, our gratitude for every gift
is limitless. Each and every donation is critical
to driving epilepsy research forward toward
a cure. Thank you.

To donate to CURE, please visit
[CUREEPILEPSY.ORG/DONATE/2020SPRING](https://cureepilepsy.org/donate/2020spring)

Fiscal Year 2019: January 1 to December 31

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CURE CHAMPIONS 2019

1:26 The Art of Epilepsy - Boston	Land Grant Brewing Celebration
21-Day Detox	Lauren Runs for a CURE
24-Hour Livestream for a CURE	Lemonade for Adelaide
All-Guard Auto Alarm	Lori Sapio Photo Shoot
Barry's Bootcamp	Million Dollar Quartet
Blo Blow Dry Grand Opening	Molly's Birthday Fundraiser
Charitable Cars Donation	Mother's Day T-shirt Sale
Comic Book Launch	Orange Theory Fundraiser
Coral's Crusaders Fundraiser	PennyWars
Criteo Fundraiser	Purple Day Concert
Diamond Paint-A-Thon	Purple Ribbon Gaming Event
Dressage for a Cause	Quiz for a Cause Trivia Night
Easter Basket Candy Drive	Race For Epilepsy
Ella's Race for a CURE	Raw Gamers Twitch Stream
Epilepsy Stigma Awareness Event	Rock for a CURE
Epilepsy: Up Close and Personal (Chicago Salon)	Salesforce Concert
Evan's Facebook Campaign	School Fundraiser
Fitzgerald Physical Therapy Golf Outing Fundraiser	Sean's 1st Birthday
Fundraiser for Olivia	Shutouts for Seizures
Gibi's Twitch Fundraiser	Silent Auction for a CURE
Girl Scout Troop Fundraiser	Skate for Alex
Golf Outing Fundraiser	Songs of Love and Revolution
Hamilcast Fundraiser	Stache for a CURE
Hamiltunes	Team CURE - Chicago Half-Marathon
House of Blues Concert	Team CURE - NYC Marathon
Ice Cream for a CURE	Teresa's Birthday Benefit
Indy Mini Marathon	UMES Strides for Epilepsy 5K
Joey's Song Benefit Concert	Vera's Birthday Fundraiser
Jumpathon at Altitude	Wizard World Comic Con Chicago
Kuder Wedding Gifts	Womens Empowerment Symposium
Lamorna Robert's UK Trivia Event	Yoga for a CURE



EADDL 2019 photos thanks to Brian Kramer Photography
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