

CURE

CURE is the leading nongovernmental agency fully committed to funding research in the epilepsies. CURE is at the forefront of epilepsy research, raising millions to fund innovative research and other initiatives that will lead the way to a cure.

Letter from Susan Axelrod and Gardiner Lapham



As mothers of children who have been deeply affected by epilepsy, we are extremely grateful for your support and want to share with you some of CURE's highlights from 2013. We are proud to also declare that 88% of our funds were invested in our mission—among the highest for charities nationwide.

CURE invested more than \$4M in research and related activities such as scientific conferences in 2013. The majority supported cutting-edge research grants, of which the applications received were extremely competitive and filled with state-of-the-art science that promises to advance our understanding of the epilepsies. We expanded our global reach, now funding researchers in 13 countries.

CURE was pleased to announce an exciting new partnership which took off in 2013, with the Howard Hughes Medical Institute's Medical Research Fellows Program. CURE will provide financial support for up to three medical students each year to conduct mentored research on epilepsy.

Also in 2013, we launched the *Frontiers in Research Seminar Series*. The series is an effort to share innovative epilepsy topics and discoveries with a goal of attracting the best and brightest minds into the field of epilepsy research. We anticipate 10 seminars to be sponsored at different institutions each academic year offering presentations to a wide audience of clinicians, medical students, young investigators, basic science researchers and interested supporters.

The year saw exciting progress for the eight teams of investigators participating in our Infantile Spasms Research Initiative. We continue to support their collaborative research aimed at finding a cure for this rare and devastating childhood epilepsy syndrome. This "dream team" of scientists span adult and pediatric neurology, basic mechanisms of the epilepsies, animal modeling, human genetics and clinical trial design and execution. We are proud to be at the forefront of team science.

Scientific advancements abounded through CURE- sponsored research in 2013, including the discovery by grantee Dr. Peter Crino, who found important new evidence that Human Papillomavirus (HPV), the most common cause of cervical cancer, is linked to epilepsy-causing brain defects that occur in children. This breakthrough discovery may lead to a definable cause and treatment for focal cortical dysplasia type IIB epilepsy.

We were pleased to publish the *2013 State of Research in the Epilepsies Report*. Findings include many promising trends, such as the increase in collaboration evident throughout the field. But major challenges were identified, including the sobering news that funding of epilepsy research, per patient affected, continues to be inadequate.

But, we are making strides. Our 15th Annual CURE Chicago Benefit, with more than 1,000 people in attendance, raised an unprecedented \$1.2 million. Tireless volunteer energy from coast to coast has driven a record number of activities and fundraisers, without which CURE would not stand where we do today, as the largest private funder of epilepsy research.

2013 was clearly a transformative year. We welcomed new board members from across the country, who bring expertise, talent and insight to our organization. Driven by their passion to find a cure for epilepsy, they join us in thanking you for your commitment and support of biomedical research in this critically important area. The progress we are witnessing is phenomenal because of you. And because of you, too, the future is filled with promise.

With sincere appreciation,

Susan Axelrod
Founding Chair

Gardiner Lapham
Board of Directors Chair

CURE's transformative research program has supported more than 165 brilliant scientists and labs in 13 countries. Since its inception in 1998, CURE has raised more than \$28 million for research program activities. CURE invests more than 88% of its funds in its mission, among the highest percentage for charities nationwide.



EXTRAORDINARY
FAMILY RAISES FUNDS
FOR EPILEPSY
WITH HELP FROM
MLB GREATS

Sitting on the side of his daughter's hospital bed, after brain surgery to determine where her seizures emanated from failed, David Fradkin knew that they had two choices—to give up or to get going. Since giving up was out of the question, David and his then 10 year-old daughter Sarah began to brainstorm ideas. What was initially born out of heartache has



led to an extremely successful effort to spread awareness about epilepsy and raise funds for research for a cure. “You can sit around and mope or you can do something about it,” said the Southbury, Connecticut man. “There is no other option.”

“We are just ordinary people doing extraordinary things.”

David Fradkin, Southbury, CT

Sarah and her family—including her dad, David; mom, Monica; and brothers, Noah, 11 and Max, 8—have dealt with Sarah's uncontrollable seizures since she was diagnosed with epilepsy at age 6. Since her diagnosis, Sarah has been on 18 different anti-convulsant medications and a modified ketogenic diet, all of which have failed.

When first diagnosed, Sarah suffered hundreds of seizures a day. Several months later, she experienced a three-year hiatus of seizures, only to have them return again. Then this year, she was seizure-free for another nine months. Once again, they came back.

"We were hoping she had grown out of them," Monica Fradkin said. "It's like being punched in the stomach because you are not prepared for it."

Sarah knows she is a part of a frightening statistic.

"One in 26 people get diagnosed (with epilepsy in their lifetime)," Sarah said. "I think it's important for people to know that."

The Fradkin family point out that epilepsy affects more people than multiple sclerosis, cerebral palsy, muscular dystrophy and Parkinson's combined—yet receives fewer federal research dollars per patient than each of these. In addition, more people die each year from epilepsy than do from breast cancer, however there is no comparison to the amount of funding and awareness that breast cancer receives.

So as part of their family's effort to help with both the awareness and funding for epilepsy research, in 2011, the Fradkins created an annual event called S4 (Sarah & Southbury Strikeout Seizures). The event features a 2.4 mile walk, food, games, a silent auction and more—all to benefit Citizens United for Research in Epilepsy (CURE).

Over the past two years, S4 has raised about \$240,000. The 2014 event was held on June 7 and raised more than \$100,000, funding a research grant for CURE.

The Fradkins are far from alone with their fundraising efforts. David Fradkin, who owns a baseball apparel company, called on a few famous friends for some help.



Lets Strikeout Seizures & Cure Epilepsy
www.S4epilepsywalk.com

Team Captain
Sarah Fradkin

The S4 team includes baseball all-stars such as Paul Molitor; Jim Thome; Ruben Amaro; Tim Wakefield; Carl Willis; Eric Wedge; Chris Carpenter; Pat Hentgen; Sandy Alomar, Jr.; Bruce Bochy; Charles Nagy; Robby Thompson; Mark Shapiro; Bud Black; Brian Schneider Tom Candiotti; and Buddy Bell, who himself has epilepsy. Baseball memorabilia

and one-of-a-kind experiences with these players, former players and coaches are available for auction before and during the S4 event.





“This S4 team is definitely going to find a cure, not only for Sarah, but for others suffering from epilepsy,” David Fradkin said.

Recently, Sarah spoke at an event in Newtown, Connecticut, in front of over 250 people and told them of her daily struggles, noting that she is one of 3 million people living with epilepsy in the U.S..

Later that night an 11-year-old boy came up to the Fradkins table and introduced himself saying, “I am one of those 3 million people, too.”

When she is not receiving attention for her fundraising efforts, Sarah has similar hopes and dreams like many 13-year-old girls have.

“I’ve always wanted to be an actress,” said the pretty, brown-haired girl, who also excels at swimming and soccer.

And despite the herculean efforts of the family, David Fradkin said they aren’t doing anything that anyone else can’t do.

“We are just ordinary people doing extraordinary things,” he said. “Life is not about waiting for the storm to pass, it’s about learning to dance in the rain.”

CURE CREW EVENTS

CURE wishes to thank the following individuals and organizations for their remarkable fundraising efforts in 2013.





2013 Events

\$200,000 and above

**Christopher Donalty
Benefit for a CURE**
Utica, NY

\$150,000-\$199,999

**Kuwait Embassy
Dinner 2013**
Washington, DC

\$100,000-\$149,999

S4 Walk for Epilepsy
Southbury, CT

**Drive for CURE
2013**
Wheaton, IL

Hope4SUDEP
Worldwide

\$25,000-\$99,999

San Francisco Benefit
San Francisco, CA

\$10,000-\$24,999

Hugh-A-Thon
Western Springs, IL

Joey's Song 2013
Madison, WI

Building CURE Globally
Worldwide

**North Shore Century
Ride for CURE**
Chicago, IL

**Madison Friends
of CURE 2013**
Madison, WI

RE: Epilepsy 2013
Highwood, IL

Running for Samson
Cleveland, OH

Fly for Faith
Boca Raton, FL

\$5,000-\$9,999

**Clipper Round the
World**
Cape Town, South Africa
to Western Australia

Shutouts for Seizures
Madison, WI

The Cupid Chase
Senoia, GA

Blue Jeans Ball
Harrisville, RI

**Third Annual
Teresa's Birthday
Benefit for CURE**
San Francisco, CA

Art from the HeART
Los Angeles, CA

**White House
Correspondents
Brunch 2013**
Washington, DC

Houston Dinner 2013
Houston, TX

CURE365
Northbrook, IL

\$2,500-\$4,999

Fencing for a Cause
Winnetka, IL

CURE and the City
Santa Monica, CA

**Kyle's Run for
a Memory 5K**
Victor, NY

Maddie's Marathon
Washington, DC

Wrestling for a CURE
Salt Lake City, UT

**Natalie Jane's
Birthday Party**
Topeka, KS

\$1,000-\$2,499

Rica's Marathon
Victoria, British Columbia

Team Scott
Hoboken, NJ

Don's Birthday
Alexandria, VA

Cornhole for CURE
Ludington, MI

Barbara's Birthday
Topeka, KS

Up to \$999

Rock for CURE
Evansville, IN

Running for a CURE
Washington, DC

Victoria Marathon
Victoria, British Columbia

**Lyndsay Kappel Sale
2013**
North Canton, OH

Gobble Job 5K
Marietta, GA

**AN INSPIRATION
GONE TOO SOON
TO EPILEPSY**

At almost 37, Cameron Benninghoven had the wisdom of an old soul and the wonder of a young child. He was the picture of good health and fitness—except for the epilepsy that he had been diagnosed with at the age of 16. But that was under control with medicine, and in all of those years he only had a handful of seizures. It was one of those seizures, however, that would take the life of this thriving, good-looking, adventurous and successful young man during the night of November 4, 2009,



from a phenomenon known as sudden unexpected death from epilepsy (SUDEP). “When Cameron died, we had never heard of SUDEP,” said his mother, Ellen Benninghoven. “We had never even dreamed Cameron could die from epilepsy.”

“Cameron is a reminder that we study SUDEP because it has a real human toll. The people and families who suffer SUDEP are not just a statistic.”

Edward Glasscock, PhD, Louisiana State University Health Sciences Center

Ellen's sister immediately looked up SUDEP on the internet and found the only organization in the U.S. that was doing research in the area—CURE. The family asked that in lieu of flowers, donations be sent to CURE in Cameron's name and a new relationship dedicated to help find a cure for SUDEP was formed.

Ellen and her long-time partner, Dr. Michael Schafer, set out to fund a CURE research grant for Edward Glasscock, PhD, at, Louisiana State University Health Sciences Center, entitled, "*Pharmacological reversal of cardiorespiratory deficiency in the Kcna1-null model of SUDEP.*"

"A few months ago, I asked Ellen if she could send me some pictures of Cameron so I could include them in presentations and seminars I give on SUDEP and put up on the wall of my lab," Dr. Glasscock said. "Cameron is a reminder that we study SUDEP because it has a real human toll. The people and families who suffer SUDEP are not just a statistic."

Cameron continues to be quite the inspiration. According to his parents, he was as beautiful on the inside as he was on the outside.

"He literally loved everything about life," said Ellen. "Everybody was just so enamored with him."

Ellen Benninghoven with her son Cameron



Tributes

Andy Abplanalp
Teofilo Adame
Blaise Aguirre, MD
Angelina Ahrens
Kyle Akers
Rima Al Sabah
Gregory Albert
Hannah Albus
Marisa Alexander
Elizabeth Alford
Melissa Jane Allen
Nicholas Alexander
George Allen
The Mother of Dr. David
Center and Family
Greg Anderson
Randy Anderson
Andrea Andrea
Jade Andrews
Duthaler Andy
Kathryn S. Anschutz
Ellie Archer
Deziree Arguelles
Ramie & Merri L. Arian
Isabella Armitage
Susan V. Armstrong
Adam Ashley
Lauren Axelrod
Susan & David Axelrod
My Buddy Dave from
Case Hall Back in the day
Dylan Baird
Adam Baldonado
Nicholas Barber
Emily Barrett
Ryan Barrett
Julie Bashkin
Balarka A. Batabyal
Noam Bauman
Michael Baumgartner
Aline Rose Bautista
Tyler Bazemore
Bryant Bechtold
Michele Beck
Aaron Becker
Buddy Bell
Chaim Bell
David Bellamy
Michael Bembery
Tony Benjamin
Joan & Kirk Bennett
Cameron Benninghoven

Ellen Benninghoven
Jim and Erika Beran
Carol Bergmann
Chance Birkicht
Susan Bailey Black
Drs. Heather &
Samantha Block
Linnea Bloom
Nate Bloom
Helen Boen
Luke Boles
Elizabeth Boone
Johyn Borden
Kimberly Borden
Paul Borden-Smith
Richard Boswell
Mike Bottone
Mary Bowman
Cameron Boyd
Cindy Boyd
Marian Bradley-Kohr
Melissa Brauningner
Bridgett Marie
Braunscheidel
Thomas S. Bridges
Ruth Bronston
Charlotte Brown
George Brucks
Robert Buckley
Ella Bull
Olivia Grace Bullis
Carrie Burns
Debra Cafaro & Terrance
Livingston
Owen Cahillane
Seth Camisione
Sheryl Kamen & Staff
Camp Blue Ridge
Michael & Lori Canter
Mom and Dad Capretto
Martin Carlson
John Carmichael
Jeff & Bobbi Carroll
Christopher Cassell
Karen Castrianni
Robert H. Chadderdon
Leon Chavarria
Adam Chefitz
Ben Chefitz
Mitchell Chefitz
Samson Chefitz
Eunice Cherry
Howard Chess

Ellen believes that societal pressures kept her son from going to a doctor regularly and being checked to see if he needed to increase his medication.

“People who have epilepsy have difficulty getting jobs, getting insurance,” she said. “You can’t get a driver’s license if you have had a seizure within 12 months.”

The couple honors their son with their work with CURE and making sure they spread awareness about SUDEP.

“Our concern is two-fold,” Michael said. “That meaningful research and awareness about SUDEP are increased.

“I’m a physician and I didn’t even know about the dangers of SUDEP,” Michael continued. “He lived a perfectly normal life with the occasional seizure.”

Michael said that he believes that many neurologists worry that it is enough of a burden for parents and patients to be told they have epilepsy.

“They don’t want to also burden them with the possibility that they could die from it,” Michael said. “We want to reverse that.”

Facts about SUDEP

- > 1/100 people have a seizure disorder; 1/1000 people with epilepsy die every year of SUDEP.**
- > People who have uncontrolled seizures are at heightened risk for SUDEP.**
- > SUDEP takes more lives annually in the United States than Febrile infection related epilepsy syndrome (FIRES) and sudden infant death syndrome (SIDS) combined.**
- > A person with epilepsy has a more than 20 times higher rate of sudden death than does the general population.**

Tributes cont.

**Jakob Chu
Mark Cochran
Kyle Coggins
Donna Cohen
Brantley Coleman
Chris Colfer
Mike Collins
Mirabel Condon
Haley Congdon
Mary Ellen & Chris Connelly
Danny Cooke Corcoran Family
Caitlin Corkery
Kaylene Cottgias
Dorothy Faith Cozzens
Heather C. Craig
Callie R. Craik
Catherine Crescenti
Katherine Rose Cresto
Neil Creveling
Patrick Crowe
Ella Claire Cunneen
Chelsea Curley
Mark Danford Treadwell
Melissa Daugherty
Jason Davidson
Susan Davies
Anne Marie Davine
Meredith Davis
Mary Ellen De Carlo
Justin De La Garza
Ann Decker
Matt Decker
Robert Decker
Dan Delfosse
Katy DeLorenzo
Nicole Demmon
Uday Deo
James Derby
Vincent DeSanctis
Amit Dhadwal
Paula Diamond
Maria & David Dichiaro
Sandy Dietz
Ann DiPetta
Tracy Dixon-Salazar
Stacey Dodd
Maura Dolan
Peter Dombek
Christopher Donalty
Frank Donalty
Siina Doran
Erma E. Duben
Erika Dubreuil
Reagan Duhon
Melvyn Durchslag
Andy Lowell Duthaler
Jennifer Eaton
Lindey Epps
Jason Epstein
George Erickson
Marilyn Evans
Gretchen Everham
Samantha Ewendt
Wendy Fallon Ballasch
Auvil Family
Katie Faulkner
Katya Fay
Roz Feinberg
Tony & Josephine Ferrante
Barbara Ferraro
David Fields
Herman Fine
Elaine Fitch
Timothy B. Fitzgerald
Patricia Fitzsimons
Jessica Flynn
Eric Folan
Ryan A. Forim
Alexis Forman
The Camiscione Family
Fostoria Rotary Club
Sarah Fradkin
Jeanette Waniak Francis
Bonnie Franklin
Andrew Frascella
Carol Friedman
Sally Friedman
Robbie Funston
Laura Gabor
Charlie Galbraith
Paul Gallagher
Paige Gamble
Karan Gamble
Barbara Gannaway
Kara Gebhart
Mary Genco
Eitan Gewold
Tissie Gilbert
Patrick Gillespie
Patrick Gilmore
Emily Gioia
Zelda Gisser
Emily Goggin
Elana Golan
Lonny Gold**

Tributes cont.

Benjy Goldman
Marah Goldman
Harper Goldsby
Tracy Gonos
Rose Gordon
Maddy Gorman
Ernie & Marion Gottlieb
Michael Gottlieb
Heidi Grabenstatter
Herb Graham
Stephen Graham
Mary Jane Granata
Aaron Green
Benjamin Mason Greenblatt
Michael, Nettie, Emma &
Nathan Greenstein
Dana & Claire Grisolano
Laura Groomes
Christopher Morgan Gulick
Diana Gyulai
Christine Hagenlocher
Emily Diane Hall
Michael Halldorson
Theresa Hallett
Joshua & Mark Halpern
Roseanne & Robert Ham
Andrew Hamilton
Madison Hanocek
Joe & Kathy Hardy
Mary Elizabeth Hargett
Chantel Harris
Ellie Hart
Ryan Hartman
Phyllis Hawthorne
Michael Healey
Alex Heldman
Paul Heldman
Roger Heldman
Josie Heller
Taylor Henderson
Robert Bradley Hendrix
Harriet Virginia Henning
Brewer Mikalle Higby
Elizabeth Higgins
Lauren Hitt
Patricia S. Hoffman
Shira Hoffman
Anderson Holder-Dodaro
Barton Holmest
William Robin Hood
Sarah Jane Hooker
Jon Hopper
Donna Lee Howe

Irene Hsu
Michael Hubbard
Kate Hylton
Tom Hynes
Henry Iida
Susan Inman
George Inness
Abigail Ivie
Christian Jackson
Zach & Heather Jackson
Judy James
Jack Janson
John B. Jay
Lawrence Jochman
Tracey Johnson
Chuck Johnston
Pc Jordan Jr.
Peter Joyce
Vinod K
Ted & Muriel Kahn
Hannah Kaplan
Emerson Kappel
Jonathan Kastner
Lewis Katz
Steve & Donna Katz
Tyler Katz
Susan & Jules Kaufman
Brian Keane
Eliza Kegg
Sean J. Kehler
Scott Keller
Kent Kelley
Ian Charles Kelly
Joseph Matthew Kessler
Maeve Kilcoyne
John King
Kristin Kinzey
Erik Kirk
Lisa Kirkpatrick
Scott Kirton
Kevin Kleiner
Mildred Kluk
Timothy S. Knupp
Michelle Koehne
C&C Koether
George Koether
Joan and Ben Koether
Mr. & Mrs. Scott Kofkin
Antoinette Kohlmeister
Calvin Kolster
Mithra Korukonda
Natasha Krol
Kyle Goodwin
Katie Lamb

Vincent Lampshire
Richard Landau
Gardiner Lapham
Henry Lapham
Alexis Ann Lastoria
Dawson Laws
Donna Lee Howe
Kai Leisher
Rodger Levin
Greg Lewis
Hadley Lewis
Erin Leyden
Christopher Liebscher
Marylin Lipkind
Leonard Liss
Gary David Liston
Debbie Cafaro & Terry
Livingston
Maggie Loesch
Kyle T. Loftus
Cindy Loman
William Lonergan
Andrew Lowell
Rick & Roberta Lowell
Alyson Lowrey
Jordon Ludtke
Augie Luedtke
Jason & Traci Lukert
Beth Lundy
Walter Lyles
Evan Macpherson
Shannon & Jeff Maier
Robert Malkmus, MD
Katelyn Mancini
Jenn Mann, MD
Scott Mannis
Gina Marcl
Ken & Sally Margolis
Tony Marino
Daniel Mark
Ronald Marra
Jessie R. Marsh
Anna Martin
Joshua Mattern
Charlie Mavon
John P. McCormick
James McIntyre
Mary Beth McIntyre
Mr. & Mrs. Kenneth B.
McIntyre
Guy McKhann, MD
Chris Mendeles
Anil Mendiratta, MD
Sharon Mikol

Calvin Miller
Constance Miller
Maggie Miller
Valerie Milnes
Joanna Milstein
Elena Monroy
Ingrid Monroy
Beth Montroy
MacKenzie Moore
Sarah Morath
Emily Morhaim
Mo & Linda Morin
Elijah & Isaiah Morris
Kim Morris
Stanley Morris
Suzanne Morrow
Melissa Murray
Kristy Leigh Music
Abigail Myers
Benjamin Myers
Grant Myers
Anna Nathan
Siobhan Neitzel
Jett Nickelson
Eric Nolan
David Matthias Nolten
Gregory Nye
Chantal O'Brien, MD
Hugh O'Donnell
MacKenzie Olsen
Clinton Ostheimer
Alyssa Pablo
Jose Antonio Paez
Greg and Eleanor Page
Emily Pantzer
Angela Pappas
Todd Parker
Jenna Parlette
Jared Pascarelli
Corey S. Patz
Shannon Peloquin
Grace Penwell
James Perfitt
Julian Peskin
Veronica Petrie
Zach Pfingston
Joshua Phetteplace
Jordan Phillippi
Amy Pike
Kimberly Piwko
Andrew Plotkowski
Ebony Poindexter
Eric Pooler
Ethan Potocki

Christine Poulson
Teddy Premo
Dean Primmer
Sandra Lee Pritchett
Nilesh Rajadhyax
Pat Rankin
Robert Rutkoff
Rebecca Ginsberg
Justin Reed
Stephen Michael Reese
Adam Regan
Jake Reibert
Leslie Reif
Adam Roberts
Joseph Robinson
Robert Roels
Gladys Roman
Belle Rose
Parker Roseen
Joshua Rosenstock
Christopher Rouse
Nisha Roy
David Francis Sacchetti
Scott Saimomd
Hazel Sakai
Savannah Salazar
Jessica Saling / Gill
Vanessa Saling / Gill
Caroline Sayre
Katie Schilthuis
Megan Schmidt
Alan Schneider
Laz & Ellen Schneider
Susan and James
Schneider, MD
Michele Schoenfeld
Alan Sear
Neil C. Shade Sr.
Christy Shake
Nikita Sharma
Rabbi Leonard & Lois Sharzer
Chernie Shayman
Malcolm Sherbine
Alice Shorr
Alice E. Shorr
Elizabeth Diane Shreves
Bruce Siegel
Randy & Lisa Siegel
Rebecca Siegel
Liz Silverman
Dave Simon
Ashok Singh
Anuradha Singh, MD
Rebecca Smits

Barry Sobolewski
Jennie Solomkin
David Solow
Clyde Alexander Sommers
Sephen C. Speck
Susan Spencer
Laura Staniland
Stacey Steele
Esther Sternman
Eitan Samuel Stern-Robbins
Twyla Stewart
Trey Strickland
Linda Keith Strohl
Debbie Stuckey
Timothy J. Sullivan, Jr.
Quinn Sullivan
Stephen R. Summers
Tammy Galleshaw Forgue
Susan Galleshaw
Eileen and Tom Sutula, MD
Robert Swidler
Gerald M. Taub
Kimberly Taube
Niko Tax
Cory Shawn Taylor
Courtney Taylor
William L. Thomas
Zachary Thompson
Russell Thompson Jr.
Alan Titunik
Samuel Brennan Toback
Emma Tollefson
Anna Tomaras
Libby Toohey
David Toye
Sullivan Turner
Livia Umeda
Bridget Van Den Bussche
Nora VanGenderen
Kelly Vasile
Emily Vaughn
Kirk Vlad
Beatrice & Samuel Vogelstein
Paulina Vokulich
Rees Volante
Matson Vollers
Hayden Ira Walker
Teresa Walsh
Jeffrey Scott Wasserman
Jenna Waterbury
Kowalski Wedding Guests
Michael James Weed
Diane Lynn Wesner
Alison White

Melissa White
Phil Whitehurst
Reginald C. Wilkins, Jr.
Janet Wilson
Nick Wojtukiewicz
Robert & Lori Wolfe
Robert Wright
Ms. Jimmie Wrightstone
Jack Wsol
Eric Wulchin
M Yang
Larry Yanowitch
Lisa Yee
Lauren Zaph
Brynne Ziegler
Edie Zusman, MD

CARING COMMUNICATIONS FIRM
FOCUSES ON A
CURE

While playing at his aunt's house, a then 10-year-old Rick Jasculca witnessed an event that still haunts his memory today and was one of three pivotal life moments that set him on a path to help find a cure for epilepsy. The now Chairman & CEO of Jasculca Terman Strategic Communications, a firm headquartered in Chicago, was playing with his cousin Joan, who was also 10, when she fell to the ground and had a seizure in front of him. He didn't



know she had epilepsy—or even what epilepsy was. “I was petrified,” Rick said. “Back then people didn’t talk about (epilepsy). After I witnessed it my parents sat me down and talked about it with me.”

Rick Jasculca and Jim Terman with the talented staff from Jasculca Terman Strategic Communications

“But with epilepsy, here’s a disease we can do something about. We have the opportunity to find a cure and we can so profoundly make a difference in so many lives.”

Rick Jasculca

So many years later, when a good friend, Susan Axelrod, approached Rick about helping out on her first annual event for her newly formed organization to provide funding for epilepsy, Rick said he was all in. He and his partner Jim Terman and the rest of the team at Jasculca Terman—which now includes two of Rick’s children who are V.P.’s at the firm—have been providing an abundance of in-kind donations ever since.

“They have been there from the very, very beginning and bring their whole team to every project that he works on for us,” said CURE Founding Chair Susan Axelrod. “Neither Rick nor Jim has ever said no to any request—no matter how big or small—and still to this day do anything we ask of them.”

The year of the first annual event, in January 1999, the guest speaker was then First Lady Hillary Rodham Clinton. As fortune would have it, Rick was also serving as the White House advance lead, so he was in charge of the First Lady’s schedule. The event was a tremendous success.

It was another personal tie, however, that would really bind Rick and his wife Judy—who sadly passed away of ovarian cancer in 2010—to the cause and convince them to continue to help the organization throughout the years. The Jasculcas have four children: Aimee, 41; Christopher, 39; Andrew, 35; and Lauren, 33. Lauren Jasculca Foley, the youngest, is about the same age as Lauren Axelrod, the daughter of Susan and David Axelrod, who has epilepsy.

“I saw them grow up on very different paths,” Rick said. “I will never forget a meeting Susan and I were both at when I told the person we were meeting with that Susan and I both had Laurens who were the same age and both full of potential. As I was telling the story both Susan and I broke down.”

In a very special moment for Rick, last year, his daughter Lauren, who is now V.P. of Operations and Special Projects for Jasculca Terman, served as the stage manager for CURE’s annual event, which again featured Hillary Clinton as guest speaker, with a guest appearance by Lauren Axelrod.

“Many of us feel we have no choice but to embrace this cause, but Rick is a person whose heart is so big that he has embraced it whole-heartedly and as passionately as if it touched his immediate family personally,” Susan said. “He is so very special and we wish we had more of him!”

The third personal tie that convinced Rick he could make a difference if he committed his time and money to CURE, was watching his wife’s brother Tom overcome polio.

“They found a cure for polio, so I said, ‘We can come up with a cure for epilepsy,’” Rick said. “I believe as a society we have an obligation to do that.”

Over the years, Jasculca Terman has provided CURE with services ranging from event planning—planning CURE’s annual events—to newsletter and annual report production. They have provided PR assistance and in the infancy of the organization, were there to open doors and make introductions.

“We have been on the scene for over three decades so we have a lot of important relationships,” he said. “We do what we can and what is necessary. We want everyone to feel that they are part of a team.”

When asked why his firm gives so much to one organization, Rick, who has served terms in both the Carter and Clinton administrations, said that the answer lies in a lesson he learned while working with the Carter Center. “At the Carter Center, they focus on democracy, human rights and



Jim Terman (left) and Rick Jasculca with President Jimmy Carter at the 2014 Publicity Club of Chicago Golden Trumpet Awards. Rick and Jim were presented with the Lifetime Achievement Award.

health care, but they focus on very specific pieces,” he explained. “In health care, they haven’t focused on the big sexy pieces. They focus on things like river blindness and guinea worm in Africa and they have completely eradicated guinea worm. So I have seen if you have a focus and a discipline you can conquer it.”

Rick said that while he and his family have been personally touched by cancer—most closely by the death of his wife Judy—he has chosen epilepsy as the disease that he wants to conquer.

“Epilepsy doesn’t have the ballyhoo of a lot of other diseases,” he said. “Over the course of a year I write a lot of checks to charities. But with epilepsy, here’s a disease that we can do something about. If we stick with it, we have the opportunity to find a cure and we can so profoundly make a difference in so many lives.”

In-Kind Kindness

AKPD Message & Media

ASGK Public Strategies

Bruce Bever Photography

Benenson Strategy Group

Deutsch, Inc.

Earhole Studios

Eli’s Cheesecake

Mike Fierros

Filmgear

**Jasculca Terman Strategic
Communications**

Judy & Scott Leisher

Mesirow Financial

Ricardo Mondragon

Cyndi Moran

Michelle Norkett

Brian Noyes

Jorge Reyes Ortiz

PRG

Sidley Austin LLP

John Sircher

Alan Thatcher

Tiffany & Co.

Walter Payton Jazz Orchestra

Zacuto

Howard Zwirn

EXPANDING **RESEARCH** AND BUSINESS **ABROAD**

Although Joel S. Marcus has no personal ties to epilepsy, he is passionate about helping to find a cure for the disease. As one of the newest members of the board of directors of CURE, Joel brings the leadership and international business experience that he has gained as Chairman, Chief Executive Officer and Founder of Alexandria Real Estate Equities, Inc. “Epilepsy is an underfunded and underserved set of diseases,” Joel said. “It is one of the most unappreciated areas of neuroscience.”

Joel believes that his experience will help CURE operate as a world-class business. CURE has been named a “Four Star Charity” by Charity Navigator—America’s largest and most trusted independent charity evaluator.

“You need to have great management, you need a financial and business strategy, and to really go after it,” he said.

Originally of Denver, Colorado, Joel founded Alexandria Real Estate Equities, Inc., the largest and leading REIT uniquely focused on collaborative and innovative science and technology campuses in urban innovation clusters, in 1994, and co-founded Alexandria Venture Investments in 1996, and the annual Alexandria Summit™ in 2011.

Joel was first introduced to CURE when he met David Axelrod, the husband of CURE Founding Chair Susan Axelrod, at a Citigroup CEO dinner.

“I’m a Republican and he’s obviously a Democrat,” Joel said. “We had a good debate. I told him I was disappointed with the administration’s work in the research and development industry.”

A friendship developed. Joel said he was impressed with Susan’s personal passion towards finding a cure

for epilepsy and David’s ability to bring the message to the people. In 2013, he invited both Susan and David to serve as panelists at the Medical Research Philanthropy Alexandria Summit, an annual gathering of scientific thought leaders, from healthcare, technology, finance, academia, government, non-profit, and reimbursement exchange insights, debate critical issues, and develop strategic, actionable outcomes to address the most critical healthcare issues facing society.

Moved by the Axelrods’ panels, Joel said he found their determination to cure epilepsy absolutely inspirational. CURE represents everything he stands for, what he has built a career and business upon—a belief in science. The combination of his convictions and newfound friendships have led him to make his first personal donation to the research organization he would become a board member of six months later.

“CURE funds paramount science and deserves to be viewed as the predominant research organization that it is. I hope to bring some business acumen from my years in the industry to help continue expanding this extraordinary research program.”

Research Organizations Supported by CURE Around the World

CURE is proud to have supported researchers at the following esteemed institutions over the years.

Albert Einstein College of Medicine, NY	Hospital for Sick Children, Canada
Ann & Robert H. Lurie Children's Hospital of Chicago, IL	Indiana University, IN
Barrow Neurological Institute, AZ	INSERM, France
Baylor College of Medicine, TX	Johns Hopkins University, MD
Ben-Gurion University of the Negev, Israel	Karolinska Institutet, Sweden
Bogomoletz Institute of Physiology, Ukraine	Legacy Emanuel Medical Center, OR
Boston College, MA	Lehigh University, PA
Boston University, MA	Leiden University Medical Center, Netherlands
Brandeis University, MA	Louisiana State University, LA
Brigham and Women's Hospital, MA	Ludwig Maximilians University, Germany
British Columbia Children's Hospital, Canada	Mario Negri Institute, Italy
Case Western Reserve University, OH	Massachusetts General Hospital, MA
Children's Hospital Colorado, CO	Max Planck Institute, FL
Children's Hospital, Boston, MA	Mayo Clinic, MN
Children's Memorial Hospital, IL	McGill University, Canada
Children's Hospital of Philadelphia, PA	NeurAccel Biosciences, CA
Children's Hospital, St. Louis, MO	New Jersey Medical School, NJ
Children's National Medical Center, Wash DC	New York Medical College, NY
CHU-Sainte-Justine, Canada	New York University, NY
Cincinnati Children's Hospital, OH	Northwestern University, IL
Cleveland Clinic, OH	Pennsylvania State University, PA
Colombia University, NY	Polytechnic Institute of New York University, NY
Cornell University, NY	Purdue University, IN
Creighton University, NE	Rush University, IL
Dana-Farber Cancer Institute, MA	Rutgers University, NJ
Dartmouth College, NH	Sapienza University of Rome, Italy
Drexel University, PA	Southern Illinois University, IL
Duke University, NC	Stanford University, CA
Emory University, GA	Temple University, PA
Epilepsy Bereaved, UK	Texas Tech University, TX
George Washington University, Wash DC	The Hebrew University of Jerusalem, Israel
Great Ormond Street Hospital for Children, UK	The Jackson Laboratory, ME
Greater Los Angeles VA Medical Center, CA	The Nathan Kline Institute, NY
Grenoble Institute of Neuroscience, France	Toronto Western Research Institute, Canada
Harvard Medical School, MA	Tufts University, MA
Harvard University, MA	University College London, UK
Helen Hayes Hospital, NY	University Hospital of Wurzburg, Germany
	University of Alabama at Birmingham, AL

**CURE
has awarded
more
than 160
cutting-edge
projects in
13 countries
around
the world
to date**

University of British Columbia, Canada
University of California, Berkeley, CA
University of California, Davis, CA
University of California, Los Angeles, CA
University of California, San Francisco, CA
University of Colorado, Denver, CO
University of Connecticut, CT
University of Florida, FL
University of Illinois Urbana Champaign, IL
University of Kuopio, Finland
University of Maryland, MD
University of Melbourne, Australia
University of Michigan, MI
University of Minnesota, MN
University of Montana, MT
University of Montreal, Canada
University of Nice-Sophia Antipolis, France
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University of Southern California, CA
University of Sydney, Australia
University of Texas Southwestern, TX
University of Toronto, Canada
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University of Utah, UT
University of Veterinary Medicine, Germany
University of Virginia, VA
University of Washington, WA
University of Wisconsin, Madison
Uppsala University, Sweden
Vanderbilt University, TN
Wake Forest University, NC
Washington University, MO
Weill Medical College of Cornell University, NY
Weizmann Institute of Science, Israel
Wesleyan University, CT
Yale University, CT

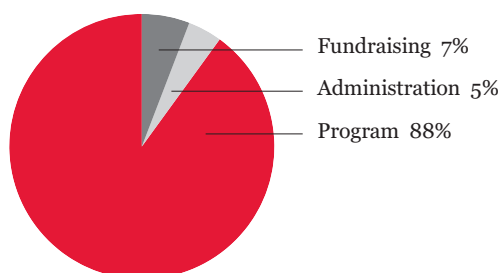
Statements of Financial Position

Years ended December 31, 2013, 2012

Audited Financial Statements

	2013			2012		
	Unrestricted	Temporarily Restricted	Total	Unrestricted	Temporarily Restricted	Total
Assets						
Cash and cash equivalents	\$ 2,930,436	\$ —	\$ 2,930,436	\$ 4,888,350	\$ 350,000	\$ 5,238,350
Investments	6,853,344	—	6,853,344	5,612,360	—	5,612,360
Grants and accounts receivable	279,039	250,000	529,039	220,880	166,666	387,546
Prepaid expenses and other assets	78,673	—	78,673	47,147	—	47,147
Fixed assets, at cost less accumulated depreciation of \$18,327 in 2013 and \$12,257 in 2012	25,616	—	25,616	23,188	—	23,188
Total Assets	\$ 10,167,108	\$ 250,000	\$ 10,417,108	\$ 10,791,925	\$ 516,666	\$ 11,308,591
Liabilities and Net Assets						
Accounts payable and accrued expenses	\$ 74,605	—	\$ 74,605	\$ 102,467	—	\$ 102,467
Grants payable	1,953,495	—	1,953,495	3,016,042	—	3,016,042
Total Liabilities	2,028,100	—	2,028,100	3,118,509	—	3,118,509
Net Assets	8,139,008	250,000	8,389,008	7,673,416	516,666	8,190,082
Total Liabilities and Net Assets	\$ 10,167,108	\$ 250,000	\$ 10,417,108	\$ 10,791,925	\$ 516,666	\$ 11,308,591

Efficiency of Expenditures



Statements of Activities and Changes in Net Assets

Years ended December 31, 2013, 2012

	2013			2012		
	Unrestricted	Temporarily Restricted	Total	Unrestricted	Temporarily Restricted	Total
Support and revenue						
Contributions	\$1,547,165	\$250,000	\$1,797,165	\$1,002,998	\$100,000	\$1,102,998
Net special events	2,501,136	—	2,501,136	3,986,108	—	3,986,108
Investment income	186,840	—	186,840	150,303	—	150,303
Other	5,293	—	5,293	5,417	—	5,417
Net assets released from restriction	516,666	(516,666)	—	716,667	(716,667)	—
Total support and revenue	4,757,100	(266,666)	4,490,434	5,861,493	(616,667)	5,244,826
Expenses						
Program services	3,857,121	—	3,857,121	4,189,960	—	4,189,960
General administration	224,593	—	224,593	179,909	—	179,909
Fundraising	308,309	—	308,309	304,291	—	304,291
Total expenses	4,390,023	—	4,390,023	4,674,160	—	4,674,160
Increase in net assets from operations	367,077	(266,666)	100,411	1,187,333	(616,667)	570,666
Change in fair value of investments	98,515	—	98,515	313,669	—	313,669
Change in net assets	465,592	(266,666)	198,926	1,501,002	(616,667)	884,335
Net assets, beginning of year	7,673,416	516,666	8,190,082	6,172,414	1,133,333	7,305,747
Net assets, end of year	\$ 8,139,008	\$ 250,000	\$ 8,389,008	\$ 7,673,416	\$ 516,666	\$ 8,190,082

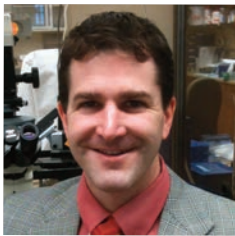
Finding and Funding Cutting-Edge Research

Every grant submitted to CURE goes through a rigorous scientific review process. Each application is evaluated on the basis of scientific merit, relevance to CURE's mission, innovation, feasibility, and likelihood to be transformative. CURE seeks to identify research aimed at curing epilepsy and lay reviewers bring a key perspective and sense of urgency to the CURE grant review process. The end result is that CURE funds the best possible science and funds researchers at all levels in their careers and from many different arenas. The CURE Lay Review Council (LRC) consists of people with epilepsy, or the loved ones of people with epilepsy, who have a special interest in understanding epilepsy research. Members of the LRC participate in CURE's grant review process and read research proposals from a lay perspective so that the stakeholder point of view is critically represented at all stages. Lay review is one of the most important aspects of CURE's unique grant review pipeline. By involving individuals who are personally affected by epilepsy in grant review, CURE keeps the patient at the heart of all the research it funds.



Grant Review Process

**Vision
Setting**



"Receiving a highly competitive CURE award is a formidable gauge of what our colleagues think of the significance and direction of our research. In the lab, CURE funding has allowed us to expand our efforts and explore novel and exciting research avenues."

Dr. Timothy Simeone, grantee, 2013

**Request
for
Proposal
(RFP)**

*CURE issues RFPs
in Summer and Fall*

**Letter
of Intent
(LOI)**

**Scientific
and Lay
Review**

**Research Committee
Members**
Susan Axelrod, Chair
Jeanne Donalty
Barbara Kelly
Scott Leisher
Sharon O'Keefe
Stacey Pigott

**Scientific
and Lay
Review**

**Full
Proposal**



"The CURE funding has enhanced my outreach and teachings efforts."

Dr. Janice Naegele,
grantee, 2013



"I get to witness the uncovering and discovery of new knowledge, totally unseen to any other human in the history of mankind, everyday."

Dr. Avtar Roopra,
grantee, 2013

**Board
of Directors
Approvals**



"This grant award means a lot to me. It enables us to do work for patients and families, which is very personal and is a highly motivating force for myself and my team to give the very best."

Dr. Detlev Boison,
grantee, 2008 and 2013





CURE RESEARCH AWARDS

CURE Research Awards

Challenge Awards

Multiple-year grants (2-3 years), with a maximum of \$250,000, for established or early career investigators exploring cutting-edge approaches to curing epilepsy

JULIE'S HOPE AWARD

John Huguenard, PhD and Jeanne Paz, PhD

Stanford University

“Closed-loop control of injury-induced and genetic seizures using temporally precise cell-type-specific optogenetic manipulation”

This work expands an exciting approach that delivers light to the brain to control the activity of specific cell types. Shining light on certain cells can specifically block seizures without affecting normal brain activities. The researchers plan to develop novel tools to determine causal links between the activity of specific cell types and what seizure types they regulate.

Janice Naegele, PhD

Wesleyan University

“GABAergic Interneuron Transplantation for Circuit Repair and Seizure Suppression in Temporal Lobe Epilepsy”

Investigations in mice with acquired temporal lobe epilepsy will examine whether transplants of a major inhibitory cell in the brain can suppress seizures by repairing dysfunctional neural circuits. Following transplantation, the researchers will study whether the transplanted cells suppress spontaneous seizures.

Prevention of Acquired Epilepsies Awards

Multiple-year grants (up to 3 years) to a maximum of \$250,000 in support of research relevant to the prevention and treatment of acquired (post-insult) epilepsies

BRIGHTER FUTURE AWARD

Detlev Boison, PhD

Legacy Emanuel Hospital and Health Center

“Prevention of Acquired Epilepsy Through an Epigenetic Intervention”

New findings suggest that chemical changes introduced into the DNA of brain cells play a fundamental role in supporting those processes that lead to the development of epilepsy. This grant is based on the discovery that adenosine, a natural anticonvulsant in the brain, reduces these chemical changes to DNA, and thereby has the potential to reverse DNA modifications in the epileptic brain. Dr. Boison seeks to establish a new treatment paradigm to make therapeutic use of a transient dose of adenosine with the goal to prevent the development of epilepsy long-term.

Shelley Russek, PhD & Amy Brooks-Kayal, MD

Boston University & University of Colorado Denver School of Medicine

“Development of Novel JAK/STAT Inhibitors for Disease Modification in Epilepsy”

Dr. Russek and Dr. Brooks-Kayal have found that an important cellular signaling pathway is activated after brain injuries that lead to epilepsy, and that inhibiting this activation reduces subsequent seizure frequency in an animal model. The proposed studies will examine novel inhibitors of this pathway with the ultimate goal of identifying those that are most efficacious in reducing or preventing seizures and/or cognitive co-morbidities in an animal model of acquired epilepsy.

CURE Research Awards

Raimondo D'Ambrosio, PhD

University of Washington

“Prevention of Posttraumatic Epilepsy with FDA-Approved Anti-Inflammatory Drugs”

The mechanisms that lead to the onset of epilepsy after head injury in humans are not known, but mounting evidence points to inflammation as a major contributor. There are numerous FDA-approved anti-inflammatory drugs which target a wide range of inflammatory mechanisms that, alone or in combination, could be antiepileptogenic. These drugs are safe and have been approved for various conditions, and could quickly enter clinical trials for the prevention of posttraumatic epilepsy, but no data are yet available to determine whether they are antiepileptogenic after head injury.

Sudden Unexpected Death in Epilepsy (SUDEP) Awards

One-year grants up to \$100,000 in support of innovative studies that will provide new directions for SUDEP research

**2013 CHRISTOPHER DONALTY
AND KYLE COGGINS MEMORIAL**

Gordon Buchanan, MD, PhD

Yale University

“Role of Vigilance State and Circadian Phase in Seizure-Related Death”

Sudden unexpected death in epilepsy (SUDEP) most commonly occurs at night, but why this happens is unknown. Dr. Buchanan and colleagues hypothesize that this may be due to sleep state-dependent and/or circadian (time-of-day) variation in the respiratory and cardiac consequences of seizures. They will employ a genetic mouse model to evaluate the effects of seizures which occur during different sleep-wake states and circadian times on breathing, heart control, and mortality.

TEAM S4 AWARD

David Paterson, PhD

Boston Children's Hospital

“Searching for Common Gene Variants in Sudden Death in Childhood with Febrile Seizures, SIDS and SUDEP”

Sudden unexpected death in childhood associated with febrile seizures (SUDC-FS) is the sudden unexpected death of a child that has a personal and family history of fever-related (febrile) seizures. These children have many features in common with individuals dying of SUDEP and sudden infant death syndrome (SIDS), including sleep-related death and discovery in the prone position. Genetic analysis of these families, as proposed in this study, provides an excellent opportunity to identify the genes responsible for SUDC-FS and therefore also SUDEP and SIDS.

Else Tolner, PhD and Arn van den Maagdenberg, PhD

Leiden University Medical Center (LUMC), the Netherlands

“Excessive Neuronal Inhibition Changes Physiological Functions and Increases SUDEP Risk”

The research will test the hypothesis that suppression of brain activity after a seizure reflects increased neuronal inhibition and is linked to fatal outcome. They will use mouse models carrying human pathogenic gene mutations that exhibit various neurological disease features including fatal seizures. By experimentally modulating the imbalance between excitatory and inhibitory neuronal activity, they expect to aggravate or ameliorate SUDEP in the mice. Thus they hope to provide a mechanistic understanding of SUDEP pathophysiology and development of diagnostic tools for identifying susceptible individuals.

Pediatric Epilepsies Awards

Two-year grants up to \$250,000 in support of research projects of relevance to the numerous debilitating and difficult to treat pediatric epilepsies

THE ROCK THE BLOCK FOR PEDIATRIC EPILEPSY RESEARCH AWARD

Edward Cooper, MD, PhD

Baylor College of Medicine

“Targeted molecular therapy for KCNQ2-associated severe pediatric epilepsy”

Potassium channels are part of the brain’s molecular machinery for electrical signaling. Mutations in the potassium channel gene KCNQ2 cause forms of epilepsy that begin within days after birth. The severity of KCNQ2-associated epilepsy varies from very mild to severe. They will develop methods for augmenting KCNQ2 activity in individuals bearing severe disease-causing mutations, using a combination of cell-based approaches and animal models.

THE VOGELSTEIN PEDIATRIC EPILEPSY AWARD

Timothy Simeone, PhD

Creighton University

“The Critical Role of PPARgamma in Ketogenic Diet Efficacy”

Elucidating the critical mediator(s) of ketogenic diet (KD) efficacy will further understanding of the basic mechanisms of epilepsy and open new avenues of drug discovery. To this end, recent findings implicate a regulator of gene expression called PPARgamma as a mediator of KD anti-seizure efficacy. The proposed studies will test investigational drugs, determine relevant functional mechanisms and explore possible strategies of reducing the stringency of the KD.

Innovator Awards

One-year grants up to \$50,000 in support of the exploration of a highly innovative new concept or untested theory that addresses an important problem relevant to epilepsy

THE ROCK THE BLOCK FOR PEDIATRIC EPILEPSY RESEARCH AWARD

J. Marie Hardwick, PhD

Johns Hopkins University

“Autophagy defect in epilepsy”

Using yeast genetics as a tool to find new regulators of cell death, they identified an uncharacterized yeast gene with homology to a human gene mutated in children with a form of intractable epilepsy. By generating an animal model of this new epilepsy syndrome, researchers seek to translate this unique information from yeast to explain a new cause of epilepsy and to provide a model for testing new therapies.

Christophe Heinrich, PhD and Antoine Depaulis, PhD

Grenoble Institute of Neuroscience, INSERM

“Conversion of reactive glia into neurons in Mesial Temporal Lobe Epilepsy: a new way to generate GABAergic interneurons and reduce seizure activity?”

Mesio-Temporal Lobe Epilepsy (MTLE), the most common form of intractable epilepsy, is associated with loss of inhibitory neurons and proliferation of glial cells, both of which have been suggested to play a critical role in epilepsy development. Therefore, a procedure to reverse these changes represents an innovative strategy to reduce seizures. If successful, this approach could prevent epilepsy development and/or attenuate seizures in the chronic phase of the disease.

Bruce Hermann, PhD

University of Wisconsin, Madison

Matti Sillanpaa, MD, PhD

University of Turku, Finland

**“Brain Aging in Persons with Childhood Onset Epilepsy:
A Population Based Investigation”**

The purpose of this project is to characterize patterns of cognitive and brain aging in persons with childhood onset epilepsy. This issue is addressed in a unique population-based cohort from Finland consisting of healthy individuals and persons with childhood onset epilepsies followed since childhood/adolescence, now 45-62 years old. For this project the cohort is returning for assessment of memory and other cognitive abilities, sophisticated neuroimaging to examine brain structure and function, EEG, and detailed interview. The results will provide unprecedented insights into the very long term cognitive and brain health of persons with childhood epilepsies.

Thomas McCown, PhD

University of North Carolina, Chapel Hill

**“An Essential Element for Novel, Astrocyte Focused
Epilepsy Therapies: the Creation of a Chimeric, Astrocyte
Selective Adeno-associated Virus Vector”**

Seizures impair the function of several types of cells in the brain. Specifically, impairment of the astrocyte cells leads to an environment that favors further seizure activity. To date, no means exist to efficiently express genes in astrocytes that could restore normal cellular function. If successful, this project has far reaching implications for epilepsy therapy. With an established astrocyte selective therapy, the potential exists to reverse the pro-seizure environment and subsequently prevent seizure activity.

Taking Flight Awards

One-year grants up to \$100,000 to help promote the careers of young investigators and support them as they develop an independent research focus

Nigel Jones, PhD

University of Melbourne

“DNA methylation in epilepsy”

In cases of acquired epilepsy, such as those resulting from head injury, the levels of many different proteins within the brain change dramatically. This experimental research will investigate an overarching molecular mechanism which mediates these wide-spread changes in protein expression following brain injury, and will determine whether blocking this mechanism can prevent the negative impact these protein changes exert on the brain. It is hoped that by providing a pharmacological intervention immediately following head injury in patients, they can prevent the changes in protein expression within the brain from occurring, and ultimately stop the development of the epilepsy following the injury.

Yevgeny Berdichevsky, PhD

Lehigh University

“IGF-1 signaling in posttraumatic epileptogenesis”

Traumatic brain injury activates complex molecular signals in surviving neurons. Some of these signals are thought to cause posttraumatic epilepsy. This project relies on high-throughput bioengineering methods to identify the precise roles that these signaling molecules play in the development of epilepsy. The goal is to find a combination of signaling pathways that could be inhibited for complete prevention of epilepsy with minimal side effects.

John Wolf, PhD

University of Pennsylvania

“Network and Axonal Mechanisms
Underlying the Transition to Post-Traumatic
Epilepsy Following Repetitive Mild Traumatic
Brain Injury (Concussion)”

There is an increased risk of epilepsy onset following a mild traumatic brain injury (concussion). However, the mechanisms underlying this process are unknown. They are therefore evaluating circuitry changes over time after injury and are testing a promising intervention that blocks inflammatory processes contributing to circuit dysfunction in the hippocampus. Establishing a mechanistic link between repetitive concussions and epilepsy would be a powerful way to reduce the number of new epilepsy cases.

Hiroki Taniguchi, PhD

Max Planck Florida

“Towards a chandelier cell-based cure
for epilepsy”

Development of novel strategies to safely cure epilepsy is urgent for both clinical and basic neuroscientists. Chandelier cells are the most powerful inhibitory neurons, and they can be useful for a cell transplantation therapy to reduce seizures. First, they will test if transplantation of chandelier cells into an animal model of epilepsy can reverse the seizure phenotype. Second, they will identify genetic programs that specifically lead to the development of chandelier cells.

2013 Donors

CURE thanks the following individuals, organizations and corporations that generously supported our mission during this fiscal year.

\$250,000 +

Constance Milstein & Family
John & Barbara Vogelstein
Foundation

\$100,000–\$249,999

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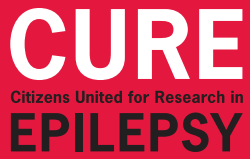
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