

CURE

Citizens United for Research in
EPILEPSY

730 North Franklin Street | Suite 404
Chicago, IL 60654
PH: 312.255.1801 | 800.765.7118
info@CUREepilepsy.org
www.CUREepilepsy.org

Nonprofit
Organization
U.S. Postage
Chicago
PAID
Permit NO. 436

CURE

Citizens United for Research in
EPILEPSY

CURE Newsletter
SUMMER '10, VOL 14

CURE is moving: 223 W. Erie St, Suite 2SW, Chicago, IL 60654

www.CUREepilepsy.org

It's time we found a cure.

CeCe
January 11, 2007–March 9, 2010

IN THIS ISSUE

MESSAGE FROM THE CHAIR 2

BOARD NEWS 3

RESEARCH NEWS 4–9

SPREADING THE WORD 10–11

EVENTS 12–15



*A younger Chris Colfer (now star of hit
TV series Glee) with his sister Hannah*
STORY PAGE 10

CURE

Honorary Board of Advisors:

U.S. Senator Herb Kohl, Chair
Milwaukee, Wisconsin

Jim Abrahams
Santa Monica, California

Richard Jasculca
Chicago, Illinois

Martin D. Penry
Winston-Salem, North Carolina

Board of Directors:

Susan Axelrod, Chair
Chicago, Illinois

Barbara Kelly, Vice-Chair
Oak Brook, Illinois

Jeanne H. Donalty, Secretary
Utica, New York

Thomas F. Hynes, Treasurer
Chicago, Illinois

LeeAnn Brigido
Lincoln, Rhode Island

Gardiner Lapham, MPH
Washington, D.C.

Connie Milstein, JD
Washington, D.C.

Randolph Siegel
New York, New York

Investment Committee:

Thomas F. Hynes, Chair
Chicago, Illinois

Craig Albert
Chicago, Illinois

Patrick Nash
Chicago, Illinois

Paul Toback
Bannockburn, Illinois

Research Review Board:

Barbara Kelly, Chair
Oak Brook, Illinois

Valerie Davis, MD, Facilitator
River Forest, Illinois

Tracy Dixon-Salazar, PhD
San Diego, California

Jill S. Fischer, PhD
Winnetka, Illinois

Stacey Pigott
Wilmette, Illinois

James Schneider, MD
Northbrook, Illinois

2010 Scientific Advisory Board:

Robert Fisher, MD, PhD
Stanford School of Medicine

Howard Goodkin, MD, PhD
University of Virginia Medical Center

Jeffrey L. Noebels, MD, PhD
Baylor College of Medicine

Ivan Soltesz, PhD
University of California, Irvine

Karen S. Wilcox, PhD
University of Utah

Executive Director:

Michelle Marciniak, MPH

Program Officer:

Danielle Davis

Program Associate:

Megan Morrow

Program Assistant:

Bridget May



Message from the Chair

This is such an exciting time for all of us at CURE, as we begin to implement our new strategic plan for growth and build on the momentum of the past few years.

Soon, you'll receive notice of our move to new and larger office space. You'll be introduced to new members of our team who will lead our more aggressive and creative research portfolio, and the development of resources required to support it. We are strengthening our commitment to advancing the understanding of the basic mechanisms underlying epilepsy, to increasing collaborative efforts among researchers, and to funding even more high-risk/potentially high-reward, cutting-edge research.

Of course, we can't do this without you and your continued trust and support. One of the most eye-opening results of the McKinsey & Co. analysis conducted for our strategic planning is that private dollars for epilepsy research total only \$4 per patient affected. Compare this to another chronic neurological disease like, say, Parkinson's Disease, which receives \$45 per patient, and you'll understand why accelerating the search for cures necessitates a significant infusion of new dollars.

We promise you that we will remain steadfast in our commitment to being the voice for patients and families and our desperate need for better answers and, ultimately, cures. We will stay true to our mission, continuing to invest your dollars wisely in cutting-edge research.

Taking this movement from our "three moms around the kitchen table" beginnings to this next step is a bit intimidating. And there will undoubtedly be a few hiccups and false starts along the way. But, the mission we embarked upon some twelve years ago will continue to guide us, and as always, we not only welcome but rely upon your participation and support as we unravel the mysteries of epilepsy—mysteries which have defied explanation, and shattered too many lives for far too long.

With deep appreciation for your continued support and participation,

Susan Axelrod

Connie Milstein Joins Board of Directors



CURE welcomes Connie Milstein to its Board of Directors. As Principal and Co-Founder of Ogden CAP Properties, LLC, Milstein oversees and guides the company's real estate, hotel, and development operations. She is also a successful attorney, entrepreneur, and philanthropist. Milstein joined CURE in December 2009.

A longtime supporter of medical research, Milstein has become an exceedingly generous and passionate advocate for epilepsy and CURE's mission.

"Connie is a true inspiration," said Gardiner Lapham, CURE Board of Directors. "She is deeply committed to finding a cure for epilepsy, and raising awareness of the true toll it takes on both the individual and the entire family. We are thrilled that she has joined our cause."

Milstein is a graduate of New York University and North Carolina Central University Law School. A proud mother and grandmother, she lives in Washington, D.C. with her husband.

faces Honors Susan Axelrod



For her tireless efforts as an epilepsy advocate and her groundbreaking work facilitating collaborations between researchers and organizations, Finding a Cure for Epilepsy and Seizures (*faces*) honored CURE's Susan Axelrod at their 10th annual New York City gala.

The New York-based nonprofit works to improve quality of life for people affected by epilepsy through research, education, and community building. The gala commemorated the 15 years that *faces* has been serving the epilepsy community.

Upon accepting her award, Axelrod spoke of the progress made to date, but emphasized the urgent need to continue all efforts that lead to accelerating the search for a cure.

Photo: Susan Axelrod and *faces* Chair Dr. Orrin Devinsky

IN-KIND
KINDNESS

In 1998, CURE was formed around a kitchen table. One hundred research grants later, and enjoying the exposure of unprecedented national media attention for epilepsy, new opportunities seem to appear around every corner. CURE's success has been due in large part to the support and friendship of many who have given graciously of their time, expertise, and services. In this issue, CURE pays tribute to the on-going, immeasurable generosity of AKPD Message and Media.

A Tribute to AKPD Message and Media

From the very beginning, AKPD has lent a hand in any way they could. They've helped raise public awareness by donating the production of CURE's annual videos, each of which is a poignant portrayal of the challenges posed by epilepsy and seizures, which is shown at events and in research labs across the country.

And when CURE outgrew the kitchen table, it was AKPD who offered the small staff a new home, donating office space, supplies, and other essential resources (including much-needed coffee!) so that so much of every dollar donated could go directly to research. And on top of that, they have been generous supporters of CURE's Annual Benefit in Chicago.

AKPD's willingness to support this fledgling organization from its very first days will always be remembered as key to the amazing success CURE has enjoyed. And although CURE is once again bursting out of its seams, and will soon be moving to new, larger office space (though just a few blocks down the street from AKPD) the friendship, and CURE's deepest appreciation, will never diminish.

CURE IS MOVING: 223 W. ERIE ST,
SUITE 2SW, CHICAGO, IL 60654

Thank you to Jasculca/Terman and Associates' VisCom department, and in particular Kelsey Krzmarzick and Elise Weiler, for newsletter design and production.

\$1.25 Million Awarded for 2010 Research Program

CURE funds seed grants to young and established investigators to explore new and promising areas of research. All awards are given in consideration of CURE's preeminent mission: "no seizures, no side effects."

CURE is proud to present on these three pages brief summaries of the cutting-edge research selected this year in the categories delineated.

Prevention of Epilepsy After Brain Injury Award

This program supports research preventing epilepsy, which results from injury to the brain, including traumatic brain injury, stroke, and brain tumor.

* THE 2010 FRIENDS FOR A CURE AWARD *

This grant was funded by donations made for CURE's Fall 2009 Every Dollar Counts campaign

Prevention of Post-Stroke Epileptogenesis



Istvan Mody, PhD
UCLA School of Medicine

Cerebrovascular brain injuries (including stroke and ischemia) account for 11% of the symptomatic epilepsies and the incidence of epilepsy after a stroke can be as high as 20%. Dr. Mody has developed a novel and specific cerebrovascular trauma model in mice that reduces the blood supply to brain areas heavily involved in the genesis of epilepsy, and has preliminary data consistent with the development of epilepsy after such trauma. His investigation will focus on understanding the mechanisms leading to the development of epilepsy after the cerebrovascular injury, and on developing novel pharmacological approaches aimed at stopping the transition from stroke to epilepsy in its tracks.

LETTERS OF INTENT FOR 2011 CHALLENGE, MULTIDISCIPLINARY, SUDEP, & PREVENTION OF BRAIN INJURY AWARDS DUE: SEPTEMBER 14, 2010

Challenge Awards

This program supports innovative projects over two or three years for established investigators.

* THE BRIGHTER FUTURE AWARD *

In honor of Lauren Axelrod, funded by a caring donor

Seizure Resistance Through Metabolic Control in a Novel Mouse Model



Gary Yellen, PhD
Harvard Medical School



Nika Danial, PhD
Dana-Farber Cancer Institute

Nearly one-third of people with epilepsy have seizures that cannot be well-treated by existing medications. The success of dietary treatment (such as the ketogenic diet) for many of these individuals suggests a powerful connection between metabolism and seizures. However, these diets are difficult to maintain, spurring a search for alternative ways to manipulate metabolism in order to prevent seizures. Drs. Danial and Yellen are collaborating on a multidisciplinary approach to this problem based on an exciting initial observation. They found that a genetic manipulation in mice that reduces the metabolism of glucose (sugars) and enhances the metabolism of ketone bodies (compounds which are a vital source of energy in the brain during fasting) can produce strong seizure resistance, which is far more dramatic than seen with the ketogenic diet. They will explore the mechanism of this effect and investigate novel therapeutic targets and approaches for epilepsy treatment.

* THE 2010 FALK MEDICAL RESEARCH TRUST AWARD *

Treating Cortical Dysplasia with Adult Human Neural Progenitor Cells



Steven Roper, MD
University of Florida

Cortical dysplasia (CD) is a problem of brain development that often causes severe epilepsy. Using an animal model of CD, Dr. Roper and his collaborators will use a novel approach to the treatment of epilepsy in CD using adult human neural progenitor cells from surgically removed tissue from individuals with intractable epilepsy. These cells will be put into rats with CD in order to replace the lost inhibitory neurons and restore normal brain function. This project offers a new direction for treatment of intractable epilepsies using targeted cellular therapies. If this research is successful, the use of adult human donor cells will facilitate the translation of this approach to treatments for individuals with epilepsy due to CD.

Multidisciplinary Award

This program brings researchers from disparate fields together for two years to explore novel approaches.

* THE HELDMAN AWARD *

JAK/STAT Inhibition to Prevent Epilepsy Development and Progression



Amy Brooks-Kayal, MD
University of Colorado, Denver
The Children's Hospital



Shelley Russek, PhD
Boston University School of Medicine

Drs. Brooks-Kayal and Russek will examine the role of an important cell signaling pathway called the JAK/STAT pathway in the development and progression of epilepsy. Their labs recently discovered that this pathway regulates brain inhibition and is activated by seizures, likely in response to an increase during seizures of the growth factor, brain derived neurotrophic factor (BDNF). Using a combination of studies in the laboratory and in animal models of epilepsy, they will use specific blockers of BDNF and the JAK/STAT pathway to reduce or prevent epilepsy development and/or progression.

Sudden Unexplained Death in Epilepsy (SUDEP) Awards

This program supports research focused on the understanding and prevention of SUDEP.

* CURE & DRAVET FOUNDATION RESEARCH AWARD *

Cardiac Arrhythmias and SUDEP in SMEI and Other Nav1.1 (SCN1A) Related Epilepsies



Sebastian Maier, MD, PhD
University Hospital of Wuerzburg



Massimo Mantegazza, PhD
IPMC, University of Nice-Sophia Antipolis

Dravet syndrome is a severe and drug resistant form of epilepsy, characterized by high mortality rates. Sudden Unexplained Death in Epilepsy (SUDEP) is the most frequent cause of death for individuals with Dravet syndrome. The majority of individuals with Dravet syndrome carry mutations in a sodium channel subtype that is found in the brain, heart, and nerves. Drs. Maier and Mantegazza will study the role of this sodium channel subtype in the heart in a model of Dravet syndrome in order to investigate the occurrence and mechanism of arrhythmias and their possible involvement in SUDEP.

* THE LEISHER FAMILY AWARD *

Role of Pharmacological Treatment in the Prevention of SUDEP



Torbjörn Tomson, MD, PhD
Karolinska Institutet



Peter Mattsson, MD, PhD
Uppsala University

Drs. Tomson and Mattsson will utilize three nationwide Swedish registries that offer unique opportunities to study the association between drug treatment and risk of Sudden Unexplained Death in Epilepsy (SUDEP). The medical records of living individuals with epilepsy will be compared to those with SUDEP with respect to use of antiepileptic drugs (AEDs) and other drugs to assess if the risk of SUDEP is related to non-adherence to prescribed AEDs, to any specific type of AED, and if concomitant use of other drugs such as some antidepressants could be protective. This study will provide essential information for the development of pharmacological treatment strategies to reduce the risks of and to prevent SUDEP.

* THE 2010 CHRISTOPHER DONALTY & KYLE COGGINS MEMORIAL AWARD FOR SUDEP RESEARCH *

Prevention of SUDEP by Serotonergic Agents in DBA/1 Mice



Carl Faingold, PhD
Southern Illinois University School of Medicine

Dr. Faingold has developed a new animal model of human Sudden Unexplained Death in Epilepsy (SUDEP), DBA/1 mice. These animals show generalized seizures and then stop breathing if not resuscitated, which is common in human SUDEP. They found that drugs that increase the level of a neurochemical (serotonin) in the brain will prevent SUDEP in these mice. The current study will examine if new drugs that have a more selective effect on serotonin will prevent the respiratory arrest that follows seizures in these mice.

MORE 2010 CURE RESEARCH CONTINUED ON PAGE 6.

** Named grant opportunities available.
Contact CURE: 312.255.1801*

New 2010 Innovator Program Funds Cutting-Edge Concepts

This program, in its first year, provides support for novel and high-risk/potentially high-reward concepts.

A New Experimental Model of Rasmussen's Encephalopathy: Understanding its Pathophysiology



LIONEL CARMANT, MD
University of Montreal

Rasmussen encephalitis (RE) is a rare but severe brain disorder that starts in childhood with seizures that become more and more frequent, and includes progressive weakness of the affected side of the body. The mechanisms of RE are still not well understood, although it appears that it is caused by dysfunction of the immune system. Dr. Carmant will utilize an animal model to identify the cause of RE and the role the immune system plays in this disorder.

Treatment of Epilepsy with a Catalytic Antioxidant



Manisha Patel, PhD
University of Colorado, Denver

The goal of this project is to study early treatment with a novel catalytic antioxidant (small molecule mimics of the body's own defenses) to prevent metabolic dysfunction and epilepsy in mice. This is a novel class of drugs that have not been tested to treat epilepsy, and if Dr. Patel's studies are successful, the drugs will halt the devastating effects of chronic seizures.

Prevention of Post-Traumatic Epilepsy by Application of Ceftriaxone Acutely After TBI



Alexander Rotenberg, MD, PhD
*Children's Hospital Boston
Harvard Medical School*

Traumatic brain injury (TBI) often leads to epilepsy with a delay that can be weeks to months after the initial trauma. At the biochemical level, the process that leads to epilepsy after TBI is in part mediated by an excess of the excitatory neurotransmitter glutamate. This project will explore the novel use of antibiotics to remove the excess glutamate acutely after brain injury in an animal model. Because these drugs are already in wide use for antibacterial treatment, Dr. Rotenberg anticipates that positive data from his studies can be rapidly translated to novel clinical trials.

Epilepsy Researchers Fight for Hope

West Lafayette, IN—This February, CURE Board member Jeanne Donalty and loyal CURE volunteer Susan Schneider traveled to Purdue University to promote the groundbreaking research being conducted there by CURE grantees Jenna Rickus, PhD and Pedro Irazoqui, PhD.

After a prologue of personal epilepsy stories drawn from CURE's website, Dr. Irazoqui spoke of his team's work developing a closed-loop neural prosthesis to predict, detect, and eventually control seizures.

Afterwards, Donalty and Schneider took questions from the audience and shared their thoughts on the urgency of the need to further such critical research. The event was a shining example of what is made possible when lay organizations and scientists join forces.



Susan Schneider, Jeanne Donalty, Dr. Pedro Irazoqui

New Grant to Help Young Researchers Take Flight

Throughout the scientific world, there is growing concern about our ability to attract and keep bright, young scientists—our future—involved and successful. To help ensure that these young individuals remain committed to epilepsy research, CURE is introducing a new grant mechanism, the Taking Flight Award. These awards will be presented to the most promising senior postdoctoral or clinical fellows, allowing them to develop a research path independent of their mentor(s).

Thanks to the overwhelming support from so many donors during the "Mother's & Father's Day Campaign," CURE will fund three inaugural Taking Flight Awards. Grant recipients will be announced in November.

CURE Renews Participation in DoD Research Program

Board Chair Susan Axelrod and Scientific Consultant Vicky Whittemore, PhD have again been selected to serve as consumer reviewers of research applications submitted to the 2010 Peer Reviewed Medical Research Program in the Congressionally Directed Medical Research Program, Department of Defense. In addition, CURE Research Review Board member Tracy Dixon-Salazar, PhD will join the review panel for the first time.

Axelrod, Whittemore, and Dixon-Salazar have been chosen for their unique perspectives as both parents and patients, who can remind researchers of the human component of the disease and advocate for patients based on firsthand, personal experiences with epilepsy.

Dixon-Salazar stated, "I'm excited to be a part of this program which pairs government, scientists, and consumers in an effort to fund the best, most relevant epilepsy research out there."

CURE Supports Epilepsy Mortality/SUDEP Meeting

The increased risk of mortality in epilepsy may be due in part to associated comorbidities, injury, direct consequences of seizures, and Sudden Unexplained Death in Epilepsy (SUDEP). There have been no large-scale studies in the United States to identify cases of death from any of these causes; thus the number of epilepsy deaths can only be estimated. Without the research and programs in place to identify cases of death in epilepsy, collect tissue and blood samples from these individuals, and to study the potential risk factors for death in epilepsy, scientists have had a difficult time understanding the risk factors for SUDEP and other causes of death in epilepsy.

CURE is supporting an upcoming conference that will bring together world experts to discuss research and the development of registries for epilepsy-related deaths. This conference is being organized in conjunction with the National Center for Chronic Disease Prevention and Human Promotion at the Centers for Disease Control (CDC), and the National Institute of Neurological Diseases and Stroke (NINDS) at the National Institutes of Health (NIH), CURE, the Epilepsy Therapy Project, and others.

A Genetic Risk for SUDEP?

Sudden Unexplained Death in Epilepsy (SUDEP) occurs when a person who has epilepsy dies unexpectedly, and no other reason for the death can be identified. The risk of sudden death is 24 times greater in patients with epilepsy than in the general population.

Until now, little research has been directed at identifying causes and risk factors for SUDEP, but recent genetic research in the laboratory of Jeffrey Noebels, MD, PhD and his collaborators at Baylor College of Medicine in Houston, Texas, are providing new clues.

Alica Goldman, MD, PhD (2009 CURE grantee) and colleagues found that a gene (KCNQ1) important in the regulation of the heart is also found in the brain. Mutations in this gene are known to be involved in the most common form of cardiac long QT syndrome in humans, which can cause sudden death. They found that mutations of this gene in animals caused seizures and dysregulation of the heart.

Albert E. Glasscock, PhD and colleagues found that animals with mutations in the gene *Kcna1* have severe seizures and die prematurely. This gene is abundant in the brain, but found only minimally, if at all, in the heart. They found that the animals had a five-fold increase in significant heart abnormalities.

These new findings provide evidence that genetic factors may be involved in SUDEP. Future research is needed to identify the role these genes and others play, what can be done to identify who is at higher risk for SUDEP, and how to minimize and eliminate risk for all individuals with epilepsy.

To read more:

<http://www.CUREepilepsy.org/news/research/sudep.asp>

CURE Takes Lead With Open Access to Publications

Individuals with epilepsy and their loved ones often turn to scientific publications for information and the newest research findings. Scientific researchers and clinicians rely on these publications to find the most innovative, up-to-date studies. However, access to these articles is often prohibited without costly subscriptions and charges—even when those studies have been supported by taxpayers.

Bay Area Scientists Share Research with Local Supporters

San Francisco, CA—Twenty Bay Area friends of CURE gathered on May 12 for a CURE Research Update, hosted by Evelyn Nussenbaum and Fred Vogelstein. Over a three hour lunch, guests had the opportunity to hear about CURE from Board Chair Susan Axelrod, followed by presentations by CURE grantees Scott Baraban, PhD (University of California, San Francisco) and Daniela Kaufer, PhD (University of California, Berkeley). Drs. Baraban and Kaufer shared how their studies have progressed, and the importance of CURE's support to not just their own research, but to the entire field of epilepsy research.

Nussenbaum also announced a new fundraiser to benefit CURE, which will be held March 25, 2011 at the Four Seasons in San Francisco. Many of the guests at the Research Update will be joining her to make this a successful inaugural event. For information and to get involved, please contact CURE.

Bold New Initiatives at the National Institutes of Health

The National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health (NIH)—the lead Institute for epilepsy research—announced three new initiatives to stimulate innovative research, increase collaboration between epilepsy researchers, and identify new treatments for epilepsy focused directly on the cause of seizures.

The Translational Research for Resistant Epilepsy and Epileptogenesis Awards will support projects intended to complete preliminary steps in the development of therapeutics to cure epilepsy, prevent the emergence of epilepsy following brain injury or in other high-risk groups, or to better treat individuals with epilepsy that does not respond to treatment.

But the tide is turning; the National Institutes of Health, CURE, and Autism Speaks are leading the way to increased and easier sharing of information by instituting Open Access policies. In fact, CURE and Autism Speaks are the only nonprofits to institute such policies, and who are collaborating with the Library of Medicine/PubMed to make sure the policies are enforced. Scientists awarded CURE research grants (beginning with those awarded this year) will be required to follow the new CURE Open Access Policy, ensuring that published articles reporting the findings of CURE-funded research will be accessible to the public for free.

Open access to scientific articles can be found at:
www.ncbi.nlm.nih.gov/pmc



Evelyn Nussenbaum, Dr. Daniela Kaufer, Dr. Scott Baraban

The Exceptional, Unconventional Research Enabling Knowledge Acceleration (EUREKA) in the Epilepsies Awards will fund innovative research focused on novel hypotheses or challenging problems, solutions to which could have high impact on biomedical or biobehavioral research in the epilepsies.

Additional new initiatives will be announced in the coming months and will support and foster collaborative research in the epilepsies.

For more information on the Translational Research for Resistant Epilepsy and Epileptogenesis Awards:
<http://grants.nih.gov/grants/guide/pa-files/PAR-10-143.html> and
<http://grants.nih.gov/grants/guide/pa-files/PAR-10-144.html>

For more information on the EUREKA Awards:
<http://grants.nih.gov/grants/guide/rfa-files/RFA-NS-11-003.html>

WHERE WE ARE IN THE SEARCH FOR A CURE

[AN INTERVIEW]

STEVE WHITE, PHD

Professor of Pharmacology & Toxicology
University of Utah



You received a CURE grant in 2007. What has been the impact?

CURE's investment in what some might consider our "risky" project has been critical to our development of an animal model of virus-induced epilepsy, which will enhance our understanding of how viral infections can lead to epilepsy. It will also hopefully aid in the early identification of novel therapies for treatment and prevention of virus-induced epilepsy. I applaud the willingness of CURE to provide seed funding for novel projects like ours that are perhaps risky and too early for funding by the National Institutes of Health.

On a very personal note, you experienced a seizure recently. Can you share how that has affected you and your professional outlook?

My perspective was forever changed when I recently experienced a generalized tonic clonic seizure. My seizure, which turned out to be a symptom of a benign brain tumor, provided me with an eye-opening glimpse into the fear and frustration, not to mention the horrors of dealing with the seizures, the unrelenting medication side effects, and the comorbidities (depression, anxiety, and other clinical symptoms) often associated with epilepsy that 50 million patients around the world deal with every day. Surgical removal of the tumor, coupled with daily anti-convulsant medication, has left me with a highly favorable prognosis, and I am thankful for every seizure-free moment. From a professional perspective, my seizure has fueled my passion for finding safer and more effective therapies for the patient with difficult to control seizures.

Where do you believe the epilepsy community should focus its resources to find a cure?

We are plagued by a lack of fully characterized models of epileptogenesis and an incomplete understanding of the underlying mechanisms that result in the development of epilepsy. As such, we need to evaluate each of the many proposed models to determine if they accurately represent what occurs in the human brain. Furthermore, we need to develop even better models so we can accelerate our ability to find answers for the person likely to develop epilepsy as a result of a genetic mutation, traumatic brain injury, stroke, tumor, or infection of the brain.

I am optimistic about the level of collaboration that has developed in recent years between patient advocacy organizations and

academia, government, and the pharmaceutical industry. At a time when resources are thin, it is critically important to work together in our search for cures and better therapies.

I also believe that the epilepsy community needs to invest much more in the training and development of junior investigators who share a passion for research and for the clinical care of patients with epilepsy. I am confident that by bringing their novel and fresh ideas to the table that new doors will open that will ultimately lead to a cure.

Your work focuses on the development of new drug therapies for epilepsy. Some patients, who are frustrated with the effectiveness and side effects of medications, may feel like the future of epilepsy research shouldn't lie in more drug development. How would you respond to this?

Each of the thirteen new therapies that have been brought to the market since 1993 has provided a greater insight into the mechanisms underlying seizures. In addition, these drugs have given the patient new options and renewed hope and many patients have benefited from their development. However, there continues to be a substantial need and I believe that my recent personal experience has made me acutely sensitive to the plight of patients whose seizures don't respond to medications, or who experience intolerable side effects. Today, more than ever, I feel as though I have a greater understanding of the concerns and frustrations of the patient and his or her caregiver. As a result, much of my research efforts will focus on developing new models of therapy-resistant epilepsy that will hopefully hasten the development of unique and potentially more effective and better tolerated therapies.

I will also continue to encourage the epilepsy community to utilize epilepsy models to systematically assess whether a drug could actually prevent the development of epilepsy in patients at risk, following an insult to the brain. I believe that through the use of well characterized animal models and a scientifically sound approach we will identify therapies that will cure or prevent one or more of the epilepsies in the very near future. Moreover, I believe that one such success will open the door to even greater advances for all people with epilepsy.

HANNAH'S *Survival* STORY

BY PAUL LEVESQUE



Not everyone meeting 14-year-old Hannah Colfer senses there's anything particularly unusual about this pleasant youngster. Those who do may conclude she has a hearing disability (she often asks for things to be repeated), or some kind of attention deficit disorder.

Few would guess that Hannah is in fact experiencing seizures right before their eyes—on average, about fifty times per hour. In most cases there are virtually no telltale physical manifestations.

Even fewer would guess that this otherwise healthy and active young lady has had close brushes with death again and again throughout her life. Her seizures are periodically severe enough to plunge her into a coma-like state that requires treatment in an intensive care unit. There's never a guarantee that such episodes won't cause permanent brain damage—or death.

It's ironic that Hannah was actually a precocious toddler; her mother Karyn called her “my little Einsteinette.” Then, at about two and a half, Hannah began slipping into little staring spells. “She'd just seem to kind of ‘zone out’ for a few seconds every now and then,” Karyn says. “I kept hoping it would pass.”

It didn't.

Tests confirmed that Hannah was experiencing absence seizures.

The neurologist prescribed a then-new seizure medication that was proving highly effective. Not only did the drug fail to bring Hannah's seizures under control, it raised huge welts all over her body. “It looked as if someone had beaten her with a chain,” says Karyn.

Hannah was quickly switched to the second-most-reliable seizure medication on the market. The welts disappeared, but soon Karyn observed open canker sores inside her daughter's mouth. Plus, once again the seizures did not diminish.

Hannah's brother Chris, star of hit TV series *Glee*, has been “absolutely selfless when it comes to his sister.”

—Karyn Colfer

One by one, all of the available seizure medications were tried in their turn. None reduced Hannah's seizures, and many produced horrible side effects. One such drug, for example, had the reputed potential of weakening bones. “They assured me the dosage

would be too low to pose a hazard,” says Karyn. “My daughter celebrated her third birthday with two broken arms in casts.”

In 1997 Karyn watched a TV movie (“First Do No Harm,” starring Meryl Streep, based on a real-life case) in which a mother puts her son suffering from epilepsy on the ketogenic diet, and his seizures come to an end.

With cautious encouragement from their neurologist, Karyn and her husband Tim brought Hannah to a nutrition specialist in Pasadena. “It was a miserable time for everybody,” Karyn says. Despite initial improvements—and although the diet works for many—Hannah's seizures gradually returned to their pre-diet levels.

Karyn and Tim were running out of options. Nothing seemed to work.

A friend told the parents about some success he'd had with Adrenocorticotrophic Hormone (ACTH). Though the ACTH injections were extremely painful, they did initially appear to be helping—until one morning Karyn entered Hannah's bedroom and found her virtually comatose, her eyes fluttering. She was rushed to the emergency room.

The neurologist informed Karyn and Tim that their daughter had graduated to status epilepticus, the deadliest form of the disease. But he insisted such an episode may never recur, and urged them not to live in fear.

Two weeks later, a previously-planned visit to Disneyland was cut short when Hannah once more slipped into status. The family made a frantic drive to the hospital. It was a harrowing experience for the parents.

Karyn and Tim subsequently learned about the Vagal Nerve Stimulator (VNS), a surgically-implanted device that can help a seizing brain “reset itself.” The implant reduced the overall number of Hannah's seizures by about half. After nearly a decade of operation the VNS unit failed; in April of this year Hannah was back in surgery to have a replacement implanted.

Today Karyn is on a mission to help find the cure for epilepsy. “If by telling Hannah's story I can motivate people to open their wallets and donate to the cause,” she says, “then something very good will have come out of all of this.”

Karyn Colfer has devoted her life to helping both her children achieve their fullest potential. Her son Chris stars in the hit TV series *Glee*. She is excited to be working with CURE to help raise awareness.

Paul Levesque is co-author of Karyn's forthcoming book *Seizing Every Day*. Paul produced a 10-minute video for CURE, in which Karyn elaborates on Hannah's story in poignant detail. The video, *Hannah's Survival Story*, is accessible on the CURE website, www.CUREepilepsy.org.



Celebrities Join CURE in D.C.

Washington, D.C.—On May 1, preceding the White House Correspondents Dinner, more than 600 guests descended on CURE friend and supporter Tammy Haddad’s garden for her annual White House Correspondents Brunch. Board Chair Susan Axelrod and Haddad took the opportunity to raise awareness about CURE and epilepsy to a gathering including journalists, politicians, government officials, and other famous party-goers, including Kim Kardashian, T. Boone and Madeleine Pickens, Matthew Morrison of *Glee*, and the Jonas Brothers.



Susan Axelrod, Madeleine and T. Boone Pickens



Susan Axelrod, the Jonas Brothers



Kim Kardashian, Susan Axelrod



Tammy Haddad, Matthew Morrison



Sara, Donna, Maggie, and John Marino



Dr. Nico Moshé and Susan Axelrod

Teachable Moments Inspire Action in Bedford

Bedford, NY—With the overwhelming support of their community, Donna and John Marino hosted the first-ever Bedford CURE Reception at the Bedford Historical Society. The event was a tremendous success, attracting nearly 120 guests.

Though they have no direct connection to epilepsy, the Marinos were deeply moved by stories from friends and in the media over the past year.

“We were so touched by Lauren Axelrod’s story,” said Donna Marino. “Now in addition to spreading the word about CURE, we have been able to contribute much-needed funds to their efforts to support research.”

The evening focused on “teachable moments,” turning accounts of epilepsy’s devastation into moving and inspirational calls to action.

The Marinos’ activism and generosity are proof that CURE’s message is spreading well beyond the epilepsy community, and that education and outreach are powerful tools in combating this disease. CURE is deeply grateful for their support.



photo credit: Gretel Truong



photo credit: Gretel Truong



photo credit: Bruce Bever Photography

Another Sold-Out Crowd at Chicago Benefit

CURE’s Annual Chicago Benefit this April drew another sold-out crowd to the Chicago Field Museum. Over 750 guests joined special guest, CBS “Evening News” anchor Katie Couric.

Raising critical research funds, the event, themed “Epilepsy Takes Center Stage,” celebrated the extraordinary media attention epilepsy and CURE have received over the past year. Cover stories in *PARADE* magazine and *Newsweek*, and a featured segment on “60 Minutes”—produced and hosted by Couric—thrust the organization into the national spotlight and resulted in a record-breaking fundraising year.

As the event’s keynote speaker, Couric drew on her own experiences with disease, the havoc it can wreak on families, and the importance of disease advocacy.

“I know what it’s like to try to bring attention to a disease that no one really wants to talk about,” said Couric, whose husband

died of colon cancer in 1998. “For too long epilepsy has remained in the shadows. We’re starting to change that.”

An estimated 12 million viewers watched the original airing of the “60 Minutes” piece, which provided an in-depth look at epilepsy through the eyes of Susan, Lauren, and David Axelrod. For her role in promoting epilepsy awareness, Couric was honored with the 2010 CURE Excellence in Journalism Award later in the evening. “I’m proud we have helped shine a light on this challenging and mysterious disease,” she said.

The night also marked the launch of CURE’s Mother’s & Father’s Day campaign, which raised funds to support exceptional young researchers in the field of epilepsy.

CURE WOULD LIKE TO EXTEND A SPECIAL THANKS TO THIS YEAR’S EVENT SPONSORS:

CAMAC | Fred Eychaner | Judy & Scott Leisher | UCB, Inc. | Abbott | Alenia North America | Allstate | AKPD Message and Media & ASGK Public Strategies
 Heidi & Craig Albert | Susan & David Axelrod | Debra Cafaro & Terrance K. Livingston | Dara & John Corkery | the Crown & Goodman Families | Richard Dennis
 Karen K. Dixon & Nan Schaffer | Exelon Corporation | Howard Gottlieb | Larry Grisolano | Hewitt Associates | Carol Jones & Thomas Hynes
 Bernadette Keller & William M. Daley | Lundbeck Inc. | Mesirow Financial | Pfizer | Power Rogers & Smith PC | Michele Schara & Randy Mehrberg
 The Strategy Group | Patricia & Glen Tullman | UBS | Walsh Construction Company

Top row from left: Katie Couric; the parents of CURE; Susan Axelrod, Senator Richard Durbin

Bottom row from left: Bill Daley, Bill Daley, Jr., Tom Hynes, Terry Dee; Susan Schneider, Diana Ware, Joanne Edelson, Julie & Jim Schneider; Eric Whitaker, Kermit Crawford, Donovan Pepper



photo credit: Smitty Images



photo credit: Gretel Truong



photo credit: Smitty Images

Milken Conference Tackles Medical Philanthropy

Los Angeles, CA—Some 3,000 people joined hundreds of panelists—renowned experts in the worlds of finance, media, health, education, philanthropy, government, and climate and energy—at the Milken Institute Global Conference on April 26–28. Among the panelists was Board Chair Susan Axelrod, who participated on the panel “Medical Philanthropy: Investing in the ‘Cure Enterprise.’” Only 3% of all scientific research funding comes from philanthropy, yet it plays an enormous role in galvanizing high-risk research.

The panel explored what aspects of medical philanthropy are currently working, how to encourage more philanthropists to invest effectively to advance the search for cures, and the importance of supporting new, young researchers.

Axelrod reflected, “It was an honor to be among so many esteemed thought leaders from such disparate fields. Nowhere else does such an amazing group of bright and motivated people come together to make a real difference and tackle today’s most pressing problems. Exploring ways to encourage medical philanthropy gave me new perspectives on how to truly change the status quo, and pave the way to the cures we are all so desperately awaiting.”

Carole King & James Taylor Benefit CURE

As a supporter of CURE and epilepsy research, Carole King teamed up with James Taylor on their extensive North American Troubadour Reunion tour to make the very best seats in the house available to benefit CURE!



Susan Axelrod, Carole King, James Taylor, CURE supporter John Rogers, Desiree Rogers, Lauren Axelrod

Senator Hatch Joins Fight to End Seizures

Salt Lake City, UT—Created by passionate volunteers who are themselves personally affected by epilepsy, the Epilepsy Association of Utah held its inaugural gala in January, awarding the Association’s 2010 Achievement Award to Senator Orrin Hatch for his work on the passage of the Americans with Disabilities Act, and featuring Board Chair Susan Axelrod as keynote speaker.

An impressive 270 guests attended, contributing vital funds to support Utah families dealing with the challenges of epilepsy. CURE grantees Steve White, PhD and Steven Bealer, PhD, and CURE Scientific Advisory Board member Karen Wilcox, PhD also showed their support by attending.



Susan Axelrod and Senator Orrin Hatch

Since hearing of the devastation seizures can cause through the advocacy of Utahns such as Becky Fenn of Lehi, whose son John has been diagnosed with epilepsy, Senator Hatch has become involved in the fight against epilepsy. He was dismayed, at the January event, to learn that epilepsy research receives very limited federal dollars compared to other diseases, and, in response, has expressed support for allocating a larger portion of federal funding to epilepsy research.

Since then, Senator Hatch has met with Dr. Story Landis, Director of the Institute of Neurological Disorders and Stroke (NINDS) to receive an update on the Institute’s funding priorities. He has also encouraged the Senate Appropriations Committee to dedicate additional funding to establish new multidisciplinary research centers, in the hopes of making a meaningful difference in the lives of the 18,000 Utahns and the three million Americans diagnosed with epilepsy.

Special Thanks for Fundraising Efforts Around the Country

Festival of Trees for CURE

Hosted by Junior Woman’s Club of Sparta
Sparta, NJ

Denver Benefit for CURE

Hosted by Kathy Judd
Denver, CO

House Party and Benefit in Honor of Calvin’s Sixth Birthday

Hosted by Christy Shake
Brunswick, ME

Local Production of Les Misérables by arrangement with Music Theatre International

Presented by Pope John XXIII High School
Sparta, NJ

3rd Mah Jongg Tournament to Benefit CURE

Hosted by Rhona Leff
Boynton Beach, FL

Dining for a Cure

Hosted by Kelly & Mark Hamilton
Peoria, IL

Kickboxing for a Cure

Hosted by Jill Axtens
Hoboken, NJ

National American Platform Tennis Association (APTA) Tournament

Special thanks to Kathy Dodd, Suzanne Lemery, and Marina Olhmuller
Philadelphia, PA

Erato Chamber Orchestra Concert Benefiting CURE

Hosted by Dennis Egolf
Chicago, IL

David’s Run

Hosted by Christine Shindler
Chesterbrook, PA

Cocktails for a Cure

Hosted by Kim Kilcoyne
Bronxville, NY

Walk for CURE!

Hosted by Colette Hough & Rachel Ablondi
Middletown, MD

Cookies for CURE

Organized by Cameron Dodd
Wilmette, IL

Madison Friends of CURE

Hosted by Eileen Sutula
Madison, WI

Gia’s Hope for a Cure

Hosted by Wendy Flammia
Miller Place, NY

2010 Gewalt Hamilton Golf Outing

Hosted by Gewalt Hamilton Associates, Inc.
Waukegan, IL

22nd Annual Loeffel Epilepsy Golf Benefit

Hosted by Loeffel Epilepsy Foundation
Lake Geneva, WI

Stay Up-to-Date with CURE

Help CURE save costs and stay green by updating your contact information!

www.CUREepilepsy.org/update

Upcoming Events

Gordon Research Conference: Mechanisms of Epilepsy & Neuronal Synchronization
August 8-13, 2010

Colby College
Waterville, ME

INFO: www.grc.org/programs.aspx?year=2010

Golf Tournament Benefiting CURE

August 23, 2010
Plainville, MA

INFO: Pat McGinty
mpcginty37@msn.com

Drive for CURE

August 26, 2010
Beach Park, IL

INFO: Susan Schneider
jschny@comcast.net

1st Annual CURE Bank of America Chicago Marathon Team

October 10, 2010
Chicago, IL

INFO: John Thoe
ericjohn.thoe@gmail.com

3rd Annual CURE New York City Benefit

Special Guest: Mayor Michael R. Bloomberg

October 14, 2010
The Roosevelt Hotel
New York, NY

INFO: info@CUREepilepsy.org

1st Annual Boston Benefit for CURE

Special Guest: Pulitzer Prize-winning author Doris Kearns Goodwin
October 15, 2010
Museum of Fine Arts, Boston
Boston, MA

INFO: info@CUREepilepsy.org

Rock the Block for Pediatric Epilepsy Research

October 16, 2010

The Chicago Illuminating Company
Chicago, IL

INFO: www.rocktheblockforcure.com

Paul’s Run for Epilepsy

October 17, 2010

Prospect Heights, IL

INFO: www.paulsrunforepilepsy.org

Golf Tournament and Dinner Benefiting CURE

October 2010
New Jersey

INFO: info@CUREepilepsy.org

San Francisco Benefit for CURE

March 25, 2011
Four Seasons Hotel
San Francisco, CA

INFO: info@CUREepilepsy.org

Contact CURE for help organizing your own fundraiser:
info@CUREepilepsy.org or
800.765.7118.

3 MILLION AMERICANS 50 MILLION WORLDWIDE

HOPERESARCHCURE

OUR MISSION

Citizens United for Research in Epilepsy (CURE) is a nonprofit organization dedicated to finding a cure for epilepsy by raising funds for research and by increasing awareness of the prevalence and devastation of this disease.

Due to the passion and generosity of families, friends, and volunteers, over 92% of funds donated support critical research and awareness programs.

CURE is a nonprofit 501 (c)(3) organization supported by the generous contributions of individuals, corporations, and foundations.
©2010 Citizens United for Research in Epilepsy. All rights reserved.