

# CURE

CITIZENS UNITED FOR RESEARCH IN

# EPILEPSY

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## 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.



## Did you know?

- Almost 500 new cases of epilepsy are diagnosed every day in the United States.
- 2.5 million Americans suffer from epilepsy.
- In over 30 percent of epilepsy patients, seizures cannot be controlled.
- Uncontrolled seizures may lead to brain damage and death.

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*Founded in 1998 by mothers of children with epilepsy, CURE's success is a direct result of the passion and dedication of families and volunteers around the country. For e-mail updates on research, events, and other epilepsy news, send your name and e-mail address to [info@CUREepilepsy.org](mailto:info@CUREepilepsy.org).*

CURE is a nonprofit 501(c)(3) organization supported by the generous contributions of individuals, corporations, and foundations.

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SCHAFFER | CONDON | CARTER

hope

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research

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[www.CUREepilepsy.org](http://www.CUREepilepsy.org)

CURE Newsletter

## **“Roast of Congressman Rahm Emanuel” Benefits CURE**

CURE and epilepsy research were the beneficiaries of a “Roast of Congressman Rahm Emanuel” (D-IL). The event, held September 20th at Union Station in Washington, DC, was in recognition of Congressman Emanuel’s unwavering leadership in the search for a cure for epilepsy.

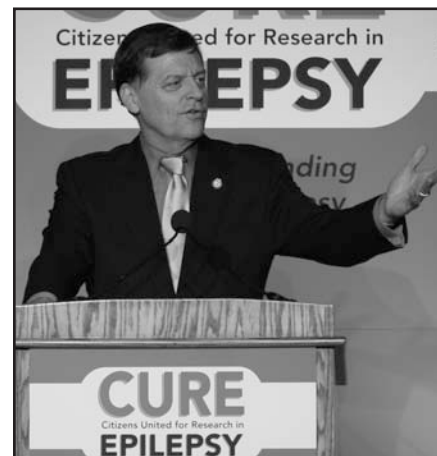
CNN Commentator Paul Begala served as Master of Ceremonies for the evening. Roasters, who entertained the sold-out crowd with personal stories and encounters with Congressman Emanuel, included Senator Hillary Rodham Clinton (D-NY), Senator Chris Dodd (D-CT), Senator Barack Obama (D-IL), Representative Tom Cole (R-OH), former Secretary of Commerce William M. Daley, and Pulitzer Prize-winning author William Safire.

Emanuel, a strong advocate of increasing



Senator Barack Obama (D-IL) describes his encounters with Congressman Emanuel at the “Roast of Rahm” event to benefit CURE last September.

federal funding for epilepsy research, took a break from the good-natured ribbing of his friends and colleagues, thanking “everyone who came out tonight to support CURE and the desperate need for more epilepsy research.”



Representative Tom Cole (R-OK) entertains the sold-out crowd, recounting his “run-ins” with Congressman Emanuel.

Proceeds from the event benefit CURE’s mission to find a cure for epilepsy through increasing funding for research and increasing awareness of the prevalence and devastation of the disease.



CURE Honorary Board Member David Axelrod, Senator Chris Dodd (D-CT), CURE Honorary Chairman Senator Herb Kohl (D-WI), Representative Rahm Emanuel (D-IL), and CURE President Susan Axelrod at the “Roast of Rahm Emanuel.”

**2006 Research Grants  
Announced as CURE  
continues to work toward  
“no seizure, no side effects.”  
(See pages 4 & 5.) The  
application deadline for  
2007 CURE Awards is  
June 16, 2006.  
Please check our web site at  
[www.CUREepilepsy.org](http://www.CUREepilepsy.org) after  
January 30, 2006 for  
updated guidelines and  
application information.**

## Depression and Epilepsy by Valerie Davis Raskin, MD

Patients with epilepsy and their doctors often report an increased rate of depression and mood disorders. Why is this?

In the past, lifestyle challenges have been blamed, including stigma, discrimination, and the stress of living with an illness with an unpredictable course. Certainly these psychosocial and vocational factors significantly impact a patient's mood and quality of life. In fact, depression in people with epilepsy has been observed for centuries and it's clear that stress and prolonged helplessness or loss of independence make individuals more vulnerable to depression. Caretakers of children with epilepsy may also be more vulnerable to depression for related reasons.

However, recently published studies provide compelling evidence that the presence of structural and energy metabolism brain abnormalities contribute to the increased risk of depression in persons with epilepsy. In other words, like epilepsy, clinical depression is a brain disease, not a weakness or inability to cope. These

abnormalities may have a highly significant role in causing mood disorders in epilepsy patients and may have implications for treatment.

The prevalence of depression in patients with uncontrolled seizures has been reported to be up to ten times higher than the general population. When seizures are well controlled, it is still two–five times higher, further evidence that depression is not merely a consequence of the impact of life with seizures.

Recognizing depression as a clinical expression of underlying brain dysfunction may lead to improved care of patients with epilepsy. Evidence suggests that most patients with epilepsy are not even screened for depression and, therefore, are not treated.

Additional research and understanding in this area is necessary to improve diagnosis and treatment and to enhance our understanding of the epileptic brain.

However, in the meantime, people with epilepsy and their families should know that clinical depression does not



Dr. Valerie Raskin

have to be part of life with seizures. Antidepressants and certain forms of talk therapy (cognitive and interpersonal therapy, for example) are often effective in completely eliminating the symptoms of depression. In most cases, antidepressants are compatible with antiepileptic medications.

If you suspect that you or someone you love is depressed, speak to your doctor about the options. Clinical depression, the most common form of mood disorders, is diagnosed when an individual has either a persistent depressed mood or loss of enjoyment or interest in one's usual activities for a minimum of two weeks, and three or more of the following symptoms:

- Sleep disturbances
- Fatigue or low energy
- Appetite or weight changes
- Agitation, or, alternatively, being noticeably slowed down
- Decreased concentration
- Feelings of worthlessness or inappropriate guilt
- Thoughts of death or suicide

*Psychiatrist Valerie Davis Raskin, MD, is the CURE Liaison to the Scientific Advisory Board and author of When Words Are Not Enough: The Women's Prescription for Depression and Anxiety.*



The Loeffel Epilepsy Golf Benefit is held each June in Lake Geneva, Wisconsin. This year, CURE has awarded the Maggie Loeffel Award to Walter M. St.-John, PhD, of Dartmouth Medical School, for his research into Sudden Unexplained Death in Epilepsy (SUDEP). Maggie's father, Maurice Loeffel, is pictured second from right above, along with Joe Darragh, Amos Reed, and Tyrone Banks. (See page 4, and 5 for a complete list of CURE's 2006 awards.)

## **Epilepsy Takes a Tragic Toll**

Each year epilepsy results in tens of thousands of deaths in the United States. Few people realize that epilepsy is a life-threatening disease, but the families who lose a loved one know it very well. The Coggins family of Rochester, NY, is one of those families.

Kyle Coggins was a junior at LeMoyne College in Syracuse, New York in 2003. He had just finished his second semester exams and had returned to his dorm room when he had a seizure. He could not be revived. Kyle was 21 years old.

The course of the disease in Kyle's case is all too familiar. It started when he was in fifth grade with absence seizures. During his adolescent years, after a seizure-free year, he had another seizure. That was a devastating blow for a teenage boy—he lost his driver's license. By the time he entered college, he was experiencing grand

mal seizures, and as is so often the case, the medications did not help.

Since his death, two "Runs" have taken place in Kyle's honor, with a portion of

***If more people are aware of Sudden Unexplained Death in Epilepsy – SUDEP, maybe more research will be done. —Donna Coggins (mother of the late Kyle Coggins)***

the monies raised going to CURE. The first Run was organized by a high school senior as his Service Project; the other was part of a 15-year-old Boy Scout's work toward his Eagle Scout badge. The Runs have become community projects as well, with volunteers including neighbors, co-workers, former coaches, and sorority sisters among others.



Kyle Coggins with his sisters Colleen and Courtney. Kyle died in 2003, as a result of his epilepsy.

As Kyle's mother, Donna Coggins, put it: "He was always helping others, and now we can help others in his name."

## **CURE to Co-sponsor Major Research Conference: "Mechanisms of Epilepsy"**

CURE will co-sponsor the first Gordon Research Conference on "Mechanisms of Epilepsy." Gordon Conferences are week-long think-tanks designed to bring together the top scientists in a field to foster communication, brainstorming, new collaborations, and new approaches. The conference will take place August 6–11, 2006, at Colby College in Waterville, Maine.

The goal of the conference is to set the stage not only for new scientific approaches, but also to develop new translational studies that will bring the newest discoveries to the bedside in the shortest possible time. Many fields in biology, chemistry, and physics have benefited from Gordon Conferences, and the time is ripe to apply this approach to epilepsy.

Confirmed participants are scientists and physician-scientists from top medical school in the country, including Stanford, the University of California, the University of Chicago, Harvard, Yale, Brown, Dartmouth, the University of Pennsylvania, Duke, and Emory to name a few. Several top scientists from Europe will also participate.

Topics to be covered include gene expression profiling in epilepsy, stem cell approaches to epilepsy, epileptogenic ion channels, epileptogenic dysgenesis, homeostatic plasticity, structural reorganization in epilepsy, hypersynchrony and non-linear dynamics, gap junctions, key events underlying epileptogenesis, and entorhino-hippocampal interplay in epilepsy.

## 2006 Research Grants Announced

CURE has selected the following research proposals for funding in 2006. Formal announcement of the awards will be made at the annual meeting of the American Epilepsy Society in Washington DC on December 5th.



Tracy Butler, MD - Weill Medical College of Cornell University, New York, NY  
***Imaging Neuroinflammation in Focal Epilepsy***

Inflammation, a vital process by which dead or damaged tissue is broken down, can be harmful when excessive or prolonged. This project will use Positron Emission Tomography (PET) scanning to examine inflammation in the brains of patients with uncontrolled focal epilepsy. This could prove helpful in planning for epilepsy surgery and may lead to the development of new strategies, including use of anti-inflammatory agents to treat and prevent epilepsy.



Steve C. Danzer, PhD - Cincinnati Children's Hospital & The University of Cincinnati, Cincinnati, OH  
***Contributions of Adult Neurogenesis to the Development of Epilepsy***

In adults, new brain cells are constantly born in the hippocampus, an area of the brain involved in many common types of epilepsy. Abnormal incorporation of these new cells into the brain may promote the development of epilepsy. This study will help clarify whether and how newborn cells are appropriately or pathologically "wired into" the brain in epilepsy. Understanding how normal brains become epileptic may lead to the development of new therapies to delay, halt, and ultimately reverse epilepsy.



Vittorio Gallo, PhD - Children's National Medical Center & George Washington University, Washington DC  
***Regeneration of Hippocampal Neurons in Mesial Temporal Lobe Epilepsy***

The goal of this proposed project is to develop a new approach to curing mesial temporal lobe epilepsy (MTLE), one of the most commonly recognized forms of childhood-onset epilepsy. This study will investigate the transfer of progenitor cells to replace inhibitory neurons lost in patients with temporal lobe epilepsy as a means of re-establishing normal function.



Michael Kubek, PhD - Indiana University School of Medicine, Indianapolis, IN  
***Intranasal Delivery of Sustained-release Anticonvulsant Neuropeptide Nanoparticles in Seizure Therapy***

Certain neuropeptides may be effective in inhibiting seizures. Unfortunately, there are challenges associated with developing neuropeptides for use by patients with epilepsy. This project will explore the use of an intranasal delivery of neuropeptide nanoparticles for seizure therapy. Positive results of this project could lead to new directions for epilepsy therapy, prevention, and ultimately a cure.



### **THE CHRISTOPHER DONALTY INTERDISCIPLINARY RESEARCH AWARD**

Jenna L. Rickus, PhD and Pedro L. Irazoqui, PhD - Purdue University, West Lafayette, IN  
***A Hybrid Cellular-Silicon Neural Prosthetic for Epilepsy***

The major treatment problems facing patients with epilepsy are resistance to drugs and unwanted side effects. Targeting treatment to a specific area of the brain immediately prior to and during a seizure would present a significant advancement. The goal of this project, which melds biology and engineering, is to develop a novel, cell-based neural prosthetic to electrically detect a seizure before it occurs and respond by stimulating transplanted cells to rapidly release GABA (a critical therapeutic target in epilepsy), thereby preventing the seizure.





#### **THE FALK MEDICAL RESEARCH TRUST AWARD**

Heidrun Potschka, DVM - University of Veterinary Medicine, Hannover, Germany

##### ***Validation of New Strategies to Overcome Pharmacoresistance of Epilepsy Based on Multidrug Transporter Overexpression***

Several genetic studies point toward a specific genetic abnormality (the overexpression of multidrug transporters) in patients with epilepsy whose seizures do not respond to medications. The first goal of this project is to test whether modifications in that gene might help these patients better respond to medications. In addition, intranasal delivery of antiepileptic drugs will be tested as a means of bypassing the blood-brain barrier to achieve sufficient delivery of medications directly to the brain.



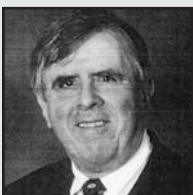
#### **THE GRAHAM GODDARD AWARD**

(sponsored by an unrestricted educational grant from UCB Pharma)

Alexander Rotenberg, MD, PhD - Boston Children's Hospital, Brookline, MA

##### ***Transcranial Magnetic Stimulation: Anticonvulsant and Antiepileptic Properties***

Transcranial magnetic stimulation (TMS) can potentially be used to interrupt ongoing seizure activity, prevent epilepsy after an event such as status epilepticus, and increase seizure-free periods. Yet, TMS is in the early stages of development, and the field would benefit from the use of animal models to evaluate whether seizures can be shortened with this technique and whether TMS can protect against the development of chronic epilepsy. This study will examine the utility of TMS in a rat model of epilepsy. The results will guide the use of TMS in patients with epilepsy and the prevention of epilepsy in those patients at risk.



#### **THE MAGGIE LOEFFEL AWARD**

Walter M. St.-John, PhD - Dartmouth Medical School, Lebanon, NH

##### ***Seizures and Respiration – A Possible Basis for SUDEP (Sudden Unexplained Death in Epilepsy)***

Although seizure-induced changes in breathing and/or in the function of the heart have been proposed as the cause for this devastating consequence of epilepsy, much research still needs to be done. This investigator will categorize changes in breathing during seizures and describe how these changes might be responsible for SUDEP.



#### **THE RHODE ISLAND AWARD**

Nikolaus J. Sucher, MD - Children's Hospital & Harvard Medical School, Boston, MA

##### ***A role for the mTOR Pathway in NMDA Receptor Mediated Epileptogenesis: a Molecular Investigation of Protein Interactions***

The NMDA receptor is crucial for the normal function of the brain. The receptor is a protein complex that is composed of multiple subunits, some of which may be critical for the development of epilepsy in patients with Tuberous Sclerosis (TSC). This study will investigate the molecular details of the interaction and function of selected proteins, which may suggest novel targets for the treatment of TSC and epilepsy.

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Members of CURE's Scientific Advisory Board met in Chicago with Board members to make final decisions on research grants to be awarded for 2006. The September meeting also focused on strategic planning for the coming year.

Seated above are Gregory L. Holmes, MD (Dartmouth Medical School); Amy Brooks-Kayal, MD (Children's Hospital of Philadelphia); and Thomas P. Sutula, MD, PhD (University of Wisconsin - Madison). Standing are Antonio V. Delgado-Escueta, MD (UCLA Comprehensive Epilepsy Program & VA Medical Center); Helen E. Scharfman, PhD (Columbia University & Center for Neural Recovery and Rehabilitation Research at Helen Hayes Hospital); Frances D. Jensen, MD (Harvard Medical School); and Michael A. Rogawski, MD, PhD (National Institute of Neurological Disorders and Stroke).



General Chair George Aney appeals to the WKTV television audience at the September telethon in Utica, NY. Funds raised at the telethon support the Christopher Donalty Interdisciplinary Research Award, a grant awarded by CURE to two or more scientists from distinct disciplines that utilize an interdisciplinary and collaborative approach in their research to cure epilepsy. This year the grant has been awarded to Jenna Rickus, PhD and Pedro Irazoqui, PhD of Purdue University. (See page 4 and 5 for the complete list of CURE's 2006 grants.)

Pictured above are Vice President and General Manager of WKTV News Vic Vettters, George Aney, CURE President Susan Axelrod, CURE Board member Jeanne Donalty, and WKTV Reporter Joleen Ferris. Jeanne Donalty's son, Christopher, died as a result of epilepsy in 2002. The telethon was held in his memory.

When a group of fraternity brothers got together last March to celebrate the 35th anniversary of their Pledge Week, one of the men suggested the reunions should be more than just reminiscing. Lonny Gold, a long-time friend of Susan and Jim Schneider, knew of their daughter's struggle with epilepsy. Julie has undergone three brain surgeries in an attempt to control her seizures.

Lonny and Jim's brother, Richard, organized the "Drive for CURE" at the Thunderhawk Golf Club in Beach Park, Illinois last September. The day included lunch, golf, and a live auction for almost 100 golfers.



Lonny Gold, second from right, initiated the "Drive for CURE"



Pictured above at the Golf Club are Bobby Frankenbush, Leo Magrini Sr., Dr. Gerry Scanlon, and Dr. Jack Picchietti.

The Leo Magrini Memorial Golf Outing was held in October at the Oak Brook Golf Club and the Butterfield Country Club in Oak Brook, Illinois. Friends and family gathered for golf and dinner in a celebration of Leo's life, with proceeds going to CURE. Leo was deeply committed to finding a cure for epilepsy after suffering debilitating seizures as a result of a brain tumor.



Megan Brown and Pat Sheehan enjoy a festive evening while raising funds for epilepsy research at the CURE Junior Board's 3rd annual fundraiser. Held at the Jefferson Tap in Chicago this fall, the evening included a raffle with Chicago Bears tickets and other prizes.

**Help Find a Cure!  
DONATE TODAY!**