

hope

CURE

CITIZENS UNITED FOR RESEARCH IN

EPILEPSY

research

Spring 2004 Vol. 4, (1)

CUREepilepsy.org

CURE Newsletter

Happy Birthday CURE! \$2 Million for Epilepsy Research in Five Years

Birthday cakes, donated by local pastry chefs, adorned the center of each dinner table as CURE celebrated its fifth birthday last November in Chicago. Looking out at Chicago's skyline, guests were greeted by the music of Chicago's Walter Payton College Prep Jazz Orchestra. Over 400 guests gathered to support CURE.

In these few years, CURE has awarded 26 grants to innovative researchers in epilepsy. CURE has successfully brought public attention to the seriousness of epilepsy and focused federal attention on allocating research dollars commensurate with the number of people affected. In addition, it has brought leading scientists

The heritage of this five year organization is really special because it was born out of the concern of parents... not just for their own kids, but for all kids.

—Paul Toback, benefit chair, Fifth Annual CURE Benefit, November 17, 2003



Benefit Chair Paul Toback addresses Fifth Annual CURE Benefit in Chicago.



Celebrating CURE's 5th Birthday are Brendan Malone, Martin Penry, Douglas Nordli, Jr., MD, Erin Malone and Philip Doran, representing CURE's Honorary Board, Scientific Advisory Board and Junior Board.

and epilepsy specialists together by co-sponsoring various conferences, including the ground-breaking "Curing Epilepsy: Focus on the Future".

It was at CURE's first annual benefit that then First Lady Hillary Rodham Clinton announced the historic conference, *Curing Epilepsy: Focus on the Future*, would take place the following year at the National Institute for Neurological Disorders and Stroke (NINDS). The conference brought over 500 experts together, and for the first time people started talking about a cure.

It was fitting then that Senator Clinton should join in celebrating the success of CURE on its fifth Birthday. Although she was unable to attend in person due to a Senate vote that day, Senator Clinton addressed the crowd by phone. Senator Clinton spoke of the invaluable contributions of CURE and renewed her pledge to work for a cure. "What began as a plea for help from three mothers who dealt every day with the challenges that epilepsy posed for their children, has become a national movement that will yield advances, and eventually a cure."

(continued on pg. 2)

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New Evidence Suggests Seizures Damage Brain

The New York Times has published a lengthy article in which some long-held beliefs about epilepsy are refuted; it also gives an overview of current thinking among physicians and researchers.¹

Many parents who witnessed their child in a full-blown seizure found it difficult

to accept that the child's brain would not be damaged. For years, doctors reassured parents that the seizure would not result in any permanent damage. But new evidence is revealing damage to the hippocampal area of the brain as a result of repeated

seizures. The hippocampus is the area of the brain involved in forming new memories.

These same people who experience seizures that are not controlled by drugs or surgery are also at higher risk of dying prematurely.

The premature deaths are attributed to a syndrome called Sudden Unexpected Death in Epilepsy Patients (SUDEP)*. According to Timothy Pedley, MD, PhD, "Relatives of patients with SUDEP consistently indicate that they wish they had been informed that epilepsy can be fatal." In patients

with intractable epilepsy, ten to fifteen out of 10,000 die unexpectedly each year.

In studies done during the last decade, researchers have come to see that seizures beget seizures. In the person with uncontrolled seizures the brain changes in a manner making it easier for seizures to take place. Researchers stress the importance of controlling seizures early, thus breaking the cycle of "seizures begetting seizures." "Even as brief as seizures are, there are consequences that last long, long after."

¹*New York Times*, February 18, 2003, D5, D8.

All quotations in this article are from this source.

*CURE is presently funding a grant to study the prevention of SUDEP.

I and others have been really concerned that epilepsy has been minimized.

—Thomas P. Sutula, MD, PhD

Seizure Freedom: Quality of Life

A recent study published in the journal *Epilepsia* found that only through a 100% reduction in the frequency of seizures can the health related quality of life (HRQOL) be improved in epilepsy patients.*

In judging the effectiveness of antiepileptic drugs (AED), the common standard has been to consider the AED effective if seizures are reduced by 50%. The authors acknowledge a growing debate concerning

the impact of only a partial reduction in the frequency of seizures, especially in people who experience a large number

These results further support striving for seizure freedom as an epilepsy care goal.*

of seizures. Does just lessening the number of seizures result in a clinically meaningful change and does it improve quality of life?

In this study, the only people to demonstrate a significant improvement in quality of life were those who had a 100% reduction in seizures. "Our findings provide further evidence to support the importance of striving for seizure freedom when caring for patients with epilepsy."

* Gretchen L. Birbeck, *et al.*, "Seizure Reduction and Quality of Life Improvements in People with Epilepsy," *Epilepsia* 43:5 (2002): 535-538.

"Happy Birthday CURE" cont. from pg. 1

Benefit Chair, Paul Toback, President and CEO, Bally Total Fitness Corporation, related the changes in his perceptions of epilepsy since his son, Sam, began having seizures at the age of six months. He had viewed epilepsy as a condition that was easily managed. But Sam's response to medications has been unpredictable.

He spoke for many parents when he said, "The only thing we know for certain is that Sam's future is uncertain."

Board member, Kathy Dodd, announced David Axelrod as the recipient of CURE's Annual Award. David serves on CURE's Honorary Board of Directors. Kathy described the countless contributions

David has made and the inspiration he provides. In presenting the award, she said, "David, as much as anyone, has given a voice to the hundreds of thousands of children affected by this disease."

The event was partially underwritten through the incredible generosity of Bill and Sheila Lambert and Fred Eychaner.

It's amazing that three Moms could have that significant an impact and really change the discussion and the face of epilepsy research in the country, and really world-wide. The impact has been extraordinary.

—Michael A. Rogawski, MD, PhD, Chief of NINDS Epilepsy Research Section (CURE 2003 Videocassette)

Central New York Event Draws Capacity Crowd to Benefit CURE

As the year 2002 began, Chris Donalty was a senior at Stetson University, planning on entering graduate school in the fall. He had made the Dean's List every semester at Stetson, so admission to an MBA program was all but assured. But his real love was baseball; he pitched for his high school team and a community team. Chris passed away February 21, 2002. Cause of death? Sudden Unexpected Death in Epilepsy Patients (SUDEP) (Please see related article on page 2).



Chris Donalty, in 1998, leaves the mound after pitching five innings, giving up no hits, and leading his high school team to victory over their biggest rivals.

Chris had one seizure in fourth grade and another in eighth grade. His doctor did not consider his condition severe enough to require medication until he had his third seizure at age 18. At that point, the familiar cycle began: try a different drug, add a new drug, increase the dosage...

Over 40,000 Americans die in seizure-related causes each year.

But out of this tragedy, Chris' parents have become some of epilepsy research's

staunches advocates. Barry and Jeanne Donalty are determined to find a cure so that other parents can be spared the pain they have endured.

A year after Chris' death, Jeanne testified before the Congressional Committee on Appropriations. Jeanne's Representative in the U.S. Congress, Congressman Sherwood Boehlert (R-NY), introduced Jeanne to the committee.

She told Chris' story: his passion for living, his love of his friends and family, his plans for the future. She remembered her thoughts

when they were told Chris had epilepsy; "Okay, we can handle this, it's treatable, it's not fatal, things could be worse." As she implored the committee to allocate increased funding for epilepsy research, Jeanne stressed the urgency of the situation. "It's too late for Chris....But it is not too late for those who currently suffer from

We are on the 'ground floor' of finally awakening the medical profession as well as the general community of the desperate need in finding a cure for epilepsy.

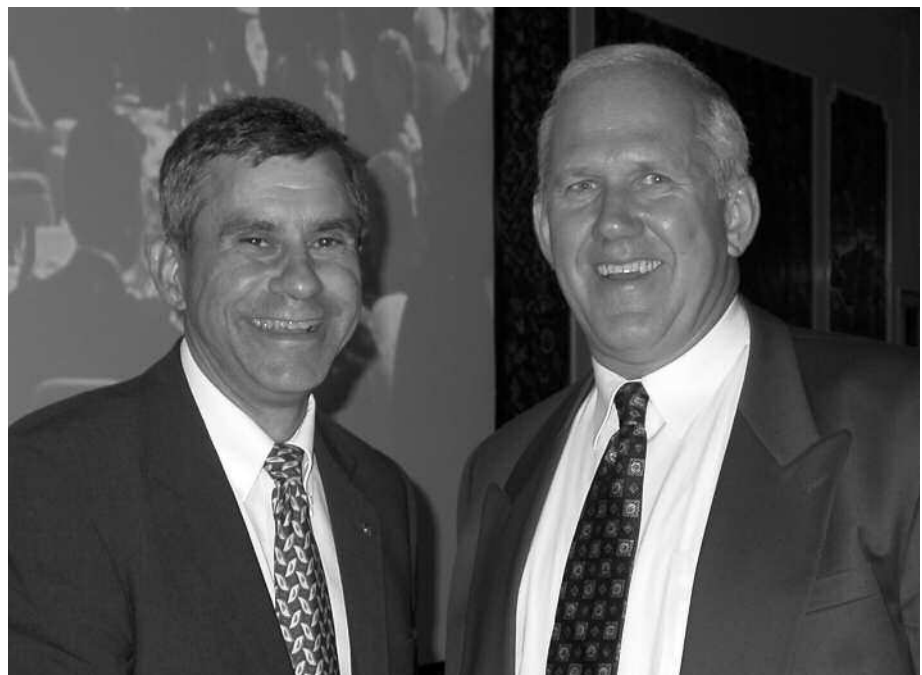
—George F. Aney, General Chairman, Christopher Donalty CURE Benefit

epilepsy, and for all those who will be diagnosed in the future."

Last September, Barry and Jeanne hosted the Christopher Donalty CURE Benefit in Central New York State. Governor George E. Pataki (NY) served as honorary chairman of the event with George F. Aney acting as general chairman of the benefit. CURE President, Susan Axelrod, addressed the capacity crowd of 800 people. She spoke of her daughter Lauren's battle with

epilepsy, of the historical neglect in epilepsy research, and the common misperception of epilepsy as a benign disease. As she expressed her gratitude to the audience, Susan also spoke to "the courage of Jeanne and Barry to face this tragedy head-on." The evening was underwritten by a generous grant from GlaxoSmithKline.

Jeanne Donalty has recently joined CURE's Board of Directors.



Larry DiCesare and Jack Fish, Vice-President of Trade and Pharmacy Sales for GlaxoSmithKline at the Christopher Donalty CURE Benefit. GSK is a major supporter of CURE and its efforts.

Make Your Voice Heard

CURE has had a significant impact on federal funding for epilepsy research. Since 1998, the budget for epilepsy related research has increased 25% at the National Institutes of Health (NIH). Over the next few months and into the summer, President Bush and Congress will be setting budget priorities for the coming year.

We must ensure that the NIH has the resources it needs to further the critical research efforts we need. The challenge is real: funding for epilepsy research could actually be decreased. To keep epilepsy research in the forefront, your voice needs to be heard.

Chairmen Regula and Specter in Washington must hear your personal stories to understand the critical need for increased funds for epilepsy research. (See contact information at right.)

In addition, please let your own representatives know by copying them on any correspondence with Chairmen Specter and Regula. If you need assistance identifying your own representatives, please go to <http://congress.org> or call CURE at 312.255.1801.

I am pleased that NIH has put epilepsy on the agenda, and now we need to make sure it stays there.

*—Senator Hillary Rodham Clinton
addressing the annual CURE Benefit,
November 17, 2003*

Let Them Hear from You

Help keep epilepsy on the agenda

Senator Arlen Specter
Chairman, Subcommittee on Labor,
Health and Human Services
SD-184
Washington, DC 20510
202.224.7216
fax: 202.228.2321
arlen_specter@specter.senate.gov

Representative Ralph Regula
Chairman, Subcommittee on Labor,
Health and Human Services
2358 RHOB
Washington, DC 20515
202.225.3508
fax: 202.225.3509
www.house.gov/regula

Rhode Island Event Supports CURE

CURE board member LeeAnn Brigido Johnson is dedicated to raising funds for epilepsy research. Each year her fundraiser in Rhode Island has a unique theme—last year's was **Hat's Off to CURE**. Perhaps it should have been **Hat's Off to LeeAnn**.

LeeAnn's son, Zachary, has epilepsy. Since he was six weeks old, Zach has had only one year of life when his seizures were controlled with medication. On a good day, he will walk a short distance with assistance. Zach is now 14 years old, and for 12 of those years, LeeAnn has been fighting for more epilepsy research.

In the beginning, it was just LeeAnn and three family friends that organized the annual event. Now the dinner committee has over 20 members, three of whom are mothers of children with epilepsy. LeeAnn described how the committee really enjoys the work; they have become personal friends, and it gives them a chance to catch up.

Over 450 people attended last year's event, where guests made their own

party hats. In addition, there was a stand-up comedian and a live auction and raffle, followed by dancing. One year, committee members Sharon and Todd MacBeth were able to persuade a local merchant to donate a hot tub, and after it was

raffled off, an additional \$10,000 had been raised for epilepsy research. According to LeeAnn, some people have come to every event, and some use it as a reunion to see old friends. Their support is a tribute to LeeAnn's dedication to epilepsy research.



CURE board member LeeAnn Brigido Johnson and committee member Sharon MacBeth toast their success at the 2003 Rhode Island Fundraiser Hat's Off to CURE.

President Spreads Message in Washington and in Europe

In February, at the invitation of UCB Pharma's new General Director Roch Doliveux, CURE President Susan Axelrod traveled to Brussels, Belgium to address the pharmaceutical company's first international meeting of senior management and top scientists in the company.

Susan presented her family's personal struggles with epilepsy. Her daughter, Lauren, has had intractable epilepsy since infancy. Her message was one of appreciation for the efforts already made by the company on behalf of people with epilepsy and encouragement of continued efforts on behalf of the many patients with epilepsy for whom there are no answers.



On March 30, Susan testified before the Congressional Appropriations Committee on Health and Human Services in Washington, DC. Introduced by Congressman Sherwood Boehlert (R-NY) she described the impact of epilepsy on her daughter's life and pleaded for more federal funding for epilepsy research. Although epilepsy affects more people than Parkinson's Disease, Multiple Sclerosis, Cerebral Palsy and Muscular Dystrophy combined, it is still not a top priority at the NIH. It is time to recognize epilepsy as a major public health problem requiring a level of federal attention which better matches the burden of the disease.

2004 CURE Events

University of Chicago Graduate School of Business Benefit

CURE is an honored recipient of funds raised at the University of Chicago Graduate School of Business *Giving Something Back* Charity Event scheduled for April 22, 2004, in Chicago. Anyone interested in making an in-kind donation for the benefit, please contact CURE at 312.255.1801.

2005 CURE Research Proposals Due

Applications for 2005 CURE grants are due June 1, 2004. Please visit CUREepilepsy.org for an application and other important information.

Loeffel June Golf Benefit

The 16th Annual Loeffel Epilepsy Benefit takes place Friday, June 18 at Hawks View Golf Club in Lake Geneva, Wisconsin. The day of golf is followed by a cocktail hour and dinner where 2005 Super Bowl tickets are included in the raffle. Call 847.382.6770 for more info.

Sixth Annual CURE Benefit Dinner

On June 21, CURE will celebrate the beginning of summer with its Sixth Annual Benefit in Chicago at the Cadillac Club in Soldier Field. Please note this annual event has moved from the fall into June (this year only). Beginning 2005, the annual Chicago benefit will be scheduled for February on an annual basis.

CURE Junior Board Fall Event

The CURE Junior Board is planning to repeat last year's successful fundraiser at the Clock Tower Café on Chicago's lakefront with an evening of dinner and dancing.

The Never Quit Comedy Golf Tournament

The annual golf tournament to benefit epilepsy research is held in memory of comedian Dave Blaine Gray. Mark your calendars for September 10 at Tumbletown Trails Golf Course in Madison, Wisconsin. Call 608.833.1716 to make reservations.

CURE Scientific Advisory Board to Meet in Chicago

CURE's Scientific Advisory Board is scheduled to meet in Chicago the weekend of September 18-19, 2004, to review research proposals and future strategies for 2005.

St. Louis Trivia Night to benefit CURE

On October 16, 2004, Chris and Frank Corrao, will host a Trivia Night in St. Louis to benefit CURE. Contact Chris at cecorrao@charter.net to get involved or for more information.

CURE Open House at AES

CURE will announce its 2005 Research Awards at the American Epilepsy Society (AES) Meetings in New Orleans during the first week of December 2004.

Check out CURE's web site for updates and event information.

CUREepilepsy.org



CURE volunteers at the 2003 Annual Loeffel Golf Outing helped make it a successful day for golf and epilepsy research.

CURE Awards \$400,000

The funding in the first five years is going to start to produce real change. And there's going to be real advancements in the understanding of epilepsy.

—Michael C. Smith, MD, Director, Rush Epilepsy Center, Chicago

Scott C. Baraban, PhD—University of California, San Francisco
Development of Novel Epilepsy Treatments Utilizing Embryonic Progenitor Cells

Sookyong Koh, MD, PhD—Children's Memorial Hospital/Northwestern University, Chicago
Therapeutic Efficacy of Environmental Enrichment Following Early-life Seizures

Vivian I. Teichberg, PhD—Weizmann Institute of Science, Israel
Specific Immunotherapy for Epilepsy via GluR3B Peptide Oral Vaccination or Anti-GluR3B PeptideAntibodies Administration

Jana Veliskova, MD, PhD—Albert Einstein College of Medicine, Bronx
Neuroprotective Effects of b-Estradiol on Seizure-Induced Hippocampal Damage

The Christopher Donalzy Memorial Award

Carl L. Faingold, PhD—Southern Illinois University, Carbondale
Prevention of Sudden Death in Epilepsy

The Falk Medical Research Trust Award (2004)

Edward B. Bromfield, MD—Brigham and Women's Hospital, Boston
Polyunsaturated Fatty Acids for Treatment of Refractory Epilepsy

The Graham Goddard Award

(sponsored by an unrestricted grant from UCB Pharma)

Karin Borges, PhD—Emory University, Atlanta
Identification and Evaluation of Neuroprotective Genes in the Primed Pilocarpine Model

The Maggie Loeffel Award

Gregory A. Worrell, MD, PhD—Mayo Clinic, Rochester
High Frequency Epileptiform Oscillations in Extratemporal Epilepsy

Innovative New Research Proposals Due June 1

CURE seeks novel research proposals that address the goal of “no seizures, no side effects.” Priority is given to innovative projects that provide new directions for epilepsy therapy and prevention. We specifically encourage studies that may not be currently fundable by other agencies, such as the NIH, because of their preliminary or unconventional nature. CURE is interested

in supporting research using human tissue in conjunction with its newly established tissue exchange program. (See *STAR*, pg. 7 or www.ndriresource.org)

Proposals are due in the CURE office by June 1, 2004 with funding available January 1, 2005. Applicants may request up to \$50,000 for one year.

In addition, in 2006, UCB Pharma

will once again sponsor a biennial grant in Neuroprotection. This is a \$50,000 grant for junior investigators who are within two years of completing their fellowship. Applications for this award will be accepted in 2005, with funding in 2006.

For application form and procedures visit CUREepilepsy.org or contact CURE directly at 312.255.1801.

CURE launches STAR: Share Tissue/Advance Research

Finding a cure for epilepsy was considered a novel idea not too long ago, but CURE made people believe it was possible. CURE has once again taken the lead by providing a seed grant for a new initiative to enhance epilepsy research. CURE, in conjunction with the National Disease Research Interchange (NDRI), has established The Epilepsy Tissue Exchange Program: Share Tissue/Advance Research (STAR).

Our goal is to try to get high quality human brain tissue, either obtained at post-mortem exams or intra-operatively from patients having surgery, into the hands of qualified epilepsy researchers.

— Peter B. Crino, MD, PhD,
Department of Neurology, University of Pennsylvania, STAR Co-Chair

Epilepsy research has traditionally been based on animal research; but animal epilepsy can never completely mimic the human condition. With the significant scientific advances of the past few years, researchers believe that the availability of human tissue will facilitate their understanding of the cell biology, physiology, biochemistry and genetics of epilepsy. The tissue will be obtained through autopsy as well as epilepsy surgery.

Prior to the STAR Epilepsy Program, there was no established program to match human tissue with specific research. NDRI is a nonprofit organization with a well-established program for tissue exchange. They are a 24 hour/7 days a week operation with over 200 collection sites around the country, and they will now be reaching out to epilepsy surgical centers. Every effort will be made to obtain accurate and detailed clinical information in order to enhance the value of the tissue samples. The infrastructure of NDRI ensures accurate and timely coordination between donors, researchers and specimens.

The STAR Steering Committee will review requests from epilepsy researchers in conjunction with NDRI. It is hoped that specimens will be available within a few weeks after acceptance of the application.

STAR Steering Committee Members:

Susan Axelrod, Co-Chair, President, Citizens United for Research in Epilepsy, (CURE)

Peter B. Crino, MD, PhD, Co-Chair, Assistant Professor, Department of Neurology, University of Pennsylvania

Michael A. Rogawski, MD, PhD, Director, Epilepsy Research Section, NINDS, NIH

Gregory L. Holmes, MD, Chief of Neurology, Neuroscience Center, Dartmouth Medical School

Dennis Spencer, MD, Chair of Neurosurgery and Acting Dean of Medicine, Yale University

Lee Ducat, President, NDRI

John Lonsdale, PhD, Research Director, NDRI.

EPILEPSY RESEARCHERS

To receive human tissue for your research, please complete the application form at: ndriresource.org. Or you may contact John Lonsdale, PhD at NDRI (jlonsdale@ndriresource.org) or 800.222.6374, ext. 271.

PATIENT DONORS

Individuals interested in making tissue donations should contact Jean Novak at NDRI regarding the Donor Program (jnovak@ndriresource.org) or 800.222.6374, ext. 250.

Department of Defense Medical Research includes Epilepsy

Due to the efforts of CURE, epilepsy is now included as one of the diseases eligible for research funds through the Department of Defense (DOD).

Military head injury is a major risk factor for epilepsy. A study of Vietnam War veterans showed that 53% of the veterans developed PostTraumatic Epilepsy (PTE) as a result of penetrating head injuries.* As hundreds of thousands of US troops return home from Iraq, there is an increasing need to address the potential health consequences, including PTE. Epilepsy following head trauma is potentially preventable, yet no effective treatment currently exists. Research in this area promises to help both civilians and non-civilians alike.

CURE is grateful to Senator Harry Reid (NV) and Representative John Murtha (PA) for recognizing the critical importance of epilepsy research to our veterans.

DOD funding for epilepsy research with military relevance is available through the U.S. Army Medical Research and Materials Command, under the Peer Reviewed Medical Research Program (PRMRP). For more information, go to <http://www.usamraa.army.mil>, and click on BAA.

*A.M. Salazar, *et al.*, "Epilepsy after Penetrating Head Injury. I. Clinical Correlates: A report of the Vietnam Head Injury Study," *Neurology* 35:10 (October 1985): 1406-14

Story C. Landis, PhD, Named Director of the NINDS

Dr. Story C. Landis was recently appointed Director of the National Institute of Neurological Disorders and Stroke (NINDS). Dr. Landis has been with the NINDS since 1995 and has worked to coordinate the agency's intramural research programs. As such, she was instrumental in bringing a sense of common purpose to the various programs involved in clinical and basic neuroscience research.

As director, Dr. Landis has reached out to patient advocacy groups, and initiated a meeting with Dr. Michael C. Smith and Susan Axelrod of the CURE Board to discuss the status of epilepsy research. CURE Board members also met Dr. Landis when she attended the announcement of CURE's 2004 research awards in December. (See *Standing Room Only* at

Announcement of 2004 Awards, below)

The NINDS is one of 27 Institutes that make up the National Institutes of Health (NIH), a federal agency. Its mission is to reduce the burden of neurological disease, and it strives to achieve this primarily by funding research in the areas of neuroscience and/or neurological disease. Consequently, epilepsy research falls under the umbrella of the NINDS research.

At the time of this writing, the NINDS had listings for almost 50 studies seeking subjects, and over two thirds of those studies were spread across the United States—not just at the NINDS headquarters in Maryland. For more information go to: <http://clinicaltrials.gov/search/?term=epilepsy>. You may also call 1.800.411.1222.

Pediatric Epilepsy: Focus of NINDS Workshop

In 2000, CURE co-sponsored the historic NIH conference *Curing Epilepsy: Focus on the Future*, where scientists really began talking about a cure. The impact of that conference continues to reverberate in the scientific epilepsy community. As a continuation of that meeting in 2000, the National Institute of Neurological Disorders and Stroke (NINDS) will host a workshop in May entitled *Pediatric Epilepsy Models*.

Much of epilepsy research has traditionally relied on the use of mature animal models in a laboratory setting. But these studies do not take into account the rapidly developing brain in an infant or child with epilepsy. The goal of the workshop will be to find a means to study epilepsy in age-specific animal models.

Standing Room Only at Announcement of 2004 Awards

CURE's 2004 research awards were announced at the annual meeting of the American Epilepsy Society (AES) in Boston last December. AES is the professional organization for physicians, scientists and health care professionals involved in the treatment and cure of epilepsy.

CURE President Susan Axelrod announced the eight awards to an overflow crowd.

Many in the audience were junior investigators, eager to learn about new opportunities to pursue their research goals.

The number of applications for 2004 grants was double that of previous years, reflecting not only the growing prominence of CURE, but also the increasing willingness of researchers to explore novel approaches to the cure of epilepsy. CURE supports those researchers who are willing to think outside the status quo in their search for a cure for epilepsy.

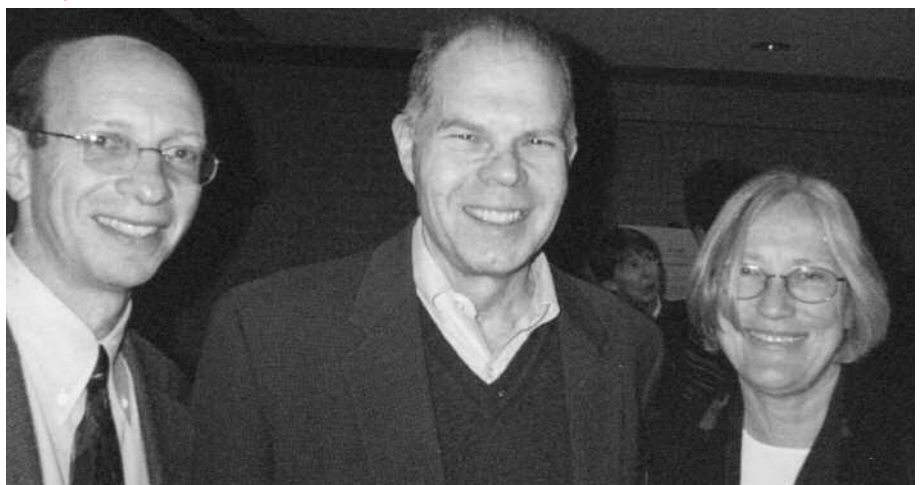
Among those in attendance were Story C. Landis, PhD, newly appointed Director of the National Institute of

Neurological Disorders and Stroke, NIH; Daniel H. Lowenstein, MD, President of AES; Jeffrey L. Noebels, MD, PhD, Immediate Past President of AES; Margaret Jacobs, Program Director, Epilepsy Research, National Institute of Neurological Disorders and Stroke, NIH;

and M. Suzanne C. Berry, MBA, CAE, Executive Director of AES. 2004 grantees, past grantees, and members of CURE's Board, CURE's Scientific Advisory Board, and CURE's Scientific Review Board were also present. (See the complete list of 2004 research awards on page 6)

...it is clear we are beginning an exciting new phase of epilepsy research that promises to make a meaningful difference to patients with seizure disorders.

— Jeffrey Noebels, MD, Immediate Past President of AES



Dr. Daniel Lowenstein, President of AES; Dr. James Burchfiel, University of Rochester Medical Center; and Dr. Story Landis, Director of the National Institute of Neurological Disorders and Stroke, NIH, at the announcement of CURE's 2004 research awards.

Scientific Advisory Board (SAB) Meets in Chicago

Last October, the SAB spent a weekend in Chicago assisting the CURE Board of Directors in the final selection of the 2004 research awards. Prior to this meeting, grant proposals had been reviewed by over 70 members of the Scientific

Review Board. CURE is very fortunate to have these eminent members of the medical community on board. The meeting was supported by an unrestricted educational grant from Ortho-McNeal Pharmaceutical.



Scientific Advisory Board Meets in Chicago: Michael C. Smith, MD, Helen E. Scharfman, PhD, Douglas Nordli, Jr., MD, Valerie Davis Raskin, MD (Facilitator), Gregory L. Holmes, MD, Michael A. Rogawski, MD, PhD

A big THANK YOU to our Scientific Advisory Board Members:

Antonio V. Delgado-Escueta, MD, UCLA Comprehensive Epilepsy Program & VA Medical Center, Los Angeles, California

Gregory L. Holmes, MD, Chief of Neurology, Neuroscience Center, Dartmouth Medical School, Lebanon, New Hampshire

Douglas Nordli, Jr., MD, Director, Epilepsy Center, Children's Memorial Hospital, Chicago, Illinois

Michael A. Rogawski, MD, PhD, Chief, Epilepsy Research Section, National Institute of Neurological Disorders and Stroke, the National Institutes of Health, Bethesda, Maryland

Helen E. Scharfman, PhD, Columbia University, New York City & Center for Neural Recovery and Rehabilitation Research, Helen Hayes Hospital, New Haverstraw, New York

Michael C. Smith, MD, Director, Rush Epilepsy Center; Associate Professor Department of Neurological Sciences, Rush University Medical Center, Chicago, Illinois

Mary L. Zupanc, MD, Medical Director, Neurology, Children's Hospital of Wisconsin; Associate Professor & Chief, Neurology, Medical College of Wisconsin, Milwaukee, Wisconsin

CURE CITIZENS UNITED FOR RESEARCH IN EPILEPSY

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Legal Counsel

Lynn D. Fleisher, Esq.

Sidley Austin Brown & Wood

Administrative Director

Deborah Cullen

CURE WORDS ARE SPREADING — *research & hope*

HARRISVILLE, RHODE ISLAND



Committee members register guests at last year's annual fundraiser organized by board member, LeeAnn Brigido Johnson. The theme was **Hat's Off to CURE**.

DEERFIELD, ILLINOIS



Guests enjoy playing with their "funny money" at Casino Night, hosted by the Junior Women's Club of Deerfield, Illinois. Last year, the Club chose CURE as the benefactor of their annual charity event.

CHICAGO LAKEFRONT



Kevin Collins, Mary Helen Cusak, Richie and Patty Collins enjoy a late 2003 summer evening at the **CURE Junior Board's first fundraiser**.

UTICA, NEW YORK



George F. Aney, General Dinner Chair, addresses the sell-out crowd at the **Christopher Donalty CURE Benefit**.

CHICAGO, ILLINOIS



In accepting the annual CURE Award from board member Kathy Dodd, David Axelrod reflected: "...to me the great reward will come when we can say that no child will go through what my child has gone through...that we can say this is a thing of the past and we have beaten it."

BLOOMINGDALE'S

CURE Volunteers worked throughout Chicagoland at Bloomingdale's Shopping Benefit Day, to raise funds for epilepsy research. The annual event benefits local charities.

GALLERY WALK

The River North area of Chicago, home to CURE's office, is the largest gallery area in Chicago. A portion of the proceeds from last year's charity gallery walk, The River North Rendezvous, was donated to CURE.

LAKE GENEVA, WISCONSIN



Four happy golfers last June at the annual **Loeffel Epilepsy Benefit**: Joe Darragh, Tim Treacy, Jerry Nadig and Maurice Loeffel.

NOTE: 2004 outing is scheduled for June 18, 2004

OAKBROOK, ILLINOIS



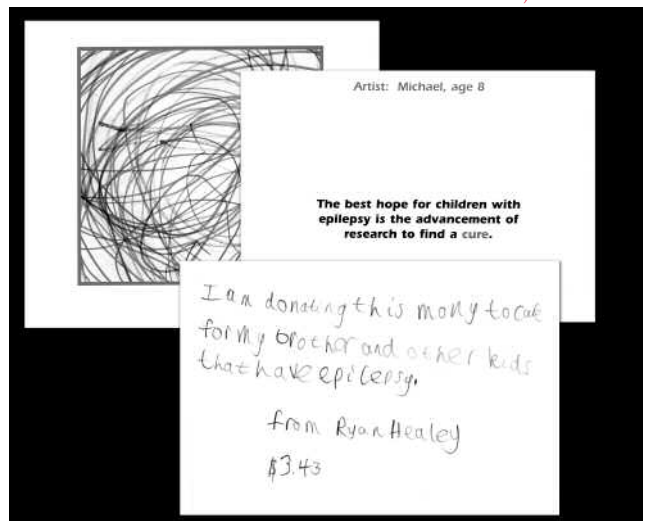
The Leo Magrini Memorial Fund Golf Outing
Leo Magrini Sr. with friends of his late son including Paul Moreschi, a grade school friend; Paul Paslaski, a college friend; and C.J. Dempsey, a high school friend. Leo Jr. suffered from epilepsy as the result of a brain tumor.

NAPERVILLE, ILLINOIS



Ann Rochester, Tim Healey, Anne Marie Healey, Tom Healey—"Tis better to give than to receive." John and Sherry Healey demonstrated the true spirit of this sentiment by turning John's 40th birthday celebration into a benefit for epilepsy research. Friends and family, who celebrated with the Healey's over cocktails and hors d'oeuvres, were asked to make gifts to CURE.

NAPERVILLE, ILLINOIS



A truly heartfelt contribution from 8-year old Ryan Healey, who desperately wants a cure for his brother, Michael.

MADISON, WISCONSIN



The Never Quit Comedy Golf Tournament
Despite the pouring rain, two golfers managed to have fun at the tournament to honor the aspiring young comedian, Dave Gray, who passed away as a result of a seizure.

**Help Spread CURE Words
Get involved.
Call 312.255.1801 or
E-mail info@CUREepilepsy.org**

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Save the Date!

June 21, 2004
Annual CURE
Benefit Dinner
Cadillac Club
at Soldier Field

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.

Epilepsy affects more people than multiple sclerosis, cerebral palsy, muscular dystrophy and Parkinson's Disease combined. Of the 2.5 million Americans with epilepsy almost 2 million experience either limited or no relief from existing treatments. The impact on the brain from uncontrolled seizures and potent medications can range from learning disabilities to mental retardation and, in a disturbingly large number of patients, even death.

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.



CURE is growing!

For email updates on research, events, and other epilepsy news, send your name and e-mail address to 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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