

# AES News

AMERICAN EPILEPSY SOCIETY

Vol. 11, No. 2

Summer 2002

## Seattle to Host 2002 Annual Meeting

The American Epilepsy Society Annual Meeting moves to the Pacific Northwest for its gathering December 6-11, 2002 at the Washington State Convention and Trade Center in Seattle. The Sheraton Seattle Hotel & Towers will serve as the Annual Meeting Headquarters.

We are excited about encompassing many of your suggestions into the organization of this year's Annual Meeting. Your responses to all those surveys over the last year have made a difference. The first change that you will notice this year is the official opening of the Scientific Program on Saturday, December 7 with a Welcome Reception and the Presidential Symposium. These are followed by the AET Symposium in a new time slot, Monday, December 9 at 8:30 a.m. The Merritt Putnam Symposium will continue to be held on Saturday with a new feature – a panel discussion during lunch. The most notable change, that is a direct result of your comments, is that the meeting will end at noon on Wednesday. We have moved the Wednesday afternoon SIGs to Monday, increased the number of posters and reduced the number of platforms to allow the meeting to end at 1:00 p.m. on Wednesday. With all that, we still managed to give you a free evening on Monday to go out on the town and enjoy Seattle.

The Presidential Symposium, to be held on Saturday, December 7 at 2:30 p.m., is organized by AES President Dr. Tom Sutula. The symposium will examine emerging experimental, clinical, genetic, and neuropsychological evidence of potential adverse effects of brief repeated seizures on the brain and behavior. Symposium II, on Tuesday, December 10 at 8:30 a.m. will address the role of parahippocampal areas in limbic synchronization under physiological conditions and examine how these neuronal networks perform elaborate epileptiform

synchronization in the normal and in the epileptic brain. Symposium III, on Wednesday, December 11 at 8:30 a.m., will focus on Neuroimmunology and Epilepsy.

The Annual Course on Sunday, December 8 is designed to aid participants in evaluating trial results, claims made based upon such results, and limitations in their interpretation. Beginning with a consideration of how pre-clinical development influences the design of clinical trials, the course will proceed to examine the regulatory environment and ethical issues associated with designing and conducting trials, then conclude with a discussion of how best to acquire the knowledge that trials cannot yield. The Annual Course, which is entitled *Assessing the Efficacy of Antiepileptic Treatments*, is chaired this year by Dr. Andrew Cole.

The Investigators' Workshops, also on December 8, will feature topics that have been selected by the Investigators' Workshop committee chaired by Drs. Carl Stafstrom and William Theodore. The workshops provide an update on cutting edge epilepsy research as well as a venue for

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## PRESIDENT'S MESSAGE



As this letter goes to press, AES members and staff are deep into firming up the program and pinning down logistics for the 2002 Annual Meeting in Seattle. This planning process actually began during the 2001 meeting in Philadelphia; a great deal of behind the scenes work goes into making our meeting the premier annual scientific and professional meeting for the epilepsy community. Planning the Annual Meeting has become an increasingly challenging task—but one that is absolutely key to the membership.

The results of surveys and a wealth of anecdotal information confirm that the Annual Meeting is the major draw for attracting and maintaining AES membership. Indeed, post-meeting and membership surveys, which are typically characterized by an unusually high rate of responses for a non-profit professional association, have consistently indicated that the Annual Meeting is an educational, scientific and financial success story and is considered the gold standard for epilepsy meetings worldwide.

Just 20 years ago, AES was a relatively small professional organization dominated by medical epileptologists, and the meeting held annually in December at the Roosevelt Hotel in New York City was a modest affair. During the mid 1980s, AES leadership recognized the desirability of expanding the meeting and diversifying AES membership to include basic scientists, nurses, psychologists, and the full range of health care professionals who contribute to advancement of knowledge and care for people with epilepsy. A successful effort was undertaken to improve the scientific and multidisciplinary quality of the meeting, and to broaden the AES membership by devel-

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## AES News

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**Editor**

Elaine Wyllie, M.D.

**Executive Director**

M. Suzanne C. Berry, CAE

**Associate Director**

Sandra L. Pizzoferrato

**Director of Meeting Services**

Steven J. Rugens, CMP

**Program Director**

Cheryl-Ann Tubby

**Membership Services**

Maria Rivera

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**AES News**

342 North Main Street  
West Hartford, CT USA 06117-2507  
Phone: (860) 586-7505  
Fax: (860) 586-7550  
E-mail: [info@aesnet.org](mailto:info@aesnet.org)  
Web site: [www.aesnet.org](http://www.aesnet.org)

Membership consists of clinicians, scientists investigating basic and clinical aspects of epilepsy, and other professionals interested in seizure disorders. Members represent both pediatric and adult aspects of epilepsy. Active membership for one year is \$170 and includes a subscription to the journal *Epilepsia*. Junior Membership is \$130 annually; *Epilepsia* subscription is optional for Junior and Corresponding members. Active and Junior membership is limited to residents of the USA, Canada, and Mexico. Corresponding membership is limited to residents outside of North America. It does not automatically include a subscription to *Epilepsia*, and fees are \$125. Senior membership is available to Active Members who have reached the age of 65.

**Editorial Deadlines**

Fall 2002 issue: August 30, 2002  
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### President's Message

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oping a meeting that was attractive to the diverse range of professional disciplines that contribute to the advancement of epilepsy care and research. As a result, the Annual Meeting has grown from a few hundred attendees to nearly 3,000 over the past 15 years, and now attracts a large and interdisciplinary group of attendees with a more diverse array of educational needs.

Not surprisingly, the length and character of the Annual Meeting has evolved during this period of growth. The current meeting format reflects decisions to incrementally add new programs and sessions that provide an attractive forum for discussion and information exchange, while still maintaining a core of scientific and educational activities that promote interdisciplinary discussion and appeal to specific disciplines and subspecialties. In part, the success of the Annual Meeting has hinged on our ability to assess our members' changing needs and make adjustments, both major and minor, and to retain content and format that has interdisciplinary interest and broad appeal.

Despite the meeting's continued success, concerns have been raised about various aspects of the annual event; its length, level of commercialism, or effectiveness in meeting the concerns of specific groups within the membership are a few examples. Hotel occupancy information at the meeting indicates that the majority of attendees participate in only a subset of the meeting, and not necessarily the major scientific and educational sessions. Many members are probably not aware of the increasing complexities of developing Annual Meeting programs that meet ACCME standards for continuing medical education credits. This has become a major, costly, and continuous process for AES staff and the Annual Meeting Committee. While tinkering with a highly successful event like our meeting runs the risk of "fixing something that isn't broken", the expressed concerns have been consistent, and suggest that some reevaluation of the meeting format and length are appropriate.

To address these concerns, we have initiated a process of evaluating the meeting and developing options for how the format and length of the meeting can continue to evolve to meet the educational and scientific needs of our growing membership. This process will be incorporated into our strate-

gic long range plan, which is being updated during 2002. Taking a close look at the Annual Meeting clearly is an important part of long range planning for the Society.

The process of evaluating the Annual Meeting began recently with a special gathering of AES leadership, which was dubbed "the meeting on the Meeting". Past, current and next-year chairs of key meeting components (such as the Scientific Program, Annual Course and Investigators' Workshop) met in Hartford on May 8 to act as a "think tank." Their role was to ask important questions about the Annual Meeting's length, content, timing, and member needs and to look to possibilities for midcourse corrections or major alterations that should be considered to ensure that the AES Annual Meeting remains a superb scientific, educational, and networking event.

The "meeting on the Meeting" group took a close look at how the Annual Meeting currently works, then developed and discussed a series of options about how the meeting might evolve in the near future. Special attention was paid to the "pros and cons" of each option. The group's goal was to frame options to present to the Strategic Planning Committee and eventually to the AES Board. Decisions about whether or how to alter the Annual Meeting will be made by the CME, Scientific Program, and Annual Meeting Committees, in conjunction with the AES Board of Directors.

You will probably notice only incremental changes in the format of the 2002 meeting in Seattle, but as the meeting planning process evolves during the next few years, issues such as meeting length, commercial support, range and balance of topics, and the mix of symposia, platform, and poster presentations will receive specific attention and consideration.

Many thanks to the AES members who attended the meeting on the Annual Meeting, including Bill Theodore, Susan Spencer, Ed Dudek, Kevin Staley, Frances Jensen, Dan Lowenstein, Jaideep Kapur, Gary Mathern, Massimo Avoli, Mike Rogawski, Carl Stafstrom, Patty O. Shafer, Paul Rutecki, Andy Cole and John Hugenard. Their enthusiasm for this important assignment, and their ability to see a range of perspectives and interests, helps remind us all of why AES is such a successful organization.

# Burdens of Epilepsy Care — Need for Advocacy and Change

Patricia Osborne Shafer RN, M.N., Comprehensive Epilepsy Center, Beth Israel Deaconess Medical Center, Boston, MA

## The Burden of Epilepsy

To some, this phrase refers to the difficulties that people with epilepsy and their families face day in and day out. The endless seizures, treatment side effects, injuries, emergency room visits or hospitalizations. The fears: of when the next seizure may occur, of what other people may think, of being a burden to family and friends, or of serious injury or death. And the consequences—learning difficulties, unemployment, behavioral or mood disorders, social isolation, family stress and stigma—that can be more detrimental and disabling than anything else.

*The epilepsy experience is unique for each person and spans the spectrum of life, with the consequences and types of issues or problems varying with age, gender, seizure type or syndrome, age of onset and a number of other variables.*

Research and clinical experience has shown that these consequences, including the economic burdens, are much greater in people who have persistent seizures. The epilepsy experience is unique for each person and spans the spectrum of life, with the consequences and types of issues or problems varying with age, gender, seizure type or syndrome, age of onset and a number of other variables. What factor is most important? We don't know that yet for sure, but we do know that seizure control matters. It is that simple.

Those of us whose lives are touched by epilepsy, either personally or professionally, know only too well what these burdens can do to individuals and families. We try

endlessly to better understand what is going on in the brain to cause seizures and how to stop them. We know that advances in science are leading us on a journey toward a cure. We try to help patients find a treatment that will help them achieve the goal of “no seizures and no side effects.” Yet we also know that for many, this goal is still very elusive; approximately 40 percent of people with epilepsy in the United States live with persistent seizures. They have not yet found the treatment that will work for them. Or maybe they are afraid to make a change and “rock the boat.” Or perhaps the refractory epilepsy is just that—refractory—and not able to be controlled with science as we know it today. Or just maybe the health care system is a major barrier to achieving these goals.

Obtaining seizure control and avoiding side effects means that patients must have access to appropriate quality care. They must first be properly diagnosed, learn about the benefits and risks of options available to them, know how to manage the seizures and the prescribed therapies, and be able to follow-up closely with their treatment team. And, since seizures are just part of the picture, people need access to the professionals and services that will help them cope with the impact of epilepsy on their lives.

All this requires a complex web of resources, including money, insurance, health care providers, tests, treatments, services, people and time. And, increasingly, it requires a mass of rules, regulations, oversight agencies and paperwork. Negotiating the health care system is similar to negotiating a field of landmines. You often don't know what to expect or how to get where you are going. The health care system is part of the burden of living with and caring for epilepsy.

## The Burdens of Health Care

Health care systems and people are de-

signed to help us, and in fact, many Americans have access to the highest level of care in the world. Unfortunately, this isn't so for many others, particularly the elderly, the poor or those with disabling health conditions such as epilepsy. Consider the following:

- Finding a primary care provider (PCP) is increasingly difficult as more and more physicians leave the field, stop seeing “new patients” (particularly those who are covered by Medicare and/or Medicaid), or accept only private pay patients.
- Those PCPs accepting patients with Medicare/Medicaid often don't have the time or resources to work with someone with a complex or “difficult” problem such as epilepsy. As a result, people with epilepsy often don't get their basic health needs met.
- There is a critical nursing shortage affecting all aspects of health care. Because of the nursing shortage, bed availability—and thus access to care and quality of care—is affected.
- Diversions from emergency rooms, and even home health care agencies, occur on a routine basis, further compromising the health and safety of patients and what little continuity of care they may have had.
- Even patients who can find someone to work with them often are faced with limitations on where they can go for specialized care, what type of providers or tests may be covered, or cumbersome and confusing preauthorization steps.
- Increasingly, both private health plans and state Medicaid programs are looking at ways to control prescription drug costs. Unfortunately, this is affecting access to

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**Burdens of Epilepsy Care***(continued from page 3)*

medications for people with seizures. Some states or plans are trying or considering “fail first” policies, whereby patients must try and fail a generic AED before they can consider a brand name drug. Or cumbersome preauthorization forms must be completed for patients to get access to a brand name drug. Some plans are limiting choice by offering higher co-pays for certain drugs.

- Patients frequently can't understand what is or isn't covered by their health plan or what is “medically necessary” (if the doctor ordered it, isn't it medically necessary?). Negotiating the health care system requires a fairly sophisticated understanding of concepts foreign to most people: co-pays vs. deductibles vs. premiums, covered services, non-covered services, beneficiaries vs. subscribers, pre-existing conditions, managed care, PPO, fee for service, advanced beneficiary notices, summary notices vs. bills, appeals processes, HIPAA and protected health information and so on.
- Providers can't understand or don't know which regulations pertain to them, or are unclear about how to implement them. In 2001, over 130 different regulations were published from the Centers for Medicare and Medicaid (CMS Communication) along with over 100 program memorandum and policy letters.
- It takes months for physicians or advanced practice nurses applying for Medicare provider numbers to complete the process. During the interim, patients can't be seen or providers are not paid.
- Nurse practitioners may be reimbursed by Medicare, but are not considered primary care providers. Does this make sense when we have a shortage of primary care providers, particularly in rural areas?
- Many of the services necessary for people with epilepsy are not covered by insurance—health education, counseling, community case management, many home health services, respite care, vocational rehabilitation, educational services or family supportive services.
- Providers typically spend more time documenting care and completing paperwork to comply with regulations than they do providing care.

This is just a short list of problem areas. Everyone can come up with their list of what is most burdensome to them. Patients and families certainly have their concerns, too. While Medicare and Medicaid are often cited as the most burdensome agencies, all types of insurers as well as many other organizations or agencies involved in regulating, overseeing, surveying, licensing, or paying for health care add to the health care burdens in our country.

**Health Care Reform: Is It Possible?**

Reforming the health care system is a monumental task and not one that is going to happen easily or soon. However, incremental steps are being taken to make the system work better. I am honored to be serving on U.S. Department of Health and Human Services Secretary Tommy Thompson's Advisory Committee on Regulatory Reform, which is tackling some of the most problematic areas. The Committee has been asked to address the burdens of health care by clarifying regulations, eliminating obsolete or unnecessary ones, suggesting changes in how regulations are implemented, and when necessary, recommending areas that may require legislative changes. Additionally, the Committee is looking at long-term processes used to create and reform regulations in health care. Public testimony and committee work is covering a range of topics such as EMTALA, HIPAA, CLIA, E & M documentation guidelines, beneficiary and provider communications, Medicare cost reporting, MDS, Oasis, ABNs, adverse event reporting mechanisms, and Medicare plus Choice, to name a few.

*The Committee has been asked to address the burdens of health care by clarifying regulations, eliminating obsolete or unnecessary ones, suggesting changes in how regulations are implemented, and when necessary, recommending areas that may require legislative changes.*

While this committee is not charged with reforming the health care system, if even just a few of the recommendations can be implemented, it may help everyone do what they are supposed to do — work with patients to treat and improve their health.

**Clinical Implications: What to Do on the Front Line**

Increasingly, health care professionals are finding it difficult to cope with and manage the stress of working in an ever-changing and regulated health care system. It takes a toll on our professional and personal lives. However, we are not alone, because patients and families are struggling in their own way to make the best out of a confusing and burdensome system at a time in their lives when they are most vulnerable. While there are no easy answers, we can all be more effective advocates and agents for change. One solution is to make your voice heard through professional organizations and advocacy groups. For example, join the AES Practice Committee, attend the Epilepsy Foundation's Public Policy Institute or join the Speak Up, Speak Out Campaign through the Epilepsy Foundation website ([www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)). And stay in touch with the American Academy of Neurology, the National Association of Epilepsy Centers, and the American Association of Neuroscience Nurses to keep abreast of issues affecting your program and practice.

However, patients and families need their voices heard as well. Our educational efforts must start with and focus on teaching patients and families how to be effective advocates and negotiate the health care maze. This may take time, but the results will be well worth the efforts and you will truly be working together as a team. Consider the following ideas:

- Teach patients/families the facts and fantasies about health care, including what they can expect and how they can access services to get their needs met.
- Make sure you refer patients and families to their insurance company regularly to seek out answers. The more the insurers or health plans hear from patients and families, the more likely their needs will be addressed. And, they must know their rights and responsibilities, including the right to appeal.

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**Burdens of Epilepsy Care**

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- If you work as part of a team, explore each person's roles and responsibilities to maximize the use of each person's expertise. Many nurses consider education and advocacy as integral parts of their role, while social workers often have extensive knowledge about community resources. They are critical members of the epilepsy care team.
- Encourage patients with complex psychosocial or clinical needs to obtain a community case manager or advocate. These people can be instrumental in accessing resources and helping patients cope with the many complex systems. Case managers may be found through some Epilepsy Foundation affiliates, managed care or state Medicaid plans, schools, Department of Vocational Rehabilitation programs, private rehabilitation counselors, Elder Services or other community groups.
- Encourage patients/families to involve the case manager in appropriate treatment planning. This is particularly helpful for patients who have limited support systems. For example, patients will find it much easier to undergo changes, such as trying a new medicine or contemplating a surgical workup, if they have a supportive person who is willing to help with the practical aspects and fears or worries of making changes.
- Share information proactively, rather than passively. A knowledgeable consumer or patient can work better with you and the health plan/insurer. And remember, it is the patient's epilepsy, not yours, so make sure you are working toward the same goals.
- Encourage patients/families to keep their own records of their needs, notes, "to do" lists, insurance issues or resources. This minimizes confusion and helps patients organize their care more easily. Computers make this very easy to do!
- If you don't have time or resources for patient/family education, refer them to Learning Libraries (found in many hospitals), trusted sources on the web, and Epilepsy Foundation affiliates.
- Help patients build self-confidence or refer them to a counselor. If patients doubt themselves, it is much harder to

*And what about teaching patients self-advocacy skills — does that come before teaching patients what type of seizures they have or the medicine you want them to take?*

manage the epilepsy, let alone negotiate the complex web of health care.

While many of the ideas given above are not new, the importance of these strategies is new. Patient education used to be the "fluff"; it was something to do when we had time. You might ask: Case managers or advocates — aren't they just working for the insurer? Not all; many of them work for the patient. And what about teaching patients self-advocacy skills — does that come before teaching patients what type of seizures they have or the medicine you want them to take? The answer is YES! It must come first. If patients are not part of the process, and a knowledgeable active part, you will be dealing with many of the burdens of epilepsy care yourself. And that means you likely will not achieve what you started out to do — to help patients with epilepsy achieve their goals and dreams.

**About the Author**

*Patricia Osborne Shafer RN, M.N. is an Epilepsy Nurse Specialist at Beth Israel Deaconess Medical Center in Boston, Massachusetts, Chair of the AES Allied Health Education Subcommittee and Chair of the Epilepsy Foundation's Professional Advisory Board. She serves on the U.S. Department of Health and Human Services Secretary's Advisory Committee for Regulatory Reform. These remarks do not reflect the collective opinion of this Advisory Committee, the Center for Medicare and Medicaid Services or the U.S. Department of Health and Human Services.*

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**AES CIRCUIT**

**Abstracts, Review Articles Now Available**



The abstracts from the 2000 and 2001 AES Annual Meeting are now available online at <http://www.aesnet.org> and can be found in the education section of the site. This new feature allows users to search by title, author, or keyword. These abstracts will be online indefinitely. Abstracts from future meetings will be added to the database, making this a valuable resource for our members and other epilepsy professionals.

The AES journal, *Epilepsy Currents*, is published six times a year. Access to the review articles for the most recent issue of the journal is available right from the homepage of the AES website. Every issue of the journal is available for download. Go to [www.aesnet.org](http://www.aesnet.org) and check the education/publication section of the website.



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## SIGnals

**Nursing SIG**

*Linda Goldenberg, M.S.N.*

The nursing SIG for AES 2001 was very well attended. Our topic of interest was treating seizures acutely. Susan Smith, M.S., University of Rochester, spoke on triaging and treating patients with seizures outside a medical setting. Lori Arentz, RN, Medical College of Wisconsin, discussed the school nurse role for students with seizure disorders. Patricia Fischer, RN, University of Illinois, outlined the protocol of treating status epilepticus.

Linda Allen and Patricia Schaefer have been the co-moderators for the past three years and will be passing the torch on this year. Our new moderators will be Linda Goldenberg and Susan Smith. The focus for 2002 will include the role of the advance practice nurse in the comprehensive epilepsy center; the societal and legal issues of epilepsy; and AEDs' therapeutic levels, signs of toxicity, and lab value interpretations.

**Quality of Life SIG**

*Samuel Wiebe M.D., M.Sc., FRCPC*

The Quality of Life and Outcomes SIG encourages interaction among audience and presenters, creating a dynamic forum conducive to lively and enriching discussions. Last year, the group enjoyed discussions on the challenges of measuring and interpreting Quality of Life (QOL) in children (Dr. Joan Austin), and on the ascertainment of minimum clinically important changes in QOL (Dr. Samuel Wiebe). This year, two exciting topics will span the spectrum of assessment and interpretation of Quality of Life in children and adults.

Early intervention in epilepsy has come to the forefront. Accordingly, new measures are being developed to assess patient-centered outcomes and QOL in children and young individuals. Drs. Annie Bye and Mark Sabaz will present and discuss their work on QOL measurement in children. They will focus on the measurement properties and clinical relevance of their Quality of Life in Childhood Epilepsy Questionnaire (QOLCE).

The development and validation of patient-centered, valid, brief QOL scales is a welcome endeavor. It is equally important to identify salient features of individual instruments that will help clinicians and researchers in making informed instrument choices for specific purposes. Dr. Frank Gilliam will discuss the measurement properties, scope

and clinical relevance of the EFA Concerns Index, a newly developed, patient-centered QOL scale.

**Clinical Pharmacology SIG**

*Timothy E Welty, Pharm.D.*

During our 2001 meeting in Philadelphia, the SIG heard two interesting discussions. Danny Shen, Ph.D., from the University of Washington, presented a review of active transporter systems in the blood brain barrier and postulated some of the potential impacts on pharmacotherapy these systems may have. H. Steve White, Ph.D., from the University of Utah, discussed work that he has done related the possibility of altering the course of epilepsy through pharmacotherapeutic interventions.

For our 2002 program, we will be exploring the application of basic science research techniques and information in clinical research and practice. Mark Leuer, Pharm.D., from the University of Arkansas, will describe microdialysis techniques and discuss potential clinical applications of this tool. Brian Alldredge, Pharm.D., from the University of California San Francisco, will describe research and programs into more rapid delivery of effective pharmacotherapy in patients who experience status epilepticus outside of the hospital.

Following these presentations the SIG will hold a brief business meeting and discuss how the SIG can more effectively contribute to AES and enhance the pharmacotherapeutic care of patients.

**Sleep and Epilepsy SIG**

*Beth A. Malow, M.D., M.S.*

Our SIG brings together AES participants interested in the interrelationship of sleep and epilepsy. The December 2002 SIG meeting will focus on the relationship of seizures to sleep in both adults and children with epilepsy. Questions addressed will include: Out of what stage of sleep do seizures occur? What can seizures during sleep teach us about the location of the epileptogenic region? How might sleep facilitate seizures and which epilepsy syndromes are the most susceptible? Speakers include Dr. Susan Herman of the University of Pennsylvania and Dr. Daniela Minecan of the University of Michigan. We hope that you will join us for these thought-provoking talks accompanied by a lively discussion.

We welcome your suggestions for future SIG meetings. Potential topics include dis-

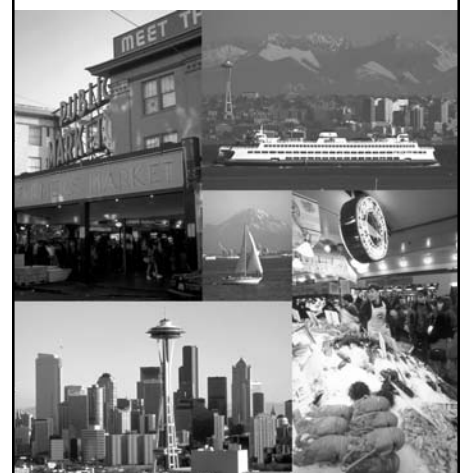
cussing the impact of treating sleep disorders in epilepsy patients on seizure control and quality of life, debating the usefulness of sleep-facilitated interictal spikes in the epilepsy surgery evaluation, and highlighting recent advances in sleep medicine relevant to the epilepsy patient. Please email Dr. Malow at [bmalow@umich.edu](mailto:bmalow@umich.edu) with any input for the group.

**Seattle to Host**

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debate on controversial areas of that research. This year's two morning workshops take up stem cells in epilepsy and the pharmacogenetics of antiepileptic drugs; the six afternoon sessions are titled *Mitochondria and Free Radicals, Neurotransmitter Transporters and Epilepsy, Functional MRI and Memory, Functional Imaging in Small Animal Models of Epilepsy, Steroid Hormones and Epilepsy, and Gamma Knife Surgery in Epilepsy*.

The 2002 Annual Meeting also will present 90 platform presentations, over 800 poster sessions, evening symposia, and industry-sponsored scientific exhibits focusing on such topics as results of clinical trials and drug development. Exhibits from over 50 commercial, governmental and educational companies will provide attendees with the latest in pharmaceuticals, publications, technology and products in the field of epilepsy.



## EF UPDATE

*Ann Scherer, Epilepsy Foundation*

## EF Campaign Piggybacks Women's Health Month

November is traditionally Epilepsy Month, when the Epilepsy Foundation nationwide mounts a special campaign to increase public awareness and understanding. But Women's Health Month in May offered a welcome opportunity to showcase the Epilepsy Foundation's Women & Epilepsy Initiative Campaign.

With support from GlaxoSmithKline, the Foundation mounted a pilot media campaign in May, backed up by special mailings, an Internet chat, and a Congressional briefing on women's issues.

The campaign, conducted with the assistance of the Fleishman Hillard public relations firm, featured print publicity and radio interviews with physicians and patients in eight demonstration cities. Hispanic media were targeted in New York, Miami, Dallas and Los Angeles, where the interviews were conducted in Spanish.

The campaign included a radio public service announcement about epilepsy in women, distributed on CDs to several hundred radio stations, as well as radio and print news releases. A special mailing of the Women & Epilepsy Initiative materials for women and their health care teams was sent to 8,500 case managers at managed care facilities, plus a special poster promoting the campaign. An additional 10,000 copies of *between us*, the Foundation's magazine for women, were distributed to epilepsy centers, affiliates, and consumers.

Patricia Osborne Shafer, RN, M.N., who chairs the Foundation's professional advisory board and is a leader of the Women & Epilepsy Initiative, was joined by fellow board member Georgia Montouris, M.D., for a special Women's Health Month chat event on the Foundation's website, taking questions from women across the country.

Finally, a Congressional briefing on epilepsy and women's health took place in May at the invitation of Rep. Corrine Brown (D-FL). Martha Morrell, M.D., Sharon McMinn, winner of the Epilepsy Foundation's 2001 "Making a Difference" Award, and Edna Kane-Williams, the Foundation's vice president for quality of life programs and research, spoke at the briefing.

## New Pediatric Epilepsy Research Partnership Awards Grants

The Partnership for Pediatric Epilepsy Research recently awarded \$300,000 in grants for research into the causes, treatment and eventual cure of childhood epilepsies.

The Partnership is a consortium of individuals and epilepsy-related organizations, including the American Epilepsy Society, the Epilepsy Foundation, Anna and Jim Fantaci, Fight Against Childhood Epilepsy (FACES), Neurotherapy Ventures Charitable Research Fund, and Parents Against Childhood Epilepsy (PACE).

Representatives of the Partnership members met in New York in May and awarded \$75,000 research grants to the following recipients:

Richard M. Myers, Ph.D., Stanford University School of Medicine, for studies to define the pathogenic mechanisms of seizures in Unverricht-Lundborg Progressive Myoclonus Epilepsy (EPMI). Dr. Myers will receive \$25,000 per year for three years.

Manesh N. Patel, Ph.D., National Jewish Medical and Research Center, for research on the role of mitochondrial superoxide in seizure susceptibility. Dr. Patel will receive \$37,500 per year for two years.

Steven N. Roper, M.D., University of Florida College of Medicine, for research on the function of inhibitory interneurons in

experimental cortical dysplasia. Dr. Roper will receive \$37,500 per year for two years.

Renato Rozenthal, M.D. and Solomon L. Moshé, M.D., Albert Einstein College of Medicine of Yeshiva University, for research on following perinatal hypoxic-ischemic insults on the extent of delayed neurotoxicity. Drs. Rozenthal and Moshé will receive \$37,500 per year for two years.

Commenting on the new research program, Eric R. Hargis, president and CEO of the Epilepsy Foundation, described it as an excellent way for those who wish to support targeted research in childhood epilepsy to contribute and to be directly involved in the process.

"The Partnership is an empowering model for individuals and families as well as for organizations with common goals," he said. "By joining together, they can have a greater impact than would be possible alone."

"This new endeavor will advance knowledge as to how and why epilepsy strikes the most vulnerable among us and provide yet another funding source for the research community. The Epilepsy Foundation is very pleased to be associated with the American Epilepsy Society and the other partners in this effort."

## PRACTICE RX

### Update on Acthar Gel

*Gregory L. Barkley, M.D., Chair, Practice Committee and  
Patricia O. Shafer, RN, M.N., Chair, EF Professional Advisory Board*

A recent change in manufacturers has assured a more reliable ongoing supply of Acthar Gel (ACTH), a product important in the treatment of infantile spasms. While this is good news, the change in companies has resulted in a substantial increase (from approximately \$50 to more than \$700 for a 5ml vial) in the cost of this product.

According to Questcor, the current manufacturer, the increase is due to the costs of acquiring Acthar Gel and changes required for its manufacture. Families are likely to find that Acthar Gel is not covered by their medical insurance. However, assistance for qualified families is available through the National Organization for Rare Diseases (NORD) patient assistance program. Families interested in this program should be instructed to call NORD at (800) 459-7599 and ask for Nancy, Marie or Bunny. Most state Medicaid agencies also will not cover Acthar Gel therapy. However, Questcor is negotiating to improve this situation. In the meantime, Questcor offers a separate patient assistance program for people on Medicaid. The toll-free number for that program is (800) 411-3065, extension 762.

The Epilepsy Foundation and the American Epilepsy Society will continue to monitor this situation and advocate that ACTH be available and affordable for children with epilepsy.

## NINDS REPORT

# So, What's Up With Drug Screening?

by James P. Stables, Program Director, Anticonvulsant Screening Program, NINDS



The Anticonvulsant Screening Project (ASP) is part of the NINDS's larger effort to combat epilepsy. The ASP started screening compounds in 1975 using two very basic models. The goal of this effort was to demonstrate effectiveness against acutely induced seizures.

Over the last 27 years, this program has tested close to 25,000 compounds submitted by approximately 150 industrial and 225 academic scientific institutions from four different continents. It is the only centralized screening facility in the world dedicated to the discovery of new therapies for patients with seizure disorders. The diversity of compounds resulting from this centralized approach has led to the marketing of drugs such as felbamate and topiramate.

The ASP has a dedicated epilepsy laboratory, located at the University of Utah, with some of the most experienced researchers in the field. The sophistication of screening has grown since the early days. Efforts are being directed at not only identifying but also differentiating potential new mechanisms of drug action. This is accomplished by utilizing 19 different *in vivo* and *in vitro* assays and models. Individual screens are continuously evaluated for their predictability of known seizure types observed in human conditions. With advances in neuroscience, along with a better understanding of basic mechanisms underlying seizure disorders, new assays can and are being examined for potential incorporation in the existing battery of tests. Models currently under evaluation may one day produce therapies that affect the processes involved in the onset and progression of the disease.

Drug selection today is extremely competitive. A new compound has to hold a clear advantage over currently available treatments. Each year the ASP evaluates hundreds of compounds in cellular and whole-animal models of convulsive phenomena. In FY 2001, the program screened over 800 compounds for anticonvulsant activity. Yet only a handful of these compounds are expected to pass the evaluative rigors required to demonstrate a unique

mode of action, increased potency and safety criteria. These selection criteria are only part of the process that determines if a potential drug candidate moves into more advanced animal toxicology and human studies. It takes about a year for a compound to go through all the different ASP screens. Animal toxicology and metabolic work often can take another 6-18 months to be completed. All this is necessary before a drug can be proposed for study in humans. Many promising compounds never make it through human studies due to unforeseen side effects, problems with absorption, metabolism, synthesis or even production and manufacturing cost.

Without all the early *in vivo/in vitro* screening provided by the ASP, the treatment choices for patients with epilepsy would be quite limited. Even with the marketing of

*Without all the early in vivo/in vitro screening provided by the ASP, the treatment choices for patients with epilepsy would be quite limited.*

several new drugs in the 1990s many thousands of patients have breakthrough seizures or just are not controlled with current therapies. The ASP is committed to finding acceptable therapy (meaning no seizures) for these patients and, one day, a cure.

In April 2002, at the Sixth Eilat Conference on New Antiepileptic Drugs held in Sicily, Italy, five of the nine new drugs presented were discovered through screening at the ASP. Some of these compounds may well be available as treatment choices in the next few years. Early animal and cell based screening are essential to help us broaden our understanding of disease processes in order to provide new therapies for our afflicted patients. As with the Cancer and Drug Abuse Institutes, NINDS' support of early drug screening provides a major resource of new treatments to millions of afflicted patients. It is an economic fact that many larger pharmaceutical firms must focus their early research efforts on markets

*Programs such as the ASP provide critically needed incentives to both the independent academic researcher and small start-up biotech companies.*

much bigger than epilepsy in order to support their research and sales infrastructure. Programs such as the ASP provide critically needed incentives to both the independent academic researcher and small start-up biotech companies. These groups lack the expertise, facilities and resources necessary for the full range of preclinical anticonvulsant screening.

Some of those 800 compounds submitted to the ASP last year, along with the hundreds submitted thus far in 2002, will ultimately become part of the drug pipeline that supplies the new agents for tomorrow's clinical trials.

## PEOPLE IN THE NEWS



**Lara M. Schrader, M.D.**, a UCLA School of Medicine clinical instructor, has been awarded the 2002 American Academy of Neurology Education & Research Foundation Corporate Roundtable Clinical Research Training Fellowship for research on low frequency repetitive transcranial stimulation as a treatment for localization related epilepsy.

Dr. Schrader accepted the award during the American Academy of Neurology's 54th Annual Meeting April 13-20, 2002 in Denver, Colorado. The AAN Corporate Roundtable Clinical Research Training Fellowship is awarded to individuals who have completed residency training during the past five years and are interested in pursuing an academic career in clinical research.

Dr. Schrader accepted the award during the American Academy of Neurology's 54th Annual Meeting April 13-20, 2002 in Denver, Colorado. The AAN Corporate Roundtable Clinical Research Training Fellowship is awarded to individuals who have completed residency training during the past five years and are interested in pursuing an academic career in clinical research.

# In Appreciation of AES. . . “Kids Speak Up” A Big Success!

These letters were among many received at the AES office by Executive Director Suzanne Berry. These “thank you” letters were sent by families attending the AES/EF funded Public Policy Institute. This program, held in March each year, prepares families to visit their legislators in DC and on the State level to advocate for epilepsy research funding.

Thank you – and the American Epilepsy Society – for sponsoring the recent Public Policy Institute in Washington DC which my children and I attended. Although Hannah and Evan are well-controlled using Depakote, we worry for their futures with continued and extended drug use. Please continue to encourage research to improve the lives of those with seizure disorders.

*Sincerely,*

*Carol, Hannah and Evan Impola*

*Dear Ms. Berry,*

My family and I wanted to thank you, and the staff of the American Epilepsy Society for sponsoring the Public Policy Institute held in conjunction with the “Kids Speak Up Conference.” My husband and I attended with our 12-year-old son, Kyle, who has had epilepsy since he was 13 months old and he was selected to attend and represent Oregon. We all had a wonderful time, and believe that the conference helped us all to better prepare for our successful Hill visits. Thank you again for sponsoring such a wonderful event.

*Sincerely,*

*Rob, Toni & Kyle Osbon*

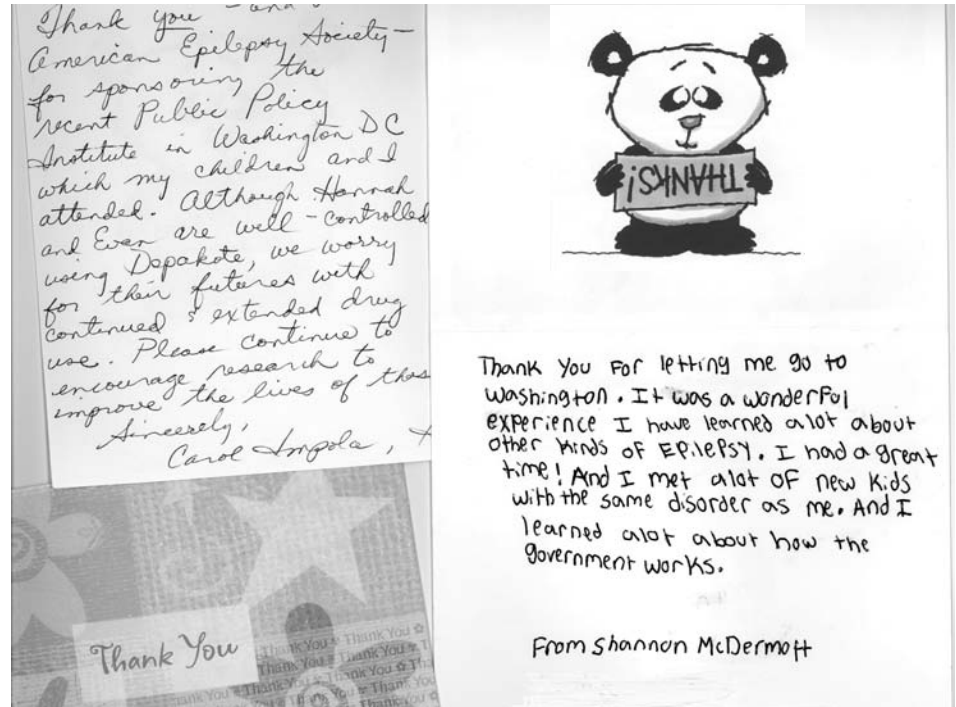
*Dear Ms. Berry,*

Derrick Roberts and his mom, Donna, would like to thank the American Epilepsy Society for sponsoring the Kids Speak Up Program. Derrick really enjoyed himself. But more important than that, he learned that it is necessary to let others know how they can help you. He really enjoyed getting his message out. So much so, he is still doing it. He did a science fair project yesterday for the elementary schools in our area and won a special award for the non-scientific (experiments are bigger) project that the student knew the best.

We hope to hear of more ways we can help with spreading the word about epilepsy.

*Sincerely,*

*Donna and Derrick Roberts*



## PEOPLE IN THE NEWS

### AES Member to Appear on PBS

AES member Douglas Nordli, Jr. M.D., will appear in the series *Children's Hospital*, a nationally broadcast documentary beginning July 2, 2002 on PBS and airing on six consecutive Tuesday nights. The documentary represents one full year of filming and production, during which film crews were allowed unprecedented access to areas typically off-limits to cameras.

The segment in which Dr. Nordli appears depicts a four-year-old patient who suffers from acute epilepsy that causes his body to involuntarily and unpredictably fall to the ground, resulting in frequent and serious injury. Viewers will witness the seizure events and follow Dr. Nordli, head of the epilepsy team at Chicago Children's Memorial Hospital, in his fight to control his patient's condition so the boy can lead a normal life. PBS chose to focus on Chicago's Children's Memorial Hospital after an extensive national search of pediatric hospitals.

A website associated with the documentary will feature biographies about the caregivers, host chat sessions with families and physicians, and offer in-depth information about childhood conditions and direct families resources.

"I was very pleased that PBS decided to highlight the concerns of children with a variety of illnesses, and in particular, children with epilepsy," says Dr. Nordli. "Because PBS followed the patient to film him at home, at school and in the hospital, the segment presents a comprehensive portrait of the day to day activities of a young patient with a difficult case of epilepsy. I hope that seeing the very real and extensive effects of epilepsy will direct more public attention to their needs and engender more interest in helping them."



AES member Douglas Nordli, Jr. M.D. will appear in a PBS special "Children's Hospital."

# Meeting-at-a-Glance

## Friday, December 6, 2002

- 8:00 a.m.-6:00 p.m.     **Registration**
- 9:00 a.m.-4:00 p.m.     **Advances in the Management of Epilepsy and the Epilepsy Clinic**
- 6:00 p.m.-7:00 p.m.     Symposia Receptions
- 7:00 p.m.-9:30 p.m.     **Spanish Symposium – Psychiatric Aspects of Epilepsy**
- Symposium—Uncovering the Mysteries: Idiopathic Generalized Epilepsies**
- Symposium— Epilepsy Plus: Medical Conditions Complicating Epilepsy Management**

## Saturday, December 7, 2002

- 7:00 a.m.- 6:00 p.m.     **Registration**
- 8:30 a.m.-1:45 p.m.     **Merritt-Putnam Symposium—Epilepsy in the New Era of the Human Genome**
- (Includes lunch)
- 2:00 p.m.                     **Welcome Reception**
- 2:30 p.m.- 5:00 p.m.     **Presidential Symposium—Consequences of Epilepsy: Cellular to Behavioral Perspectives**
- 6:00 p.m.-7:00 p.m.     Symposia Receptions
- 7:00 p.m.-9:30 p.m.     **Allied Health Symposium—Burden of Epilepsy and Employment**
- Symposium—A Doctor’s Dilemma: Neural Tube Defects from Bench to Bedside**
- Symposium—Epilepsy and the Elderly**

## Sunday, December 8, 2002

- 7:00 a.m.-6:00 p.m.     **Registration**
- 8:00 a.m.-4:00 p.m.     **Annual Course—Assessing the Efficacy of Antiepileptic Treatments**
- 8:00 a.m.-4:00 p.m.     **Investigators’ Workshop**
- 4:30 p.m.-6:00 p.m.     **Special Interest Group Meetings and Participatory Roundtables**
- 5:00 p.m.-7:00 p.m.     **Opening Reception – Exhibit Hall**
- 7:30 p.m.-10:30 p.m.   **Special Event**

## Monday, December 9, 2002

- 7:00 a.m.-6:00 p.m.     **Registration**
- 7:00 a.m.-8:30 a.m.     **Special Interest Group Meetings**
- 8:30 a.m.-11:30 a.m.     **AET Symposium—Epilepsy Therapy: Challenges of Adverse Events**
- 10:00 a.m.-5:00 p.m.     **Exhibits Open**
- 11:00 a.m.-5:00 p.m.     **Poster Session I**
- 12:00 p.m.-2:00 p.m.     **Epilepsy Research Awards Luncheon**
- 3:30 p.m.-6:00 p.m.     **Platform Sessions A-D**

## Tuesday, December 10, 2002

- 7:00 a.m.-4:00 p.m.     **Registration**
- 8:30 a.m.-11:00 a.m.     **Plenary Session — Involvement of Parahippocampal Networks In Temporal Lobe Epilepsy**
- 10:00 a.m.-5:00 p.m.     **Exhibits Open**
- 11:00 a.m.-5:00 p.m.     **Poster Session II**
- 11:30 a.m.-12:15 p.m.     **Lennox Lecture**
- 12:30 p.m.-2:00 p.m.     **Special Interest Group Meetings and Participatory Roundtables**
- 3:00 p.m.- 3:30 p.m.     Break (Exhibit Hall)
- 3:30 p.m.-6:00 p.m.     **Platform Sessions E-H**
- 6:00 p.m.-7:00 p.m.     Symposia Receptions
- 7:00 p.m.-9:30 p.m.     **Symposium—AEDs in Pediatric Epilepsy: Strategies and Limitations**
- Symposium—Consequences of Epilepsy and Its Treatment**

## Wednesday, December 11, 2002

- 7:00 a.m.-6:00 p.m.     **Registration**
- 7:30 a.m.-8:15 a.m.     **AES Business Meeting**
- 7:30 a.m.-1:00 p.m.     **Poster Session III**
- 8:30 a.m.-11:00 a.m.     **Plenary Session — Neuroimmunology and Epilepsy**
- 1:00 p.m.                     **Annual Meeting Concludes**

## Communicate Electronically With AES



### AES Web Site

**Address:** [www.aesnet.org](http://www.aesnet.org)

**Research:** Check out the Grant Program information.

**Membership:** *AES OnLine Membership Roster*. This is your resource for up-to-date contact information for your colleagues.

**Practice Management:** Patient Assistance Programs, Drug Updates and other articles

### Education/CME

Abstracts: View abstracts from the 2000 and 2001 Meetings.

Highlights from 2001

AES/ACNS Joint Meeting

Neuroprotection and Epilepsy

2000 Conference Highlights

### Listservs

Several committees have listservs established. Committees and task forces are encouraged to use this service.

### E-mail

**General:** [info@aesnet.org](mailto:info@aesnet.org)

#### Staff:

##### Executive Director

M. Suzanne C. Berry, CAE  
[sberry@aesnet.org](mailto:sberry@aesnet.org)

##### Associate Director

Sandra Pizzoferrato  
[spizzoferrato@aesnet.org](mailto:spizzoferrato@aesnet.org)

##### Director of Meeting Services

Steve Rugens, CMP  
[srugens@aesnet.org](mailto:srugens@aesnet.org)

##### Communications

Lorna Bolduc  
[lbolduc@aesnet.org](mailto:lbolduc@aesnet.org)

##### Program Director

Cheryl-Ann Tubby  
[ctubby@aesnet.org](mailto:ctubby@aesnet.org)

##### Membership Services

Maria Rivera  
[mrivera@aesnet.org](mailto:mrivera@aesnet.org)

### Fax Number

**AES Office:** (860) 586-7550

### Fax-on-Demand

Information is available on the fax-on-demand service, (860) 586-7575; request the index to see all that's available. For a directory of all of AES's documents, call AES's fax-on-demand and order document 30000.

## CALENDAR OF EVENTS

- JULY 21-AUG. 4** **ADVANCED ILAE COURSE**  
Bridging Basic with Clinical Epileptology  
San Servolo, Venice, Italy  
*Contact:* Giuliano Avanzini [avanzini@insituto-besta.it](mailto:avanzini@insituto-besta.it)  
or Marco de Curtis [dcurtis@istituto-besta.it](mailto:dcurtis@istituto-besta.it)  
[www.isnvenice.net](http://www.isnvenice.net)
- SEPTEMBER 11-14** **FOURTH ASIAN AND OCEANIAN EPILEPSY CONGRESS 2002**  
*Co-sponsored by The Japan Foundation for Neuroscience and Mental Health*  
Karuzawa Prince Hotel, Nagano, Japan  
*Contact:* <http://www.saitama-med.ac.jp/aoec4/>
- SEPTEMBER 26-28** **SIXTH ETNEAN EPILEPSY WORKSHOP**  
Electrophysiological Analysis of Epilepsy, Antiepileptic Drug Therapy and Epilepsy Surgery. Abstracts are due by June 15, 2002  
Linguaglossa, Sicily, Italy  
*Contact:* Dr. Antonino Pavone, Epilepsy-EEG unit, Garibaldi Hospital, Catania Sicily  
e-mail [hsepa@tin.it](mailto:hsepa@tin.it) or fax-voice 011-39-095-312152
- OCTOBER 4-6** **CLEVELAND CLINIC'S BLOOD BRAIN BARRIER SYMPOSIUM II**  
Peripheral Markers of Blood-Brain Barrier Failure: Diagnostic and Prognostic Tools in Neuroscience  
Cleveland, OH  
*Contact:* Ms. Martha Tobin (800) 223-2273 x53449  
(216) 445-3449 or [tobinm@ccf.org](mailto:tobinm@ccf.org)
- OCTOBER 5-9** **5TH EUROPEAN CONGRESS ON EPILEPTOLOGY**  
Madrid, Spain  
*Contact:* [epicongress@eircom.net](mailto:epicongress@eircom.net) or  
[www.epilepsymadrid2002.org](http://www.epilepsymadrid2002.org)
- DECEMBER 6-11** **AES ANNUAL MEETING**  
Washington State Convention and Trade Center  
Seattle, WA
- 2003**
- JANUARY 9-12** **2ND BIENNIAL ROCKY MOUNTAIN EPILEPSY RESEARCH AND CLINICAL CONFERENCE – NEUROPROTECTION AND CLINICAL EPILEPTOLOGY**  
Breckenridge, CO  
*Contact:* José Cavazos, MD, PhD at [cavazosj@uthscsa.edu](mailto:cavazosj@uthscsa.edu) or  
<http://home.satx.rr.com/neurology/epilepsy.html>
- MARCH 22-25** **8TH PRAGUE INTERNATIONAL SYMPOSIUM OF CHILD NEUROLOGY**  
Prague Congress Centre, Czech Republic  
*Contact:* Conference Partners, [info@conference.cz](mailto:info@conference.cz)  
Website: [www.conference.cz/childneurology](http://www.conference.cz/childneurology)
- OCTOBER 12-16** **25TH INTERNATIONAL EPILEPSY CONGRESS**  
Tunis, Tunisia  
*Contact:* [info@epilepsycongress.org](mailto:info@epilepsycongress.org) or  
[www.epilepsycongress.org](http://www.epilepsycongress.org)

## American Epilepsy Society

342 North Main Street

West Hartford, CT 06117-2507

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## The American Epilepsy Society Announces Call for Nominations for 2002 Research and Achievement

*The following awards are given annually by the AES, and will be presented  
at the December 2002 AES Annual Meeting in Seattle.*

*Deadline for submission of nominations is September 3, 2002.*

### **Epilepsy Research Awards**

A public recognition program funded by the Milken Family Foundation to encourage and reward clinical and basic science investigators whose research contributes importantly to understanding and conquering epilepsy.

### **William G. Lennox Award**

Funded by the William G. Lennox Trust Fund to advance and disseminate knowledge concerning epilepsy in all of its phases; presented to an AES member who has a record of lifetime contributions and accomplishments to the field of epilepsy.

### **AES Service Award**

Presented to an AES member in recognition of outstanding service in the field of epilepsy and exemplary contributions to the welfare of the Society and its members.

### **J. Kiffin Penry Award for Excellence in Epilepsy Care**

Funded by Abbott Laboratories to recognize an individual whose work has had a major impact on patient care and improved the quality of life for persons with epilepsy.

Instructions and forms for submitting nominations for these awards are available at [www.aesnet.org](http://www.aesnet.org) or from the American Epilepsy Society, 342 North Main Street, West Hartford, CT 06117.

**Please note: The deadline for receipt of all award nominations by AES is September 3, 2002.**

