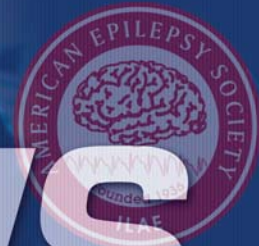


AES NEWS



62nd AES Annual Meeting and 2nd Biennial North American Regional Congress

The 62nd Annual Meeting of the American Epilepsy Society is rapidly approaching. Hopefully you are planning to join us December 5-9, 2008 in Seattle, WA for this great learning and networking opportunity. The Annual Meeting Planning Committees have worked hard to make good use of your time, while giving you plenty of opportunity for education and networking.

Some of the schedule highlights include:

- The Annual Fundamentals of Epilepsy Symposium will kick off the meeting at Noon on Friday.
- Friday evening features both the Hot Topics Symposium and a Childhood Absence Epilepsy Symposium to give you plenty of choices.
- A short panel discussion on the suicidality risk in AEDs will follow the Hot Topics Symposium.
- The annual Antiepileptic Therapies Symposium has been moved to Saturday evening at 5:00 p.m.
- Two new Keynote sessions have been added to the Investigators' Workshops on Sunday at 1:30 p.m. Featured speakers will be the Basic Science and Clinical Science Research Recognition awardees.
- Special Interest Groups have been added on Sunday evening starting at 7:30 p.m. following the all-attendee Lennox/Lombroso Research Trust Fund Reception.
- The North American Commission of ILAE holds its Biennial Symposium Monday at 7:00 p.m.
- The Special Interest Groups close out the meeting on Tuesday with two sessions at 12:45 p.m. and 2:30 p.m.

Recognizing the importance of networking, the Annual Meeting Planning Committees have built in several opportunities for you. Most evening symposia have a reception before the programs. There are three poster sessions with a total of six uncontested poster author present times, not counting the two Investigators' Workshop Poster Sessions. None of the author present times are scheduled at the crack of dawn this year. All are in the afternoon or evening ensuring good attendance. The Sunday night, Lennox/Lombroso Research Trust Fund Reception is a great opportunity to catch up with your colleagues. Other opportunities for networking in small groups are the Fellows Reception and of course the 38 Special Interest Groups.

The annual meeting abstracts will again be distributed on CD-ROM. This CD-ROM is scheduled to appear in your October issue of *Epilepsia*. All abstracts will be available on the AES Web site and additional CDs will be available in the program book. Abstracts will also be available and citable on the Blackwell Web site. The CD contains all the abstracts for the poster sessions, the Pediatric Highlights sessions, the Platform Sessions and the Investigators' Workshop Posters and Sessions. Dates and times of presentations will be included. It will be searchable by author/institution, title, date/time/session, categories and free text. This helps you use your time more efficiently by browsing the abstracts ahead of time and only printing the ones you are interested in.

We continue our efforts to make the Annual Meeting more "green." This year symposia handouts will be available on the AES Web site a couple of weeks before the program, so you can print out the ones you think you will need. In addition, a CD with all the handout materials will be distributed to all attendees at registration. There will be no paper handouts distributed at any of the sessions.

For details on the meeting, abstracts and registration go to www.aesnet.org/Visitors/AnnualMeeting/.

Task Force Reports on SUDEP Calls for Multidisciplinary Research Workshop

The American Epilepsy Society / Epilepsy Foundation Task Force on sudden unexplained death in epilepsy (SUDEP) has completed its report and recommendations for better scientific understanding and prevention of the phenomenon.

The SUDEP Task Force was convened by the Society and the Epilepsy Foundation in March 2007 to assess the state of knowledge about SUDEP, delineate approaches to discussing SUDEP with patients and their families, and recommend research directions and potential preventive measures.

While there is a tremendous need for both basic and clinical research in SUDEP, the report acknowledges that studies at single research centers would have too few SUDEP cases to yield knowledge beyond that already known about the phenomenon. Therefore, several of the task force recommendations concern establishing and garnering support for a multi-center program of SUDEP research.

A barrier in SUDEP investigations, says the report, "is the low autopsy rate in SUDEP suspects and the incompleteness of autopsy information." Elson L. So, M.D., who chairs the Task Force with Tess L. Sierzant, RN, M.S., notes that, "A recent study of U.S. coroners and medical examiners showed that SUDEP was not consistently cited as the cause of death, even when criteria for the diagnosis were met."

To address this problem, the Task Force recommends the development of uniform criteria for SUDEP determination, including protocols for complete autopsy

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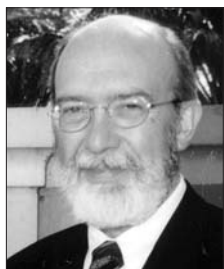
Editorial Deadlines

Winter 2009 – January 12, 2009
Spring/Summer 2009 – May 4, 2009
Fall 2009 – August 17, 2008

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.

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FROM THE PRESIDENT



As I write this column, which punctuates the eighth month of my presidency of AES, I am watching the tail of Hurricane Hannah whip rain around our house just north of New Haven. The hurricanes and the anxiety of national politics offer many metaphors for the turbulence affecting American health and science societies this year. Continuous constriction of industrial support for our educational programs and continued low NIH funding for our critical research raises concern about whether our levees will hold strong.

The members of this organization, however, never cease to amaze me with their devotion to this Society as a cornerstone that not only will buttress foul weather but provide the foundation for growing new educational and research venues for all epilepsy professionals. I would like to summarize just a few of the program advances this summer since we last communicated.

During the last few months, the SUDEP Task Force, an AES / Epilepsy Foundation working group, has completed its report on research priorities and what education and advocacy efforts are needed to better understand the disorder and prevent its occurrence. The full report, summarized in this issue, is available on the members-only section of the AES Web site

The revitalized Web Content Committee has launched a new navigation structure for the AES Web site and is in the process of updating and enhancing the online content. The committee is currently piloting a message board for members to facilitate communication among members and encourage the discussion of professional issues and special interest group topics. You will find more information on the message board elsewhere in this issue.

The Access to Continuity of Supply Task Force continues to move forward addressing concerns over the potential differences in the effectiveness of anticonvulsant drug formulations. Discussions with the FDA and NIH on the need for multicenter research and the design of a protocol for research to validate present concerns have been ongoing. The committee is pursuing a multicenter research project, perhaps jointly funded by government and the private sector.

Representatives of the Advocacy Committee recently met with representatives of a number of our sister organizations to discuss mutual advocacy goals, identify gaps in the epilepsy advocacy agenda, and achieve closer coordination of our efforts. An example of the need for a coordinated advocacy response arose recently when a FDA panel voted to place a suicide risk warning label on all past, present and future antiepileptic medications. The AES helped organize a response that will be sent to the FDA and the media and made available to our prescribing physicians and patients. This response will be endorsed by the national leadership of neurology, psychiatry, and the epilepsy organizations.

The metaphor of AES as a buttress and foundation must be complemented by the adaptability of our membership. AES is a dynamic organization that continues to evolve along with the needs of its members and the changing environment in which we exist as a professional society. We are actively participating in the development of performance measures and standards in our field; engaged in supporting the long process necessary to obtain sub-specialty accreditation and certification in epileptology, and maintaining AES's established position as an exemplary ACCME-accredited CME education provider. To enhance AES's ability to continue providing the highest quality education, the Board authorized the Council on Education to engage a half-time epilepsy content expert to serve staff as a Medical Content Specialist.

Of course the largest endeavor of the Society each year is the Annual Meeting. This is rapidly approaching and portends to be one of the best ever. This year we are host to the Second Biennial North American Regional Congress which will support a wonderful international symposium along with the usual eclectic menu of the main meeting that will bring us the cutting edge of patient care and clinical and basic research. I look forward to seeing you all there.

Dennis Spencer, M.D.

EPILEPSY FOUNDATION

No More Seizures Campaign Encourages Partnership Between Patients and Providers

By Kenneth Lowenberg, Senior Director, Web and Print Publishing

The Epilepsy Foundation has launched a new campaign to encourage people with epilepsy who have settled for less-than-optimal care to reconsider their full range of treatment options. *No More Seizures* encourages people with epilepsy to become active partners with their medical professional in managing treatment. The *No More Seizures* Web site (www.nomoreseizures.org) includes resources for visitors to better understand treatment options, to know more about all available medications, to track their seizures more effectively, and to improve their conversation with health care providers. In addition, the site has a sample letter for users to bring to their pharmacists to help ensure that the medication filled at the pharmacy is clearly the medication prescribed.

The *No More Seizures* campaign was launched recently as the result of a study conducted by the Epilepsy Foundation and the American Epilepsy Society in 2007, and supported through a sponsorship by Pfizer Inc.

One should never give up hope that their condition will improve. Most of those surveyed said that the search for better seizure control is a partnership with their doctors.

According to the survey, that is not always the case.

Here is what the survey found:

- Only about half of the people surveyed said that their doctors ever discussed with them other treatment options or what to expect from their treatment.

Patients can improve communication by taking an active role in their medical care, writing a list of questions before seeing the doctor, and making notes of the answers.

- One in four said they did not know what their doctor would consider to be a significant improvement in seizure control.

Having a treatment goal is key to staying motivated and managing epilepsy. Patients should discuss and come to an agreement with their doctor on what would be a significant improvement in control

- About half of those surveyed also said their doctors did not discuss epilepsy's impact on such things as day-to-day activities, mood and difficulty sleeping.

It is not always easy for patients to tell what is or is not related to epilepsy or its treatment. Patients can help their doctors by sharing all they feel and experience, such as feelings of depression, problems with memory or thinking, often feeling sleepy, and other feelings or sensations that do not feel normal.

- About one in five feels they are more concerned than their doctor about medication side effects.

By sharing what they feel and experience, patients also alert their doctors to potential medication side effects. This allows doctors to make adjustments in the dosage or change medications that may reduce or eliminate unwanted side effects.

- One in ten said they underestimate the number of seizures when talking to their doctors, either because

they fail to record their seizures or they are unable to recall or even to know when a seizure happens.

Patient seizure reports are often best estimates. But even they provide vital information essential to the best of care.

- A small number of those surveyed said they reported fewer seizures than they experienced because they did not want their doctor to know how many seizures they were actually having.

Patients who under report seizures deprive themselves of their best chance for reducing seizures and improving their condition.

Information about the *No More Seizures* campaign will be distributed through the Epilepsy Foundation's affiliates, their Web sites and a toll-free information line,

800.332.1000. To reach those who believe nothing can be done to improve their condition, the campaign will reach out through general neurologists' offices and through the news media.

A new multi-state study by the Centers for Disease Control and Prevention (CDC) also supports the

value of this new initiative. The CDC study indicated about 1% of adults has active epilepsy, and many may not be receiving the best possible medical treatment.

According to the study, 1.65% of non-institutionalized adults from 19 states reported ever being told by a doctor that they had a seizure disorder or epilepsy; and nearly 1% were active cases, which means they are taking medicine for their seizure disorder or have had a seizure within the past three months. The study also found that nearly half (44 percent) of adults with active epilepsy reported having recent seizures. Of those, 65 percent said they had more than one seizure in the past three months.

"We applaud CDC for conducting this study because many people with epilepsy assume this is as good as it gets; they are not aware there are other treatment options and believe they just have to live with it," said Eric R. Hargis, president and CEO of the Epilepsy Foundation. "Certainly not everyone will achieve the goal of no seizures and no side effects, but with our basic education and empowerment messages we're trying to increase the number of those who can. This is what the *No More Seizures* campaign is all about."

The *No More Seizures* campaign creation was overseen by the Epilepsy Foundation's Professional Advisory Board led by Bruce Hermann, Ph.D. and Page Pennell, M.D.

"As an organization committed to finding new treatment options through research to help reduce seizure activity, it is frustrating to know that some doctors are using age-old therapies and not customizing patient care with more current options," said Hargis. "That's why *No More Seizures* is so vital."

"Our goal is to encourage people with epilepsy to know about new treatments, seek the care of a neurologist and engage doctors in conversations to help them manage their specific type of the condition," Hargis added.

One should never give up hope that their condition will improve.

NINDS UPDATE

Emerging Topics in Epilepsy Research

By Margaret Jacobs

Dementia of Alzheimer's Disease (AD) and Epilepsy.

Epidemiologic, clinical and animal-model studies have suggested an association between epilepsy and AD. Central to this are observations that 10 to 20% of AD patients have at least one unprovoked seizure. In addition, AD patients with seizures have greater cognitive impairment than those without. The co-occurrence of epileptiform activity and AD suggests a shared pathogenesis at the molecular, cellular and network level. Support for this comes from recent work using AD mouse models which showed an association between increased levels of A β -peptide, one of the causative agents of AD, and epileptiform activity in the brain areas involved in memory formation. These findings suggest that the accumulation of A β -peptide may trigger epileptiform activity in neuronal populations most at risk for neurodegeneration in AD, and that the epileptiform activity may itself contribute to the dysfunction of circuitry that subserves memory formation. The therapeutic implications include the possibility that antiepileptic drugs will suppress seizure and epileptiform activity and improve cognition in AD patients.

Sudden Unexplained/Unexpected Death in Epilepsy (SUDEP).

The phenomenon of SUDEP is a devastating event that occurs at a rate of one in 150-person years in individuals with uncontrolled seizures. Despite considerable interest by the medical and lay communities in the past two decades, the mechanisms of SUDEP and the methods of

preventing its occurrence are largely unknown. In March 2007, a task force was formed consisting of members with different clinical and research backgrounds and representatives of consumer groups and the government. After studying the available literature, it became clear how much was unknown in areas of epidemiology, genetics, underlying mechanisms, cardiorespiratory and autonomic function. In addition, there are no clinical guidelines as to when, how and what to discuss with patients and their families about the risks of SUDEP.

These topics will be explored in two workshops this fall sponsored by NINDS with additional funding by the National Institute on Aging, AES, CURE, EF, the Alzheimer's Association and the Fidelity Foundation. The purpose is to encourage interactions between epilepsy investigators and those in related fields. These are first steps in what we hope will be an ongoing process to accelerate basic, translational, and clinical research in these areas. The SUDEP SIG at the December AES meeting will continue the dialogue by expanding issues raised at the workshop and gain input from others interested in the topic. The AD – Epilepsy Workshop will make members of these research communities aware of the convergence of the two diseases. In addition, it will inform NINDS and NIA staff on this topic and aid in prioritizing scientific goals and implementing programs to advance the field.

Benefits of AES Annual Meeting Registration

Up to **26.25** AMA PRA Category 1 Credits™

Up to **5** Nursing CE hours

16 symposia and lectures

Access to 38 Special Interest Groups

Investigators' Workshops

Free internet available in the Cyber Café every day

At least 2 continental breakfasts

4 lunches

At least 4 receptions where you can network with colleagues

Access to exhibitors for 3 days

Access to poster presenters for a total of 12 hours over 3 days

Access to almost 1,000 posters

Scientific Exhibits where you can learn more about new industry developments

Participate in four award ceremonies celebrating the accomplishments of your peers

A CD with abstracts from poster and platform presentations

A CD with all the handouts and slides from all the symposia

4 platform sessions, one focusing on pediatric Issues

AES Scores High in Management Review

An independent review and comparison of AES to similar nonprofit medical societies indicates that the Society is well managed, and is performing at or above industry benchmarks. The review and analysis of AES in terms of size and scope of its operations was conducted in May and June of this year by The Forbes Group management consulting firm.

The report revealed AES's investment in program services was about one to three million dollars above program funds invested by any of the four similar organizations. This high level of AES program investment was achieved even though the Society has the lowest fee for annual dues among organizations to which it was compared. AES's greater ability to support programs is largely due to income from sponsored educational grants, awards and fellowships, revenues from publications and journals, and registration fees.

In comparison to similar organizations, AES's current management and general expenses are either similar or far below. Management and general expenses include personnel, accounting, insurance and office management. The bottom line is that AES is meeting or exceeding industry benchmarks for most functional expense areas.

The report said that AES must continue to achieve the Accreditation Council for Continuing Medical Education (ACCME)'s highest accreditation level to remain better positioned to receive corporate funding. It noted also that, "ACCME accreditation standards provide a level of oversight to AES's industry relationships that ensures that CME activities are free from commercial bias." Additionally, AES has developed a set of Industry Standards and Guidelines based on principles and rules established by relevant professional and governmental bodies.

Recommendations for improving the effectiveness of AES as an organization included more Board training to clarify roles and responsibilities of a nonprofit Board and improving communication between the Executive Committee and Board of Directors. In addition the review recommended that leadership determine what types and levels of financial support are appropriate for the organization. With industry support (sponsorships, grants, etc.) levels changing, the organization needs to discuss whether to look elsewhere for revenue or to reduce programming.

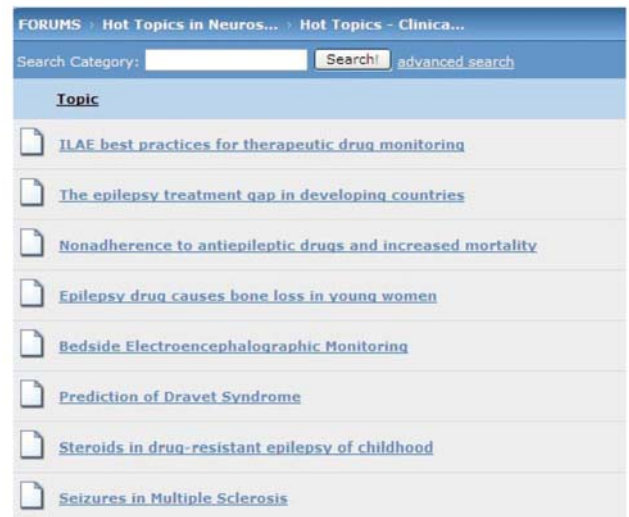
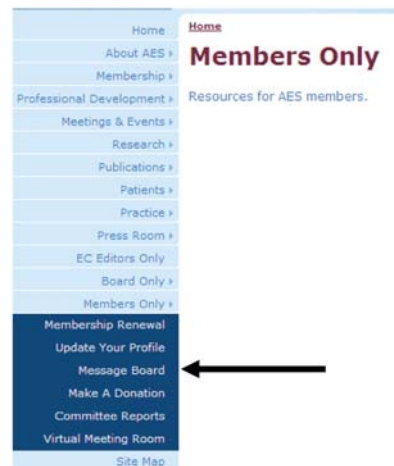
AES Online Message Board

The AES Web Content Committee recently launched a new resource that will enhance communication between AES members. As part of a package of Web site improvements, a Message Board has been added to the Members-Only section. This new feature has been seeded with eleven topic areas to get you started.

"This technology will allow members to discuss professional issues in the same way that we send e-mail messages to colleagues," states Dr. Jose E. Cavzos, Chair of the AES Web Content Committee. "There is an entire section dedicated to SIGs, and every SIG has one area for posting message threads regarding issues of concern to that SIG. You could potentially discuss emerging issues and poll SIG members year round."

You can participate in discussions from the Special Interest Groups or with your peers on other topics. Current topic areas include: *Epilepsy Currents*; Hot Topics in Neuroscience; Method/Protocol Questions; Meetings and Courses; Jobs; Grants/Fellowships; Coding/ICD9 and Other Practice Issues; Advocacy Issues; and Fellows and Residents.

The Message Board cannot be accessed by non-members. The link is under the Members-Only tab which only appears after you log in using your Member ID and Password.



Samples of discussion topics

FROM THE BOARD ROOM

Interview with Board Member Patricia Osborne Shafer, RN, M.N.



Patty Shafer is a clinical nurse specialist in the Comprehensive Epilepsy Department of Beth Israel Deaconess Medical Center in Boston, MA as well as a Resource Specialist and Contributing Editor for Epilepsy.com. She has provided teaching on epilepsy to nurses and other healthcare professionals for over 25 years.

Q Why did you join?

A At my first AES meeting, in 1983, there were only about 12 nurses. Nancy Santilli organized a meeting of this group. You could say that this was the first Special Interest Group (SIG) of epilepsy nurses! Shortly after, we started a 'Nursing Brainstorming' Group which in retrospect was an informal precursor to the Professionals in Epilepsy Care Steering Group which was started by Joan Austin during her presidency.

As a member of AES, I was hoping to learn what nurses in other places were doing so I could learn more about epilepsy and develop my own practice. At the time, I was the only epilepsy nurse at my center. Looking back, I have learned more than I could have ever anticipated from my colleagues — my nursing colleagues and those from all the disciplines that make up AES. I hope that I have been able to share just as much. The number of nurses and other non-physician epilepsy professionals has grown significantly, with many actively involved in AES committees and leadership. We all owe a debt of thanks to that small group of nurses who first joined AES and encouraged all of us to do the same.

Let me add a personal note here. I have lived with epilepsy since I was 7 years old and my son had seizures for a while. So, I had a vested interest in AES and in the epilepsy community as a whole. Yet, I was reluctant to join AES given my personal background. I was afraid I wouldn't be taken seriously or would be looked at differently since I was a consumer as well as a professional in this area. I am glad to say that I was wrong in these assumptions. I think my personal background helped me look at the field a bit differently, but didn't inhibit my involvement.

Q What would you say is the biggest benefit of membership?

A The biggest benefit to me is the friendships I have made and the networking among colleagues that has become such a critical part of my practice and life. To a nurse new to epilepsy, the professional education is certainly the most important benefit. A nurse can not get the same quality and quantity of learning about epilepsy from any other professional organization. The learning never ends and I find that even as an experienced nurse, I gain more and more each year. The collegial relationships and networking become more important over the years, offering a type of experiential learning that is critical to my ongoing professional development.

Q What volunteer roles have you had within AES?

A At first, I stayed within the 'nursing community,' chairing the Nursing SIG, and starting the Nursing

Research SIG with Joan Austin. However, to get more nurses involved and increase the visibility of nurses in the Society, I realized that we needed to get more nurses involved at all levels of the Society. I think that I have been on most committees or task forces at one time or another, such as the Scientific Review Committee, the Practice Committee, Guidelines Task Force, Annual Course, Professionals in Epilepsy Care (PEC) Task Force and Steering Committee, Strategic and Long-Range Planning, Task Force for North American Declaration on Epilepsy, and the Board of Directors.

Q What pearls of wisdom can you give to newer members thinking about volunteering?

A Don't be afraid to volunteer, in fact, jump at the chance. It's a great opportunity to learn about yourself, your colleagues, and your organization. If you want to make a difference you can in this Society. However, don't just volunteer once. Stay with it and develop your leadership skills. There's no downside to volunteering for AES. Whether you do one or more committees or task forces, you'll enjoy the experience and AES will certainly gain from your involvement.

Q As you complete your term, what can you say are your greatest accomplishments?

A I will be completing my term as Chair of the PEC Steering Committee and my term as a member of the Board of Directors. My greatest accomplishments? I don't know — I guess time will tell how successful or important my contributions have been. I certainly was proud to be chosen to lead the PEC Task Force and help put into motion the important contributions of the Task Force. There is still much work to be done, however, and I hope that many people continue to volunteer and drive this area.

I hope that over the years I have helped establish some credibility within the epilepsy community, increase the visibility of epilepsy nurses, and promote the importance of their role in the care of people with epilepsy.

For the future, AES and all its members needs to think carefully of where we are going, where we should be going, and how we are going to get there. Education has clearly become a year round need and the Society needs to reach out to the broader community with our educational programs. The financial pressures that all organizations are faced with will be our greatest challenge going forward as well as how we can contribute more effectively as a global partner. Most importantly, we must remember why we are here — to improve the care and lives of people with epilepsy and their families.

Q What have you learned from volunteering at the AES?

A I couldn't even begin to say what I have learned from AES. In general, I've learned that being a volunteer gives you back more than you can give and while you may need to devote some time, it's well worth the benefits you will receive. Volunteering at AES helps you really understand how the organization works and gives you the opportunity to make a difference. There are very few organizations that depend so much on their members and that work so well with each other!

Two New Educational Initiatives Launched

The Educational Development Committee, a sub-committee of AES's Council on Education recently launched two new continuing medical education programs. Epilepsy Update: A Case Series and The Visiting Professor Series. Both programs are geared to the general neurologist and other health care professionals involved in the care of patients with epilepsy. Both programs were developed as an outcome of the AES needs assessment conducted in 2005-2006 which determined that there is need to provide epilepsy education to general neurologists.

Epilepsy Update: A Case Series is a four-page publication designed to provide practical solutions to common epilepsy problems that general neurologists routinely face. The articles, designed to be straightforward and useful, are based on consensus from experts in the field. Six issues will be printed in 2008, each based on cases illustrating treatment issues in epilepsy. Each *Epilepsy Update* is focused on a single theme and contains practical advice from the perspective of an epileptologist on medical, psychological, and quality-of-life problems faced by a patient with epilepsy. Members of the editorial board include: Edward H. Bertram, M.D., Joan K. Austin, D.N.S., RN, Frank G. Gilliam, M.D., MPH, Howard P. Goodkin, M.D., Ph.D., and Michael R. Sperling, M.D. The first issue featured the topic, "Making the Diagnosis: Is It Really Epilepsy?" Future topics include antiepileptic drug therapy, epilepsy surgery, pediatrics and women's issues. The publication is supported by an educational grant from Ortho-McNeil Janssen Scientific Affairs, LLC.

The Visiting Professor series is a live activity held in community hospitals around the country. A follow-up to the regional symposia, "A Comprehensive Review of Epilepsy Management" held in 2007, the AES Visiting Professor Series is a series of programs taking place in community hospitals throughout the United States. This CME-accredited program provides clinical background and basic information on the treatment of epilepsy and is intended to educate general practitioners, family practitioners, internists and other healthcare professionals within community hospital setting. Selected faculty travel to local community hospitals to provide a program that is scheduled during an already allotted educational time, such as Grand Rounds. Programs have been scheduled in California, Maryland, Virginia, Florida, and Alaska.

The Co-Chairs are Anne Anderson, M.D. and Sheryl Haut, M.D. The Steering Committee consists of Sunita Dergalust, Pharm.D., BCPS, Elizabeth Waterhouse, M.D., Kent Kelley, M.D., and Rebecca J. Schultz, RN, M.S.N., CPNP. The program is supported by an educational grant from Pfizer Inc.



Help Spread the News

Dear AES Members,

We are sending this message to you as Program Chairs of the AES Visiting Professor Series Committee and also on behalf of the Steering Committee for this educational program. Steering Committee members for the series include: Sunita Dergalust, Pharm.D., BCPS, Elizabeth Waterhouse, MD, Kent Kelley, MD, and Rebecca J. Schultz, RN, M.S.N., CPNP. This program is being developed by the AES and is supported by an educational grant from Pfizer.

The AES Visiting Professor Series is a series of institution-based programs taking place in community hospitals throughout the United States. This CME-accredited program provides clinical background and basic information on the treatment of epilepsy. This program is intended to educate general practitioners, family practitioners, internists and other healthcare professionals within community hospital settings. For each program, selected faculty travel to local community hospitals to provide education on epilepsy to interested physicians and healthcare professionals. At each hospital, these programs are being scheduled during an already allotted educational time, such as Grand Rounds.

We are looking to identify specific community hospitals that might be interested in having this program at their hospital or medical center. We are asking you, as a member of the AES, to help us identify potential hospitals within your community. Institutions that may be considered "underserved" would be most ideal for this series. Also, please keep in mind that this program is intended for nonepilepsy specialists.

If there is a community hospital in your area that you feel may benefit from this educational program, please e-mail the name and location to: jamsden@aesnet.org. If you have a contact at that hospital, please also provide that information in your e-mail.

The Steering Committee for the AES Visiting Professor Series appreciates your feedback!

Kind Regards,

Anne Anderson, M.D.
Sheryl Haut, M.D.

Meet the AES Staff

Leadership



M. Suzanne C. Berry, M.B.A., CAE
Sue Berry, Executive Director of AES is also the Executive Vice-President of Association Resources, an association management company that has provided full management services to AES since 1990. Her past association experience spans working with state, national, and international

associations in a variety of areas, including serving as executive director of two international groups. She has developed national certification programs and has overseen the management of a certification board.

Sue has an undergraduate degree in marketing and an MBA from Northeastern University. She is a member of the American Society of Association Executives (ASAE), and has been a frequent speaker and presenter at ASAE conferences. Sue earned the designation of Certified Association Executive in 1995, held only by 10% of association executive directors in the country. She serves on the Key Committee to the ASAE Board of Directors and just recently completed a term as its Chair. She is a board member of the Epilepsy Foundation and the HMC Foundation (Health Care Marketing and Communications Education).



Cheryl-Ann Tubby, IOM, CPP
Cheryl-Ann, Assistant Executive Director joined AES eight years ago with over 10 years of experience in the education and non-profit worlds. Prior to joining AES, she worked as a corporate trainer for Aetna and as a department manager for a non-profit health agency. At AES, Cheryl-Ann's

responsibilities include coordinating committee activities, updating the Web site, managing Professionals in Epilepsy Care educational programs to ensure compliance with CE requirements, developing the AES budget, coordinating the AES News and the Annual Report. She holds a B.S. in Business Management and an IOM (an organizational management certificate program sponsored by the U.S. Chamber of Commerce) and has become a Certified Program Planner (LERN) as well. Cheryl-Ann is an active volunteer in several organizations including participating in an annual house-building trip with her church and acting as treasurer for a small foundation.



Jean Fazzino
Jean Fazzino, Leadership Liaison joined AES two years ago with over eight years of experience at the Connecticut Bar Association. Jean has experience in various areas of a nonprofit organization including membership services, continuing education, publications and Web site. Jean currently

works closely with the AES Executive Director and Leadership. She also maintains the leadership area of the AES Web site and is the staff liaison for the Web Content Committee. Jean has an Associate of Sciences degree, majoring in Early Childhood Education. She ran a home daycare while raising two boys with her husband of 28 years. She owns a small home-based jewelry business designing and making jewelry.

Membership



Kathy Hucks
Kathy Hucks, Membership Services, gained her experience in the non-profit world while working for child-care programs, and community organizations. She has a degree from Central CT State University in

Elementary Education and is certified in Connecticut to teach grades K – 6. Kathy was the program director for a before- and after-school child-care program and summer camp, and has worked as a classroom teacher for a Head Start program. She has also been the membership coordinator for a 4,000 member heating-oil cooperative. Her experience includes working with boards of directors, managing budgets, developing membership, and organizing events for large groups. She is an active volunteer in several non-profit organizations and is on two boards of directors.

Education Department



Jeffrey D. Melin, M.Ed., CMP
Jeff Melin joined AES in 2004 with 13 years of independent meeting and event planning and association management. Jeff holds the title of Director of Education and has been involved in the development and management of several online products. He has been Director of Education and Member

Services at the Massachusetts Aging Services Association and has managed member/vendor relations, multi-discipline continuing education, a regional conference and trade show, and fund-raising events. He has been active in the Professional Convention Management Association, serving as board treasurer of the New England chapter and earning a chapter award for his financial and investment management assistance. He obtained his Master's Degree in Adult Education from Worcester State College. He is a member of the Alliance for Continuing Medical Education and has made multiple presentations at their national annual meetings.



Cindy Johansson
Cindy joined AES in 1993. She has many years of experience in banking, public relations, and association management. As an Education Project Manager, she organizes and coordinates symposia and faculty for the annual meeting and year round programs (i.e., supplements, monographs, Webcasts, and regional meetings). She has managed over 150 speakers and served as liaison with the Annual Meeting Committee, the Council on Education, and the content reviewers. She is in charge of maintaining and documenting CME files according to ACCME guidelines, and updating policies and procedures according to new ACCME guidelines that are issued, including those of the Standards for Commercial Support. Cindy graduated from Lasell College in Boston, MA, with an Associate's degree in Business.



Sandra L. Pizzoferrato
Sandy Pizzoferrato joined AES in 1990. She has worked in the association management and non-profit sector since 1984, initially with the Connecticut Bar Association. Sandy was the Associate Director of AES until 2003 when she decided to work part-time so she could raise her twins,

Alyssandra and Jonathan. Her responsibilities focus on continuing medical education. She supports some of the Annual Meeting activities and some year round activities. Her knowledge and experience facilitates considerable interaction with volunteer leaders, boards, committees, and members. Sandy received her Bachelor's degree in Speech and Public Communication from the University of Maryland. She completed the General Management Certificate Program conducted by the American Association of Association Executives and is an active member of the Alliance for Continuing Medical Education.

SIGnals

SIGnals provides ongoing information on the activities of AES Special Interest Groups (SIGs). For more information on current SIGs or guidelines for creating a SIG, visit the AES Web site at www.aesnet.org.

Ketogenic Diet

Eric H.W. Kossoff, M.D.

The ketogenic diet creates a ketotic state, but is that why it works? Does ketosis really matter? Most researchers agree that therapeutic diets are more complicated and probably work via multiple mechanisms for epilepsy, let alone for other possible neurologic indications such as brain tumors and autism. In this year's ketogenic diet SIG, we will examine this hot topic in depth. We will have three researchers approach this question each in a different way — first a basic scientist (Dr. Mac Burnham, Toronto), then a clinical researcher (Dr. Elaine Wirrell, Rochester, MN), finally, a nutritionist (Dr. Liz Neal, London). There will be plenty of time for questions and debate as usual.

Pediatric Epilepsy: Case Discussions

Elaine Wyllie, M.D.

Please join us so that we can learn from each other and from our experience with pediatric patients! Our seasoned faculty will present exciting cases from their own clinical practice, and also comment on selected cases presented by you or other SIG members. Topics will include diagnosis and treatment of epileptic seizures; seizure semiology and EEG features of epilepsy in children; innovative approaches to treatment; recognition and management of congenital and acquired etiologies of pediatric epilepsy; and age-related factors in epilepsy surgery. If you wish to submit a pediatric epilepsy case that taught you an important clinical point and impacted your practice strategy, please send your PowerPoint presentation by e-mail to wylliee@ccf.org. Please include MRIs, EEGs, and seizure videos as applicable, plus a summary and brief discussion at the end. No more than 12 slides per case, please — we want to include as many fantastic cases as time will allow!

Epidemiology

Dale C. Hesdorffer, Ph.D.

This year, the Epidemiology SIG group will focus on comorbidities in epilepsy, specifically neuropsychiatric, cognitive and other medical comorbidities. New data indicate not only that these comorbidities are associated with an increased risk for developing epilepsy, but they also influence the course of epilepsy. Discussions will concentrate on a review of the epidemiological evidence for these comorbidities in childhood and adult epilepsy. After a brief outline of the methodological issues by Dr. Hesdorffer, Dr. Kanner will address the psychiatric comorbidities, specifically ADHD, major depression and suicidality. Dr. Ludvigsson will discuss comorbidity with migraine, Dr. Berg will address comorbid cognitive delays/learning disabilities, CP and autism in children, and Dr. Sander will describe comorbidity with other medical conditions. We anticipate an exciting exchange and elucidation of new lines of inquiry.

SUDEP

Elson L. So, M.D. and Tess L. Sierzant, RN, M.S.

Discussants: Margaret Jacobs, Jeffrey L. Noebels, M.D., Ph.D. and Georgia D. Montouris, M.D.

Since last year's SUDEP SIG meeting in Philadelphia, the AES & EF Joint Task Force on SUDEP has completed its report and recommendations. An overview of the Task Force Report will be presented at this year's SIG. The goal is to solicit comments on issues involving SUDEP research and education. The SUDEP rate in medically-refractory epilepsy patients is about one in 150 person-years — a rate that

requires an unusually large study population for yielding sufficient data. Therefore, traditional methods of clinical investigations may not work in determining the cause of SUDEP. The lack of detectable and reliable markers also makes it difficult to identify and follow patients at high risk. The prevailing low rates of complete autopsies present special challenges to SUDEP studies. Basic science research must be encouraged to better guide the direction of clinical investigations into the cause and prevention of SUDEP. The limitations in existing SUDEP knowledge underscore the importance of educating patients, families, and healthcare providers. SIG participants will also discuss the Task Force recommendations of "who, when and how" to counsel about SUDEP.

Neurostimulation

Douglas Labar, M.D. and James Wheless, M.D.

Neurostimulation therapy for epilepsy continues to be an evolving field. New treatment targets, strategies and mechanisms of action are emerging. For this year's Special Interest Group, we will have speakers discussing each of these topics. Dr. Ana Luisa Velasco of the Hospital General de Mexico will present her clinical investigation work on open-loop direct temporal and extra-temporal cortical stimulation. Dr. Walter Besio of the University of Rhode Island will review his experimental work on concentric ring electrodes for focal brain stimulation as an antiepileptic therapy. Dr. Paul Boon will update us on his recent research into mechanisms of action of deep brain stimulation and vagus nerve stimulation.

EEG SIG: How deep in the brain can you see with EEG and MEG?

Jean Gotman, Ph.D.

EEG electrodes are placed on the scalp and MEG sensors are placed above the scalp, but we are obviously interested in what happens within the brain. Can we only trust these modalities to tell us about what is happening in superficial cortical layers or can we also see deep in sulci and in deep regions such as the hippocampus, the intrahemispheric fissure, the thalamus? Are temporal-lobe spikes recorded on the scalp generated in the hippocampus? Are generalized spike-wave discharges generated in mesial frontal regions? Can MEG see deeper than EEG? Is there a difference between evoked and spontaneous activity? If these modalities allow us to see deep in the brain, why does intracerebral EEG look so different from scalp EEG? We will discuss the theoretical aspects of source modeling as well as comparisons with intracerebral electrodes to attempt to find answers to the above questions.

If time permits, we may also address the related question of how far do intracerebral and subdural electrodes see.

Speakers include: Jean Gotman, Ph.D.: "How real are models?," Richard Wennberg, M.D., FRCP: "How deep does the EEG see?," Robert Knowlton, M.D.: "Does MEG see even deeper?," and Frans Leijten, M.D., Ph.D.: "Depth sensitivity profiles."

Clinical Nursing

Sarah Kiel, M.S.N., CRNP

Adult and pediatric case presentations will highlight emergencies encountered in the epilepsy monitoring unit (EMU). We will also review the available literature addressing EMU safety. This will allow for discussion provoked by the Saturday morning symposium on the process of developing an expert consensus for EMU patient safety. Speakers: Linda Allen, RN, B.S.N.; Pat Dean, M.S.N., ARNP; and Delia Nicholas, M.S.N., CPNP

Signals

Continued from page 9

Pregnancy Registry Outcomes*Cynthia L. Harden, M.D. and Georgia Montouris, M.D.*

The Pregnancy Outcomes SIG is designed to be a resource for information regarding pregnancy-related outcomes in women with epilepsy. Presentations of the most up-to-date information from the major antiepileptic drug (AED) pregnancy registries and other data regarding pregnancy outcomes will be discussed. The goal is to improve the ability to make evidence-based decisions in treating women of childbearing age who have epilepsy.

Speakers from each of the major independent registries will be invited to provide updated information and participate in discussions of the clinical implications of present data and the knowledge gaps requiring additional research.

Tuberous Sclerosis Complex (TSC) – Infantile Spasms and TSC: Potential Mechanisms and Impact on Cognitive Development*Vicky Whittemore, Ph.D. and Gregory Holmes, M.D.*

Tuberous Sclerosis Complex (TSC) is an autosomal dominant genetic disorder resulting from a mutation in either the TSC1 gene (hamartin) on chromosome 9 or the TSC2 gene (tuberin) on chromosome 16. The proteins form a complex that functions to regulate mTOR in this important signaling pathway.

Seizures are the most common presenting symptom in children with TSC, with more than 30% of children with TSC presenting with infantile spasms. Understanding the underlying mechanisms of infantile spasms in TSC, the efficacy of vigabatrin to treat this type of seizure in children with TSC, and the impact of infantile spasms on cognitive development in TSC may lead to better treatments and therapies for all individuals who develop infantile spasms.

The SIG, Tuesday at 2:30 p.m.: Ayla Humphrey, Ph.D., Cambridge University, Cambridge, UK; John W. Swann, Ph.D., Baylor College of Medicine, Houston, TX.

Junior Investigator Workshop*Audrey Yee, M.D.*

Please join in an exciting, interactive round-table discussion at the Jr. Investigator SIG as we welcome the following expert panelists: Frances Jensen, Dan Lowenstein, John Swann. Our panelists will touch on finding a mentor, healthy mentoring relationships, and becoming an effective mentor.

MEG/MSI: Clinical Application of MSI and Other Functional Neuroimaging Modalities*Wenbo Zhang, M.D., Ph.D.*

More and more neuroimaging modalities have been applied to the presurgical evaluation for epilepsy patients. MSI, as a unique imaging tool, has been integrated into the presurgical procedure recently. It plays an important role in surgical candidate selection, guidance of grid placement and outcome prediction for epilepsy patients. MSI also maps the eloquent cortex for both epilepsy and brain tumor patients. When it is integrated with various functional neuroimaging tools, such as SPECT, PET, DTI, functional MRI etc., more precise localization of epileptogenic zone and eloquent cortex can be achieved. This year (2008) the MEG/MSI SIG will focus on the integration of MEG/MSI with other neuroimaging modalities and cortical mapping in clinical practice. Comparisons and challenges considering different neuroimaging modalities and invasive mapping will be discussed. Faculty includes Dr. Gregory Barkley

from Henry Ford Hospital in Detroit; Dr. Robert Knowlton from University of Alabama at Birmingham; Dr. Marta Santiuste from Centro Medico Teknon in Barcelona, Spain and Dr. Jing Xiang from Cincinnati Children's Hospital. Please join us!

Task Force Reports on SUDEP

Continued from page 1

examination, and an awareness campaign aimed at patients, families, coroners, and medical examiners on the need for complete autopsy examinations in suspected cases.

The challenge of educating the lay and medical communities about SUDEP is significant. At issue is determining methods preferred by lay persons in learning about SUDEP, the development of balanced, comprehensive information, and execution of a broad-scale campaign utilizing all appropriate media and educational venues to reach the lay and professional audience. The effort should involve both established epilepsy organizations or institutions and professional organizations that have wide interests in neurology/neuroscience and child/family healthcare.

SUDEP prevention efforts can be directed only against its reported risk factors, since the underlying pathologic mechanisms are unknown. A few factors are modifiable to potentially lower SUDEP risk, namely uncontrolled seizures, especially tonic-clonic seizures; long epilepsy duration; sub-therapeutic AED levels; and number of AEDs used. Risk reduction under these circumstances rests largely in adherence to established principles in epilepsy treatment.

SUDEP is a delicate subject not easily broached with patients. The devastating nature of SUDEP, dearth of knowledge about its causes, and lack of definitive preventive measures may overwhelm or upset some patients and families. The task force recommendations also address if, when, what and how SUDEP should be discussed with patients and caregivers.

The report recommends convening of a multidisciplinary workshop, including experts in sudden cardiac death, sudden infant death syndrome (SIDS), genetic disorders, and autonomic dysfunction, to refine current lines of research and to identify additional areas of research in mechanisms underlying SUDEP.

The full Report of the American Epilepsy Society and the Epilepsy Foundation Joint Task Force on SUDEP (Sudden Unexplained Death in Epilepsy) is available on the AES Web site at www.aesnet.org.

Is It Unexplained or Unexpected?

In discussions about SUDEP the terms sudden unexplained and sudden unexpected are heard almost interchangeably. But to Elson L. So, M.D., there is a difference.

Most unexpected deaths in epilepsy are explainable; the result of drowning or trauma, for example. "Moreover," he says, "the unexpected nature of SUDEP is already conveyed by the word sudden." He prefers the term 'unexplained,' "which emphasizes that the mystery and challenge of SUDEP result from a lack of knowledge about the condition."

North American Regional Caribbean Congress — A Success!

By Amza Ali, M.D., FRCP

Clinicians from the English-speaking Caribbean, Latin America, North America and Europe gathered at the First North American Regional Caribbean Congress of Epilepsy, which took place in Montego Bay, Jamaica from May 30-31, 2008. The event was a truly collaborative endeavor involving the North American Regional (NAR) Commission of the International League Against Epilepsy (ILAE), the Jamaican League Against Epilepsy (JLAE), the Jamaican Epilepsy Association (JEA), the American Epilepsy Society (AES), and The Canadian League Against Epilepsy (CLAE), as well as the international corporations Novartis and Bank of Nova Scotia.

Under the leadership of Dr. Amza Ali (President of the JLAE, NAR Commission Member) and Dr. Robert Fisher (NAR Commission Member), Co-Chairs of the Congress, this inaugural and well-attended event marks a new chapter in the development of academic activities focusing on epilepsy in the English-speaking Caribbean region.

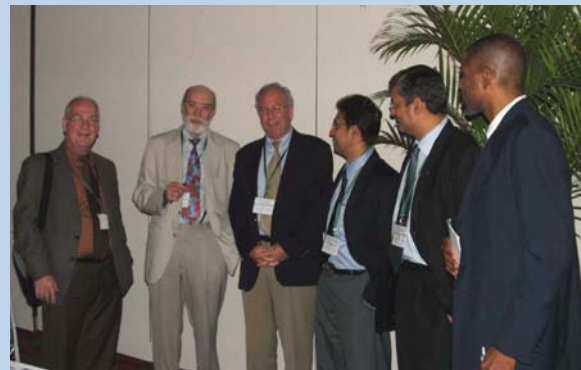
The high profile of the Congress was evident by the participation of regional dignitaries and of regional and international speakers. During the official opening ceremony, the Honourable Rudyard Spencer, Minister of Health of Jamaica, eloquently acknowledged the difficulties and stigma facing persons with epilepsy, and pledged his commitment to work with the JLAE and JEA to improve the care and quality-of-life of people with epilepsy in Jamaica. Professor Peter Wolf, President of the ILAE, gave the opening address in which he emphasized the significance of this academic event, and acknowledged the effort of organizers and contributors in bringing the congress to fruition.

Although inclement weather impeded the attendance of two of the regional speakers, both were able to give their presentations via tele-cast. International speakers included Drs. Robert Fisher (USA), Dennis Spencer (USA, AES President), Martin Brodie (UK, ILAE Treasurer), Jeffrey Noebels (USA), William Theodore (USA), Kimford Meador (USA), Eugene Ramsay (USA), Basim Uthman (USA), David Clarke (USA - Jamaica), Franz Chaves Sell (Costa Rica), and Samuel Wiebe

(Canada, chair of North American Commission of ILAE). These speakers covered a wide variety of topics, ranging from basic clinical principles through medical and surgical management, to cutting edge genetic concepts.

Regional speakers and session chairs included Drs. Amza Ali (Jamaica, President of the JLAE), Colin McKenzie (University of the West Indies), Hafeezul Mohammed (President of the Association of Consultant Physicians of Jamaica), Professor Robert Gray (University of the West Indies), Judy Tapper (Jamaica), Rainford Wilks (Jamaica), David Corbin (Barbados), Sean Marquez (Barbados), Roberto Rico (Curaçao) and Neil Cruz (US Virgin Islands). Speakers in these sessions provided insightful descriptions of their work in the epidemiological, medical and psychosocial aspects of epilepsy in the Caribbean region. The sessions culminated in lively question and answer periods which engaged a keen audience and extended into the evening.

The success of the First North American Regional Caribbean Congress of Epilepsy allows us to envisage an era of new initiatives and collaborations that will lead to better care and quality of life of patients with epilepsy in this region.



Left to right: Eugene Ramsay (USA), Dennis Spencer (USA), Jeff Noebels (USA), Amza Ali (JA), Hafeezul Mohammed (JA), Colin McKenzie (JA) share a moment between academic sessions.



Dennis Spencer and other AES members and family at the 2008 Epilepsy Walk

Members in the News

AES would like to congratulate two members and icons of neuroscience who turned 90 years old this summer: Dr. Brenda Milner and Dr. William Feindel. Both continue to contribute to the field through the Montreal Neurological Institute. Dr. Milner, an eminent neuropsychologist is a past William G. Lennox Awardee and Dr. Feindel, a neurosurgeon and former Director of the Montreal Neurological Institute is a past winner of the J. Kiffin Penry Excellence in Epilepsy Care Award. On behalf of the members of AES we thank them for their contributions to the field of epilepsy and wish them a very happy birthday.

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CALENDAR OF EVENTS

November 3-7, 2008

Society for Neuroscience
Annual Meeting
San Diego, CA

November 5-8, 2008

5th Congreso Latinoamericano
de Epilepsia (ILAE & IBE)
Montevideo, Uruguay

November 5-8, 2008

Child Neurology Society
Annual Meeting
Santa Clara, CA

December 5-9, 2008

2nd Biennial North American
Regional Epilepsy Congress
AES 62nd Annual Meeting
Seattle, WA

March 4-7, 2009

American Society for
Experimental Neurotherapeutics
11th Annual Meeting
Arlington, VA

June 28 - July 2, 2009

28th International
Epilepsy Congress
Budapest, Hungary