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From the Information Officer

The International Epilepsy Agenda Moves Forward



From its beginning over 100 years ago, the League has been built on the central idea that the problems experienced by those who have epilepsy transcend national boundaries and cultural identities. No matter where they live in the world, people with epilepsy experience poor access to effective treatment, prejudice against them because they have the disease, and social isolation that often limits their education and long-term economic welfare. The economic burdens of the disease are well known.

These problems are as true now as they were 100 years ago. One could conclude that no progress has been made, but comparing then to now tells us otherwise. More people with epilepsy now have their seizures controlled and many in the public eye no longer try to hide their epilepsy. But we know the old issues remain for the majority who suffer from the disease. In the last 20 years there have been radical changes in the epilepsy community's approach to improving care and changing attitudes among the general public. First there was the Global Campaign Against Epilepsy's "Out of the Shadows" program which demonstrated just how many people were not receiving treatment for their epilepsy and how effective treatment radically changed lives for the better. The next major steps were the PanAmerican Health Organization's Strategy and Plan of Action on Epilepsy, the European Written Declaration on Epilepsy and the American Institute of Medicine's report on epilepsy (*Epilepsy across the Spectrum: Promoting Health and Understanding*). Each highlighted how epilepsy care did not receive the attention or resources that corresponded to the health and economic burden the disease creates, and all called for specific actions. The PanAmerican and European agreements called on governments to improve care, access to care and treatment for the many psychosocial consequences of epilepsy.

These activities have all led to important steps to improving the quality of life for all of those whose lives

are affected by epilepsy in many countries. Another major step has been taken. In February, the Executive Board of the World Health Organization approved a [resolution on the global burden of epilepsy](#). This resolution clearly outlines the significant burdens on health, psychosocial well-being and economic status imposed by epilepsy. It calls on all member nations to make epilepsy a national health care priority and to provide the resources to improve access of care and to ameliorate the affects of stigma. This resolution now moves to the World Health Assembly for approval in May. This resolution came about through the efforts of a number of our colleagues and was led by the Presidents of the ILAE and IBE, Emilio Perucca and Athanasios Covanis. We ask all of our members to contact their national representatives to the Assembly to support this important resolution.

Progress, however, will not come from resolutions alone. They make the issues important, but it will be up to each chapter to lead the efforts in each country, and the conditions vary greatly across the world. In this issue of *Epigraph* there are articles that highlight some of the key issues in our newest region, Africa, and how a very individualized approach is needed for each country and region. Although the solutions may be country or region specific, the creativity of our members keeps us moving forward.

Ed Bertram, Information officer

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From the Vice President



Tatsuya Tanaka

Dear friends of the ILAE Community,

It has been almost two years since the beginning of the current Management Committee at the Montreal International Epilepsy Congress in 2013. In these two years it has been an extraordinary pleasure to work with my dear colleagues Emilio Perucca (President), Nico Moshé (Past President), Helen Cross (Secretary-General) and Samuel Wiebe (Treasurer).

The International League Against Epilepsy has achieved worldwide success over the first century of its existence. This success is reflected by the steady growth of League activities in all of our regions (Europe, North America, Latin America, Eastern Mediterranean Africa and Asia/Oceania) and the expanded collaboration among the regions with joint multinational educational and research activities. The expansion has been greatest in the last two decades, and it has been a privilege for me to participate in the League leadership during this exciting period.

As the scope and membership of the League expanded, it became clear that there was a real need to represent our constituency better, and the first and major step the League took was amending its constitution to ensure participation of all regions in the governance of the League at the highest level with membership to the Executive Committee and the Management Committee. When I was First Vice President in the previous Executive Committee (2009-2013), a Constitution Task Force was created to amend the Constitution and Bylaws under the direction of President Nico Moshé. The amended constitution was ratified by the General Assembly at the Rome International Epilepsy Congress in 2011. These new guides for League function assured that all regions would be represented and have a voice in League governance.

One of the important constitutional changes is the direct election of the chairs of the regional commission by the member chapters of each region. This change ended the practice of the Executive Committee appointing the chairs and has assured that the voice of each region is more reflective of the wishes of the chapters. The elected Regional Chair will also now be a member of the Executive Committee, which will improve communications not only between the leadership of the League and the regions but also across regions, for the benefit of the ILAE as an international organization. It's a very positive change that I have experienced first-hand because I served under the old and new Constitution and Bylaws.

The elected Chairs of six regional commissions are Drs Amadou Gallo Diop (Africa), Byung-In Lee (Asia-Oceania), Hassan Hosny (Eastern Mediterranean), Meir Bialer (Europe), Marco Medina (Latin America), and Sheryl Haut (North America). According to the new constitution, regional chairs are now members of the ILAE Executive Committee. However, because the rules, conditions and history of each region are very different from each other, we are in the process of harmonizing the election process for all regions. For the election of the regional Chair and the members of each regional commission, it is important that the ILAE Constitution and By-Laws be applied for each regional election. Discussions with the new Election Task Force (Helen Cross, Chair), Constitution Task Force and Executive Committee are underway to resolve these important issues for the consistency and transparency of the Regional Elections.



Emilio Perucca
President

What I have enjoyed most about my service are the people with whom I work on the Management Committee. The unique backgrounds and personalities of each has brought the needed diverse perspectives but common purpose that are necessary for the League to prosper and grow.

Emilio Perucca, our President, is a true Italian gentleman and outstanding neuro-pharmacologist. Starting life in a small town on Lake Maggiore on the Italian-Swiss border, he has become an internationally known neuro-pharmacologist and epilepsy researcher. But he also has an extraordinary knowledge of flowers and plants across the world. I have learned much from his straight-forward decision-making.



Helen Cross
Secretary-
General

Helen Cross, our Secretary-General is known to all as an international leader in pediatric neurology and epilepsy. Her great organizational skills have kept the League moving forward by staying on top of the many issues that we are dealing with and by making sure we do not lose track of anything. In Japan I often awaken to a message from Helen that keeps me focused on what we are doing, and through our many calls, I have come to understand and appreciate the English accent much better.



Sam Wiebe
Treasurer

Samuel Wiebe, our Treasurer, is perhaps our most international member. He was born and raised in Mexico, but is now one of the leading Canadian epilepsy researchers. His quiet personality is well suited to his role during these turbulent financial times. In addition to the many aspects of financial management that he has taught me, I have profited from his deep knowledge of literature and world cinematology, that extends to such Japanese classics as "Narayamabushikou."

Nico Moshé, our Past President, is known to all. As President his outstanding leadership helped shape many of the changes in the organization and direction of the League to make it more reflective of our membership and the 21st century. He, like several others in the Management Committee, is a global

citizen. Born in Greece and trained in the US, he refers to himself proudly as "Nico from the Bronx." Most of us know him as that rare breed of outstanding clinical and basic researcher who has also trained many of the rising stars in clinical and laboratory epilepsy research.



Nico Moshé
Past President

All of these colleagues complement my own international experience. I left Japan to study neurophysiology and kindling with Robert Naquet in Gif-sur-Yvette and then traveled to Montréal to learn epilepsy surgery from Professor Andre Olivier. I took these two skills along with a knowledge and love of French wine back to Japan. My cultural tendencies have also caused Nico to nominate me as official ILAE photographer.

In the remainder of this term, I believe it is our mission to continue and further enhance collaborative international education, training, and research to improve the quality of life for all the people with epilepsy, regardless of gender, age, geographic location and economic status.

I have been encouraged by the recent WHO Executive Board resolution on epilepsy. This event, which came through the sustained efforts of Emilio and Thanos Covanis of the IBE, has energized all of us because we may soon be successful in bringing real benefit to people with epilepsy around the world.

Tatsuya Tanaka, Vice President

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Traditional Healers and the Treatment of Epilepsy: An African Perspective

One of the major themes at the 2014 African Epilepsy Congress was the role of traditional healers in the treatment of epilepsy. Although no one knows for sure, it is likely that the majority of people with epilepsy go to these caregivers who are established and respected members of their communities. There are many reasons why people who have had seizures consult traditional healers first. The African Epilepsy Congress brought together practitioners of traditional and modern medicine in a single venue to discuss their differing points of view on the causes for the disease and how it might be treated. The discussions provided extraordinary insights into the patients' beliefs about their disease, the implication of the disease within the community, and their understanding of how the disease should be treated.



Edward Kija

In preparing this article, I interviewed two traditional healers: Gugu Ngubane and Gugu Madlakes who work in the countryside around Cape Town, South Africa; Ms Johannan Keikelame, a social worker who has done a number of studies on the role of traditional healers in treating epilepsy in rural South Africa; and Professor Daliwonga Magazi, a pediatric neurologist from the University of Limpopo, South Africa.

All agreed that the importance of the traditional healers arises from the complex beliefs about the causes of epilepsy, which influences the interpretation of the disease and how it should be treated. Traditional healers define epilepsy as a disease caused by confusion of brain nerves, and the actual seizure is the action done by the person when sick with epilepsy, a sickness that is always present and active. Many consider a person with epilepsy to be possessed and the condition is often viewed as punishment for wrongdoings of the family. However, in some cases a person may be convulsing for a greater good. In these cases the convulsions could be an attempt to remove bad spirits surrounding the family, and by convulsing, the bad spirits are removed. In other cases the convulsions may be a calling from the ancestors for that person to be a traditional healer. Until that person accepts the calling, the convulsions will continue. The definition and the belief about the possible causes are the same for a child and an adult, but the causes most often have a spiritual basis.

Although the spiritual causes have a major position in the traditional beliefs about the basis of epilepsy, there are other, more sinister forces that may bring the illness about. Witchcraft, bewitchment, poisoning, the presence of an evil spirit, or the casting of a spell on a family by someone who is jealous are all considered possible causes of epilepsy. In this theory of disease there are forces inside the afflicted person that fight with the blood and cause the disease.

These beliefs play a major role in people's choices of treatment. They choose to follow traditional treatment paths in part because they believe that traditional medicines work well in people with epilepsy, and the natural history of seizures and epilepsy may help support the beliefs. For febrile seizures, there may be only a single seizure, so treatment appears effective. Some forms of epilepsy have only rare seizures, so again treatment may appear effective. If the basis for the seizures is believed to be witchcraft or possession by evil spirits, the treatment must be more spiritual, and that treatment cannot be delivered in a hospital. Ultimately many people choose to seek help from the traditional healers because they believe that epilepsy must be treated by traditional medicine.

Although the lack of access to modern medicines often plays a significant role in people's seeking help from traditional healers, people also don't go to hospital because it often appears that modern medicine does not work and doctors prescribe the same medication every time and the seizures still persist. There is often the expectation that the modern medicines will cure the disease, so when the medication runs out or people stop taking the drug, the seizures return, so they see little benefit from the medicine or the effort to obtain it. Still, some people believe that occasionally modern medicines do work to treat seizures. However, if evil spirits are diagnosed as the cause then the spirit has to be removed first by a traditional healer before medications can work. For some patients who have what would be diagnosed by modern practitioners as psychogenic seizures, it is quite possible that traditional practices could be far more effective than modern. There are no data on this potential area of better efficacy of traditional practice.

Traditional medicine can have an important role in the treatment of epilepsy when used together with modern approaches. The local healers can help identify patients in the community and refer them to a hospital. Some practitioners believe that some of the traditional medicines have a true anticonvulsant effect, while others believe that some mix of western anticonvulsants with traditional medicines will be more effective. It is important to remember that traditional healers have a very strong influence on their local community, and they may play a huge role in reducing the stigma of epilepsy in the community. They do sometimes refer patients to hospitals and clinics. Once they have removed the evil spirit, the patient can be referred to a hospital. Some healers feel that once a patient sustains a burn from a seizure then that patient can no longer be treated by traditional medicine and has to be referred to a hospital.

Another reason for going to a traditional healer is the difficulty in accessing modern medicine from a village. There are no adequate local support services, and it can be very expensive to travel to the health facility. Further, the family may be required to purchase expensive medicines and pay for expensive tests,

although no comparison has been made between the costs of traditional versus modern medicine. The traditional healers may also be preferred because they have a more holistic approach and occasionally visit the family for history-taking. Even when the family does not have money, the patient will be treated and the family will thank the traditional healer later. These local practitioners will not advertise, because patients will come based on recommendations by other people who have been treated by them.

In developing the much-needed infrastructure for epilepsy care, it is likely that the traditional healers will play a role. They are trusted by the local community, and they work within the local belief system of the causes and treatments of epilepsy. It may be best, until conditions in the communities change significantly, that traditional healers be educated in the basics of epilepsy care and that the medical community work in partnership with them.

In Senegal the neurologists have given day-long workshops with the traditional healers as part of a broader outreach to improve knowledge and care about the disease. These workshops were built around a respect for the position and role that these local leaders have in their communities as well as the recognition that the healers could become important partners. The healers were receptive to the western concepts about epilepsy. Although it remains unclear how these new relationships between traditional and modern will evolve, these workshops have come at a time when epilepsy and seizures have risen from seventh on the list of reasons for referral to hospitals to second.

In a region of the world with limited medical resources this collaboration with the recognized community medical professionals may provide new avenues to providing much needed access to care for people with epilepsy. Perhaps the key to this successful collaboration is the development of a respectful partnership with the traditional healers. They often play a major role in transitioning people with epilepsy from the older, more spiritual understanding of the epilepsies to the current neurobiological concepts of the disease.

About the Author

Dr Edward Kija is a consultant Pediatrician and a Lecturer from Muhimbili University in Tanzania currently doing a Fellowship in Pediatric Neurology at Red Cross War Memorial Children's Hospital in Capetown, South Africa supported by the African Pediatric Fellowship Program. He did his undergraduate and postgraduate training in Tanzania at the University of Dar es Salaam and Muhimbili University, respectively. He has been working as a consultant Pediatrician for the Muhimbili National Hospital in Dar es Salaam, Tanzania since 2011.

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The First Francophone Teaching Course of the Commission for African Affairs a True Success!



Lionel Carmant, MD
Professor of Neurology and Pediatrics
CHU Sainte-Justine, Université de Montréal



Amadou Gallo Diop, MD
Professor of Neurology and Medicine
CHU Fann, Université de Dakar

The first Francophone teaching session of the Commission of African Affairs was held from 15 July to 18 July 2013 in Dakar, Senegal. This session was scheduled to take place initially in 2012 in Bamako, Mali, but was moved to Dakar due to the political unrest in Mali.

Despite the change in location, the course was given to more than 100 French-speaking neurologists, neurology residents and neurosurgeons. This included the target population this course was initially created for, the Malian primary care physicians, also known as RARE network. The Malian group was well represented with 15 members: 12 primary care physicians, two neurologists and one neurosurgeon.

Also significant was the presence of participants from all French-speaking Africa, a number of which are part of the Dakar neurology program, including the Masters in Epileptology. Countries represented included: Cameroon, Burkina Faso, Tunisia, Ivory Coast, Congo and of course Senegal.



The first Francophone teaching session of the Commission of African Affairs

The topics of interest were put together by Pr Gallo Diop (Senegal) and Dr Youssoufa Maiga (Mali). A group of neurologists, neurosurgeons, neuro-radiologists and neuro-epidemiologists shared the task of providing the avid learners with a four-day course. Teachers included Drs Diop, Touré, Ndiaye, Ba, Seybou, Fall, Sow, Seck and Basse from Senegal; Drs Koumaré, Landouré, Nimaga and Mamadou from Mali; and Drs Carmant, Mercier and Nguyen from Canada, who obtained a grant from the North-American Commission and University of Montreal to partner with French-speaking countries of the CAA.

The course was a comprehensive review of epilepsy going from basic sciences and the physiological basis

of EEG on day one, to diagnosis, classification and treatment of the epilepsies on day two, followed by investigation and surgical/alternative approach to the refractory epilepsies on day three, including a case-review session, and finally on day four, review of the CAA programs already in place. The meeting led to numerous exchanges including partnerships to start a ketogenic diet program in Dakar as well as epilepsy surgery programs in both Dakar and Bamako for lesional epilepsies including patients with MR proven mesial temporal sclerosis.

All participants expressed their high level of satisfaction after the course and a second course is already in preparation for 2015-2016. The course has solidified the partnership between the Canadian League and Senegalese and Malian Leagues as well as the partnership program between the North American Commission and the Commission for African Affairs.

We would like to thank the ILAE for their support of this program.

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Building Infrastructure on the Road to Improving Epilepsy Care in Africa



Roland Chidi Ibekwe

There is no question that the lack of resources is a major, if not the major, impediment to even minimal appropriate epilepsy care in many regions and countries of the world. Although Africa is not alone in this regard, it is a problem that is common to most countries on the continent. At the recent African Epilepsy Congress in Cape Town, this topic was widely discussed. It was clear from the presentations and from spontaneous conversations that happened throughout the meeting that the major issues were shared by most countries and that many shared the same ideas for solving the problem.

At the Congress, I had the opportunity to speak with a number of epilepsy leaders from all corners of Africa regarding their thoughts about the basis for the problem and about improving the situation for the millions of Africans who suffer from epilepsy and its consequences. I spoke with Professor Charles Newton of Kenya, Professor Gallo Diop of Senegal, Dr Celestine Kaputu Kalala Malu of the Democratic Republic of Congo, Dr George Chagaluka of Malawi, Dr Omar Siddiqi of Zambia, Professor Jo Wilmshurst of South Africa and Professor Daliwonga Malazi of South Africa.

There was essentially universal agreement on the greatest need: trained personnel who understand the issues associated with epilepsy. As Professor Newton indicated, the greatest single need for epilepsy care is training of health workers especially in the peripheral clinics. Most treatment gaps occur in rural areas where health workers lack knowledge about the disease and its treatment, and many countries have only a handful of health care workers who are knowledgeable about epilepsy. Second on the list was access to antiepileptic drugs, which is limited by cost, availability (patients in many countries have only a limited choice of these drugs which have erratic availability) and knowledge of how to use them.

In addition to limited expertise and availability of effective medications, there is a simple lack of awareness that treatment exists. Professor Magazi noted that greater awareness about the disease and its treatment will go a long way to improving care. This issue looms larger the farther one is from urban settings where knowledge about modern medicine is often quite limited. Some of those interviewed indicated that this lack of awareness may be a far greater impediment than the potential costs of

treatment. Professor Newton noted that the costs of seeing a physician and obtaining antiepileptic medications may not be much different than the fees of a traditional healer. However these comparisons can be difficult, as one requires cash and the other is often paid in goods. Paying for services also varies from country to country. In some countries, there are a few people who have private health insurance. In some countries there is no insurance and payment is entirely out of pocket. In a few, such as Malawi and Zambia, care is free to all at government hospitals. For those who don't have insurance in South Africa, there is expectation of payment, but payment is on a sliding scale, depending on the patient's resources.

To combat the widespread ignorance about the disease, a number of groups are actively developing epilepsy awareness programs. Professor Diop said that the Senegalese Epilepsy Association regularly provides information through radio programs and newspapers. In addition there are regular workshops about epilepsy in schools and to women's associations. They have also had several workshops with traditional healers. All of these efforts have resulted in a significant increase in hospital visits for seizures and epilepsy. The Kenya Association for the Welfare of people with Epilepsy (KAWE) has a number of programs to raise awareness, and there is a television melodrama that includes someone with epilepsy. Still utilization of resources is low and stigmatization is still high. According to Dr Malu the National League Against Epilepsy in the Democratic Republic of Congo is developing an awareness program that is in part aimed at politicians and other decision-makers. Epilepsy South Africa also has radio programs to increase awareness. Across the continent it is essential to reach the people in positions of influence, as they are the ones who must be reached if national infrastructure for epilepsy is to be improved. Dr Saddiqi told me that in Zambia the International Bureau for Epilepsy (IBE) association has worked hard to increase awareness at the Ministry of Health, which has resulted in improved resources for epilepsy. Some of the countries have individualized awareness programs to educate patients, families and small groups. These programs involve personal contact, often with a social worker or nurse. However, as Professor Wilmshurst pointed out, even though these programs are effective, there are simply not enough trained people involved to reach everyone.

One of the greatest obstacles faced in improving epilepsy care throughout the region is the low priority it receives in the public health arena. This observation was a universal comment among all of the people whom I interviewed. Infectious disease, especially the well known HIV pandemic that affects millions of people in many African countries, is receiving greater attention because of the high mortality. But, as Professor Newton pointed out, there are other reasons as well. In Kenya, he explained that another reason for the low priority for epilepsy is the common perception of epilepsy, which is viewed with the associated stigma and belief that people affected by the disease have limited intellectual capacity. For these reasons the public health benefit of treatment will show little gain for the investment of national resources. However, it is not so bleak everywhere. Dr. Saddiqi explained that in Zambia, the awareness programs initiated by the local IBE group have convinced the health ministry that greater support was a good investment for the country.

Because the lack of human expertise is a major impediment to progress, training programs are essential to improving epilepsy care. There appears to be more variability across countries in the existence and nature of training resources. Some countries, such as Senegal, Kenya, the Democratic Republic of Congo and South Africa, have some neurologists and a few epilepsy specialists (although very few for the size of the population); others such as Malawi and Zambia have less than five each. In almost all instances, these specialists are concentrated in the major urban centers. There are neurology training programs in Senegal, Kenya, the Democratic Republic of Congo and South Africa. In Senegal there is a diploma program for epilepsy as part of advanced medical training, and in South Africa there are several epilepsy centers in the tertiary medical centers at which additional epilepsy training takes place. The amount of time dedicated to epilepsy education is limited for doctors in training. Similarly, training for nurses and medical officers may include a very basic introduction to epilepsy. KAWE in Kenya does provide some training for community health workers. Diagnostic facilities such as MRI and EEG are available on a limited basis, but again

these are in the major population centers and hard to reach for many.

Although there is always the reaction to send physicians out of Africa to obtain the needed training, there was unanimity among the leaders with whom I spoke that such an approach is generally not useful. First, many who go abroad choose to stay abroad. Just as important, the training they receive outside of Africa has little relevance to many of the conditions they will encounter or to the resources they will have at home to do their work. All agreed that training should happen locally, and training is the key to solving the critical manpower shortage that is the basis for improving epilepsy care.

All of the African leaders look forward to the day when treatment is not limited by patient resources, poor access to medications, and the lack of expertise. What impressed me in my discussions at the Epilepsy Congress is the enthusiasm and dedication in the African epilepsy community. There was optimism tempered with the recognition of the current realities. It is clear that much progress has been made already, and that this progress is a good sign for the future.

About the Author

Dr Roland Chidi Ibekwe is a Senior Lecturer in Pediatrics at the University of Nigeria and Consultant Pediatrician at Child Neurology unit of the department of Pediatrics, University of Nigeria Teaching Hospital Enugu. He is currently pursuing a Pediatric Neurology Fellowship at the Red Cross War Memorial Children's Hospital and the University of Cape Town courtesy of the African Pediatric Fellowship Programme (APFP). He did his undergraduate training at the University of Port Harcourt and his postgraduate training in Pediatrics at the University of Nigeria Teaching Hospital Enugu.

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Preventing Epilepsy After Injury



Astrid Nehlig

In recent years, one of the stated goals in the development of new treatments for epilepsy has been the prevention of the disease or modifying its underlying nature so that it has less impact on one's quality of life. Many researchers have tried to prevent the development of epilepsy after an injury or to lessen the severity of seizures that do develop. To date none of the approaches have resulted in strong or reproducible effects. In a presentation at the European Congress on Epileptology, Astrid Nehlig from Strasbourg reviewed the goals for antiepileptogenesis, what has been tried and what must be considered if epilepsy prevention is to become an achievable goal in the future.

As she noted, epileptogenesis is the series of changes that takes place in the brain after an injury that result in spontaneous seizures or that allows the progression of the epilepsy after the first seizures. Professor Nehlig pointed out that the process is complex with many steps and changes that we do not understand. In the current models of acquired epilepsy, it is not clear which changes may contribute to the development of epilepsy and which are a response to the injury and play no role in seizures.

It is possible that some changes could actually be working to prevent the development of epilepsy. The

changes that occur after trauma, status epilepticus, and stroke include neuronal loss and changes in the blood brain barrier and in metabolism. There are certainly epigenetic processes that result in expression of different receptors and channels. Further there is glial activation and inflammation and rearrangement of neuronal circuits. She pointed out that with all of these changes in many regions it is difficult to know which of them are critical to epileptogenesis and which are irrelevant to it.

To date antiepileptogenic clinical and preclinical trials have not prevented epilepsy. Trials with a number of antiepileptic drugs or drugs which block activity at identified neurotransmitter receptors have not been successful. Various anti-inflammatory agents have been tried without major success. There have been attempts at gene therapy with various genes attached to virus as well as stem cell transplantation without significant benefit. Some studies have reported reduction in seizure frequency or the intensity of the behavioral seizures, but these results are difficult to interpret as in untreated animals there is great variation in outcomes.

Dr Nehlig pointed out that we do not know which molecular targets could play the critical role nor where we should direct treatment and when. The focus of efforts to date has been primarily the hippocampus in the models of limbic epilepsy, but there are other cortical and subcortical regions that may be just as important and should be targeted. Thus, failure to date may be from the failure to treat all of the contributing brain regions. Timing of treatment is also important. There is a cascade of events from the time of the injury to the first seizure and beyond, so it is likely that treatment targets will change over time. What may work at one time may have no effect at other times.

The problem is further compounded by the multiple causes and very distinct pathophysiologies across the different epilepsy types. As with many of the degenerative disorders there is a great need to identify mechanisms for which we can develop effective therapies. Epilepsy has the advantage in that our models have many parallels to the human disease, but perhaps the most important effort will be to focus on the changes that occur throughout the seizure generating regions during the development of epilepsy.

In her concluding remarks she suggested that our current efforts to prevent or ameliorate epilepsy are not likely to achieve the goal. However, Dr Nehlig did offer a path forward. It is most important to understand the changes that are involved in the development of epilepsy and when these changes occur. Because there are likely to be more than one and probably a number of mechanisms involved at different times in the evolution of the disease, we may ultimately need a combination of sequential treatments. At present, in view of our limited understanding of what is happening, any treatment will largely be based on speculation. In this situation, success will mostly be the result of pure chance. As we consider what should be targeted, Professor Nehlig emphasized the need to look at the whole epileptic circuit, and not just a single region such as the hippocampus. Further, because how the brain recovers may be influenced by factors in the environment, some attention should be given to the environment in which recovery occurs. She ended with the message that although we are not yet there, a careful evaluation of the many factors that contribute to epileptogenesis may get us there.

Looking at more brain regions

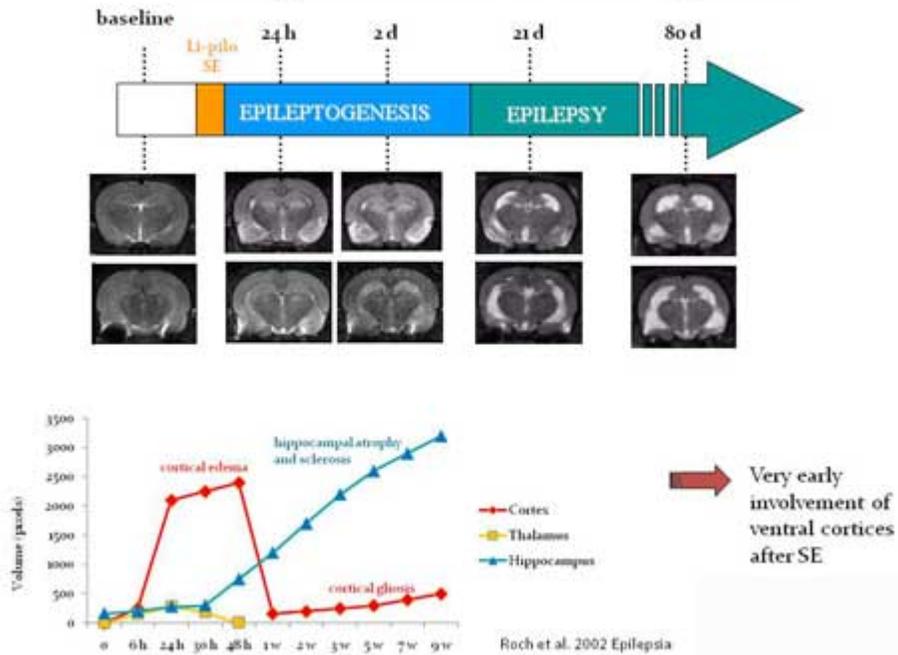
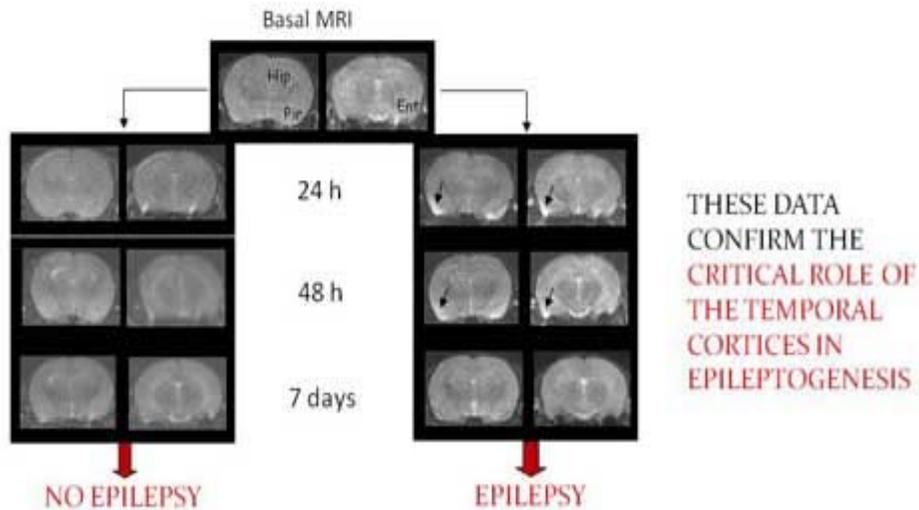


Figure 1: Time course of some of the changes that happen during the development of epilepsy after an episode of Status Epilepticus induced by lithium-pilocarpine. Top line shows the time line of epileptogenesis with the first spontaneous seizures beginning a week or more after the injury. The series of MRI scans demonstrates the evolution of changes with edema in the early phases after injury and the late development of atrophy. The graph plots the volume of the changes in edema and atrophy over time.

MRI in PN21 rats after Li-pilo SE

All PN21 rats develop SE but only a subgroup becomes epileptic



➤ The early signal in temporal cortices is predictive of epilepsy at this age

Figure 2: Injury of temporal cortices predicts development of epilepsy. All of the young rats (21 days old) develop Status Epilepticus, but only those with injury develop epilepsy.

Preventing Death in Epilepsy

It is well recognized that people with epilepsy have a much greater mortality rate than the general population. In recent years Sudden Unexpected Death in Epilepsy (SUDEP) has received much, and appropriate, attention, but its causes and a solution for this great tragedy remain elusive. However, there are a number of other reasons for the increased risk of death among those who suffer from the disease, and many of these causes can be reduced or eliminated. At the European Epilepsy Congress in Stockholm, Professor Torbjörn Tomson of the Karolinska Institute reviewed these other causes and some of the measures that might be taken.



Torbjörn Tomson

In epilepsy there are many contributors to higher mortality. In some cases, the underlying cause of the epilepsy is progressive and fatal and in other cases, while rare, the treatment itself, often from a drug reaction results in an early death. However, it is the epilepsy and seizures themselves which contribute the greatest to the increased number of premature deaths. Although SUDEP is the cause that attracts the greatest attention, especially in western countries, in other parts of the world injuries sustained during a seizure are a major and at times overwhelming contributor to epilepsy related mortality. Status Epilepticus, especially in regions with poor emergency services, can also be a major cause. Suicide, on the other hand, is an often underestimated or unrecognized cause of death in people with epilepsy and is no doubt associated with the high prevalence of depression among these individuals.

One of the important points that Dr Tomson made was that the mortality varied greatly across countries and that the causes of death were different and related to the conditions in each country. For example, in rural China drowning is the overwhelming primary cause of death (about 45% of all epilepsy-related deaths) among people with epilepsy, whereas in Kenya Status Epilepticus caused almost 40% of all epilepsy associated deaths (Figure 1).

Epilepsy related causes of death in different populations

Relative contribution to all deaths %

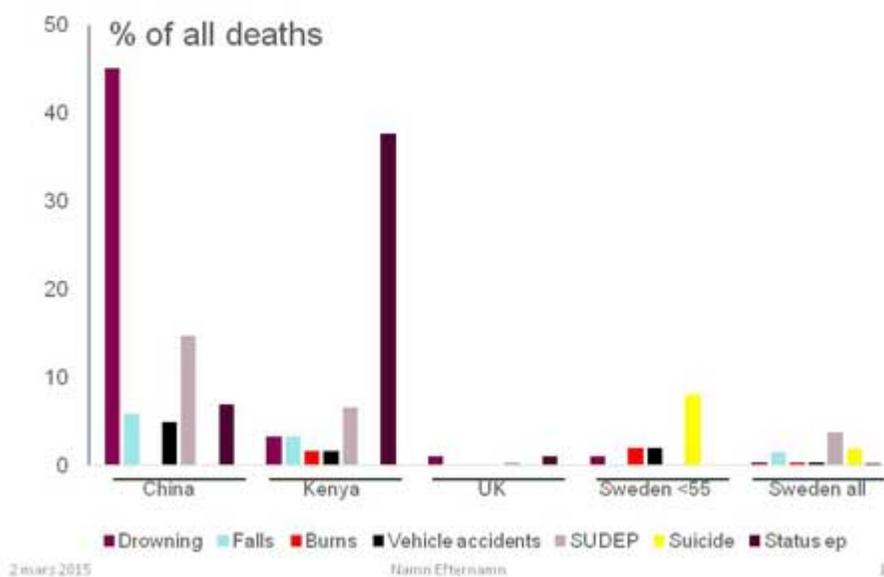


Figure 1. Causes of epilepsy-related deaths in four different countries. The figure emphasizes the issues that need to be addressed to reduce mortalities vary across cultures and resources. Of note, in Sweden, the risks also shift with age, with suicide being a leading cause among younger patients.

Although the data don't exist for many countries, suicide is a significant contributor as well, and numerous studies have the consistent finding that the risk for suicide is well above the rate found in the general population (Figure 2). These observations emphasize that, with proper interventions and precautions (and, in many countries of the world simply the availability of adequate treatment) the risk of epilepsy associated deaths can be reduced.

Suicide in Epilepsy Patients

Overall SMR 3.3 (95% CI 2.8-3.7)

FULL-LENGTH ORIGINAL RESEARCH
Suicide in people with epilepsy: How great is the risk?
 *Gail S. Bell, *Athanasios Gaitatzis, †Catherine L. Bell, †Anthony L. Johnson, and †Joachim W. Sander

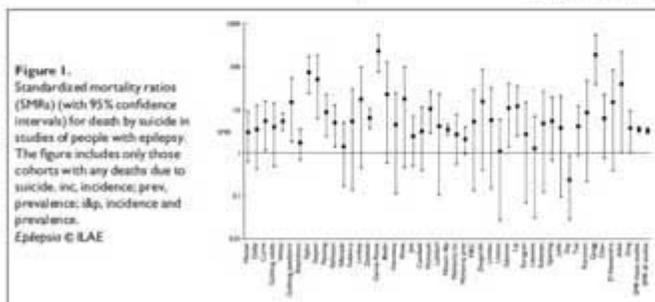


Figure 2. Risk for suicide among patients with epilepsy is greatly elevated in comparison to the general population. Summary of the standardized mortality rate in multiple studies.

The importance of treatment in reducing death rates has been emphasized by a number of studies. At

present there are no data to determine whether more aggressive treatment of depression reduces suicide risk, but there is information regarding treatment and the risk of SUDEP. Dr Tomson reported several analyses of studies that indicated that medical non-compliance greatly increased the risk of SUDEP. He also presented data that suggested that monotherapy reduced the risk compared with no treatment, whereas being on three or more antiepileptic drugs increased the risk. Whether being on monotherapy indicated a less severe form of epilepsy with less risk or whether multiple medications increased the risk independent of disease severity will require further studies. In resource poor countries it has clearly been demonstrated that death rates decrease when people are on medications. The issue of effective treatment and SUDEP has also entered into the discussion for clinical trials, in which the mortality rate was much greater in the placebo arm and in the effective treatment arm (6.9 vs 0.9 deaths per 1000 patient years respectively). The issue of seizure control and SUDEP has also entered the surgical literature. Multiple studies have found that overall mortality as well as death from SUDEP was greatly reduced if patients were seizure free following surgery (Figure 3).

Can successful epilepsy surgery reduce mortality?

Source	Cases n	Deaths	Association with seizure control
Vickrey 1997	202 surgery 46 non-surgery	14 (7%) 9 (20%)	
Salanova 2002	215 TLE	11 (%)	seizure free: 3 (2%) recurrent: 8 (12%)
Nilsson 2003	586 surgery 212 non-surgery	14 SMR 4.9 5 SMR 7.9	None of 5 SUDEP seizure free
Sperling 2005	583 surgery	19 SMR 3.6	seizure free: 1 SMR 0.5 recurrent: 18 SMR 5.8
Bell 2009	561 surgery 641 non-surgery	19 (7 epilepsy-rel) 40 (24 epilepsy-rel)	None of 5 SUDEP seizure free
Seymour 2012	360 TLE	19 SMR 2.0	2 of 6 SUDEPs seizure free

Figure 3. Epilepsy surgery reduces mortality from all causes, including SUDEP. All studies suggest the value of stopping seizures in preventing deaths.

At the end of his presentation Professor Tomson made several important observations and suggestions. First, it is important to remember that preventable causes of death vary considerably from country to country, so that interventions to reduce epilepsy mortality will vary as well. In all cases minimizing seizure related accidents should be a health-care priority. Because seizure control significantly improves mortality rates, all efforts should be made to bring seizures, especially convulsive seizures, under control, either by medication or surgery. Finally, to reduce death rates, it is also important to address depression from which so many people with epilepsy suffer. The talk emphasized the importance of addressing the issues of safety as part of the treatment of epilepsy.

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Awards

Christina Roseti – The Morris-Coole Epilepsia Prize



The Morris-Coole *Epilepsia* Prize is an annual ILAE award given in



recognition of an outstanding research paper published in *Epilepsia* the previous year on any field of epilepsy research, either clinical or basic. Established through the generosity of Christopher and Sandra Morris-Coole, the prize is now supported by the ILAE, with the intention of stimulating excellence in epilepsy research as well as rewarding young researchers for outstanding contributions to the field. Recipients receive \$5,000 and an insignia pin and present the Morris-Coole Epilepsia lecture at the Awards Symposium during the International Epilepsy Congress. The winner of the 2012 Morris-Coole Epilepsia Prize is **Cristina Roseti** for her article,

"Fractalkine/CX3CL1 modulates GABAA currents in human temporal lobe epilepsy" (Cristina Roseti, Sergio Fucile, Clotilde Lauro, Katuscia Martinello, Cristina Bertolini, Vincenzo Esposito, Addolorata Mascia, Myriam Catalano, Eleonora Aronica, Cristina Limatola, Eleonora Palma. *Epilepsia* 54(10):1834-1844, 2013. Article first published online 13 September 2013; DOI: 10.1111/epi.12354).

[Read more...](#)

Samuel F Berkovic – Companion of the Order of Australia



Samuel F Berkovic was one of seven Australians recognized as a Companion of the Order of Australia by Queen Elizabeth on this year's Australia Day Honours List (26 January 2014). It is one of the highest national awards in the country and is reserved for "eminent achievement and merit of the highest degree in service to Australia or to humanity at large."

Sam received the honor "for eminent service to biomedical research in the field of epilepsy genetics as a leading academic and clinician, to the study of neurology on a national and international level, and as an ambassador for Australian medical science education." Sam and his colleagues have been leaders for many years in making major contributions to our understanding of the genetic mechanisms underlying some forms of epilepsy.

Sam is a very active contributor to ILAE activities, being currently a member and past chair of the Commission on Genetics. [More about Australia Day awards...](#)

H Steven White – Lifetime Accelerator Award



Steven White, PhD, professor of pharmacology and toxicology and principal investigator of the National Institutes of Health-sponsored Anticonvulsant Drug Development (ADD) Program at the University of Utah College of Pharmacy, has been named the 2014 recipient of the Epilepsy Foundation's Lifetime Accelerator Award, in recognition of his commitment and pioneering contributions to the field of epilepsy and seizures. Dr. White was honored at the 4th Biennial Epilepsy Pipeline Conference 2014, held 5 to 7 June 2014, at the Hyatt Regency San Francisco.

The Lifetime Accelerator Award was established in 2012 to honor physicians, scientists, industry leaders, and other individuals who have demonstrated a lifelong commitment to bringing new therapies to people living with epilepsy. Recipients are chosen by an independent committee of global thought leaders and clinical investigators in epilepsy and seizure therapy discovery and development. [More...](#)

Ingrid Scheffer – Officer of the Order of Australia



Ingrid Scheffer, Past Chair of the Classification and Terminology Commission of the ILAE, was appointed an Officer (AO) of the Order of Australia in the Queen's Birthday Honours List for distinguished service to medicine as a clinician, academic and mentor, and for research into identifying epilepsy syndromes and genes.

Prof Scheffer puts her success down to collaborating with a fantastic team, including Professor Sam Berkovic. Their work and research helped to uncover the first gene for epilepsy and to identify many of the known epilepsy genes from the human body's 25,000 genes.

"It means that patients all over the world can be diagnosed and their doctors can go looking for mutations of the genes," she said. "Our work helps to figure out the best treatment and also can provide accurate genetic reproductive counselling." [Read more...](#)

Devender Bhalla's AAN Award



Devender Bhalla, MD, PhD, is working full-time as a researcher with the University of Limoges and Institut d'Epidemiologie et de Neurologie Tropicales and INSERM U1094 Tropical Neuroepidemiology. He is a member and the Treasurer of the International League Against Epilepsy (ILAE) Task Force of Seizures and Epilepsy in the Tropics. Dr. Bhalla has published several articles and book chapters and has presented at various international congresses and conferences. He re-launched and strengthened the Cambodian Society of Neurology (CSN), which has conducted a number of independent activities in neurology and epilepsy and is a chapter candidate of the ILAE. Dr Bhalla received the Bruce S Schoenberg award in Neuroepidemiology in 2014.

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Obituary: Yukio Fukuyama (1928-2014)



Dr Yukio Fukuyama passed away peacefully at his home on Thursday, 17 July 2014, due to pneumonia. He had experienced a dramatic recovery from surgery in April 2012 for intracranial bleeding in the right putamen. He had decided to undergo surgery after receiving a full explanation, employing pictures, from the operating neurosurgeons, myself and a young colleague from our department. He was 86 years old. It is with great sadness that we announce this loss, the passing of a true pioneer in the field of pediatric neurology who chaired our Department of Pediatrics at Tokyo Women's Medical University, for a quarter of a century, teaching and mentoring young doctors and leading us into the 21st century.



The depth and breadth of his accomplishments are a testament to his commitment to patients, their families, the university, his co-workers and advances in pediatric neurology worldwide. He will be sorely missed by friends and colleagues alike, thanks to his tireless efforts to advance Child Neurology, always based on his belief in “slow but

steady, life is long” progress. Not only was Professor Fukuyama a life-long teacher and mentor, he was also a leader in the field of Pediatric Neurology throughout the world. [Read complete tribute.](#)

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Obituary: Karen Gale, PhD (1948 - 2014)



The epilepsy community has lost a truly unique and powerful voice with the recent death of Karen Gale, Professor of Pharmacology at Georgetown University in Washington, DC. The basic statistics of her life as a researcher were that she had her early education in New York City, her undergraduate degree at the University of Michigan and her PhD in Psychology from the University of Washington in 1975. After several years at the National Institute of Mental Health in the Laboratory of Preclinical Pharmacology with Erminio Costa she joined the faculty of Georgetown University where she was a dynamic force in the Department of Pharmacology for the remainder of her life and rose to the rank of professor and was one of the founders and the director of the Georgetown Interdisciplinary Program in Neuroscience.

Her research career was one of consistent excellence. Her first two publications were in *Nature* and *Science*, and 36 years later, she and her trainees were still publishing in such journals as the *Journal of Neuroscience*, *PloS One* and *The Proceedings of the National Academy of Science*, publishing 169 articles along the way.

Although Karen had a research agenda that was as wide as her active intellect, she was best known for her examination of subcortical circuitry, its pharmacological manipulation and how altering their activity affected behavior. Her pioneering research on the critical roles of subcortical structures, including the substantia nigra on seizure control and propagation has had a major role in our understanding of the distributed nature of seizures and how they might be controlled. Her more recent work on the comorbidities of epilepsy including deleterious effects of antiepileptic compounds on neural development has stimulated great discussion within the epilepsy community. Although she was best known in epilepsy circles for her attention to the limbic system with an emphasis on glutamate and GABA-mediated influences on epileptic seizures and memory, her work on the neural substrates of Parkinsonism and cocaine-induced hyperkinesias extended her influence in the field of the neurobiology of disease. She was well ahead of the field with her emphasis on brain circuitry. Her contributions were recognized with the Epilepsy Research Recognition Award from the American Society of Pharmacology and Therapeutics in 1995 and the posthumous Extraordinary Contribution Award from the American Epilepsy Society.

Although Dr Gale left an indelible mark as a researcher and educator, she is perhaps best known as a stalwart advocate for faculty, students and staff. She influenced and encouraged the careers and professional development of many junior colleagues. Karen was also recognized for her tireless commitment to the development of early career investigators, women and minority scientists in the

epilepsy community through mentorship and advocacy. She started the Women in Epilepsy interest group at the American Epilepsy Society, and it was a special event as a male to be invited to attend as an honorary member. There are very few people who have the vision, drive and strength of personality that Karen had, and even fewer who put these traits to the good use that she did. She is greatly missed. Georgetown University has established the "[The Karen Gale Memorial Lecture for Women in Neuroscience](#)" to memorialize this remarkable colleague and awarded her the prestigious [Presidential Fellows Medal](#) in October 2014.

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Farewells Listing on ILAE Website

The ILAE hosts a [Farewells](#) web page where we commemorate our departed colleagues in epilepsy and the contributions that they have made to the field. It is our intention that this section for memorials be open to obituaries for anyone who has been active in the field of epilepsy in any capacity: clinical, social, scientific, psychological, to name but a few. There are no academic, professional or geographical requirements to be considered for inclusion in this section. There are many great things that are done locally to improve the lives of people with epilepsy, efforts that are critical in the battle against this condition. Unfortunately some of the most important contributions are done away from the limelight and may not catch the attention of the larger international community. It is the intention of this section that anyone who has been active in the field be included and have their efforts and successes more widely known. The only real criterion is that the individual worked to help relieve the burden of epilepsy somewhere in the world.

The memorial articles are written by those who knew the person. The goal is to tell your colleagues in epilepsy who this individual was and what the contributions were. Photographs are welcome.

There are two parts to this section: recent deaths and archives. The latter allows League members to learn about those who have gone before and the contributions they made. It also acts as a resource for those who wish to look into the history of epilepsy and those who contributed to it. We look forward to your remembrances of our valued departed colleagues. Please send them or any comments or suggestions that you may have to farewells@ilae.org. We will also welcome multiple remembrances from our members. The success of this project depends entirely on your efforts to help preserve the memories and the accomplishments of our friends and colleagues.

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EpiNet

 EpiNet (www.epinet.co.nz), an international collaborative clinical epilepsy research project endorsed by the New Zealand Chapter, continues to seek participation from ILAE chapter members. Current studies include "**What is a seizure,**" which is an online study designed to determine how consistently physicians interpret case histories. It involves 32 case histories with different clinical presentations. Everyone who completes the 32 cases before the end of March 2014 will go into the draw to win a holiday of a lifetime in New Zealand.

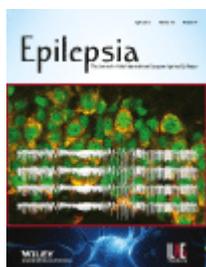
EpiNet comprises a secure patient database, into which doctors can enter details on any person with epilepsy. It can be used by doctors from any country, provided they get approval from their IRB or other relevant authority. Currently, there are over 5000 patients in the EpiNet database. Patients have been registered from 20 countries. The platform has been created to facilitate investigator-led research, and in

particular to perform simple, multi-center, pragmatic randomized controlled trials.

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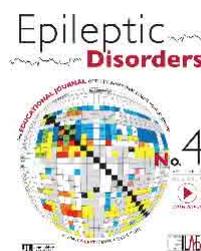
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Upcoming Congresses and Educational Events



5–9 September 2015
Istanbul, Turkey

31st International Epilepsy Congress

www.epilepsyistanbul2015.org

[Why attend the 31st IEC in Istanbul?](#)

11-15 September 2016
12th European Congress on Epileptology
The Prague Congress Centre, Czech Republic

www.epilepsyistanbul2015.org

Chapter Congresses



Deutsche Gesellschaft für
Epileptologie e.V.
Deutsche Sektion der Internationalen Liga gegen Epilepsie

22-25 April , 2015
9th Common Congress of the German, Austrian and Swiss Leagues
Against Epilepsy
Dresden, Germany



More: www.epilepsie2015.de

22-23 May 2015

4th Annual Emirati League Against Epilepsy Congress

Dubai, UAE

Congress website: www.congress2015.elae.ae

8-19 June 2015

5th SEIN Course on Clinical Epileptology

Stichting Epilepsie Instellingen Nederland (SEIN), the Netherlands

The course objective is to improve diagnosis and treatment of epilepsy in the student's own clinical setting by offering young doctors the opportunity to follow a short, yet comprehensive and practically oriented training in clinical epileptology in both lectures and interactive workshops/discussion sessions.

Application Deadline: 24 October, 2014

Information: cmorton@sein.nl

12-13 June, 2015

20th Korean Epilepsy Congress (KEC 2015)

Dynamic Collaboration in Epilepsy Care

Kimdaejung Convention Center, Gwangju, Korea

[Fellowship Program](#) | [Fellowship Application](#): **Deadline 15 April**

Abstract deadline 17 April. Registration deadline 29 May

[Announcement, program and registration](#)

Website: EpilepsyKorea.org



2016



Deutsche Gesellschaft für
Epileptologie e.V.
Deutsche Sektion der Internationalen Liga gegen Epilepsie

3-5 March 2016

53rd Annual Congress of the German League Against Epilepsy

Jena, Germany

More: www.epilepsie2016.de



9-11 June, 2016

Brazilian Epilepsy Congress

Recife, Brazil

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