



Fall 2015

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A message from the ILAE President



Emilio Perucca
President, ILAE

As 2015 draws to a close, it is appropriate to look back at events and achievements that affected our community during the past 12 months. The year started in the most auspicious way with the approval, on February 2, of the Resolution on the Burden of Epilepsy by the Executive Board of the World Health Organization (WHO). The Resolution was approved unanimously by the 168th World Health Assembly (WHA) on May 26, 2015. This event, which comes almost 20 years after the establishment of the Global Campaign against Epilepsy, is a true milestone made possible by the long-standing collaboration of ILAE, IBE and WHO in promoting improved epilepsy care and expanded epilepsy research (1). Above all, the Resolution represents the outcome of truly remarkable efforts made by ILAE Chapters and IBE Associations in sensitizing their governments about the unmet needs of people with epilepsy. With the WHA Resolution, our members now have a powerful tool to engage governments and health authorities into stepping up concrete actions to improve epilepsy services, promote awareness and education, and support epilepsy research.

The League would not exist without the support and dedication of thousands of epilepsy professionals worldwide. The many volunteers who contribute to our Commissions and Task Forces have been working tirelessly and produced 16 published reports over the last two years. Some of the latest include a report on the classification of status epilepticus (2), a systematic review of existing epilepsy guidelines (3), a report outlining the ILAE-

approved methodology for the preparation of future epilepsy guidelines (4), and a report providing general guidance for the participation of people with epilepsy in sport activities (5).

In addition, the Seizure Type Classification Task Force has recently finalized a report on the operational classification of seizure types (6). Because of its pivotal importance, this report will undergo the approval process that applies to "official" ILAE position documents: the report will soon be placed on the League's website, input will be solicited from the entire community, and an ad hoc task force will be appointed to ensure that the comments received are evaluated and incorporated into the final version as appropriate.

A sister ILAE position document, the report by the Commission for Classification and Terminology, which refines the 2010 proposal on the classification of the epilepsies (7), already received extensive public feedback, and a roadmap involving further engagement of our community has been implemented aiming at reaching consensus on the most critical issues and publishing the final version before the end of the current term. Because of the many unique aspects of seizures in neonates, a Task Force on Neonatal Seizures has also been established to address ways by which neonatal seizures and epilepsies can be integrated into the new classification schemes. A brief update on the work being undertaken by this Task Force appears in this issue of Epigraph.

As you are surely aware, in 2013 the League expanded its publication portfolio through the acquisition of *Epileptic Disorders* as its educational journal. Recognizing that existing journals do not allow us to fully address the diverse needs of our constituency, we decided to launch, before the end of 2016, a new research-based open-access journal. More information about this important development will be made available in the coming months.

Publications are only one of many ways by which ILAE advances epilepsy knowledge and education. The [31st International Epilepsy Congress \(IEC\)](#) took place in Istanbul in September 2015 and provided a rich educational and scientific program attended by over 2,700 delegates. Preparations for the [3rd Eastern Mediterranean Epilepsy Congress](#) (hosted jointly with the Emirati League against Epilepsy) in Dubai, 4-5 March 2016, the [11th Asian and Oceanian Epilepsy Congress](#) (Hong Kong, 13-16 May 2016), the [9th Latin American Congress on Epilepsy](#) (Cancun, Mexico, 20-23 August 2016), and the [12th European Congress on Epileptology](#) (Prague, 11-15 September 2016) are well under way.

In addition, we continue to invest a major portion of our resources into epilepsy courses, training programs, and other initiatives especially aimed at supporting young colleagues committed to epilepsy care and research. Examples of these activities featured in this issue of Epigraph include the ALADE fellowships, the reorganization and expansion of our distance education programs (VIREPA), and a highly successful initiative, spearheaded by our North American Commission at the Istanbul IEC, to mentor and promote the epilepsy leaders of tomorrow.

We recognize the value of partnering with our Chapters and with other organizations and scientific societies in activities that bring added value to our mission. Thus, we continue to work closely with IBE in promoting epilepsy awareness and in advocating for support of epilepsy research. The Joint ILAE/AES Translational Research Task Force is making important progress in producing recommendations to improve the quality and translational value of preclinical research. The League worked closely with the World Federation of Neurology (WFN) in promoting the WHA Resolution on Epilepsy, in supporting World Brain Day (which for 2015 was dedicated to epilepsy), and in finalizing a well-attended epilepsy program at the recent World Congress of Neurology in Santiago, Chile. Likewise, collaborative

initiatives are ongoing with the European Academy of Neurology in relation to the organization of courses and congresses, and with the International Federation of Clinical Neurophysiology Societies (IFCN) in relation to the program of the 31st International Congress on Clinical Neurophysiology due to take place in Washington DC, USA, in May 2018.

I cannot close my brief summary of 2015 ILAE events without remembering two great leaders of our community who left us in recent months. [Jean Aicardi](#), a much loved physician and scientist who mentored so many leaders in child neurology and epileptology, passed away on August 3. [Hanneke de Boer](#), the advocacy champion who fought for decades for the rights of people with epilepsy worldwide, left us on October 12. Although these giants are no longer with us physically, they are still vividly alive in our memory and will continue to inspire our community for generations to come.

Emilio Perucca
President

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The Bhutan Epilepsy Project



Damber Nirola, in-country principal investigator, and Farrah Mateen, principal investigator, of the Bhutan Epilepsy Project

The Bhutan Epilepsy Project is a prospective study in the Himalayan Kingdom of Bhutan, a small landlocked country of less than one million people. Bhutan is a unique location with its combination of traditional beliefs and promulgation of gross national happiness, which is the measure by which Bhutan determines its national development.

Like many countries worldwide, Bhutan lacks a neurologist. Therefore, epilepsy care *de facto* becomes the purview of primary health care workers and other specialists. Epilepsy patients in Bhutan are seen through the Department of Psychiatry's Outpatient Clinic at the Jigme Dorji Wangchuck National Referral (JDWNR) Hospital in Thimphu, Bhutan's capital. It is an approximately 350-bed hospital with several outpatient clinics and was named after the king who died in 1972. Dr. Damber Nirola, the head of the Department of

Psychiatry, cares for several hundred epilepsy patients. Pediatric patients are managed through the country's pediatricians and health care workers. In general, approximately half of Bhutanese patients self-report that they also receive care through the prevalent traditional medicine services available in the country.

There were several reasons for choosing Bhutan for this project, first and foremost of which is the absolute need for epilepsy services and care. Second, in view of its "developing economy" status, Bhutan is an excellent place for introducing disruptive technologies. Because it has a high rate of mobile phone ownership, the country lends itself well to the use of these phones for epilepsy related apps. For example, there were previously no EEG technicians or working EEG machines in Bhutan, but the project has implemented the use of a mobile phone app coupled with a 14-lead headset. This technology allows EEGs to be recorded at one site but read in other countries. Further, because Bhutan has a rugged terrain with many rural communities, there are frequent difficulties with transportation. Finally, there is a high burden of epilepsy.



Figure 1. Joseph Cohen, Chief EEG Technician at the Massachusetts General Hospital, performs an EEG on a

The Bhutan Epilepsy Project has enrolled approximately 275 people with known epilepsy or suspected seizures since summer 2014. The main research goal is to characterize risk factors, awareness, and diagnosis of epilepsy in Bhutan. The project employs a smartphone-based electroencephalogram (EEG) app, the Smartphone Brain Scanner-2, designed by my collaborators at the Danish Technical University (Arek Stopczynski, PhD and Lars Kai Hansen, PhD). The smartphone app has several advantages in lower-income settings where neurologists are relatively few or absent. For instance, the app is battery-powered,

participant at the JDW National Referral Hospital in Bhutan.



Figure 2. Ap Bokto: Bhutanese hero. The bottom image shows him holding a sign warning against cysticercosis



Figure 3. Lhab Tshering, Research Coordinator, Bhutan Epilepsy Project, interviews a monk who is participating in the project.

compatible with headsets with pre-positioned leads on "caps," user-friendly, and much less costly than standard EEG.

The Bhutan Epilepsy Project involves a team of more than 30 people in several countries to bring epilepsy research and care to Bhutan. Dr Nirola leads the current care of epilepsy patients at the JDWNR Hospital. Dr Nidup in the Department of Radiology supervises MRI acquisition and interpretation, and Dr Tshokey and Ms Sonam Paydon in the Department of Pathology perform *T. solium* testing in blood for the diagnosis of neurocysticercosis.

The access to technology and new human resources for health among Bhutanese people with epilepsy in our study is meant to improve their epilepsy management for the long term. The Bhutan Epilepsy Project has involved many colleagues from Massachusetts General Hospital, Sunnybrook Hospital in Toronto, and the University of Manitoba. Their skills include epilepsy treatment, neurocritical care, EEG technology use, and EEG interpretation.

In Thimphu, we depend on Sonam Deki, BComm and Lhab Tshering, BSc, for project management as well as translation, organization, and continuity to the project. They are essential to all aspects of the project by making it relevant and sensitive to the local context. In Boston, our project is coordinated nearly full time by Sarah Clark, BSc, who leads data quality control and international coordination among the many co-investigators.

So far, we have amassed nearly 1,000 EEGs, including the first neonatal EEGs performed in Bhutan (Figure 1). In addition, we have provided clinical recommendations for many Bhutanese people living with epilepsy. Participants have come from all 20 districts of the mountainous country. In addition, I was a guest on an hour-long epilepsy awareness radio program for Sun Valley Radio in Thimphu, and the team has collaborated with Athang Studios to produce an epilepsy awareness cartoon with the Bhutanese hero, Ap Bokto, which was released in late summer 2015 (Figure 2). To get a sense of the country and people please look at our short film entitled *The Curse* ([View video here](#)), which received the American Academy of Neurology's 2015 film festival award. It was directed by Discovery Himalayas in Bhutan and depicts the story of Karma, a young boy who died of epilepsy — likely due to an unintentional injury — in rural Bhutan. Karma's story reminds us of the tragedy of epilepsy in countries where we have more work yet to do.

Financially, we are thankful for the support of Massachusetts General Hospital, Grand Challenges Canada, Thrasher Research Foundation, and an educational grant of the World Federation of Neurology as well as travel grants from various sources including the Massachusetts General Hospital Center for Global Health and Partners Innovation Center.

The Bhutan Epilepsy Project has grown well beyond the humble ambitions we started with, incorporating community outreach, full time local staff, and emerging technologies for more than twice the number of participants than we had originally thought we would enroll. We are thankful for the opportunity to work in Bhutan, to mutually educate North American and Bhutanese people, and to attempt to sustainably improve the status and care of people with epilepsy in Bhutan (Figure 3). We are now in the second year of the project and are keen to continue our project for the longer term in Bhutan and beyond. We hope this project can become a model for developing epilepsy programs in countries with limited resources and expertise.

Submitted 26 July 2015 by Farrah Mateen, MD, PhD, Massachusetts General Hospital & Harvard Medical School, Boston, MA, for the ILAE newsletter. Revised October 23, 2015.

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A Remarkable Round-Table of Experts: Arranged Marriages in People with Epilepsy



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"To disclose (epilepsy) or not (during marital negotiations)?" This was the topic of an intense debate at the University College, London, Grand Challenges Initiative-supported round-table meeting of about 25 experts held on April 19, 2015 at Ludhiana, Punjab, India.



Experts and volunteers at the UCL Grand Challenges Small Grant Initiative Round-Table Meeting to discuss arranged marriages in people with epilepsy. Ludhiana, India, April 19, 2015.

Neurologists, physicians and other professionals caring for people with epilepsy (PWE) across many South Asian countries and to some extent other resource-limited countries are faced with this dilemma time and again. Yet, the physicians have no well-founded answers when young, unmarried PWE and their families approach them with the question. The question almost always is whether or not to inform their prospective suitors that they are affected by epilepsy.

"To reveal or to conceal" is a dilemma faced by almost all PWE in a variety of circumstances all over. However, the problem is further compounded when PWE go through arranged marriages.

Arranged marriages are particularly common (accounting for nearly 80% of all marriages) in India and much of South Asia (including Pakistan, Bangladesh, Nepal and Sri Lanka). In these countries, parents or elders in the family choose marriage partners for younger unmarried people and hence negotiate marriages on the basis of religion, caste, physical features, economic status, and educational achievements. In these arranged marriages, the potential marriage partners get very little opportunity to meet before marriage and hence to discuss both appealing and undesirable attributes (e.g., epilepsy). Furthermore, hiding epilepsy during marital negotiations is underpinned by the intensely felt stigma associated with epilepsy.

Societal beliefs about epilepsy

Epilepsy was equated with insanity and hence a legitimate ground for divorce under the Hindu Marriage Act in India. The act was amended by the Indian Parliament largely due to the efforts of neurologists across the country in 1999 and epilepsy is no longer a ground for divorce. Nevertheless, societal beliefs regarding epilepsy remain intensely negative and PWE experience high levels of both felt and enacted stigma during marital negotiations.

The round-table brought experienced epilepsy specialists, social scientists, social activists and legal and administrative experts together to deliberate on ways and means of dealing with the situation. The expert opinion generated was based on scanty published literature, individual opinion of the experts and discussions on several transcripts of physician-patient discussions specifically on this subject. The experts agreed that both "felt" and "enacted" stigma associated with epilepsy during marital negotiations was heavily gendered and affected women much more than men. Beyond this, the experts felt that there were huge knowledge gaps. To what extent epilepsy impacts marriage prospects in the context of arranged marriages has not been adequately documented. However, although the precise burden of the problem has not yet been fathomed, the felt stigma associated with epilepsy is the primary reason for hiding epilepsy during negotiations in arranged marriages.



Experts at the round-table meeting included neurologists, social scientists, social activists, and administrative, media and legal experts.

Hiding epilepsy in arranged marriages however, comes with a heavy cost. Women with epilepsy move to patrilocal conjugal dwellings after marriage and under the circumstances are deprived of the much required social and family support they were able to garner in their natal homes. Because the fact that they have epilepsy is under wraps, these women have no choice but to take their epilepsy medications in a clandestine manner (often by putting the epilepsy medicines in vitamin bottles). This inevitably leads to compromised adherence to epilepsy medications. Also, for the same reason, PWE are unable to make the required visits to physicians at a time when frequent consultations with physicians are much required to deal with contraception, pregnancy planning and childbirth.

Who counsels PWE in seeking matrimonial alliance through arranged marriages? Our guest experts from England posed this question and wondered whether neurologists had the time and expertise to counsel PWE on their matrimonial designs. In most of South Asia and other resource-poor countries, in which arranged marriages are common, marriage counsellors are few and far apart and do not have specific experience in tackling epilepsy-related matrimonial issues. As a result the responsibility falls squarely on the physicians who have been following the PWE in their clinics.

There is no "one size fits all" formula to counsel PWE regarding matrimony. Neurologists should bring up the topic for discussion early on. Often parents of an adolescent girl visit the neurologist full of trepidation: "How will we get her married?"; "Who will marry a person with epilepsy?" At this stage, it is crucial to counsel them in an accurate yet optimistic manner about the mostly benign nature of epilepsy with the possibility of remission, and the practicalities of marriage, sexual relationships, pregnancy, childbirth and child-rearing. Perhaps more important is to emphasize the importance of empowering the girl child with education and the later prospect of employment so that epilepsy however disparaging is relegated to the background by favorable attributes such as job-worthiness and a good income at the time of marital negotiations.

The father of 24 year old Sushma (name changed) met the neurologist with a hope for a solution. He was desperate to get his daughter married as is societal practice in much of South Asia (Here, it is the parents and extended families who are responsible for deciding a suitable match for young women and men of marriageable age). On several occasions, when he and his wife disclosed the fact that Sushma sometimes would have epileptic seizures for which she needed to take epilepsy medications, the marital negotiations between his and the prospective bridegroom's families were called off forthwith. He had several questions including whether and how could Sushma's epilepsy medications be stopped before getting her married but he was conclusive about one issue: He would not disclose the fact that Sushma had epilepsy in any of the future matrimonial negotiations.

"Whether to disclose (epilepsy during marital negotiations) or not to and when to disclose" is ultimately a decision of the individual and his/her family. However, the neurologist might play a useful role by emphasizing the importance of disclosure at the appropriate time. It is probably fitting to apprise PWE and their families seeking matrimonial alliances through arranged marriages about the problems of hiding epilepsy in as intimate a relationship as marriage.

The best way out is a turnaround in people's attitudes and beliefs — however, this might take a long time. A concerted effort is desirable at multiple levels to take away the stigma associated with epilepsy. Undoubtedly, neurologists should take the lead but also take the help of other sectors — governmental, legal, policy-makers, social activists and so forth.

The round-table meeting set the pace for a multidisciplinary approach but with emphasis on what should be done by neurologists and professionals caring for PWE. One conclusion echoed: There is much to be done and this is just the beginning.

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Marriage and Epilepsy: Struggles of Women Living with Epilepsy in Kerala, South India



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The psychosocial burden associated with the stigma of living with epilepsy can be a bigger hurdle than the disease itself. Many studies from developing countries that have looked at the burden of stigma have shown the struggles that people living with epilepsy face, particularly women living with epilepsy.

I recently conducted an ethnographic study on epilepsy, its psychosocial consequences and its treatment gap among women in the outskirts of Kozhikode district of Kerala, South India. These are women who were identified as receiving treatment from traditional healers and who were either not on any AEDs or receiving AEDs intermittently. The study describes their daily lives; their thoughts and perceptions about epilepsy; and their customs, traditions and beliefs regarding the disease. Spending a maximum of two weeks' time with each participant, data were collected through in-depth interviews, participant observation and field notes.

Potential participants were identified from local traditional healers' consultation areas, and through word of mouth. One of the problems encountered in the conduct of this study was that I came to be recognized as the "epilepsy lady" by the women I contacted, even though I dressed traditionally while conducting the study and spoke Malayalam with native fluency.

For this reason, of the 21 potential participants identified, in spite of assured confidentiality, 8 women of marriage age or their families refused to allow the women to be part of an "epilepsy" study for fear of being recognized by the community as someone with epilepsy and for fear of disadvantages in marriage negotiation. Comments from these potential participants included: "Can't we talk over the phone? If you come here,

neighbors will enquire ... they will come to know [about her epilepsy]...” “There is nothing I want to talk [to anyone] regarding this disease...” In a mother's words regarding her daughter who has epilepsy: “After waiting long, people have started approaching us with marriage proposals for her. If she is participating [in the study], she may stay at home forever [without getting married].”

Six women eventually enrolled and completed the study. The general belief in the community about epilepsy was that it was caused by certain supernatural forces, including possession by evil spirits, casting of spells by someone else or curse of God. Although the initial treatment sought was allopathic medications (AEDs), eventually the women transitioned to traditional medicines. All participants, irrespective of their religious beliefs and faith, had conducted rituals, prayers, and offerings as suggested by the faith healers as well as those that were in accordance with their convictions.

The story of two of those women and their struggles with marriage and marriage negotiations are illustrative of the many issues associated with marriage in women with epilepsy.

Ms. Sudha was a 45 year old unemployed woman with elementary school education. Her first seizure was in a bus when she was 13 years old. Along with many changes these seizures brought to her life, the biggest was the termination of all her education options. When she was 15, her parents, who were illiterate, started worrying about finding an appropriate bridegroom for her. They concealed the history of her epilepsy and married her to an already married man much older than she. She continued living with her parents because they considered her to be their responsibility and her husband visited her a few days every week.

Nine years later, upon witnessing a seizure, her husband felt cheated and blamed the participant and her family. He took his wife to a neurologist in the city for treatment but later divorced her. She brought up her two daughters while depending on the rest of her family for financial support and the charity from well-wishers in her community. Her lamentations of living with the disease continued when she found that her disease was also affecting marriage negotiations for her daughters. She has tried different types of treatments for her epilepsy and is currently on AEDs, though not on prescribed dosage due to financial constraints and side-effects of the medications. Obtaining AEDs requires



Traditional firewood stove in rural Kerala. A common source of burn injuries for women with epilepsy.



Working in Kerala kitchen grinding coconut on a stone.

that she travel approximately 2 hours each way with the further cost of doctor's fees and transportation. She also has to plan to purchase the medications during this visit because the pharmacy in the neighborhood village does not sell the medicines she needs.

Ms Girija is a 29 year old woman with graduate education holding a clerical job in a local shoe company. She is the mother of a two year old child. She has nocturnal seizures and describes them as catamenial in pattern. Like other participants, she has undergone many types of treatments for her seizures. Her family took her to a hospital when she had her first seizure and she was started on AEDs. Immediately after this, her grandfather, who did black magic, conducted rituals and gave her an amulet to wear around her waist. At the time of the interview, she was on treatment from the traditional healer who was slowly weaning her off the AEDs and increasing the dose of traditional medicine.

Concealing her history of epilepsy, her parents got her married three years ago. She had seizure reduction around the time of her marriage and thought it inappropriate to conceal her epilepsy from her fiancé then. However, her husband came to know about her disease when he enquired in the pharmacy about the purpose of the medication she was taking and later witnessed one of her seizures. He felt cheated and blamed her family for concealing her epilepsy from him. He started behaving differently, consuming alcohol and emotionally abusing her. His words to her were: “You have this disease, your family cheated me, and so now, whatever I do, you have to adjust accordingly and live.” They also stopped social interactions, especially visiting her husband's family for fear of disclosure of her seizures.

Her family feels guilty and feels responsible for her care, supports her in child care, and provides financial support for epilepsy treatment. She quietly tolerates the emotional struggles and says: “If I have to tell anyone about his behavior, I will also have to explain my disease and I don't want that.” She regretted being married, wished her husband realized that her disease was not her mistake, and was emotional throughout the conversation on life after marriage.

All four participants in the study who started experiencing seizures prior to marriage had stories about struggles of living with epilepsy after marriage and during marriage negotiation. Their stories reflect the need for culturally appropriate intervention to create awareness and to educate the public regarding epilepsy and thereby reduce stigma. Further research is deemed important to better understand the attitude of community stakeholders regarding epilepsy and in providing acceptance of and access to more effective treatments.



Making Ayurvedic medicinal oil.



Preparing herbals at a local medicinal company.

ILAE Leadership Development Program at Istanbul IEC

The League has established the ambitious goal of a world in which no one's life is limited by epilepsy. This goal requires the involvement of thousands across the globe in a focused effort to break down barriers and open possibilities for people who face legal and cultural limitations that are imposed on them. Such an action requires the involvement of people who understand the disease and its consequences as well as the society within which a person with epilepsy lives. There are over 100 League national chapters and as many or more national attitudes about the disease. Making progress requires that initiative be taken in each country to change perceptions and the support for combating the disease.

The League has had a number of successes in the last 20 years since the Global Campaign Against Epilepsy began, including the Pan American Health Organization's Plan of Action, the European Written Declaration on Epilepsy and the recent World Health Assembly Resolution. These successes required a vision as well as effort and leadership. However, the ultimate success of these international political actions will depend on efforts at the national level.

With the identified need for greater numbers of members with the skills to develop local plans and advance the cause of improved epilepsy care around the world, the League, through the North American Commission, created the Leadership Development Program, guided by Sheryl Haut and Jaideep Kapur. This workshop is based on programs that have been in place in North America and Europe for some years to help professionals in the early stages of their careers understand what is involved in organizing and managing initiatives and projects.



Sheryl Haut



Jaideep Kapur

The program is not intended to be a complete management techniques course, rather it is designed to give professionals who have not been trained in management a basic understanding of how organizations work and how one can work with organizations to achieve important goals.

There were a total of 21 participants in this inaugural course, with the largest numbers coming from Europe (7) and Asia (6). They were selected from a total of 38 eligible applicants based on their past experience, their contributions or relation to epilepsy and on letters of recommendation. The course was divided into one and a half days. The first day was composed of presentations by many senior members of the League on such topics as strategic planning, financial planning, communication (oral, written and electronic), and management essentials as well as how to create and develop a League chapter. The following half day was devoted to a

review of the DISC profile that each participant completed before arriving at the meeting. The DISC profile has become a standard industry and management tool to evaluate how a person will behave in certain environments and situations. However, it is often used, as it was in this course, to help a person get to know oneself and others better in order to understand how each may interact in different situations.



At the end of the meeting the overall evaluation from the participants was quite positive, but each participant took away different messages. What follows is a sampling of comments from five different people addressing their impressions of the course.



Pauline Samia is a Senior Instructor and Consultant Paediatric Neurologist at the Aga Khan University in Nairobi, Kenya. Epilepsy makes up the majority of her clinical practice, and she applied to the course because she was interested in helping to move care for children with epilepsy forward in Kenya as well as the East African region. Several of the areas that she found particularly valuable included the process for strategic planning to develop goals, and how one needs to work in teams to accomplish those goals. She also learned about the importance of time management. She intends to use her new skills to help the Kenyan chapter achieve its goals.



Rosa Michaelis is a third year Neurology Resident from Germany. Epilepsy has been an area of great interest to her since she was a medical student because of the potential mind-brain interaction and how it might contribute to seizure initiation. She learned of the program from the German chapter and wanted to participate because she likes to develop things and thought this course might give her useful tools. Several important things she learned was how to run a meeting while keeping people involved and the importance of having a vision to help serve as a guide.



Seinn Mya Mya Aye is an adult neurologist at the Yangon General Hospital in Myanmar, a major teaching hospital. In addition to her clinical duties she is part of the collaboration between the national Ministry of Health and the World Health Organization on an epilepsy demonstration project. She was interested in taking the course because she had experienced that there are always many obstacles to getting things done at all professional levels. The program gave her ideas on how to resolve conflicts and overcome the obstacles to achieve objectives. The course also gave her new ideas on how to manage time, people and budgets.



Asel Jusupova is an adult neurologist from Bishkek, Kyrgyzstan. She is involved with teaching medical students and treating patients in outpatient and inpatient settings. She is also the secretary for the Kyrgyz League Against Epilepsy. Her goal in taking this course was to increase awareness about epilepsy to improve its treatment nationally. She learned the importance of establishing goals and how to begin conversations on how to resolve system problems in the treatment of epilepsy with the health care authorities.



Rodolfo Callejas-Rojas is an adult neurologist in Mexico City who is now in training to learn EEG. He wants to develop a career in epilepsy with the eventual goal of creating an epilepsy center in a region of the country without such services at present. In this course he learned much about many aspects of management but also about the techniques he can apply when approaching others about solving problems. The talks emphasized to him the importance of forming networks of people who have a common goal and how he might develop those networks.

All of the participants reported that the most valuable part of the workshop was the DISC personality profile discussion on the second day. Each stated that the insights about their personality type with regard to particular strengths and weaknesses would be put to use while developing and working in teams to develop and carry out plans. They also noted that this exercise pointed out how differences in personality can affect group interactions, which may determine the success or failure of a plan or project. Although the course did not provide solutions for every potential conflict, it did make all aware of how unrecognized personality differences can derail projects very quickly unless they are addressed early.

The League looks forward to learning how this course helps the participants advance their own professional careers as well as the cause of epilepsy at the national level. The diversity of the participants geographically as well as professionally is important because the needs for epilepsy care, while different from country to country, cross many areas of expertise from the social to the laboratory with many points in between. What is needed for epilepsy care to advance is strong and effective voices to address each of those needs, and we hope that this workshop can help increase those numbers.

ALADE Epilepsy Fellowships 2015



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Uruguay*

Throughout the world, there is a severe shortage of medical professionals with expertise in epilepsy, and Latin America is no exception. ALADE (“Academia Latinoamericana de Epilepsia”) has developed a number of training opportunities to improve this shortage, including itinerant courses, educational materials in the form of books and brochures, as well as ALADE courses during the Latin American (LA) Regional Congresses. To accelerate and strengthen the training opportunities, ALADE has initiated Latin American epilepsy fellowships. We undertook this initiative because in many countries the opportunity to focus training on epilepsy is limited or non-existent and because there is no dedicated funding to cover the expenses of a trainee from outside the country.

The ALADE Fellowships began in 2011 as part of the educational activities of ALADE and the ILAE Commission on Latin American Affairs. The main objective has been to decrease the treatment gap in a number of Latin American countries. One of the ways of achieving this goal was to “train the trainers,” in order to obtain a multiplying effect by transferring knowledge from one institution to another through a trainee. The other idea behind this initiative was to take advantage of the training facilities of established epilepsy centers within the region and as a means of decentralizing the usual north-south academic flow. There is already evidence that the training experience in a country with similar cultural and economic conditions to one's own is more relevant to the trainee's clinical practice as opposed to the experience one might have in systems that are totally different.

Funding is essential to the success of this effort, and these programs are funded by the ILAE through the budget of the Latin American Commission in an amount of US \$12,000 per selected candidate for a 12 month period. The professionals who are eligible to apply for the fellowships need to be child or adult neurologists or neurosurgeons from Latin America and be interested in spending one training year at an established Latin American epilepsy center.

In turn, for these centers to qualify to be included in the list from which the selected candidates make their choice, each must have a reputation for being an established institution known to carry out assistance, education and research activities in the field of epilepsy with structured courses in clinical epileptology or surgery. This year nine centers from five countries were included in this group. Before the application review takes place, these centers must inform ALADE of their willingness to receive fellows and about the number of child and/or adult neurologists they can accommodate, which in general is one to three.

To publicize the program widely, we made the call for 2015 Fellowships through the ILAE Web and via all LA chapters. Accompanying the call, other documents containing the rules of ALADE fellowships and a list of LA epilepsy centers willing to receive fellows were also uploaded to the Web page and sent to the chapters.

This year there were 13 candidates. The applications were analyzed according to a set of pre-established selection criteria. These criteria included previous scientific productivity, reasons to apply for the fellowship stated in a letter, prior participation in educational activities, country of origin (and previous training opportunities), as well as engagement with the activities of the institution (preferably university) to which the

candidate belongs. There was funding for a total of 3 fellows; a fourth wished to make use of the opportunity and was able to find funding elsewhere. This year's fellows are:



Dr Vanessa Benjumea (Colombia) is going to H. Ramos Mejía, Buenos Aires, Argentina. She completed her neurology residence at CES University, Medellín, Antioquia, Colombia.



Dr Eva López (Venezuela) will go to the F.I.R.E. Center, Cartagena, Colombia. She completed her general neurology training at Ciudad Hospitalaria “Dr Enrique Tejeras,” Valencia, Estado Carabobo.



Dr Liza Núñez (Perú) chose to go to the Clínica Las Condes, Santiago, Chile. She is an adult neurologist at the department of epilepsy, Instituto de Ciencias Neurológicas, Lima, Perú.



Dr Martha Ríos (Cuba) selected H. Clínicas, Riberão Preto, Brazil. She is a pediatric neurosurgeon who studied at “Juan Manuel Márquez” Hospital, La Habana.

At the end of their stay, the fellows are expected to send a report on their academic experience and the corresponding centers as well to submit a progress report and evaluation of their guests. A follow-up evaluation of the fellows from previous years is being initiated.

ALADE and the Latin American Commission hope that all the fellowships result in a very positive training period that may contribute to improved epilepsy care in the region!

Alejandro Scaramelli
ALADE President

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Classifying Seizures in the Very Young: Initial Plans of the Neonatal Seizure Task Force (part of ILAE Commission on Classification & Terminology)



*Ronit Pressler, MB, PhD, MD
Honorary Senior Lecturer and
Consultant in Clinical*

Seizures are the most common neurological emergency in the neonatal period and are associated with considerable mortality and morbidity. Neonatal seizures are usually acute and often subclinical. They may show discrete clinical manifestations that are often difficult to differentiate from movements seen in sick preterm or term babies. Hence, the need for EEG confirmation for the diagnosis of neonatal seizures is now widely accepted. All of this makes the integration into a classification serving all ages difficult, which is reflected by the fact that, until recently, the ILAE classifications did not include neonatal seizures.

Consequently other classifications have been published by neonatologists and paediatric neurologists, that are specific to the neonatal period (Volpe, 1989; Mizrahi and Kellaway, 1987). A recent survey at the 9th international conference of

Neurophysiology
Great Ormond Street Hospital, UCL
Institute of Child Health, London

brain monitoring and neuroprotection in the newborn (Cork, 2015) has shown that most neonatologists either do not classify neonatal seizures or use the Volpe classification. Although simple to use, this classification has the disadvantage that it is based purely on clinical manifestation and disregards the need for EEG diagnosis, consequently subclinical seizures are ignored and many non-seizure events are classified as seizures.

Although there are a number of single centre studies to describe seizure semiology with EEG (Watanabe et al. 1977; Mizrahi and Kellaway, 1987; Nagarajan et al. 2012), no multicentre collaboration has so far come to a consensus on how best to define, characterise and classify/organise neonatal seizures.



The development of a new classification for epilepsy has been the major focus of the ILAE Commission on Classification and Terminology over last few years. One of the aims of the new classification of the epilepsies was to have unifying concepts for seizures for all ages and thus “neonatal seizures are no longer regarded as a separate entity. Seizures in neonates can be classified within the proposed scheme.” However this position is controversial, as it does not take into account the particular complexities in this age group including acute aetiologies, high electrographic seizure burden and management within the intensive care setting. In 2014, a new Task Force on Neonatal Seizures was established with the assignment to develop ways in which neonatal seizures and epilepsies can be integrated into the new classification of the epilepsies.

At that time a set of guiding principles was established for the new classification. The classification should address seven key points.

1. Take into account the specificities of seizures at different gestational ages. The developing brain changes rapidly and how it will support seizures will change considerably over several weeks.
2. Be based on electro-clinical phenotyping. There are many behaviours that are seen in a premature or sick neonate that difficult to classify on clinical appearance alone. Physiological confirmation is needed.
3. Reflect the pathophysiological origin / aetiology of events. The prognosis of a child with neonatal seizures is related to the cause.
4. Emphasise the key role of EEG in the diagnosis of neonatal seizures. Patterns on recordings vary with age, there must be consensus on what patterns constitute seizures so that suspicious behaviours can be identified as seizures.
5. Have implications for the management and treatment of events. It is important to determine which treatments under specific situations will be beneficial.
6. Be acceptable to epileptologists, neonatologists, paediatricians and neurologists alike. To be useful in providing a common language for clinicians treating neonates all parties have to agree that it is a useful approach.



7. Be applicable in all health care settings. A classification is not useful if it can only be applied at a limited number of facilities.

A meta-analysis of electro-clinical semiology of term and preterm seizures is being prepared as a point of reference. We are currently working on a diagnostic framework to describe neonatal seizures which can be used in conjunction with the new classification of the epilepsies using the same concepts and terminology. This will be verified via a retrospective collection of clinical and video-EEG data on seizures in neonates of different gestational ages for electro-clinical phenotyping.

Task Force members: Ronit Pressler (Chair), Sameer Zuberi, Elissa Yozawitz, Perrine Plouin, Roberta Cilio, Magda Nunes, Sampsa Vanhatalo, Eli Mizrahi, Nico Moshé (Management Committee Liaison).

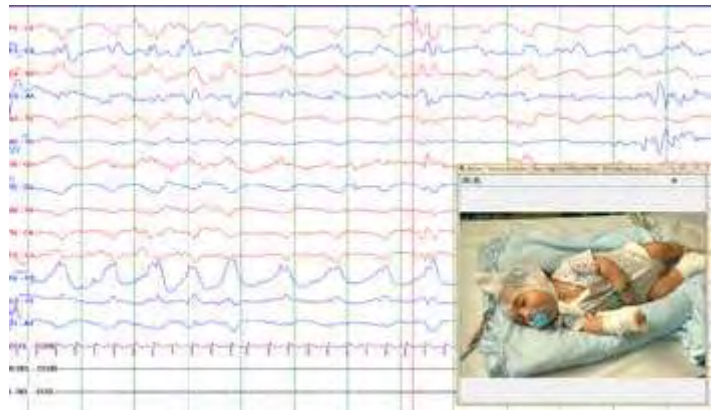
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VIREPA



Emilio Perucca
President



Samuel Wiebe
Epilepsy Education Task
Force



Jaime Carrizosa
Chair, Education
Commission



Walter van Emde Boas,
Chair, Distance
Education
Task Force

The ILAE VIREPA Distance Education Program started in 2004 as an initiative of the Commission on European Affairs and was formally incorporated into the overall educational activities of the ILAE in 2009. Since its inception, over 650 students from 88 countries have participated in 37 VIREPA courses. Participant evaluations have been consistently and overwhelmingly positive regarding new knowledge gained and the relevance of the courses to professional practice.

The success of any educational enterprise is dependent on the human element and the quality and credibility of the product. VIREPA's course directors and tutors represent a gathering of dedicated experts from around the world committed to the task of providing high quality content. We are extremely grateful to these individuals for their efforts, expertise and commitment.

We put great value on the continuation of the League's distance education activities. To allow global access for greater numbers of participants to the first class educational resources and materials the League has at hand, and to do so in a financially viable manner, some modifications to the League's distance education program are required. These modifications will focus particularly on those VIREPA courses that traditionally were not fully subscribed. For those courses, a new more flexible structure will be implemented, which will reduce the time demands for tutors while allowing a greater degree of software interactivity and a substantial reduction of registration fees for participants. The fully subscribed VIREPA EEG Basic, Advanced and Pediatric courses will continue to be implemented in their current form.

The distance education programs of the ILAE have a strong foundation and tradition, and the Epilepsy Education Task Force is working tirelessly to expand them in content, improve their accessibility and diversify them to meet the need of different types of health care professionals. [The VIREPA course directors and tutors](#) have been a cornerstone of these programs and we look forward to working with them to ensure optimal use of their talents and dedication in the continuing evolution of the League's educational mission and programs.

Emilio Perucca, President

Sam Wiebe, Chair, Epilepsy Education Task Force

Jaime Carrizosa, Chair, Education Commission

Walter van Emde Boas, Chair, Distance Education Task Force

Obituary: Jean Aicardi (1926 – 2015)



It is with a great sense of sadness and loss that we learned of the passing of Jean Aicardi, who died the morning of August 3, 2015. Jean was born in 1926 in Rambouillet, France. He earned his MD from the Faculté de Médecine in Paris in 1955 and had his early professional training at the Hôpital des Enfants Malades, also in Paris. It is how he lived those many years that made him an extraordinary figure in epilepsy and child neurology. As he noted, his entry into this field was not planned, rather it came about through almost chance encounters in his early training in Paris with mentors and colleagues who were interested in neurology and children. There was no defined training program, but as with many highly successful people, he found a path forward through many obstacles, including the lack of formal support for physicians who wished to enter the field of child neurology.

Although his many successes were the result of his genius and hard work, he gave much credit to his friends, partners and colleagues in France, in Europe and on the other side of the Atlantic for what he learned and what he created. He was a Director of Research for INSERM until his mandatory retirement at age 65, but official retirement did not stop his life's mission to help children with neurological problems. He continued his work at Miami Children's Hospital and at the Institute of Child Health in London well into his 70s. He was an author on over 400 articles and was the founder of *Epileptic Disorders*, which has become the ILAE educational journal. He mentored many who are now national and

international leaders in child neurology as well as in epilepsy. His legacy is as much in his successes as it is in the success of those he taught and inspired.

Submitted by Ed Bertram

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Obituary: Hanneke de Boer (1946 – 2015)



When Hanneke de Boer died peacefully in her own home after a long illness faced with great dignity a light was extinguished on a life devoted to sufferers with epilepsy. Hanneke was one of the longest serving and greatest advocates of people with epilepsy of all ages, not only in her much loved country, The Netherlands, but across the world.

Hanneke was born in 1946 and at the age of 19 she first joined SEIN (Stichting Epilepsie Instellingen Nederland) as a vocational consultant, where she remained until shortly before her death. She was committed to empowering people with epilepsy to find employment by interacting personally with them and with potential employers. She was also engaged in the lives of her patients and often freely provided support to those struggling with their education courses.

Hanneke's dedication to promoting the needs and advancing the hopes and aspirations of people with epilepsy and their families by personal and collective action is testified not only by her track record, but also by our own personal observations and reflections. At the professional level she had an extraordinary capacity for detailed attention to agendas, priorities, plans of action, and minutes. But implementing such actions and goals required considerable diplomatic and social skills, which she combined with a steely determination.

[Read complete obituary and testimonials](#)

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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 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

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. 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 5,000 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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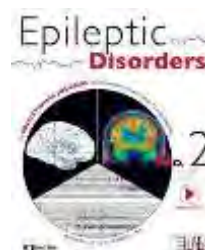
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Upcoming Congresses and Educational Events



4-5 March 2016

**3rd East Mediterranean Epilepsy Congress (EMEC) and
5th UAE Epilepsy Congress**

Dubai

Hosted jointly by the ILAE, IBE, and the Emirati League Against Epilepsy
Abstract submissions are accepted until 15 January 2016

<http://cemaepilepsy2016.org/>



13-16 May 2016
11th Asian & Oceanian Epilepsy Congress
Hong Kong

More details on congress website: www.epilepsyhongkong2016.org



20-23 August 2016
9th Latin American Congress on Epilepsy
Cancún, Mexico

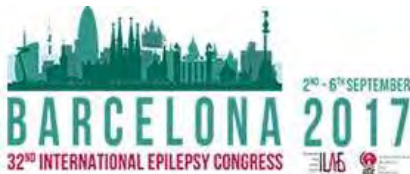
Website: www.epilepsycancun2016.org/



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

www.epilepsyprague2016.org

2017



2-6 September 2017
32nd International Epilepsy Congress
Barcelona, Spain

Congress website: www.epilepsybarcelona2017.org

Chapter Congresses



4-8 December, 2015
American Epilepsy Society 69th Annual Meeting
Pennsylvania Convention Center, Philadelphia, PA
Website: www.aesnet.org

6 December, 6 pm
Ketogenic Diet SIG



3-5 March 2016
53rd Annual Congress of the German League Against Epilepsy
Jena, Germany
Website: www.epilepsie2016.de



12-14 May 2016
Ukrainian League Against Epilepsy
Age and gender aspects of epilepsy through the prism of time
Lviv, Ukraine
Information: lepilep@i.ua



9-11 June, 2016
Brazilian Epilepsy Congress
Recife, Brazil

[Complete Current Congress Listing](#)

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