

Epigraph Volume 18 Issue 2, Fall 2016

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Fall 2016

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From the Information Officer

The International Epilepsy Agenda Moves Forward



One of the goals of *Epigraph* is to publicize how our colleagues are improving the lives of people with epilepsy with quiet but important steps forward. These steps are key to chipping away at the many barriers to care and to social acceptance. In this issue of *Epigraph* there are stories about efforts in education and system reform by patients and by our professional colleagues.

Epilepsy Awareness Day in Disneyland was established in 2013 to allow patients to present their perspectives about their challenges and how they have overcome them. These gatherings allow patients and families to overcome their sense of isolation as they learn there are others who share their experiences. The next Epilepsy Awareness Day is November 2nd and 3rd in Anaheim, California. Another patient-based effort is the Brain Recovery Project that is focused on patients who have undergone a

hemispherectomy, to help families understand the challenges in recovery and how to meet them. It is a year-round effort and resource with an annual meeting for patients and specialized therapists to find paths forward to the best possible quality of life.

One of the great problems faced by all people with epilepsy is the fragmented care that exists in most health care systems. Carter Sned reports on the new integrated system and plan of care in Ontario for people with epilepsy. This article provides a good introduction to how the system was organized. The many guidelines that the Ontario health care system developed over the last several years on the way to this integrated system have been placed on our website. It is a good example of how vision and persistence can move epilepsy care forward.

Lack of knowledge about epilepsy is common to almost all countries, and courses specifically for primary care physicians have been under development for many years. Our Latin American colleagues

have developed two approaches. One is the new online instructor-led program for primary care physicians in which the participants learn the basic principles of diagnosis and treatment from epileptologists throughout the region. The second is a more traditional course held at national primary care conferences. The high participation has emphasized the desire of primary care professionals to treat epilepsy better.

EpilepsyDiagnosis.org was created several years ago to provide accurate information, including video examples of seizure types, and it has developed a significant following. Kate Riney summarizes its current state and where it is going in the near future. It has become an outstanding resource for quick information as well as for teaching, and more should make use of this resource.

Our chapters and their members are leading the efforts to improve access to knowledgeable epilepsy care. In this issue, we celebrate the 20th anniversary of the Epilepsy Society of Thailand. During its first 20 years, the EST has almost doubled in size and has worked to create practical clinical practice guidelines, a quick reference handbook and an EEG textbook in Thai. Like the rest of the epilepsy community, our Thai colleagues face enormous challenges in improving access to epilepsy care, but a milestone anniversary such as this allows us to take stock of how far one can go in a short 20 years.

We hope you find these articles useful and, in some cases, inspirational about what can be done. If you have a story to share about the challenges and successes in moving the efforts to minimize the effects of epilepsy on people, please let us know (info@ilae.org).

Ed Bertram, Information Officer

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A message from the ILAE President Elect



Sam Wiebe
President Elect, ILAE

Dear Colleagues,

First of all, I am honoured to have been elected as President of the ILAE for the period 2017-2021. Thank you for entrusting me to serve our organization in this key leadership role, which I look forward to with much anticipation. The next step in assembling the leadership team for the new term is the elections of the officers who will serve on the management committee, followed by elections of the regional chairs who will constitute the new executive committee. Together, we will work on reaching the objectives that have been broadly set out in my candidacy statement. There is much to be done. I look to the tasks ahead with excitement and anticipation, but also with a good dose of realism. Achieving our goals will require energy and dedication, but especially collaboration and transparency. New ideas and new approaches are welcome.

In my current role as Treasurer, I am happy to report that the League's finances are stable. The financial policies adopted by the League are achieving the intended goal, which is a sustainable organization able to carry out its mission in the face of declining revenues from various sources.

Notable successes at an international level include a favourable renewal of our contract with Wiley Blackwell for the publication of *Epilepsia*; the launch of the League's third journal, *Epilepsia Open*, which will take place during the European Congress of Epileptology in Prague in September 2016; an increasing impact factor of our main journal, *Epilepsia*; and successful regional congresses in Asia and Latin America with reduced registration fees. In addition, commissions and task forces continue to create invaluable educational and scientific resources for a broad range of purposes and audiences. We have become a leaner, more efficient organization, and this will allow us to expand our activities and pursue new enterprises.

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The Brain Recovery Project Focuses On Research And Resources After Pediatric Epilepsy Surgery



Monika Jones (pictured here in 2011 with board member Dr. Gary Mathern) and her husband, Brad Jones, co-founded The Brain Recovery Project. Ms. Jones, an attorney, was the principal investigator on the NIH R 13 grant to partially fund the 2014 scientific workshop on brain plasticity, hemispheric specialization, and neuro-rehabilitation after cerebral hemispherectomy. Her oldest son Henry was born with total hemimegalencephaly and required a hemispherectomy at three months old.

Hemispherectomy for intractable epilepsy in children who have extensive unilateral congenital or acquired abnormalities has had a major beneficial effect on the seizures, with rates of reported seizure freedom between 50 and 80%. Parents of these children are well-informed about the resultant hemiparesis and visual field deficits, but often understand much less about the other, often more subtle deficits that follow the removal of a hemisphere. Although the consequent impairments can be significant, they must be measured against what will occur if the seizures are left uncontrolled — near certain catastrophic regression of intellectual and motor function and possible death. About one-fifth of hemispherectomy patients are gainfully employed and even fewer live independently. There is no doubt that the surgery, when successful, significantly improves the quality of life for patient and family, but families are often left unprepared for the many educational challenges that lie ahead. They often don't recognize the problems, and, more importantly, they don't know how to navigate the educational and medical systems to find the needed therapies, if they are even available.

Since 2009, families from around the world impacted by hemispherectomy surgery have gathered annually in various parts of the United States to learn from experts and connect with families on a similar journey. Originally organized by the Hemispherectomy Foundation, the [International Hemispherectomy Conference and Family Reunion](#) (fondly referred to as HEMICON) is now solely hosted by [The Brain Recovery Project](#), a U.S.-based not-for-profit corporation which funds new research and provides parents

with resources to better understand how they can maximize functional outcomes after pediatric epilepsy surgery.



Children who had hemispherectomy as young as 28 days old were in attendance at this annual two-day conference, as well as adults who had hemispherectomy in childhood (one of whom holds a master's degree in social work). Physicians and specialists from Colorado Hospital of Colorado, the Craig Hospital, the Coleman Institute for Cognitive Disabilities, and other facilities were presented at the conference.

Because parents often report that they were not fully aware of all the post-operative effects of the procedure, the conference's main goal is to arm parents and caregivers with the knowledge they need to help their child reach their full potential in all functional areas throughout their lifespan. As part of The Brain Recovery Project's overall parent education initiative, the conference included sessions to address:

1. **Vision:** Often misunderstood by parents to be only a loss of peripheral vision, homonymous hemianopsia is the loss of the entire visual field opposite the removed hemisphere. This permanent and irreversible visual impairment can have a profound effect on how the child navigates their environment and learns to read. [Dr. Robert Enzenauer](#) and [Lynn Hellerstein, OD](#), discussed this impairment and techniques to help children cope with this extensive field loss.
2. **Hearing:** Although children after hemispherectomy will pass a pure tone hearing test, problems with [dichotic listening](#), [sound localization](#), and [understanding speech in noise](#) are common because the auditory cortex is removed or disconnected in the procedure. Parents also report [misophonia](#) and [hyperacusis](#), sometimes to the point that the child is unable to fully participate in school and social outings. [Dr. Frank Musiek](#), a renowned researcher in the field of central (neural) auditory processing, introduced families to the neuro-anatomical causes of central auditory processing disorders.
3. **Literacy:** One recent paper which addressed [functional outcomes after hemispherectomy](#) in a cohort of over 100 children and adults, found that only 43% of children above the age of six could read satisfactorily. The conference included a [four-hour educational session](#) to help parents understand U.S. special education law in order to obtain the necessary intensive instructional intervention needed to help their child acquire literacy in school.
4. **Hydrocephalus:** Hydrocephalus after hemispherectomy is a concern throughout the lifespan. A [comprehensive, multi-institutional review](#) of 690 patients who had hemispherectomy in childhood found that 20% acquired hydrocephalus after functional hemispherectomy and 30% after anatomical hemispherectomy, with 27% requiring shunts more than 90 days after surgery. [Dr. Michael Handler](#), a collaborator in the study, introduced the group to the dynamics of cerebrospinal fluid and hydrocephalus, as well as explained symptoms of hydrocephalus. This [infographic](#) summarizing the study's findings was also provided to the families.
5. **Endocrine:** Although poorly documented in the research literature, neuro-endocrine challenges after hemispherectomy surgery, including precocious puberty or adrenarche, central diabetes

insipidus, and growth issues are reported by families. [Dr. Phillip Zeitler](#) introduced parents to the neuro-endocrine system and discussed how brain surgery, hydrocephalus, and brain malformations can affect it.



Multiple generations of one family enjoy the conference



Jayna, who had hemispherectomy at 28 days old for hemimegalencephaly; Jayna's mom, Sunshine; Abby, who had hemispherectomy at age 4 for Rasmussen's encephalitis; Levon, who had hemispherectomy at age one for cortical dysplasia

Other topics were addressed as well, including surgeries to improve hand function and current research on the use of [cannabis to control seizures uncontrolled by surgery](#). A special track for adults who had childhood hemispherectomy was added this year and included workshops on [self-advocacy](#) and transitioning to college, as well as a very popular [social skills workshop](#) for both teens and adults. By far the most impactful session addressed [how a parent can keep their child safe from sexual abuse](#), an important yet sobering topic for parents of children with intellectual challenges. Because children with an intellectual disability are [four times more likely](#) to experience sexual abuse than those without, this session was one of the best-attended sessions at the conference.

Most importantly, the conference provided families with an opportunity to connect in-person with other families they have met on social media with similar etiologies and outcomes. The last night of the conference always includes a grand finale gala and this year was no different. The highlight of the evening was definitely [Levon Epstein's rendition](#) of "Ain't No Man" by the Avett Brothers.

Research is also conducted at the conference each year. The [UCLA Rare Epilepsies and Brain Disease Tissue Bank](#) collected saliva from over 70 children and adults with brain malformations to better understand the underlying causes of diseases like Rasmussen's encephalitis, cortical dysplasia, and other conditions. The University of Minnesota's [Institute of Child Development](#) assessed several children to better understand [social and emotional impairments after hemispherectomy](#). Historically, various researchers have collected data on literacy skills after hemispherectomy surgery.

Primarily focused on post-hemispherectomy functional outcomes for the past several years, The Brain Recovery Project has funded over \$200,000 in research at the California Institute of Technology, Rancho Research Institute, Teacher's College of Columbia, Travis Research Institute, and Rochester Institute of Technology. In 2014, the organization hosted an [international workshop](#) on brain plasticity, hemispheric specialization, and neuro-rehabilitation after cerebral hemispherectomy, which brought together researchers and clinicians, funded in part by the National Institutes of Health, and plans to hold this conference triennially. Their collaboration with [Rancho Research Institute](#) has produced [Robocamp](#), the

world's first robotics-assisted physical and occupational therapy summer camp for children with similar disabilities.

The Brain Recovery Project also collaborates with the [e-NABLE](#) community, with the goal of designing a 3D-printed hand exoskeleton which can help children and adults with hemiplegia use their affected hand. Still in its early design phases, the [Airy Arm](#) may soon be an inexpensive solution to help with rough grasp of objects, including soda cans, bicycle handles, and toys.

Researchers interested in working with The Brain Recovery Project should contact Monika Jones, President and Co-founder, at mjones@brainrecoveryproject.org.

Ms. Jones, an attorney, was the principal investigator on the NIH R 13 grant to partially fund the 2014 scientific workshop on brain plasticity, hemispheric specialization, and neuro-rehabilitation after cerebral hemispherectomy. Her oldest son, Henry, was born with total hemimegalencephaly and required a hemispherectomy at three months old.

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A Population Based Strategy for Comprehensive Epilepsy Care in Ontario, Canada



*O. Carter Snead III, M.D.
Co-Chair, Ontario Epilepsy
Implementation Task Force*

Ontario has 95,000 people with epilepsy, 15,000 of whom are children. As is true everywhere else in the world, about one-third of these people (30,000-35,000) have medically refractory epilepsy. Also as is true throughout the world, prior to 2013 the care that Ontarians with epilepsy received was uneven and their access to surgical evaluation varied from capricious to non-existent, even in the face of a very good single-payer health care system.

There were several reasons for this situation, including a lack of awareness amongst primary care providers and neurologists of the value of epilepsy surgery, as well as a patchwork referral pattern for those patients with uncontrolled seizures. Further, there was a major lack of understanding in the government of the scope of the problem of epilepsy in Ontario, about the role of epilepsy surgery and its value in reducing the burden of illness, and the costs of epilepsy to the system. Finally, there was the problem of geography. The majority of people in Ontario live in the southern part of the province, so services are sometimes difficult to provide to the far-flung regions of Northern Ontario (Figure 1). Since 2013, the Ontario Ministry of Health and Long Term Care [MOHLTC] has taken on these challenges and established the first population-based strategy for comprehensive epilepsy care in North America.



Figure 1. Map of Canada. The red arrow points to the approximate division between Southern Ontario, where most of the population and medical resources are, and the large expanse of Northern Ontario, with a lower population density and more widely dispersed health care facilities.

Comprehensive epilepsy care in Ontario

In response to an expert panel report on epilepsy care in the Province of Ontario in 2011, the MOHLTC regionalized epilepsy care with the establishment of Adult and Pediatric District Epilepsy Centers (DEC) and Adult and Pediatric Regional Epilepsy Surgery Centers of Excellence (RESCE) in 2013. As well, the MOHLTC created an Epilepsy Implementation Task Force [EITF] to develop an integrated system for epilepsy care in Ontario. The EITF brings together senior clinicians and administrators from the Ontario epilepsy community to improve access by coordinating resources and wait lists, establishing standardized diagnostic and surgical protocols across centres, and developing support for primary care providers. As part of this mandate, the EITF has created a series of Provincial Guidelines for primary care providers and community neurologists. (LINKS TO PAPERS ON ILAE PAGE)

In addition, the EITF was asked to develop educational programs for primary care providers and community neurologists. The Ontario EITF set the criteria for a comprehensive epilepsy program (CEP) of integrated care for the management of individuals with epilepsy within a multidisciplinary team. The CEP covers various aspects of care, including medical (epileptologists), psychosocial (social workers and neuropsychologists) and skilled epilepsy nursing care (nurse practitioners). The pProgram also covers nutritional management (dietitian) and appropriate neurodiagnostic investigations. The latter includes all hardware and personnel for neuroimaging and neurophysiology, including an EMU with protected beds, capability for presurgical diagnostic evaluation, and established links to Community Epilepsy Agencies. Full infrastructure is provided within the system for surgical management of appropriate candidates.

The *District Epilepsy Centre* (DEC) houses a comprehensive epilepsy program that provides all appropriate epilepsy-related clinical services except for epilepsy surgery. A DEC provides basic

investigations necessary to determine candidacy for epilepsy surgery, including assessment by an epileptologist, and full EMU capability, including neuropsychological evaluations. The **Regional Epilepsy Surgery Centre of Excellence (RESCs)** also houses a comprehensive epilepsy program that provides all the services available in a DEC, with the addition of all necessary facilities for state-of-the-art epilepsy surgery.

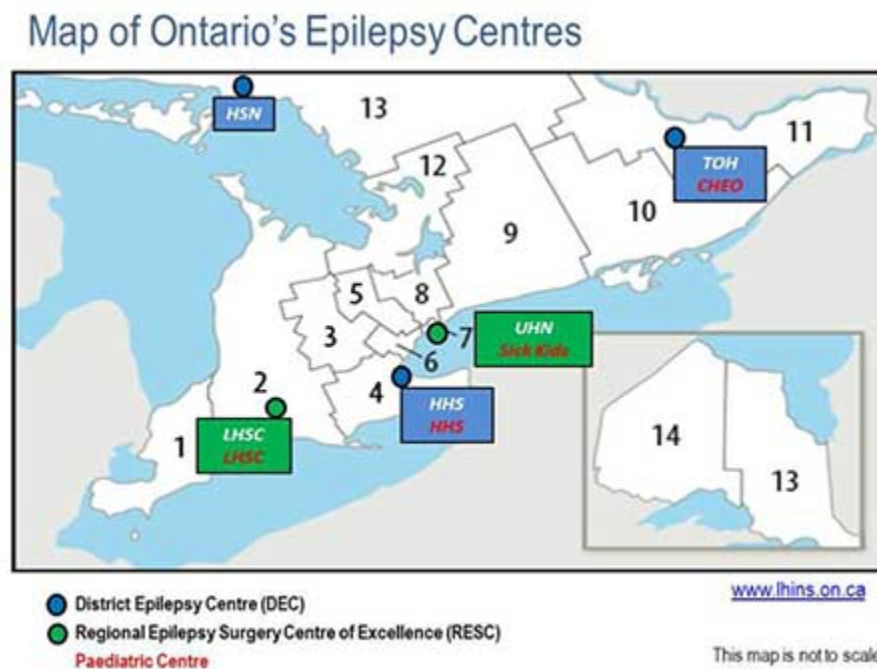


Figure 2. DEC hospitals include Health Sciences North in Sudbury [both adults and children], an adult DEC at Hamilton Health Sciences Centre, a paediatric DEC at Hamilton Health Sciences Children’s Hospital, an adult DEC at the Ottawa Hospital, and a Paediatric DEC at Children’s Hospital of Eastern Ontario. Current RESCs are London Health Sciences Centre [Adult and Paediatric], Hospital for Sick Children [Paediatric], and University Health Network (Toronto Western Hospital – Adult).

How the system works

Where possible, anyone with new onset of epilepsy will be referred by their primary care provider to a neurologist who will obtain an EEG and make first-line treatment recommendations to be managed by their primary care provider. Those patients who failed to respond to a conventional first-line anticonvulsant medication, or who had complex epilepsy from the onset (such as multiple or frequent seizures or status epilepticus) are referred to the DEC where appropriate medical management recommendations are developed, psychosocial support provided, and a connection with local community epilepsy agencies established. A preliminary evaluation of a patient's candidacy for epilepsy surgery is made at the DEC, and, if the patient is a candidate for surgery, he/she is referred to a RESC for further evaluation.

Ontario's Comprehensive Epilepsy Program Model

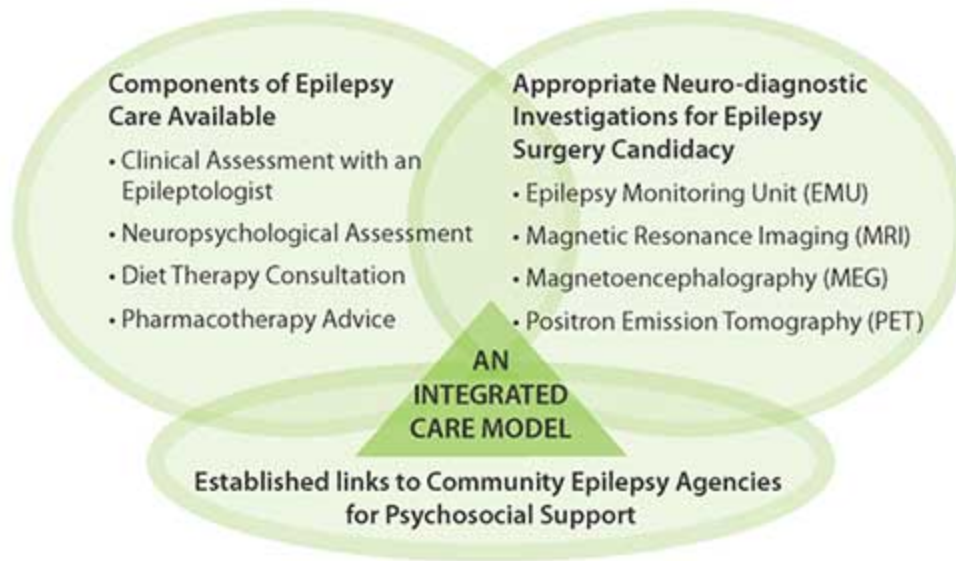


Figure 3. The Ontario Comprehensive Epilepsy Program Organization: How a patient can move through the care system

How did we engage government?

In 2007, the Ontario Health Technology Advisory Committee (OHTAC) reviewed functional brain imaging modalities and made a recommendation to examine the use of magnetoencephalography (MEG) in the determination of surgical candidacy in children with medically refractory epilepsy. The results of this field evaluation [see Lim M, et al. *Epilepsy Res* 2013;107:286-96] were then presented to OHTAC in January 2011. A subsequent expert panel recommended in August 2011 that Ontarians of all ages who suffer from epilepsy should have universal access to quality, evidence-based, comprehensive medical and surgical epilepsy care at the right time and in the right place.

Further, the expert panel determined that epilepsy care in Ontario at that time left much to be desired. At that time, a child or adult with new onset epilepsy would most likely be seen initially either in the Emergency Department or by a primary care provider with no standardized approach to diagnosis and treatment. If the seizures subsequently declared themselves as medically refractory, the patient may or may not have been referred for a surgical evaluation. There was no support system for patients and their families, nor were there evidence-based clinical guidelines in place regarding medical or surgical treatment. The expert panel pointed out that, based on the sheer numbers of patients with epilepsy and their impact on the health care system, epilepsy was a major public health issue in Ontario which, to date, had been inadequately addressed. The expert panel further opined that the major reasons for this state of affairs was a problem in attitude and awareness amongst physicians, including neurologists, who care for these adults and children with epilepsy, appropriate allocation of resources, and geographic problems given the huge sprawling size of the province. The expert panel made a number of recommendations that were adopted by the MOHLTC and led to the new provincial comprehensive epilepsy strategy. (LINK TO RECS ON ILAE WEB PAGE)

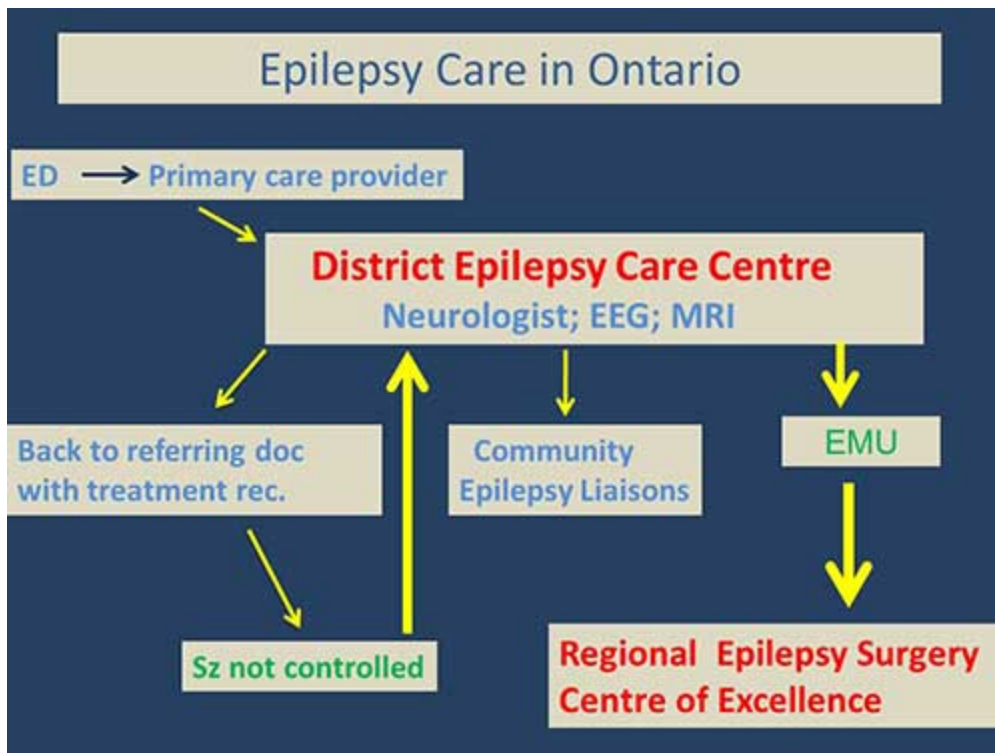


Figure 4. The services provided by the components of the Ontario Comprehensive Epilepsy Program.

Why these efforts have succeeded so far

- Ontario has an evidence-based system for the evaluation of proposed programs for MOHLTC funding, and the data about the burden and costs of epilepsy in the province supported the panel's recommendations.
- The involved hospitals, professional providers of epilepsy care in Ontario, and the community epilepsy agencies supported the recommendations.
- The government funded all of the infrastructure for the DECCs and RESCs and provided the administrative infrastructure to make the plan happen. The government's desire to improve access to epilepsy surgery throughout the province led to the EITF's designation as a subgroup of Provincial Neurosurgery Ontario (PNO), a provincial committee working to develop a comprehensive neurosurgical system. The EITF works with PNO to support equitable and timely access to neurosurgical care, including epilepsy surgery, and to help maintain the province's neurosurgical capacity. The administrative support for all of the work of EITF, without which none of this would have happened, is supplied by the Ministry through Critical Care Services Ontario (www.criticalcareontario.ca).
- It is absolutely critical for anyone who wishes to emulate our success to memorize the following sentence: *The main reason we were successful is that we put a face to epilepsy in every presentation to government.* Jim Bowen from the PATH group at McMaster University and I made virtually every presentation to multiple government agencies within MOHLTC, from our initial presentation to OHTAC in March 2011, to our final presentation to senior managers of MOHLTC in the winter of 2012. In every single presentation we made over the two years it took us to get this initiative funded, I always presented the same patient, Anthony, a young boy with medically refractory localization-related epilepsy who was cured by epilepsy surgery. Each presentation of Anthony always met with the same result – everyone in the room was blown away by the human tragedy of epilepsy, by what Anthony and his family had to deal with, and by the thrill of a dramatic surgical success in a child with medically refractory epilepsy and the hugely

positive impact on Anthony's life occasioned by this outcome. It was Anthony who got us where we are today.

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Bringing Epilepsy Education to Primary Care Initiatives in Latin America



Patricia Braga



Jaime Carrizosa

Although significant advances in the understanding of epilepsy have been achieved, and many therapeutic options have become available, there is a persisting gap in the management of these patients. This diagnostic and therapeutic gap has a major impact in those regions where health care depends almost exclusively on primary care systems. A number of chapters of the ILAE have developed programs to train primary care physicians and bring them into the epilepsy care network. Two different approaches have been taken in Latin America to increase the understanding about epilepsy among our primary care colleagues.

The main goal of this initiative was to decrease this gap through training courses devoted to physicians and other health care professionals working in primary care settings in any country of Latin America. The first program was developed by the Education Commission of the ILAE as an online course conducted over eight weeks across multiple Latin American countries. The second was a traditional lecture series course directed toward primary care professionals. This course was linked to a regular national meeting and was organized by ALADE (the Latin American Epilepsy Academy) of the Latin American Commission together with the Latin American Commission of the IBE.

The online course

For the online course aimed at improving the understanding of epilepsy among primary care physicians, several issues were addressed. First, the organizers wanted to learn the feasibility of an online course in the region for front line health care providers. They also wanted to learn if the participants could achieve predefined learning goals on the topic, which could be measured by reliable evaluation tools. This pilot course was organized by the Education Commission of the International League Against Epilepsy (ILAE), and involved an international teaching staff of 16 volunteer instructors from across the region. The course was jointly managed with the Facultad de Medicina, Universidad de la República, Uruguay, which was responsible for the development and management of the virtual platform and online course format.

The inaugural course was held from October 5, 2015 to November 30, 2015 and included eight topic-specific modules of one week duration each. The areas covered included epidemiology, seizure

semiology, differential diagnosis, diagnostic procedures, drug treatment, interaction of health care levels in management, non-pharmacological treatment basics, and social and legal aspects.

The 16-member Latin American teaching team (Table 1) developed the didactic material that was included in virtual repositories. It included teaching presentations and documents in Spanish and Portuguese, as well as learning tasks to be developed during the module. These tasks were structured as problem-solving or case-discussion exercises that were to be discussed in the forum of the module, among participants and with the tutors.

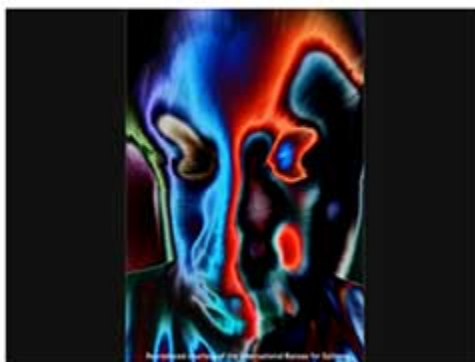
Table 1: Teaching staff of the online course, "Epilepsy in Primary Care, 2015"

	<i>Tutors:</i>
	Jorge Burneo (Peru-Canada)
	Eduardo Barragán (Mexico)
	Elza Marcia Yacubian (Brazil)
	Guilca Contreras (Venezuela)
	Kette Valente (Brazil)
<i>Coordination:</i>	Rodrigo Solarte (Colombia)
Patricia Braga, Jaime Carrizosa	Ana Carolina Coan (Brazil)
	Alicia Bogacz (Uruguay)
<i>Virtual platform:</i> Gonzalo Ferreira,	Angélica Uscátegui (Colombia)
Carlos Costa, Pablo Uriarte	Katia Lin (Brazil)
	Viviana Venegas (Chile)
	Patricia Braga (Uruguay)
	Lilia Morales (Cuba)
	Laura Guilhoto (Brazil)
	Jaime Carrizosa (Colombia)
	Alvaro Izquierdo (Colombia)

It was estimated that the course would require five hours for each participant to accomplish the tasks and achieve the specific learning goals defined for each module, for a total of 40 hours for the entire course. On the last day of each module, a self-evaluation task was made available, including automatic backup with the correct answer and its explanation.

EPILEPSIAS PARA ATENCIÓN PRIMARIA 2015

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1 - Contrato didáctico - Leer aquí

2 - Cronograma, Coordinación y Docentes participantes

Virtual platform front page

The final examination, available only online at predefined dates, was a 24-item multiple-choice questionnaire on different topics of the course. Passing the course required achieving a 60% threshold on this exam. This course provided 41 CME credits (Escuela de Graduados, Facultad de Medicina, Universidad de la República, Uruguay). The ILAE supported the effort with a budget of USD 4,000, and the course had revenues of USD 1,520. A differential inscription rate was established according to the socioeconomic status of each Latin American country.

The participants

The course had 38 participants, of which five had previous training in neurology or neurophysiology. At the time of the course, 22 worked in the first level of healthcare. Participants originated from nine different Latin American countries: Bolivia, Colombia, Costa Rica, Cuba, Honduras, Peru, Dominican Republic, Uruguay and Venezuela. The course was announced through national ILAE chapters which provided the information to their local medical associations, health authorities and their own mailing lists. Interested physicians applied and were chosen to participate based on their country (to assure a good geographic representation), academic background and involvement in primary care.

The course used the Moodle online learning platform that was designed to allow for interactive instruction as well as collaboration. It was built by the informatics group of the Medical School in Montevideo (Facultad de Medicina, Universidad de la República). This effort was supported in part by the ILAE to cover the costs of maintaining the platform, and technical and administrative support for preparing the course and maintaining the records. The final examination was taken by 32 (84%) students, all of whom passed the test and seven (22%) had scores over 90%.

Course evaluation

Questionnaires for evaluation of the course were distributed: 29 students and 13 tutors replied. Students ranked the course as low-to-intermediate difficulty that required an effort of four to six hours/week. 95% rated the interactive experience as good to very good, and 97% would recommend this course to other colleagues. 20% felt confident on epilepsy patients' management before the course, and the confidence level increased to 65% after the course.

Half of the tutors had already had some experience with virtual courses; they had estimated a weekly effort of 5-7 hours during their modules. In general, the teaching experience was rated as very good to excellent. In fact, all teachers remained interested in being tutors in the future, and they even considered the possibility of developing virtual courses on other topics.

ALADE course in El Salvador

The other effort in training primary care physicians took place when the Salvadorian Association of Neurological Sciences – ACNES – organized for the fifth time at its International Practical Neurology Congress for Non Neurologists in San Salvador from the April 28-30, 2016. The organizers contacted the Latin American Academy on Epilepsy – ALADE – of the Latin American Commission of the ILAE to develop epilepsy as one of the main topics of the congress. The young audience of nearly 150 persons was mainly composed of general practitioners, family doctors, pediatricians and specialists in internal medicine. In a country with more than 10 million people and only 20 neurologists, a course in neurology for non-neurologists was considered a priority.

The course, which was taught over three days, included 12 hours of interactive teaching that covered the following themes: a) epilepsy: diagnosis and treatment b) epilepsy in primary care c) seizure semiology d) social aspects of epilepsy e) refractory epilepsy and f) case discussions for possible surgical treatment.

Special emphasis was placed on considering epilepsy as a public health priority (WHO draft) and the urgent need to build up the Salvadorian Chapter of the IBE. The course allowed for frequent personal contacts to be made with people who were interested in working to strengthen the epilepsy effort nationally.



Organizers of the ALADE course in El Salvador

The commitment by organizers and attendees at the congress venues, Social Security Hospital and the Intercontinental Hotel, was remarkable; even after long discussions, speakers were approached for further answers and explanations on specific topics. Special thanks and recognition for their generous efforts as speakers were offered to Guilca Contreras (Venezuela), Mario Alonso (Mexico), and Jaime Carrizosa (Colombia) who were ILAE – ALADE representatives, and to Alicia Bogacz as the IBE representative. At the end of the course, there was general agreement by the participants and the organizers that such meetings on epilepsy needed to continue, not only in El Salvador, but should be jointly planned with other Central American countries.

Conclusion

The experience with these two courses emphasizes the value and need for epilepsy training for primary care physicians. The experience of the pilot course of distance education through information and communication technologies, devoted to primary care professionals in Latin America, showed positive results on all predefined specific aims of the project: attendance, feasibility and achievement of learning goals. Evaluation tools were easy to apply. Further validation with mid-term evaluation of knowledge and impact is under development. The advantage of the face-to-face traditional course was that it allowed for a more personal contact between participants and tutors. Having multiple options for teaching primary care practitioners is of great value to meet the learning styles and preferences of the participants, as not everyone feels comfortable taking an online course, nor can everyone travel to a meeting.

Current challenges can be summarized as consolidating the initiatives and optimizing the inclusion of the targeted population, particularly developing a bilingual platform (Spanish-Portuguese). Long-term challenges would include continuous updates to content, balance between stability and renewal of teaching staff, financial sustainability and adaptation to emerging technologies.

A second course has just been completed and a third online course is scheduled to begin September 26th. For more information and to register for the course, interested individuals may contact epi.aps.online@gmail.com . Further descriptions are available at [2016 CONVOCATORIA CORSO ONLINE.pdf](#)

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EpilepsyDiagnosis.Org – a novel online diagnostic manual of the epilepsies



Kate Riney

Although there is much information on the internet about epilepsy and seizures, there is a glaring absence of a single source of information that aligns with the international classification and provides an organized presentation of the many seizure types and syndromes to help with diagnosis and treatment. This information gap was recognized and led to the ILAE's [EpilepsyDiagnosis.Org](#) project which was formally launched in September 2014. It has been a unique resource in medicine and has harnessed the power of the internet to present the complexity of the significant amount of new information now available about the epilepsies and their etiologies, in a manner that is concise, current and accessible to a global audience. It is as relevant to those in primary and secondary health care settings as it is to those in tertiary epileptology practice. It is also showing promise as an instructional and training resource for those who are new to medicine.

The project [EpilepsyDiagnosis.org](#) was conceived and developed by the ILAE's Commission on Classification and Terminology (2009-2013), and this commission's Diagnostic Manual Taskforce (Table 1), in partnership with eResearch at the University of Melbourne, Australia. The project has been further developed by the ILAE's Commission on Classification and Terminology (2013-2017), and this commission's EpilepsyDiagnosis.Org and Syndromes Task Force (Table 1).

Table 2: Individuals responsible for the development of EpilepsyDiagnosis.org

Members of the ILAE's Commission on Classification and Terminology (2009-2013), and this commission's Diagnostic Manual Taskforce:

Ingrid Scheffer, Sameer Zuberi, Sam Berkovic, Pippo Capovilla, Helen Zhang, Doug Nordli, Jeff Buchalter, Lynette Sadleir, Anne Berg, Mary Connolly, Laura Guilhoto, Edouard Hirsch, Sam Wiebe, Christian Korff, Andrew Lux, Yoshimi Sogawa, Elaine Wirrell, Stephan Schuele, Kate Riney.

Members of the ILAE's Commission on Classification and Terminology (2013-2017)

EpilepsyDiagnosis.Org and Syndromes Taskforce: Roberto Caraballo, Kate Riney, Norimichi Higurashi, Vivek Jain, Floor Jansen, Mike Kerr, Lieven Lagae, John Paul Leach, Ingrid Scheffer, Rima Nabbout, Elizabeth Thiele, Federico Vigevano, Khaled Zamel, Sameer Zuberi, Muhammad Salisu, Nerses Bebek.

Since the release of EpilepsyDiagnosis.org, its reach has steadily increased, month-over-month. Currently, approximately 10,000 unique visitors access the site each month from around the world, viewing EpilepsyDiagnosis.Org pages more than 40,000 times per month. Users of the website span professional groups that range from those in primary care to those working in tertiary health care settings (Table 3). The ongoing growth in user engagement with EpilepsyDiagnosis.Org continues to occur “organically,” through relevance of the website content to those in clinical practices where epilepsy is diagnosed and managed.

Table 3: Visitors to EpilepsyDiagnosis.Org by professional background (top 10, accounting for 52% of all visitors)

Secondary Health Care – Adult Neurology 8%
Secondary Health Care – Pediatrics General 7%
Postgraduate Medical Trainee – Adult Medicine 6%
Secondary Health Care – Pediatric Neurology 6%
Tertiary Health Care – Pediatric Neurology 6%
Tertiary Health Care – Adult Neurology 5%
Primary Health Care – General Practice 4%
Postgraduate Medical Trainee – Pediatric Medicine 4%
Primary Health Care – Other 4%
Tertiary Health Care – Pediatric Epileptologist 4%

Goals

The goals of EpilepsyDiagnosis.org are:

- To make available, in an easy-to-understand format, the latest concepts relating to seizures and the epilepsies.
- To assist clinicians, particularly those in primary and secondary health care settings anywhere in the world, who look after people with epilepsy to diagnose seizure type(s), classify epilepsy, diagnose epilepsy syndromes and define the etiology.
- To provide an educational resource that is current for personal learning and small group teaching settings.

What you will find on the EpilepsyDiagnosis.Org website

abnormalities associated with epilepsy, especially newer information regarding their genetic bases. The site now includes a “tour de force” of the following structural etiologies for epilepsy:

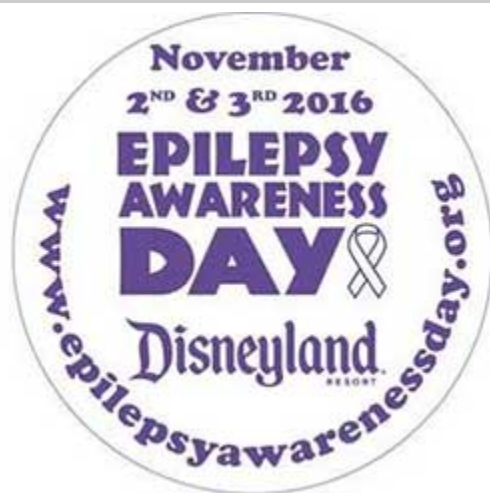
- o malformations of cortical development: focal cortical dysplasia, tuberous sclerosis, lissencephaly, subcortical band heterotopia, grey matter heterotopia, polymicrogyria, hemimegalencephaly, schizencephaly and hypothalamic hamartoma
- o vascular malformations: cerebral angioma, Sturge-Weber syndrome and arteriovenous malformation
- o hippocampal sclerosis
- o hypoxic-ischemic: stroke and hypoxic ischemic brain injury
- o traumatic brain injury
- o tumors: dysembryoplastic neuroepithelial tumors and ganglioglioma, and
- o porencephalic cysts

EpilepsyDiagnosis.Org complements resources available through *Epileptic Disorders*, ILAE’s official educational journal, for professionals with particular interest in epilepsy. However, EpilepsyDiagnosis.Org, through its open access format, also provides an increased reach to health professionals from primary and secondary health care settings who see patients with epilepsy, and is relevant for community organizations and for the general public due to the simple and clear presentation of information.

Please visit and use this site at www.epilepsydiagnosis.org. Your comments and suggestions are welcome.

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Epilepsy Awareness Day



Epilepsy Awareness Day at Disneyland began in 2013. Our main goal in starting this patient- and family-oriented celebration was to help raise awareness about the common challenges that are faced every day by people affected by the disease and to end the stigma that so many with epilepsy face. The event has been held each November, and in 2015 the third annual Epilepsy Awareness Day and Education Expo at Disneyland took place. The program has grown from 972 people in 2013 to 2,000 at the most recent in 2015, and it has become a truly national and international event. Participants came from 13 countries and all of the continents, and almost all of the 50 states in the U.S. In addition, the event has brought in many patient organizations and enjoyed the support of 27 sponsors, and the participation of 60 patient organizations.



Epilepsy Awareness Day 2015

The event began simply with the goal of bringing patients and families with a member with epilepsy together for support at Disneyland. However, at that event, we were approached inside the Disneyland park by an epileptologist who noted that we had done a great job gathering people, but that we had failed in our duty to educate and empower people with a learning and networking venue. From that comment, the Educational EXPO was born. We have used the EXPO to provide new information about new treatment options, new medications, new technologies and devices. It also gives people whose lives have been affected by epilepsy the opportunity to share experiences about treatments and how they are dealing with the challenges brought by epilepsy. Several physicians paid us the ultimate compliment by saying that they had never seen such a gathering of physicians and patients anywhere before.



Candy and Brad Levy

Our own involvement in creating this event came from having a child with epilepsy. Having epilepsy or a family member with epilepsy, especially uncontrolled epilepsy, comes with a whole set of issues that are experienced only by people with this disease. As a result, people feel isolated and have no one to talk to about the problems, and they don't know how to deal with these problems. This event helps overcome the isolation as people can come together and learn from one another how to find solutions. In addition, participants have the opportunity to learn from vendors about products that are available that can alleviate some of the burden.

Each year, we have seen how people leave the event with a greater understanding of what they can do. They leave with a greater sense of empowerment because they know they are not alone and have met others who can help. We receive numerous emails, many with photos from prior events and the most heartfelt stories telling us how much the event meant to them. For many, it was life changing, being able to meet and speak to doctors and with other people who had a complete understanding of their specific condition. People leave the event feeling stronger about spreading the word to raise awareness about epilepsy.



Seizure dogs and their friends



Members of Talking About Curing Autism talk to meeting attendees at the Expo session

Making this event known has been purely grassroots. Epilepsy Awareness Day has no major corporate backing, no celebrity spokespeople and no advertising budget. We use Facebook, Instagram, and our website to promote and create attention. We ship boxes of postcards to epilepsy groups around the nation and they distribute them at group gatherings and to physicians' offices. We have an email version as well that our supporters use to help increase awareness. Last year, we were fortunate enough to have the International League Against Epilepsy (ILAE) promoting the event, which gathered attention from a more international audience that traveled to California. The participation of the ILAE, the International Bureau for Epilepsy (IBE), Epilepsy Foundation of America (EFA) and Citizens United for Research in Epilepsy (CURE) helped them fulfill their commitment to unite the world's epilepsy communities and greatly increased EADDL's visibility.

For the 2016 event, we will continue to use the methods that have worked to get the word out, but we have also strengthened the partnership with CURE to promote their new initiative, the Day of Science program, and we expect CURE to add a new level of media attention. For 2016, we expect to draw approximately 80 national and regional epilepsy support groups, more than 20 national epilepsy centers and over 2,500 guests from six continents. We have been able to add epilepsy centers from Canada, Guatemala and all across the USA in order to accommodate the demographics of our guests. We are also offering more physician guest speakers, as well as in-depth workshops on some of the most requested topics such as diet for epilepsy, understanding more about EEG, and service and seizure dogs.

Our journey into epilepsy was not planned, but rather brought on by having a child with uncontrolled epilepsy. Our family's path started with uncontrolled seizures, a long road of being misdiagnosed, and ending with successful epilepsy surgery in February 2009. Our daughter, Sofie, has been seizure free for over seven years, and she is acting like a teenager, enjoying aerial acrobatics, and beginning her courses to become a registered EEG technologist, in addition to finishing her sophomore year of high school. Life has been quite a ride, but making this journey with Sofie gave us a commitment to help other families who are dealing with all of the problems that epilepsy brings, and to find a way to have a normal life. The comments we receive back from participants tell us that there is a great need for gatherings such as Epilepsy Awareness Day.

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Celebrating the 20th Anniversary of the Thai Epilepsy Society



The Epilepsy Society of Thailand (EST) was established on May 22, 1996 by a small group of physicians who shared a common interest in epilepsy. The main objectives of this organization were to improve the standard of care for people with epilepsy, to improve the quality of treatment for epilepsy, and to provide up-to-date knowledge to general practitioners and patients. The principal founder of the society, Professor Pongsakdi Visudhiphan was the first president of EST. He and the General Secretary, Dr. Somchai Towanabut, labored diligently to enable Thailand to become a chapter of the ILAE one year after the establishment of the Society.

The EST was formally announced as the Thailand Chapter of ILAE in Dublin, Ireland during the 22nd International Epilepsy Congress in 1997. After the establishment of the EST, Professor Pongsakdi Visudhiphan was EST's President from 1996 to 2007, followed by Professor Surang Chiemchanya, from 2007 to 2009, and Dr. Somchai Towanabut from 2009 to 2015. The current president of the EST is Professor Anannit Visudtibhan. During its first decade, EST had 252 members, and the membership has steadily increased to 491 members in this 20th anniversary year.



Kamornwan Katanyuwong, M.D.
Editor-in-Chief: Epilepsy Digest,
official bulletin of EST
Anannit Visudtibhan, M.D., Professor,
Pediatrics and Pediatric Neurology
President of EST

“Epilepsy in Everyday Life” was the theme of this year's Epilepsy Society of Thailand's congress held in Bangkok. Didactic lectures, key lectures given by international speakers, symposia, and case discussions were all integrated into the two-day congress with a one-day, pre-congress EEG workshop. The EST was privileged to have lectures by Professor Emilio Perucca, the President of the ILAE, and Professor William E. Rosenfeld during the academic sessions. The luncheon lecture, “ILAE President's Perspective on Global Care for People with Epilepsy,” given by Professor Perucca, was the hallmark of this congress, which confirms the direction of EST in the future. The Congress succeeded in achieving its goals of increasing the awareness of epilepsy by physicians who care for people with epilepsy in Thailand, and the continuation of the Chapter's vision from its beginnings into its future. The Epilepsy Society of Thailand is proud of what it has accomplished in its 20 years of existence.

One of the goals of the EST is to improve knowledge of epilepsy among physicians and medical personnel. One of the main methods for achieving this goal is the annual epilepsy conference in the capital city, Bangkok. This meeting provides basic and advanced EEG workshops every other year. The conference aims to provide scientific knowledge to members and participants. Each year, internationally known epileptologists are invited to give one to two lectures. In addition, regional epilepsy conferences have been organized in the northern, southern and eastern parts of Thailand.

To improve treatment, the EST developed epilepsy clinical practice guidelines for the country to reduce the variation of treatment which might affect the quality of care for people with epilepsy. These

guidelines are a landmark of cooperation among many academic institutions, and both non-government and government organizations in Thailand. The fourth version will be launched by the end of 2016.



Three editions of Clinical Practice Guidelines for epilepsy, Thailand



Handbook of Epilepsy and EEG textbook in Thai language

In addition we, created a Quick Reference Handbook of Epilepsy and one EEG textbook in Thai. They have been published and serve as major academic resources.

The Epilepsy Society of Thailand is also working to train more specialists. We have created a two-day annual epilepsy course for neurology residents and pediatric neurology fellows held each August since 2010. This course is free-of-charge for these in-training physicians.

The program of this course consists of essential topics on epilepsy. In addition, epilepsy case conferences have been set-up to improve the quality of care for patients with pharmacological resistance epilepsy, since 2011. The participants are experts on surgical treatment for epilepsy from epilepsy centers in the country. These conferences are also a part of epilepsy fellowship training. Most of the discussed patients were surgical candidates who required expert opinions. Because EEG is such a central part of epilepsy diagnosis and treatment, the EST has created an EEG course to provide academic knowledge and supervision for EEG technicians and to increase the number of EEG technicians.



Photos from the 20th Annual Epilepsy Conference, Bangkok, Thailand

The EST has developed its own website to increase learning resources by means of information technology. The bulletin, “Epilepsy Digest,” contains academic articles on epilepsy. Initially, it was

published by EST three to four times per year and was mailed to members as a printed bulletin until 2014. Since 2015, three issues each year have been integrated into the website, www.thaiepilepsysociety.com, which is free-of-charge and can be accessed by anyone.

The Epilepsy Society of Thailand has led three multicenter epilepsy research studies. The first was a survey of medical facilities for epilepsy care in provincial government hospitals in 2002. This study was followed by an examination of the quality of life in people with epilepsy held in 2008 and a third, broader survey of facilities and treatment for patients with epilepsy was conducted in 2009.

Our success has come in part by close cooperation with the Epilepsy Association of Thailand (EAT). We have supported every activity of the EAT since it was established in 2002. The EST has assisted the EAT in providing basic knowledge of epilepsy to patients and the public, and in increasing public awareness of epilepsy via various activities and modalities, such as mass media and social media including newspapers, broadcast radio and television. Recently, the Epilepsy Association of Thailand initiated popular epilepsy camps for patients with epilepsy and their caregivers. In addition, the EST and EAT recognize the international events for the awareness of epilepsy, which are the “International Epilepsy Day” and the “Purple Day.”

The EST has recognized for many years the value and importance of participation in activities beyond Thailand’s borders. With the support from the ILAE and its Commission on Asian and Oceanian Affairs, EST has hosted two international epilepsy conferences in Bangkok: The 5th Asian and Oceanian Epilepsy Congress in 2005 and the ASEPA Workshop on Epilepsy Surgery in 2013. To develop our expertise further and to strengthen academic collaboration, the EST visited epilepsy centers in Australia in 2002 and Japan in 2012. Professor Pongsakdi Visudhiphan was recognized in 2012 by the Commission on Asian and Oceanian affairs as one of the leaders in the region for his extraordinary contributions to epilepsy care. He was one of the Achievement Award winners at the Epilepsy Congress in Manila.

Since its establishment, the EST has made contributions to various aspects of epilepsy treatment and care. The most important achievements are the increased standard of care for patients with epilepsy, and the improved perspective toward epilepsy by patients as well as the general public. There are many factors that led to the achievements of the Society, such as the foundation laid by Prof. Visudhiphan and other pioneers in epilepsy, the mixture of the team members, the teamwork tradition, and the long-standing support from international colleagues and organizations, including the ILAE.

However challenges for improving epilepsy care in Thailand remain. Two great challenges include persuading the Thai government to integrate epilepsy into government-support service plan and the creation of no-border networking for epilepsy care. There is a need to increase the participation of the public to expand knowledge and awareness of epilepsy, and we have to develop better epidemiological information to improve epilepsy care. To meet those challenges, the Society has added additional goals which are expected to be achieved in the near future:

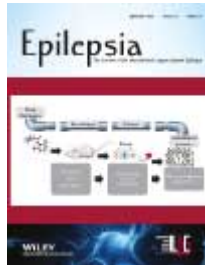
- i. Co-operation with the government to increase the awareness of this illness
- ii. Access for people with epilepsy throughout the country to proper treatment, including epilepsy surgery and other treatment modalities that are necessary for them
- iii. Initiation and the coordination of research which would provide information to improve the quality of care for people with epilepsy
- iv. Development of a partnership that supports and shares resources in genetic epilepsy cases
- v. Maintain an ongoing relationship with the Epilepsy Association of Thailand and hope the patients themselves will be the leaders of their association

There is much more to be done and obstacles are to be expected. Through experience gained from the past 20 years and the support by ILAE since 1997, the EST has grown and strengthened. We are particularly honored to have been selected as the host for the 33rd International Epilepsy Congress in Bangkok. EST is looking forward to a bright future not only for the society but for the people with epilepsy in Thailand.

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Research



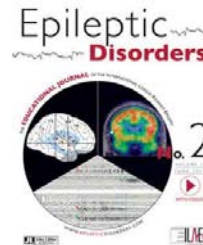
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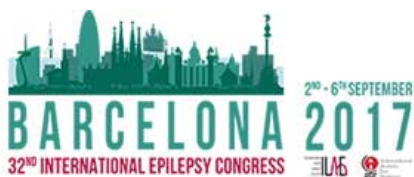
Upcoming Congresses and Educational Events



16 – 18 February 2017
4th East Mediterranean Epilepsy Congress
Luxor, Egypt
Website: www.epilepsyluxor2017.org



5 – 7 May 2017
3rd African Epilepsy Congress
Dakar, Senegal
Website: www.epilepsydakar2017.org



2-6 September 2017
32nd International Epilepsy Congress
Barcelona, Spain
Website: www.epilepsybarcelona2017.org



21 – 24 June 2018
12th Asian and Oceanian Epilepsy Congress
Bali, Indonesia
Website: www.epilepsybali2018.org

Chapter Congresses



14-16 October 2016
Canadian League Against Epilepsy Biennial Scientific Meeting
Quebec City, Quebec
[Congress Website](#)



28 October 2016
Status Epilepticus: Autumn Meeting of the Danish Epilepsy Society
Rigshospitalet, Auditorium 1
[Program](#)



7 – 10 November 2016
Journées Françaises de l'Epilepsie
Ligue Française contre l'épilepsie
Toulouse, France
Website: www.jfe-congres.fr/



11-13 November 2016
6th Annual Saudi Epilepsy Society Conference
King Abdulaziz University, Jeddah, Saudi Arabia
www.saudi-mcn.com



2 – 6 December 2016
AES 70th Annual Meeting and 6th Biennial Regional American Congress
Houston, TX, USA
[Website](#)



3 – 4 February 2017
10th Qatar Epilepsy Symposium
Doha, Qatar
Information: boulenouar.mesraoua@wanadoo.fr



18 – 19 February 2017
ECON 2017: 18th Joint Annual Conference
Indian Epilepsy Association & Indian Epilepsy Society
Hotel Maurya, Patna (Bihar), India
Website: www.econ2017.com



3 – 6 May 2017

**Annual Meeting of the Austrian and German Society for
Epileptology and the Swiss Epilepsy-League**

Jahrestagung der Deutschen und Österreichischen Gesellschaften für
Epileptologie
und der Schweizerischen Epilepsie-Liga
Vienna, Austria

Website: www.epilepsie-tagung.de

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