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INTERNATIONAL LEAGUE AGAINST EPILEPSY ILAE Established 1909 — Professionals in Epilepsy Care

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INTERNATIONAL LEAGUE AGAINST EPILEPSY ILAE Epigraph
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Secretary General's Report

Helen Cross
Secretary General, ILAE

The Secretary General has a number of responsibilities for the League including the oversight of official records of the ILAE, promotion of chapter development as well as the processing and maintenance of reports of Commissions and Task Forces, submitting them for approval to the Executive Committee.; The initial six months of this term has been a busy time.

The League continues to grow. The Executive Committee have granted provisional acceptance to two further chapters: Myanmar and Belarus. Definitive acceptance will be submitted to the vote of the ILAE General Assembly, the next to take place during the 31st International Epilepsy Congress in Istanbul, Turkey in September 2015. Formal acceptance will increase the number of League chapters to 115, which, because we have interest from other countries in becoming new League chapters, we expect the number will increase further.

The world looks to the League as the ultimate authority for providing guidance in our understanding about seizures and the epilepsies. There has been, however, no formal process for vetting proposals with the thousands of experts that make up our membership. To allow for a global perspective into these issues, a new system has been developed to ensure feedback and comment from the membership is taken into consideration on position documents produced by the ILAE. The paper outlining an operational clinical definition of epilepsy was put out for public consultation on the ILAE website. This request attracted over 300 comments from around the world. A Task Force was then set up chaired by Robert Fisher whose remit was to edit the document based on the comments raised. The finalised document is now in press in *Epilepsia*.

The Commission for Classification have produced a document adding refinement to the Organisation of the Epilepsies published in 2010. This document has also been to public consultation on the ILAE website and over 100 thoughtful comments have been received. A similar process will be undertaken as for the Definition paper – namely a Task Force will be established to review all comments and edit the document as appropriate.

For years the records and history of the League have travelled around the world in boxes, residing wherever they could find an accepting domicile, most recently in Switzerland. To preserve these important documents and make them available to anyone who wished to study the League's evolution, a more permanent home was needed. Simon Shorvon opened discussions with the Wellcome Trust, which provides a permanent repository for medically related historical documents, and we are happy to announce that the Archives of the ILAE have been moved to the Wellcome Trust, London. Archiving is currently ongoing, and, once complete, a process will be developed by which individuals will be invited to donate historical materials as appropriate. For any further information please contact me (**h.cross@ucl.ac.uk**).

During my first six months as Secretary General I have had the great pleasure of working with wonderful colleagues on the Executive Committee and meeting so many people from around the world who are dedicated to the League's mission. I look forward to the coming years in which we will work together to improve the lives of those affected by epilepsy.

Helen Cross
ILAE Secretary General

Treasurer's Report

Samuel Wiebe
ILAE Treasurer

As a new year begins, I look forward with anticipation to my mandate as ILAE treasurer, which is to overview the financial well-being of the organization, while keeping a steady focus on our common cause – i.e., to improve the lives of people with epilepsy around the world. This means continued support to achieve our shared goals of addressing the treatment gap, promoting epilepsy care and research, fostering education, mentoring younger generations, and advocating for people with epilepsy.

The financial landscape for organizations such as the ILAE is changing rather radically, creating challenges that need to be addressed promptly to maintain our financial health. The ILAE relies on two main sources of revenue – i.e., our journal *Epilepsia*, and our International and Regional Congresses.The relationship with traditional sources of funding has changed, resulting in a steady decline in the level of revenue from our congresses over the last 3 years. This trend is now well established, and it is unlikely to revert in the near future. Appropriate action is required.

It is evident that for the ILAE to thrive in the new financial environment we will need to take a hard look at our expenditures, aiming to maximize efficiencies in our operations, in the level of support of various ILAE activities, and also in the costs of our congresses. Under the previous ILAE executive, operational costs were already substantially streamlined and reduced. We will continue to revise our fixed and variable operational and administrative costs to gain efficiencies wherever possible. We will also need to ponder the level of support that is realistic for our Commissions and Task forces, without compromising our mission. Importantly, we will need to look at creative ways of organizing our Congresses in order to minimize expenditures, while maintaining high academic and educational standards and relevance to our membership.

Revenue from our journal *Epilepsia* is stable under the current contract. However, we are facing the challenges imposed by novel publishing strategies, as well as by the incorporation of our new educational journal *Epileptic Disorders.* There is intense competition in the publishing world and we need to be vigilant and creative to maximize impact, fulfill our mission and generate revenue as we move forward in 2014.

In addition, the ILAE has the mandate to build sufficient investment reserves to ensure that the organization can achieve a sustainable level of financial independence from other sources. Our portfolio's performance was very good in 2013, thanks to the sage advise provided by our excellent Financial Advisory Committee, and to the favorable market conditions. If these conditions prevail, we may be cautiously optimistic about achieving our long-term goals. However, the markets are uncertain and we need to be prepared for less favorable returns in the future.

I believe that we are prepared to face these challenges. Grasping new opportunities will require readiness to adapt and to change. As Treasurer, I look forward to working collectively with all of you to address the tasks ahead, and to support and enhance the important work or our members to accomplish our League's mission.

Samuel Wiebe
ILAE Treasurer

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Coming Soon! New Definitions and Classification System of Status Epilepticus

Dan Lowenstein

Eugen Trinka

Ingrid Scheffer

Understanding the pathophysiology of status epilepticus and improving its treatment has been impeded in part because status epilepticus is often considered by many as a single condition with a single therapeutic approach. Better definition of the different types of status epilepticus would be an important first step in moving things forward to better treatment. With that goal the ILAE has created a task force to develop a system of classification of status epilepticus. We would like to share with you the issues that led to this assignment and the progress that we have made so far.

Status epilepticus (SE), considered the most extreme form of a seizure, was included in the classification of seizures of the ILAE in 1970 and 1981. In the first ILAE seizure classification, which was developed in 1964 and approved in 1970, SE was defined in the addendum of the publication as a "*seizure that persists for a sufficient length of time or is repeated frequently enough to produce a fixed and enduring condition.*" SE was divided into partial, generalized or unilateral types, and basically mirrored the seizure classification. In the revision of 1981, the definition was minimally changed into a "*seizure"* that "*persists for a sufficient length of time or is repeated frequently enough that recovery between attacks does not occur."* Again, the distinction between partial, generalised and epilepsia partialis continua (EPC) was mentioned in the addendum of the Classification, without further details. These concepts, while highly valuable, were imprecise as they did not define the duration of a seizure that was "fixed and enduring" or "sufficient length", nor was there a clinical description (semiology) of the type of SE.

Over the past three decades, many experts in the field have suggested specific durations of time to define SE, generally ranging from 5 to 30 minutes. However, this wide range in durations still presented a practical dilemma, as accepted practice has universally been to treat abnormally prolonged, generalized convulsive seizures promptly (i.e. not to wait 30 minutes). The obvious discrepancy between the limited knowledge of the pathophysiology and the need to treat patients rapidly led to the concept of an *operational* and a *conceptual* definition proposed by Lowenstein and colleagues in 1999. Generalized convulsive SE, in adults and children older than 5 yrs, was operationally defined as "*… ≥ 5minutes of (a) continuous seizure or (b) two or more discrete seizures between which there is incomplete recovery of consciousness".* This time frame has been generally accepted by the clinical community and used to guide when emergency treatment of generalised convulsive SE should be commenced. As a basic research (or conceptual) definition, the group suggested the following: *"Generalized, convulsive status epilepticus refers to a condition in which there is failure of the "normal" factors that serve to terminate a typical GTCS"*. Though this distinction, between a pragmatic, operational definition and a basic research definition of generalised convulsive status has guided the treatment of generalised convulsive SE, other forms of SE have not been addressed.

Given these developments, as well as the lack of clarity about the definitions for different forms of SE, the ILAE recognized the need to revise the Classification of SE and charged task forces under the Commission of Classification and Terminology and the Commission on Epidemiology to revise the classification of SE. These task forces have worked jointly over the past two years to produce a set of definitions and classification system for SE. What follows is an outline of the general concepts that are the underpinnings of this new system.

The **proposed, new definition** is as follows: SE represents the failure of the mechanisms responsible for seizure termination, leading to *continuous seizure activity* (t1) that might lead to *long term consequences* (t2) including neuronal death, neuronal injury, and alteration of neuronal networks, depending on the type and duration of SE.

This definition is conceptual, with two **operational dimensions**: the first is the length of the seizure and the time point **(t1)** when the seizure should be regarded as "*continuous seizure activity"*. The second time point is the time **(t2)** of ongoing seizure activity that leads to long-term consequences. In the case of convulsive (tonic-clonic) SE, both time points are based on evidence from animal experiments and clinical research. Data are not yet available for other forms of SE, but as knowledge and understanding increases, time points can be defined for specific forms of SE based on scientific evidence and incorporated into the definition, without necessarily changing the underlying concepts. This division into two time points has clear clinical implications: The time point of operational dimension 1 determines the time at which treatment should be considered or started, while the time point of operational dimension 2 determines how aggressively treatment should be implemented in order to prevent long term consequences.

Importantly, the time domain may differ considerably between different forms of SE. For example, there is substantial experimental evidence to suggest that generalized, convulsive SE lasting more than 30 minutes is associated with irreversible neuronal injury. However, the duration of seizure activity that leads to injury is much less clear with focal dyscognitive seizures and absence seizures. Thus, the joint task force settled on various t1 and t2 timepoints for different seizures types (see Table 1), and recognized that some of these cannot be defined with certainty given our current lack of understanding of the underlying pathophysiology.

Table 1: Proposed operational dimensions of SE

Type of SE	**Operational Dimension 1 Time (t1), when a seizure is likely to be prolonged leading to continuous seizure activity**	**Operational Dimension 2** **Time (t2), when a seizure may cause long term consequences (including neuronal injury, neuronal death, alteration of neuronal networks and functional deficits)**
Tonic-clonic SE	5 minutes	30 minutes
Focal Dyscognitive SE	*10 minutes (?)*	*>60 minutes*
Absence SE	*10-15 minutes*	*Unknown*

The joint task force has also proposed a **new diagnostic classification system** of SE that will provide a framework for clinical diagnosis, investigation and therapeutic approaches for each patient. There are four axes: 1) semiology; 2) aetiology; 3) EEG correlates; and 4) age. Axis 1 (semiology) lists different forms of SE divided into those with prominent motor systems, those without prominent motor systems, and currently indeterminate conditions (such as acute confusional states with epileptiform EEG patterns). Axis 2 (aetiology) is divided into categories of known and unknown causes. Axis 3 (EEG correlates) adopts the latest recommendations by consensus panels to use the following descriptors for the EEG: name of pattern, morphology, location, time-related features, modulation, and effect of intervention. Finally, Axis 4 divides age groups into neonatal, infancy, childhood, adolescent and adulthood, and elderly.

These proposed new definitions and classification scheme will now be reviewed by *Epilepsia* with a view to publication as a Proposal. Community comments will be welcomed as further consideration and experience is gained with this Proposal over time. Responses to the community experience will then be considered in a final document over the next year or two to develop an accepted Classification system and definitions for status epilepticus.

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San Servolo

The San Servolo Epilepsy Summer Course is at its 12th edition in 2014 and has acquired with time a reputation in the epilepsy community as one of the most attractive and challenging training experiences for students and faculty.

The idea of an Epilepsy Summer Course was conceived in 2001 and was immediately supported by several friends attending an Epilepsy Conference in Venice, Italy. A founding committee composed by Giuliano Avanzini, Marco de Curtis, Francesco Paladin, Yehezkel Ben Ari, Pete Engel, Uwe Heinemann, Istvan Mody, Nico Moshe, Tim Pedley, and Peter Wolf met in Venice in the same year to design a strategy, under the patronage of the International School of Neurological Sciences in Venice (ISNV), affiliated to the Venice International University. The organizers were concerned that there were not enough next generation basic and clinical researchers entering the field of epilepsy. To provide a forum in which these students and post-graduate trainees received a solid introduction to epilepsy and epilepsy research, the founding committee developed a general plan for training courses primarily aimed at young researchers and clinicians with an established interest in epileptology. The general outline included formal lectures, tutorials, practical sessions, journal clubs and special interactive lectures aimed at developing a link between clinical and basic epileptology. The most innovative idea was to ask groups of students to develop, with the assistance of senior tutors, a research project that was presented evaluated in a friendly competition at the end of the course.

The first "Bridging basic with clinical epileptology" course, supported by the NATO SCIENCE PROGRAMME, was held in the summer of 2002 at the ISNV didactic facilities located on the San Servolo Island (at right), a location ideally suited for residential courses. The former monastery has lecture halls, class rooms, dining and recreational

facilities located 20 minutes from Venice's famous San Marco plaza. The students had free access to didactic material (histological samples of epileptic tissue; video-EEG material from animal models and humans; imaging supports; electrophysiology experiment simulations, etc.) under the supervision of the tutors. The strong commitment of the outstanding international faculty and the motivation of the trainees contributed to the great success of the course. This success prompted the ISNV to establish the Epilepsy Summer Course as an important yearly educational event. The success of the research project developed by the students encouraged us to make this particular activity as a central core of the course program ever since.

The Epilepsy Summer School is now permanently established under the supervision of the Scientific Committee composed by Giuliano Avanzini (as ISNV president and Summer School Director), Francesco Paladin (as ISNV director), Marco de Curtis (as co-founder of the Summer School), and two Course Directors. In order to create a permanent link with the ILAE activities, it was decided that one of the Directors of each Course would be the Chair of the ILAE Commission relevant to the Course focus. The 13 Courses held since 2002 are:

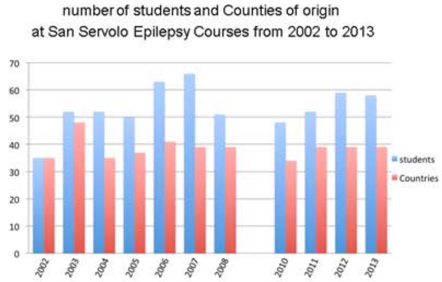
1. **Bridging basic with clinical epileptology** – 21 July-4 August 2002; Directors: G. Avanzini (Italy) and A. Mrabet (Tunisia)
2. **From basic knowledge to rational prescribing in epilepsy** –10-19 July 2003; Directors: E. Perucca (Italy) and T. Tomson (Sweden)
3. **Epilepsy in children: neurobiological, clinical and therapeutic approach** –11-22 July 2004; Directors: R. Guerrini (Italy) and Solomon Moshé (USA)
4. **Bridging basic with clinical epileptology-2** –18-27 July 2005; Directors: Marco de Curtis (Italy) and Esper A. Cavalheiro (Brazil)
5. **Surgically remediable epilepsies** –27 July-8 August 2006; Directors: Gregor Wieser (Switzerland), Giorgio Lo Russo (Italy)
6. **Clinical and therapeutic approaches to Childhood epilepsy** - 23 July-3 August 2007; Directors: Helen Cross (UK), Bernardo Dalla Bernardina (Italy)
7. **Bridging basic with clinical epileptology-3** –27 July-8 August 2008; Directors: Uwe Heinemann (Germany), Marco de Curtis (Italy)
8. **From Basic Knowledge to rational prescribing in epilepsy-2** –19-30 July 2010; Directors Michel Baulac (France), Steve Schachter (USA)
9. **Bridging Basic with Clinical Epileptology-4** –17-29 July 2011; Directors: Marco de Curtis (Italy), Astrud Nehlig (France) and Jeff Noebels (USA)
10. **Management of seizures and epilepsies among neonate and infants** –14-26 July 2012; Directors: Federico Vigevano (Italy), Perinne Plouin (France)
11. **Brain exploration and epilepsy surgery** –14-26 July 2013; Directors: Roberto Spreafico (Italy), Tatsuya Tanaka (Japan)
12. **Bridging Basic with Clinical Epileptology-5** –July 20-August 1, 2014; Directors Marco de Curtis (Italy), Jerome Engel (USA)

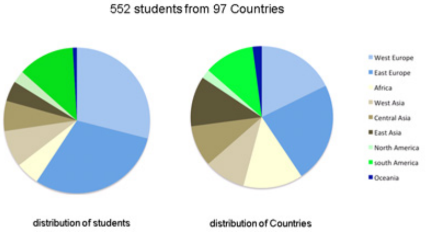
On 21-24 June 2009, a **San Servolo Course Alumni Conference** was held in Pécs (Hungary) in conjunction with the celebration of the centennial anniversary of the ILAE foundation. It was a truly gratifying experience to see how many program participants have continued on in academic careers in epilepsy.

The support of the organizations listed below made it possible to offer about 30 fellowships per year for the participation of students from less advantaged geographical areas and was essential to cover the travel and accommodation expenses of the faculty.

- 2002 NATO
- 2006-2008: European Union (EU): Human Resources and Mobility Marie Curie Actions ("EPILEARN" project)
- since 2003: ILAE Commission whose chair is co-director of the course
- 2006-2013: ILAE Commission of European Affairs (CEA): special support for students from Eastern Europe

Pharmaceutical industry support has been enthusiastic in the past but has progressively reduced in the last two years.
Overall, 552 students from 97 countries attended the courses (see figures below). The initial policy of keeping the student number within 35 was modified according to the experience that an optimal interaction between teachers and students could be obtained with a larger student attendance. The most represented Region in all Courses was Europe, followed by the Asia-Oceania. This regional distribution reflects in part the size of the regional professional epilepsy communities, which is particularly large in Europe where the greatest number of ILAE Chapters is concentrated, and the source of financial support that is mainly from European Organizations.





The success of the San Servolo Epilepsy Summer School is demonstrated by the growing number of applications, that are currently three times the number of accepted students. The success of the Courses is due to the generous commitment of the directors, lecturers and tutors who share their outstanding experience and live in close communication with the students for the full period of the Courses. Their contribution helped create a high degree of motivation in the students, whose scientific and professional endowments made their interaction with the faculty particularly effective. We acknowledge their enthusiasm for making the San Servolo Epilepsy Summer School such an exciting and stimulating event by presenting the readers with the picture of the happy group of students attending the seventh summer course. (see photo at right)

Last but not least we would like to specially thank Metella Paterlini and Valentina Guarino for taking care of the organization with high efficiency and charming courtesy.

Info and contacts: Metella Paterlini e-mail: **epilepsysummercourse@univiu.org**, fax no: +39-02-700445211

Programs and organization details can be found at: **www.univiu.org** and **www.ilae.org**

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Latin-American Summer School on Epilepsy

The idea of creating a Latin-American Summer School on Epilepsy (LASSE) began in 2005 and was conceived following the original Summer School of San Servolo in Venice, Italy, which for many years had been attracting young people from around the world and leading them to discover, guided by renowned epileptologists, the many issues we encounter daily when we are face to face with a person with epilepsy.

With the help of colleagues devoted to health education and supported by, at that time, the newly created Education Commission by the ILAE Executive Committee, we immediately recognized that LASSE could not be simply the transposition of the Venice school to Latin-America, either because the professional development follows different patterns in most Latin American countries which is associated with an uneven scientific literacy, or because the socio-economic development of the region needed to be identified with utmost care. It is true that at least one thing was in our favor: only two languages with the same Latin origin are spoken in this region with almost 600 million inhabitants, i.e., Portuguese and Spanish.


Lasse 2012 students and faculty

Numerous questions then began to pop into our minds: What would be the most appropriate venue? What would be the appropriate number of students? Which Latin American health professionals have a greater need to learn? Should we insist on clinical training or on a balance between clinical content and neurobiological knowledge? But, more importantly, how much would this cost, and which organization would give the financial support? The answer to the latter question solved most of the other questions, because only the state of São Paulo in Brazil has a tradition of supporting events for science and technology education through the São Paulo Research Foundation (FAPESP).

Excited about this possibility, the first LASSE was then scheduled for the southern hemisphere summer of 2007. Even for the non-believing members of the organizing committee, the venue seemed to be a miracle: near the international airport of Sao Paulo in an area with little economic development but still very green (typical of Latin America), 60 simple but clean rooms and delicious homemade food for an unbeatable price. (see photos below)

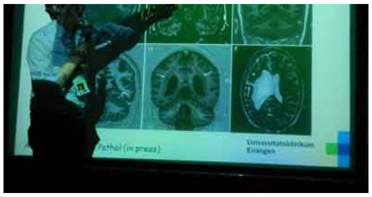
Thus, the first LASSE was held in the Santa Monica Hotel and Convention Centre located in São Paulo. The facility is an Augustinian organization for social welfare engaged in the development of the underprivileged population living in the outskirts of the city. The first edition of LASSE took place between 4 and 14 February 2007, and was focused on the "Translational Aspects of the Epilepsies". More than 20 lecturers and tutors from different parts of the world came to share, generously, their knowledge with over 60 students from various Latin American countries. With the support of Epilepsy Leagues of Brazil and Portugal it was possible to include some students from Mozambique and Angola (Africa), an activity that became, thereafter, regular for all other LASSEs.

At the end of the first LASSE, we all felt surrounded by a mixed atmosphere of excitement, physical exhaustion and gratitude for the good results. Elza Marcia Yacubian expressed the emotions most accurately. In a text published elsewhere, she wrote:

"Portuguese, Spanish, 'Spanguese' and English. These official languages listed in the scientific program announced the informality of the meeting. These different sounds were heard together in a secluded nook near São Paulo, Brazil, surrounded by a poor neighborhood on the outskirts of the Cantareira forest where, in a friendly atmosphere, basic, medical professionals and health scientists discussed the translational aspects of epileptology! In the morning sessions, the participants of the first LASSE studied the 10-20 system of electrode placement. After lunch, they performed volumetric measurements of medial temporal lobe structures on workstations assembled especially for this activity. After dinner, the focus was the Racine classification of epileptic seizures in rodent models. Believe it or not, these activities occurred in February 2007 where 60 young epileptologists were locked from the outside world! Starting at 8 am and ending only at 10 pm, each day was received as a gift by the participants, all linked to health services in Latin America".

Since then, every edition of LASSE has been different, but equally exciting. With the decisive support of the Latin American Commission, the Latin-American Academy (ALADE) and Education Commission, it was possible to include students coming from less economically developed countries in the region that, over the years, recognized the importance of LASSE to promote education of the young generation of health professionals.

Today, it is common to find former students participating, as lecturer or organizer, in local or regional Conferences. Others are members of ILAE Commissions or task-forces while some participate in regional or international research networks. But surely, most are helping people with epilepsy to be treated with respect and dignity.



We sincerely hope that LASSE had, at least, helped them to discover the inner qualities needed to develop their professional and human potential. It was very exciting to hear a statement made by a participant of the meeting of former LASSE students during the Latin American Congress in Quito, Ecuador, "I was taken out of the shadows". This and many other expressions of thanks and support are the major forces that drive us, the organizers, teachers, tutors and general staff, to continue with the Latin-American Summer School of Epilepsy.

The 8th edition of LASSE takes place in February, 2014. The central theme will focus on the relationship of epilepsy with the neurodegenerative diseases and aging. This moment will be particularly important for all those who have, directly or indirectly, contributed to the success of our summer school: LASSE will complete its first 500 students. And we have to thank all those who, with a big open heart, contributed to reaching all of these students. What about the future? LASSE and several other educational opportunities have played a pivotal role in the way epilepsy is understood, studied, monitored and treated in the Latin-American region. Thus, the future can only be better.

For more information: **www.lasse.med.br**

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Developing Therapeutic Patient Education Programs in France

Marielle Prevos-Morgant

Philippe Derambure

Edouard Hirsch

The idea of Therapeutic Patient Education (TPE) in France takes its roots in a desire of changing the approach to epilepsy care. Development of TPE started from the difficulties that patients and health care professionals are facing when trying to understand the objectives of Epilepsy treatments, often prescribed at the end of a very short visit. More than just counting seizures, prescribing drugs or discussing surgery, others individual factors (mood, behavior, self esteem), specific to each patient should be taken into account. Indeed, teaching is most efficient with the involvement of the person the message is addressed to so that the patient can fully be part of the process.

From Conception to Birth (1992-2006)

In English speaking countries (UK, USA, Canada), epilepsy nurses play a major role in the health care system (1-3). They answer patients' questions and are in charge of follow-up consultations, but are also entitled to renew prescriptions and join research activities. For TPE, the gap has been huge between our French and other healthcare systems. Some epileptologists *(E Hirsch, S Dupont, P Ryvlin, B De Toffol, H Vespignani, A Arzimanoglou, A Biraben, P Derambure)*, initially supported these views against the opinions of the community. However, we started intuitively without institutional support or a predetermined method, what would become the infant TPE program (7). The supervised studies done in English speaking and Scandinavian countries (UK, US, New Zealand, Norway) showed the success of this program and were very helpful (4-6). We set up the first phase by informing patients about their disease using literature especially made for them with a clear and simple message. Patients also received instruction during their long hours of EEG recordings (5).The evaluation of the patient's initial knowledge (essential in the TPE program) was lacking at this point. Para-medicals were integrated (*E Hirsch, JP Gagnepain)* in the national congress of the "Ligue Française Contre l'Epilepsie" with a half-day session at first dedicated mainly to the neuro-physiological aspects but then specifically dedicated to TPE (*P Derambure, MP Prevos-Morgant)* as it is known today.

From Birth to Childhood (2007-2009)

With the arrival of a new industrial partner, we started a TPE pilot program. The first step consisted in collecting patients needs, to develop a program and a pedagogical support kit, still used by many teams *(S Dupont)*. The second step consisted of testing this formalized program (consisting of 3-4 sessions) and the pedagogical tool with patients and then evaluating their results *(Hirsch E, Ryvlin P, Dupont S)*. The first conclusions of this pilot program were that TPE was suitable for epileptic patients in three situations: 1) When discussing the diagnosis and explaining the consequences on the patient's life, 2) When dealing with a patient's drug resistance, 3) In support of medical exams and surgical treatments. At the same time this program showed also difficulties: 1) The absence of a patient's interest, 2) The heterogeneity of pathological situations, 3) The lack of suitability of group sessions for some patients (10).

From Childhood to Adolescence (2010-2014)

From 2010, under the heading of the LFCE-TPE commission *(M Prevos-Morgant, P Derambure)*, the number of TPE programs have multiplied, not only in University Hospitals but also in some General Hospitals and Centers specialized in the medical and social support of people with epilepsy. At the moment, there are more than 15 programs certified by regional health agencies. The financial situation is complicated as each center has to rely on its own resources. Starting in 2009, a transnational France-Germany program was developed and financed by the European Union for three years (9). One of the goals of this program was to improve the support to adult patients with drug-resistant epilepsies and to finance a nurse for three years who would be totally dedicated to TPE. This national dynamic allowed the staffs to get experience in TPE through field-based practice. Suitable patients were identified (10): 1) At the hospital during a 24 hours stay or more, 2) During follow-up consultations when patients could benefit immediately from individual sessions.

From Adolescence to Maturity (perspectives, 2015-2020)

With French Healthcare facing difficulties (constant increase in expenses, income stagnation), will there be any room for TPE in Epileptology in 2020? Certainly, if cost-benefit studies demonstrate, as they have in the Northern Scandinavian countries, that this approach is not only improving the patients' welfare, but also allowing economic savings. TPE will also remain a holistic caring tool if it can be integrated into a broader scheme, including the training of nurses specialized in epilepsy. However, TPE remains a delicate instrument for the nursing-educator. Difficult or unwanted information together with insufficient attention to individual needs can result in catastrophic reactions, as a patient's feelings and illness can be very hard to grasp.

Conclusion

TPE in France will be what patients and health care professionals shall make it. TPE is no longer an infant program. However in order to cover country needs, involvement of others will be essential. Due to difficulties of training related in part to Epilepsy's heterogeneity, active participation of "Patients Partners Educators" is still under debate in France (11). Involvement of Pharmacists could be an effective option (12). TPE can only succeed if professional and patient remain side by side during the process. In order to help the patient to understand what is happening, TPE must be considered as a maieutic method, which, according to Socrates, is a method eliciting knowledge through interrogation and logical reasoning. "*Hence people realized that, while thinking they knew, they knew nothing.*"

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Epilepsy Society of the Caribbean

The Epilepsy Society of the Caribbean: The First Multinational Chapter of the ILAE

Authors: Dave F Clarke, Amza Ali, Tamika Haynes-Robinson and Aubrey Webson

Lack of personnel and a paucity of adequate investigative tools have negatively impacted the provision of care for adults and children with Epilepsy in many English speaking Caribbean countries. Neurologists in Jamaica, Barbados and Trinidad provide their populations with some of these services; however lack of knowledge, stigma, inadequate finances, the necessity for travel and other logistical barriers have impeded continuous inter-island Neurological services.

In 2006 Drs. Ali and Clarke met and held in-depth discussions with the Dean and other physicians at the Queen Elizabeth Hospital, Barbados (2006). There the idea of a regional Society was discussed. These two individuals, who had lived in 7 Caribbean countries and visited many more between them, suggested that such a society should serve the English speaking Caribbean and all other Caribbean members willing to participate. Several names including The Caribbean Epilepsy Society, Caribbean League Against Epilepsy, West Indian Epilepsy Society and other names were proposed. Eventually, with the input from health professionals in many island countries, the name agreed upon was the Epilepsy Society of the Caribbean (ESC).

The ESC was by no means the first ILAE member in the region. Cuba and the Dominican Republic have established Societies. Islands affiliated with France, Holland, the USA and the United Kingdom have representation to varying degrees in their respective Epilepsy Associations. However the independent Countries in the English Speaking Caribbean, including Guyana, had no representation. Physicians, Neuropsychologists and other interested parties in Jamaica established the Jamaican League Against Epilepsy (JLAE) in 2001. This society initiated educational programs and expanded awareness of Epilepsy throughout Jamaica. A visiting Professorship sponsored by the North American Commission of the ILAE in 2008 opened the avenue for Caribbean nationals living in the USA to become involved in the JLAE and re-invigorated the talk of a regional society. The JLAE encouraged the formation of a local chapter of the International Bureau of Epilepsy (IBE). With the launch of the Jamaican Epilepsy Association in 2002, with Mrs. Nora Perez as President, many social advances have been made. The JLAE, until its absorption into the ESC, and the JEA were close partners in many initiatives, including the establishment of the first Video-EEG Centre in the English-speaking Caribbean in 2004.

This very complex archipelago of islands, although each individually unique, has been linked together by history and culture. Close inter-island relationships have been fostered, often out of necessity, in governance, trade, education, sports and in some cases currency. The transition of the JLAE to an overarching society inclusive of the English Speaking Caribbean, our French, Dutch, and Spanish sister-islands and our international friends and colleagues was therefore a logical succession. With a large Caribbean medical diaspora in the USA, Canada and Europe we hoped this inclusive, vibrant and visible society would attract their interest and involvement. The mandate was significant: this organization through excellence of clinical care, education, and research would strive to change false beliefs and attitudes about epilepsy and to improve the social, psychological and medical health of individuals throughout the region with epilepsy.

The first draft of the constitution heavily paralleled the constitution of a similar sister organization 'The Caribbean Cardiac Society'. The President of this society offered assistance and so did the Director of Perkins International, Dr. Aubrey Webson, who has introduced and implemented developmental programs throughout Africa and the Caribbean. In 2010 this first draft was discussed with members throughout the region, representatives from the

North American Commission and the President and other Executive members of the ILAE. Numerous iterations followed, with oversight and assistance of Dr. Peter Wolf, Past-president of the ILAE, Dr Samuel Wiebe, the Secretary-General of the ILAE and other ILAE, AES and NAC executives, to whom we remain profoundly grateful.

Written into the constitution was a proviso that there are no more than two elected members from each country, regardless of size and population. Founding members also wanted to include different sub-specialties from inception, as the intention was to ensure holistic care to all people with epilepsy (PWE). The need for continued sharing of ideas and support from other like-minded societies in the region was realized and sought after. We were formally accepted by the International League Against Epilepsy in 2012 as a new and the first Multi-nation Chapter.

As expected, the process of changing Epilepsy care in the region has at times been slow, as it requires substantial cultural and attitudinal change. Education has been our main tool. The biennial North American Regional Caribbean Congresses have featured experts in the field from the Caribbean, USA, Canada and Europe about issues affecting PWE. The inaugural conference and second were held in Jamaica (Montego Bay and Kingston) in 2008 and 2010. The third conference was held in Antigua in 2012 (photo at right). Our 4th North American Regional Caribbean Congress will be held from the 22nd to the 24th of May 2014 at the Bay Garden Hotel and Conference Centre in St. Lucia. 150-200 participants are anticipated in what has become a talked about, eagerly anticipated meeting where experienced professionals in the field can be approached on a one-on-one basis in a relaxed tropical setting and strong alliances fostered.

Discussing the day's meeting and future collaboration after a day of informative lectures at the 3rd North American Regional Caribbean Congress on Epilepsy.

Otherwise, regional Continuous Medical Educational Conferences are ongoing and address clinical care (medical and surgical), social issues and the need for change to a more holistic approach, to improve the quality of life of children and adults with epilepsy. Members of the Society have partnered with other regional organizations such as the Caribbean Pediatric College and the Caribbean Surgical Society to provide Epilepsy Education. Radio interviews, newspaper articles and television interviews are just some of the outreach methods used thus far. A website has been created and educational material is actively added to it. Facebook, Twitter and other social media are followed by our Secretariat. Engagement with the general public via forums often occurs; these meetings will continue to expand in the future.

Clinics are held quarterly in several islands where no neurological clinics are present. The inaugural clinic was held in Antigua in 2010 and St. Lucia (photo left below) and Tobago (photo right below) were added in 2012. One to two day clinics are held at each site, with the entire inter-island trip lasting approximately one week. Management decisions are discussed with patients and their physicians and changes made when necessary. All volunteer Physicians are fully licensed in the respective Countries. Regional physicians attend and actively participate in clinics and educational forums are held as a part of most visits. 413 patient visits have been documented (302 in Antigua, 93 in St. Lucia, 18 in Tobago). No EEG's or trained EEG technologists are available in islands without neurological services; therefore this necessary investigative technique was introduced (through sponsorship by Dell Children's Comprehensive Epilepsy Program). EEGs have been done in 124 patients so far (age range 17 months to 78 years) 33 adults and 91 children. 97% had not had prior EEGs. EEG services during clinics will be provided until local EEG technologists are trained. EEG training is being provided, mainly by on the job training, with material assistance provided by the American Board of EEG technologists. However there are plans for 3 month training sessions with partnering regional hospitals where this service is offered. Because of several requests by regional Pediatricians, a Physiatrist was introduced as a part of the visiting clinical team and Neuropsychology will be started and hopefully expanded within the region by Dr. Tammy Haynes Robinson, recently trained at Yale as a part of an Epilepsy Surgical Initiative between that institution and the University of the West Indies.

Clinic, EEGs and lectures by local and visiting physicians at Scarborough Regional Hospital in Tobago.

A comprehensive approach to care (physical therapy, speech therapy, occupational therapy, EEG's etc.) at St. Lucia's Child Developmental Center.

Recently governmental bodies have sought involvement - the Medical Benefit Scheme in Antigua, in the Educational outreach, or assisted or expressed a desire to participate in improving care (St. Lucia and Tobago's Health Ministries). Improvement in treatment options have been made by expanding the formulary of the Organization of Eastern Caribbean States (efforts of Caribbean Physicians and Gregory Krauss's group from John's Hopkins). Dietary management will be introduced in March 2014, again through collaborative efforts between US and Caribbean Pediatric Neurologists and supportive expertise from the USA (Dietician Specialists Beth Zupec and Mary Beth Joy).

A Joint Epilepsy Surgery Program is being organized and introduced in Jamaica. As mentioned previously, Dr Tammy Haynes-Robinson, Neuropsychologist recently returned from Yale having completed training in the area of epilepsy-related neuropsychology including presurgical assessment. A Neurosurgeon is also presently being trained in epilepsy surgery by Professor Dennis Spencer at Yale. The ultimate goal of this program is to provide regional surgical care for PWE. An expansion of the ongoing Telemedicine program throughout the Eastern Caribbean is in the planning process.

An ongoing epilepsy case conference at the University of the West Indies Hospital, Mona, Jamaica.

Research is also being encouraged throughout the region. A screening tool has been piloted to identify children at risk for seizures where EEGs may not be readily available and has been accepted for publication. A recently completed inter-island collaborative study about medical care in Epilepsy will soon be submitted for publication. Abstracts have been presented at the ILAE AES and NARCCE. Other collaborative efforts are welcomed. It is the intention that the ESC will play an important facilitator role in these collaborations, as the only Caribbean institution solely dedicated to the advancement of epilepsy care.

Much remains to be done. Discriminatory acts still occur, whether by preventing children with epilepsy adequate access to educational resources, high adult unemployment, lack of access to driving because of no driving laws or archaic driving laws precluding driving in many countries, false beliefs and attitudes or simply lack of knowledge. Caribbean people for more than a century have together faced and overcome adversity, in arenas as diverse as sport and politics. The Epilepsy Society of the Caribbean with the help of our friends throughout the North American region, of which we are a small but active part, will continue to advocate for improved clinical care, education and research for those who bravely struggle with epilepsy in the Caribbean.

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Obituary: John Freeman, M.D.

John M. Freeman, an internationally renowned Johns Hopkins pediatric neurologist and medical ethicist whose iconoclastic questioning of established medical practices revolutionized the treatment of pediatric epilepsy and advanced the development of modern biomedical ethics, died on Friday, Jan. 3, of cardiovascular disease. He was 80.

Freeman's forceful advocacy of two long-abandoned therapies—one requiring a strict, unconventional high-fat diet, the other involving surgery to remove half of the brain of children tormented by unremitting seizures—led to their revival and current acceptance as effective treatments.

In the early 1990s, Freeman, founding head of Johns Hopkins' Division of Pediatric Neurology and director of its Birth Defects Clinic, as well as director of what now is the John M. Freeman Pediatric Epilepsy Center, began reviving the use of the long-ignored ketogenic diet (KD) for the treatment of childhood epilepsy.

A high-fat, low-carbohydrate regimen that changes the body's metabolism so that the brain gets its energy from ketones, a fat byproduct, rather than glucose, or sugar, initially was developed in the 1920s, but it was largely abandoned once chemical antiseizure medications such as Dilantin (phenytoin) were created in the late 1930s. As recently as 1995, many physicians no longer considered the ketogenic diet a viable treatment.

Freeman's "resurrection" of the diet, which completely ended the epileptic seizures of many patients, was accomplished "virtually all by himself, against great skepticism and opposition," according to neurologist Guy McKhann, founding head of Johns Hopkins' Department of Neurology.

Among those who were permanently cured of epileptic seizures by Freeman's ketogenic diet was the son of Hollywood producer, writer and director Jim Abrahams, who then led an extensive publicity campaign to promote the treatment in the late 1990s.

Abrahams, whose films included *Airplane* and the *Naked Gun* series of comedies, created The Charlie Foundation, named for his son, to promote the diet. He produced an educational DVD for parents and health care professionals, collaborated on a *Dateline* program about KD, and produced a 1997 made-for-TV movie about it, *First Do No Harm*, narrated by his friend Meryl Streep. He also funded the first edition of Freeman's book, *Ketogenic Diets: Treatments for Epilepsy and Other Disorders*, written with Millicent Kelly and Jennifer Freeman. It now is in its fifth printing.

"John provided hope for my family when no one else would," Abrahams said. "He was utterly unafraid to take a position against most of his colleagues in favor of diet therapy for epilepsy based on decades of his experience when the science had yet to catch up. He and his team from Hopkins provided a cure for my son Charlie when no one else could."

Today, the ketogenic diet is a mainstream medical treatment, with centers now offering it in more than 45 countries worldwide. New studies indicate it may also be an effective treatment for autism, brain tumors, Alzheimer's disease and diabetes.

Freeman also was a mentor to Johns Hopkins' famed pediatric neurosurgeon Benjamin Carson, encouraging him to revive the long-abandoned use of hemispherectomies, or the removal of half of the brain, to curtail the crippling seizures suffered by young patients whose cases they shared.

"His partnership with Ben Carson proved that children devastated by intractable seizures could be restored to fully functional levels with hemispherectomy," says George Dover, director of Johns Hopkins' Department of Pediatrics.

Carson recalls Freeman as “a wonderful mentor and teacher” who “helped work out many of the techniques and problems associated with cerebral hemispherectomy, as well as many other neurosurgical issues affecting patients from around the world. He cared deeply about the patients and had very admirable relationships with many of them and their parents. His shoes will be hard to fill.”

“John Freeman exemplified the very best attributes of a Hopkins professor,” says Dover. “He mentored two generations of pediatric neurologists and pediatricians, many of whom are now leaders in their fields. His clinical acumen transcended conventional wisdom—or dogma—and he pushed all around him to think about better ways to treat pediatric neurology patients.

Among Freeman’s protégés was Eileen P.G. “Patti” Vining, now a professor of neurology and pediatrics who became his successor as head of Johns Hopkins’ pediatric epilepsy center that now bears his name.

“I grew up with him,” Vining said, “and found much of the joy of medicine through him.”

“He was stubborn—and he had great courage. When he realized that children with devastating epilepsies involving one half of their brains were doomed, he was able to convince hesitant surgeons to live in the present and begin to perform hemispherectomies again. He believed we had better procedures and technologies that would make it safe.

“He couldn’t and wouldn’t abandon those children and their families to a life without a rational option. They have loved him ever since.”

Along with Vining and the late Diana J. Pillas, Freeman wrote the landmark, award-winning 1990 book, *Seizures and Epilepsy in Childhood: A Guide for Parents*. Now in its third edition, it is recognized as the standard resource for parents who need comprehensive medical information about their child with epilepsy.

In addition, Freeman conducted influential studies demonstrating that infants with fever-induced seizures do not require medication, showing that the side effects of medication can outweigh the benefits and that children who suffer only one or two such seizures can go untreated with little risk of recurrence.

An outspoken advocate of patient rights throughout his career, Freeman wrote extensively on the ethical and medical conundrums surrounding the treatment of severely ill newborns with congenital defects. In 2001, he published the still-influential book, *Tough Decisions: A Casebook in Medical Ethics*, co-authored with Kevin McConnell, professor of philosophy at Saint Mary’s College, Notre Dame, Indiana.

George Dover observes that Freeman’s “generation of pediatric neurologists often were faced with making diagnoses of conditions for which there was little if any therapy.”

“It was this reality that I believe pushed him very early on to recognize and ask the toughest questions: Who do we treat and when does treatment cause more problems than not treating? He was a pioneer in bringing ethical considerations into the mainstream of the pediatric training programs at Hopkins. He and his wife, Elaine, have championed clinical scholarship for the formal training of ethics in the clinical training programs.”

Freeman showed special concern for maintaining the dignity of individual patients and striving to ensure that each had as independent, fulfilling and as close to normal life as possible. He was the founding chairman of the Johns Hopkins Hospital Ethics Committee and co-director of an undergraduate medical student course in bioethics. He was a member of the original faculty of the Johns Hopkins Berman Institute of Bioethics and established the Freeman Family Fund in Clinical Bioethics to help support the salary of a faculty member to teach that subject.

“He was an institutional visionary,” says Ruth Faden, director of the Berman Institute. “He really had this vision that we could have a world-class bioethics program at Hopkins if we never gave up. And we didn’t give up, and we did get a phenomenal first-rate program here at Hopkins, and John was just critical; he was the person who had the unflagging confidence in a future for bioethics at Johns Hopkins.”

Freeman also was “a phenomenal and extraordinary mentor,” Faden says, helping to forge the careers of dozens of future pediatric neurologists. Employing a distinctive, highly effective teaching style, he spurred the development of his protégés’ skills at critical thinking and their reluctance to accept received medical wisdom— attributes that went on to influence their subsequent, successful endeavors.

Ronald R. Peterson, president of The Johns Hopkins Hospital and Health System and executive vice president of Johns Hopkins Medicine, says, “Few Hopkins physicians have had a more profound effect than John Freeman on how we treat young patients who suffer from epilepsy andcongenital abnormalities—and on how we address the often-difficult ethical issues surrounding these potentially heartbreaking cases.”

“The sensitive, compassionate patient care to which The Johns Hopkins Hospital is dedicated has been enhanced immeasurably by John Freeman’s unwavering concern for patient dignity and determination to improve the lives of those entrusted to his care.

“As the founding chairman of The Johns Hopkins Hospital’s Ethics Committee, a member of the original faculty of the Johns Hopkins Berman Institute of Bioethics, and co-creator with his wife, Elaine Freeman, of the Freeman Family Fund in Clinical Bioethics, John Freeman ensured that even after his retirement from active practice, we constantly maintain the highest standards and deepest concern for all our patients,” Peterson says.

Born in Brooklyn, N.Y., Freeman was a 1954 honors graduate of Amherst College and a 1958 graduate of the Johns Hopkins University School of Medicine. After completing his pediatrics internship and residency at Hopkins in 1961, he undertook a three-year fellowship in neurology and child neurology at Columbia Presbyterian Medical Center. He then conducted two additional years of studies at the Walter Reed Army Institute of Research before joining the faculty at Stanford University in 1966. He returned to Johns Hopkins in 1969 and rose through the academic ranks, becoming a full professor in pediatrics and neurology before being named the Lederer Professor of Pediatric Epilepsy in 1991. He became an emeritus professor in 2007.

Freeman received numerous awards, including the American Epilepsy Society’s J. Kiffin Penry Award for Epilepsy Care in 2001 and its William G. Lennox Award in 2003; the Lifetime Achievement Award of the Epilepsy Foundation of America, and the Child Neurology Society’s highest honor, the Hower Award, in 2004.

The Hower Award’s citation praised Freeman’s “characteristic unwillingness to accept even ‘well-established management principles’ without freshly and critically examining their basis.” It described his four-decade career as one in which he “played the role of gadfly, critic and skeptic, the asker of well-formulated questions.”

“John eventually acknowledged that he was a curmudgeon,” says Vining. “But he didn’t accept the classic definition of a crusty, ill-tempered old man. He thought of himself as willing to point out errors or hypocrisy with a sense of humor.”

Freeman’s “wonderful sense of humor” also was evident in his examinations of pediatric patients, which were “meant to be playful,” Vining recalled.

“Just watching a child play—often with carefully chosen objects—might be all you needed to make a diagnosis. And John playing with the child, usually sitting on the floor, is an image I will always have of him. He needed to do it because he was so tall. He wanted to do it because it was fun. He taught generations of neurologists and pediatricians that you could perform a very thorough neuropsychological examination of a child with the coins in your pocket."

Freeman is survived by his wife of 57 years, Elaine Kaplan Freeman, Johns Hopkins Medicine's former vice president of corporate communications, who served as head of the public affairs and marketing office from 1982 to 2005; two sons, Andrew D. Freeman of Baltimore and Joshua L. Freeman of Chevy Chase, Md.; one daughter, Jennifer B. Freeman of New York City; and six grandchildren. Survivors also include his brother, Donald D. Freeman of Silver Spring, and a step-sister, Laura Lippman Sager of New York City.

Services were held Monday, January 6, 2014 at 2 p.m. at Sol Levinson and Bros. Funeral Home, 8900 Reisterstown Rd. at Mt. Wilson Lane, Pikesville, MD, 21208. Contributions in memory of Dr. Freeman may be made to the Freeman Clinical Bioethics Fund at the Berman Bioethics Institute, Johns Hopkins University, 3400 N. Charles St., Baltimore, MD 21218, or to the John M. Freeman Leadership Endowment in the JHU Department of Neurology.

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Obituary: Dr Michael Donald Hills

21 March 1941 – 1 May 2013

It was with great sadness that the international epilepsy world heard of the unexpected death of Dr. Michael Donald Hills, known to us all as Mike Hills. It is not easy to write about Mike at this point in time. Much has been said already by many people, in many ways. This obituary echoes their words.

Mike was an Honorary Fellow of the Department of Psychology at the University of Waikato, Hamilton, New Zealand. Born and educated in Wellington, New Zealand, he obtained his PhD in 1973 from the Australian National University, Canberra, after a study of intergenerational values disparity in migrant families. His interest in researching and teaching in the disability field for over the past forty years originated in his own experience of epilepsy throughout adulthood.

He had been on the IBE Executive Committee for 12 years, serving two terms as Secretary General and a further term as Vice President.

Mike made a significant contribution to the objectives of IBE and ILAE. In his role as Secretary General of IBE he understood the constitution and the rules of good governance and could be relied upon to interpret the constitution with insightful observations when some hard decisions were being considered. Without fail, he gave his views with eagerness and enthusiasm. His dedication to every task presented to him was carried out diligently. He was always willing to pitch in with a smile, and was often the source of wise insights and advice.

After stepping down from the IBE Executive Committee, Mike continued to support IBE as a member of the Task Force that took on the monumental task of drafting IBE's current Constitution. The introduction of the new Constitution marked a watershed in IBE's existence – introducing seven regional structures and, more importantly, the first fully elected executive committee. In more recent years, since IBE's first democratic elections in 2005, Mike has been a member of the Election Task Force, first as its Chair and, more recently, as a Member.

At the time of his death Mike was a Board Member of Epilepsy New Zealand; Executive Committee Member of the New Zealand League Against Epilepsy; a member of the Elections Task Force for the International Bureau for Epilepsy; he was on the Council of the New Zealand Neurological Foundation Past President of the New Zealand Psychological Society and Chairperson of the University of Waikato Department of Psychology.

However, there was so much more to Mike than involvement on committees and task forces. He was a true ambassador for epilepsy, a living spirit of what can be achieved despite a diagnosis of epilepsy. His gentle spirit and kind heart acted as a magnet for people with epilepsy. He was always ready to share words of wisdom or pragmatic advice to those who approached him. He spoke eloquently on his life lived with epilepsy, the good times, and the bad, and won a huge fan base as a result. His calm presence was greatly admired, particularly by young people with epilepsy in the Asian & Oceanic region – a region close to his heart.

Mike's colleagues around the world greatly admired his insight into every situation. This is evident from the words of those who worked with him since 1993 on hearing of his passing:
from USA – We will never forget his unbridled enthusiasm to help people with epilepsy and fight for the cause;
from Africa – This really is a great loss to our organisations;
from Sweden – This kind and wise man always brought sharp and intelligent advice to whatever problem faced;
from Malta – He was such a gentleman, so positive and always so friendly; from Ireland – He was a terrific role model for people with epilepsy around the world and particularly in the Asian region;
from Holland – We will miss Mike, the entire epilepsy world will miss Mike."

As testament to the respect in which Mike was held by the global epilepsy community, he received two of the greatest awards that IBE and ILAE can bestow. He received the Ambassador for Epilepsy Award in 1999 in Prague, Czech Republic and the Social Accomplishment Award in Budapest, Hungary, in 2009. Nationally Mike was appointed Officer of the New Zealand Order of Merit for services to persons with epilepsy and the community in 2002.

These awards recognise Mike's outstanding personal contribution to activities that have resulted in a significant advance in the social well-being and/or quality of life for people with epilepsy.

ILAE together with IBE salute Mike's achievements. They will continue to work towards the improvement of the quality of life of people with epilepsy and follow his shining example.

Mike was also a great family man and Marylin, his wife, was his constant companion especially when he travelled to epilepsy gatherings. He was also a lifelong rugby enthusiast and had been very active with many teams. Watching his beloved New Zealand "All Blacks" win the world cup in 2011 gave him huge pleasure.

For those who knew Mike May 1st was a very sad day. Mike was a kind man, a true gentleman and an excellent example of someone with epilepsy who lived life to the full. He will be remembered with great fondness.

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Obituary: Harry Meinardi

In Memoriam Harry Meinardi

Harry Meinardi
Nice, 20 February 1932 – The Hague, 20 December 2013

Monument Commemorating Boys Imprisoned in Concentration Camps during the Pacific War. Bronbeek, Arnhem, The Netherlands (reproduced from Dr. Meinardi's Farewell Letter, December 2013)

The end of 2013 brought sad news for all those who care for people with epilepsy around the world. Just a few days before Christmas, Harry Meinardi died peacefully in The Hague, The Netherlands, the city where he lived for the last part of his highly active life. His passing away is a huge loss for the epilepsy community. Just to indicate his stature and degree of involvement in professional as well as lay advocacy activities, Dr. Meinardi was the only person ever to be elected to the Presidency of both the International League against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE).

Harry Meinardi was born in Nice, France, on February 20th, 1932. At the time of his birth, his parents lived in the Dutch East Indies (currently Indonesia), where his father worked in the sugar industry and his mother worked as a physician in government hospitals. When Harry was 7 years old, his father went to Burma (Myanmar) where the sugar industry seemed to be more prosperous, and later to India to escape the Japanese invasion of South East Asia. Harry remained with his mother and brother Jan in the Dutch East Indies, which in 1942 was itself invaded by the Japanese during the Pacific War. Harry's mother was arrested and died in prison, and little Harry himself was imprisoned in Semarang Bangkong, a Japanese concentration camp for boys and old men, where he remained until August 23, 1945, 8 days after the end of the war.

That period had a profound influence on his life, and I remember him sharing with me and other colleagues his memories of happy as well as tragic moments of his childhood in the Far East, as well as his love for that country and its people. Up to the last few weeks of his life, he was secretary of the *Bangkonger*, the little journal of the former inmates of the concentration camp, and attended in Arnhem the commemoration of the victims of the Pacific War. Touchingly, just before his death he forwarded to me and to other friends a picture that he took at the Arnhem commemorations of a statue representing a concentration camp boy, naked apart from his shorts and carrying the tools of the forced labour: a patjol (an Indonesian type spade) and an axe.

In February 1946, he was repatriated to The Netherlands as a war orphan, together with his brother Jan and accompanied by aunt Hella, his mother's sister. After attending a Grammar School in The Hague, he entered the Medical School at Leyden University, where he obtained his M.D. degree in 1957. While working part-time as a student in the Endocrinology Laboratory, he got to know the "Meer en Bosch" centre for patients with epilepsy (today known as Stichting Epilepsie Instellingen Nederland - SEIN). This encounter was a landmark event not only for his scientific career, but for the whole world of epileptology. His newly acquired interest in epilepsy led him to engage, soon after his graduation as a physician, in a three-year research project under the guidance of Professor Jan-Willem Duyff, on the effect on nerve tissue of a recently developed progesterone derivative. This project, that led him to acquire his Ph.D. diploma in 1960, was the outset of his studies on the occurrence of seizures in connection with the menstrual cycle.

After obtaining a professional certification in Neuropsychiatry in 1961, he accepted a fellowship position in Biochemistry and Mathematics at the Rockefeller University in New York, where he worked from 1962 to 1966 under the guidance of Dr. Lyman C. Craig. It was during his stay at Rockefeller that he isolated from brain tissue a peptide of 27 amino acids with the properties of substance P which was found to provoke epileptiform discharges when applied to the brain in picomolar amounts. In 1966, he moved back to the Netherlands to take up employment at the Institute for Epilepsy Management (Instituut voor Epilepsiebestrijding) in Heemstede. That was the beginning of an outstanding career that led him to progress from the position of Neuropsychiatrist/Research Scientist (1966-1968) to Director of Research (1968-1975), General Director (1975-1982) and Director of Epileptology (1982-1992). From 1984 to 2000 he was also Professor of Epileptology at the Catholic University of Nijmegen – one of the very first academic chairs in epileptology in the whole of Europe - as a well deserved recognition of his scientific contribution and dedication to teach and disseminate knowledge on the epilepsies.

His scientific contribution spanned across several key aspects of experimental and clinical epileptology. He was one of the pioneers who demonstrated the importance of pharmacokinetic variability as a factor affecting interindividual differences in the response to antiepileptic drugs (AEDs), and the value of therapeutic drug monitoring in the optimization of epilepsy therapy. In fact, well before I had the privilege to meet him personally in the late seventies, his name had become very familiar to me by reading his contributions to the WODABIDOFs (Workshops on the Determination of Antiepileptic Drugs in Body Fluids), the proceedings of which taught me a lot as I was just approaching this area of research as a young trainee. His interest in pharmacology, clinical trial methodology and outcome assessment in epilepsy was a constant in his career and led him and his collaborators to contribute important findings on a wide range of topics, including the efficacy and side effects profile of old and new AEDs, the comparative teratogenicity of epilepsy treatments, the relationship between serum AED levels and clinical response, the chronopharmacology of AEDs, the relative merits of monotherapy and polytherapy in epilepsy management, and the treatment of status epilepticus.

Dr. Meinardi was a man with a vision, and will be remembered for more than his contribution to epilepsy research. In his striving to improve the life of people with epilepsy, he had clear in his mind the need not only to improve the quality of medical care, but also to address the psychological and social constraints. In that respect, he was among the first to recognise the benefits of sport for people with epilepsy: in a seminal article written 25 years ago, anticipating the theme of the ILAE Stand Up for Epilepsy Campaign, he advised physicians to "encourage epilepsy patients to participate in sporting activities to enhance their physical fitness, self-esteem, and social integration." He also promoted many initiatives to address disparities in epilepsy care and to reduce the diagnostic and treatment gap in developing countries. I remember his keen interest in herbal medicines for epilepsy, and his dream that people in the tropics could someday grow in their villages plants that could be used as inexpensive treatment against seizures. He played a key role in establishing the EPICADEC (Epilepsy Care in Developing Countries) Foundation and in promoting through it several projects in the underprivileged world. When EPICADEC ceased its activities in 2002, Dr. Meinardi generously arranged for the Foundation's residual funds to be transferred to ILAE and IBE to support the Global Campaign against Epilepsy (GCAE). Indeed, these funds are still being used in these very days to maintain GCAE projects conducted jointly by ILAE-IBE and the World Health Organization (WHO).

Dr. Meinardi's contribution to epilepsy associations and scientific societies span over several decades, and culminated in his election to the Presidency of IBE (1977-1981) and ILAE (1989-1993). He also served as Chair of the Dutch Chapter of ILAE, Chair and Executive Director of EPICADEC, Secretary of the Scientific Advisory Council of the Dutch Nationaal Epilepsie Fonds, Advisor on Epileptology to WHO, Regional Facilitator for Africa for the GCAE, member of the International Brain Research Organization (IBRO), and Honorary Consultant Professor at the Neurointernal Department, Shanxi Medical College, People's Republic of China. His achievements have been recognised by many prizes and awards, including the ILAE-IBE Ambassador for Epilepsy Award (1971), the Von Bodelschwingh Prize (1976), the Officer of the Order of Oranje Nassau, a royal distinction (1982), and, most notably, the ILAE-IBE Lifetime Achievement Award (2001).

Family portrait with wife Annemarie (far right), daughter-in-law Paula, son-in-law Giovanni, daughter Hermelyn, grandson Paolo (left to right, top row), grandchildren Anna, Elena and Pablo (from left, lower row)
and a close friend, in Nice, France, 2012.
(photograph taken by Dr. Meinardi's son, Floris)

About 10 years ago, he went into retirement but still conducted an active life, enjoying his many trips at home and abroad with his dear wife Annemarie, and visiting his beloved son Floris, daughter Hermelyn and grandchildren Paolo, Elena, Anna and Pablo. Because Hermelyn's family lived in Italy, he learnt decent Italian, which he enjoyed practising with me during our occasional telephone conversations. In the last few years his health deteriorated gradually, and I was saddened that he declined the invitation to attend the Past Presidents Symposium at the first ILAE-IBE Regional African Congress in Nairobi. Knowing how dear ILAE, IBE and Africa were to his heart, that decision must have been difficult for him to make.

Still he continued with the tradition of updating his friends at the end of each year with recollections of family activities in the previous 12 months, as well as with delightful commentaries on the history and culture of the places that he visited. His December 2013 letter came a little earlier than usual, and made it clear that it would be his last.

Harry with son Floris in the last week they spent together in September 2013

Since his early years, when as a boy he was imprisoned in a concentration camp, he lived as a soldier, fighting tirelessly to fulfil his mission for people with epilepsy. He also died as a soldier. I salute him with the same words that his beloved family wrote in the card announcing his passing away:

Those we loved, don't go away
They walk beside us every day
Unseen, unheard but always near
Still loved, still missed, still very dear.

Emilio Perucca
President of ILAE, and one of Harry's many friends

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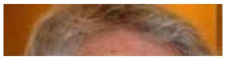
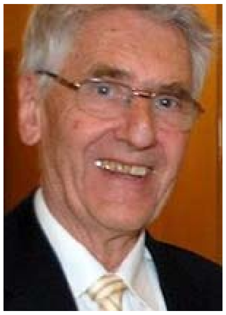
Harry Meinardi (1932-2013): A Tribute



I first met Harry in June 1968 at the European Epilepsy Conference ("European



Institute") organised by IBE in Dunblane, Scotland. As Director of Research at a major Dutch Epilepsy Institution Harry's friendly interest in my first research efforts were much appreciated by me at the time. From slightly different backgrounds we have since then been in regular contact as colleagues, collaborators and friends through our common interest in the science, treatment, care, politics and history of epilepsy.

Throughout the 1970's we both participated in the biennial "Workshops on the Determination of Antiepileptic Drugs in Body Fluids", the so-called WODADIBOF Meetings. In the late 1960's and early 1970's blood level monitoring of antiepileptic drugs was a new scientific frontier in epilepsy and Harry initiated the first meeting in Heemstede in 1972. During the 1980's we met at a series of British/Danish/Dutch ILAE Chapter meetings, culminating in the Northern European Symposium, i.e. including other Scandinavian countries, in 1989.

From 1989 to 1993 Harry was President of ILAE and I had the pleasure of supporting him on the Executive as a Vice President. When I succeeded him as President (1993-1997) Harry was likewise a very supportive Past President.
Throughout the last 45 years there have been innumerable friendly encounters at international, regional and national Conferences or Symposia (e.g. neuro-transmitters, memory functions etc) throughout the world. I particularly remember in 1991 Harry and I were both invited to lecture in Messina in Sicily and our reward was a delightful all day boat trip to the Aolian Islands, escorted by Raoul Di Perri and Franco Pisani. I also recall the occasional pleasant visit to Heemstede and to Harry's home in The Hague.

I last met Harry, appropriately enough, at the Centenary Congress of ILAE in Budapest in 2009, but since then we have continued to keep in touch and collaborate on a series of articles on the history of IBE and ILAE in International Epilepsy News.

The Netherlands has been at the forefront of the Epilepsy Movement before and since the foundation of ILAE in Budapest in 1909, in which Harry's country played a leading role. As Director of one of the most famous Epilepsy Centres in the world Harry was the epitome of that tradition following in the footsteps of Louis Muskens, Bernard Christian Ledebor, Albert Lorentz de Haas, Otto Magnus and Joop Loeber. Harry, however, was unique among them and indeed all other epileptologists in serving as President of both the Bureau (1977-1981) and the League (1989-1993). This of course reflected his commitment to every aspect of patient care and academic epileptology, from the neurochemical and neuropharmacological to the medical, social and political. This also culminated in his appointment as perhaps the first Professor of Epileptology in the world.

Edward Reynolds, Franco Pisani and Harry Meinardi meeting in Messina, Sicily, 1991

Harry's whole career was committed to people with epilepsy locally, nationally and internationally. This he carried out with great dedication, skill and diplomacy. He had a friendly and engaging style, facilitated by an almost British sense of humour, which endeared him to his professional colleagues. He was not driven by any philosophical or religious inclinations, but by practical, humanitarian and diplomatic considerations, with enormous attention to detail. The epilepsy movement has lost a great champion, reflected in his many achievements. I will personally miss our regular, friendly, humorous but ultimately serious and constructive interactions over nearly 5 decades.

Ted Reynolds

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Farewells Listing on Website

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

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

There are two parts to this section: recent deaths and archives. The latter allows League members to learn about those who have gone before and the contributions they made. It also as 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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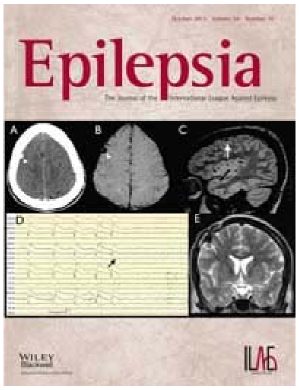
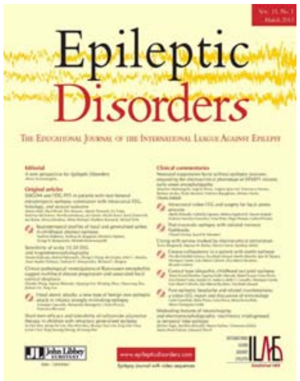
ILAE Journals

Research

Education



Epilepsia



Epileptic Disorders

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Clinical Research and Training Opportunities

Does your institution offer clinical or research fellowships in epilepsy-related disciplines (epileptology, neurophysiology, neurosurgery...)? If so, please describe your program in a few lines, and we will post it on the ILAE.org website. These listings are free of charge, and will remain on the site for six months or as appropriate. To submit your program or to ask questions contact **info@ilae.org**.

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Upcoming Congresses and Educational Events

2014 Regional Conferences

22 - 24 May
2nd African Epilepsy Congress
Cape Town, South Africa
Congress Website

29 June - 3 July, 2014
11th European Congress on Epileptology
Stockholm, Sweden
Congress website

7 - 10 August, 2014
10th Asian & Oceanian Epilepsy Congress
Singapore
Congress Website

17 - 20 September, 2014
8th Latin American Congress on Epilepsy (8th LACE)
Buenos Aires, Argentina
Congress Website

2015 Congresses

6 -10 September, 2015
31st International Epilepsy Congress
Istanbul, Turkey
www.epilepsyistanbul2015.org

Chapter Congresses

7 - 8 March, 2014
Danish Epilepsy Society Annual Meeting: Epileptic syndromes
Hotel Scandic Copenhagen
Congress Program
Register here: **bdp.areg.dk/registration/signup.php**

4 - 5 April, 2014
3rd Annual UAE Epilepsy Congress 2014
& The First Joint Emirati Saudi Epilepsy Congress
Fairmont Hotel, Dubai, UAE
Congress website: **www.congress2014.elae.ae**

22 - 24 May, 2014
4th NARCCE
(North American Regional Caribbean Conference on Epilepsy)
Bay Gardens Resorts, St.Lucia
Flyer
Register here: **www.epilepsycaribbean.org/narcce-2014.html**

12-14 June 2014
Korean Epilepsy Congress
Grand Hilton Hotel, Seoul, Korea
Abstract submission deadline: April 30, 2014
Registration deadline: May 31, 2014
Congress website: **www.epilepsykorea.org**
For information, email **ls@ls-comm.co.kr**

17 - 19 October, 2014
Canadian League Against Epilepsy (CLAE) Biennial Meeting
London, Ontario, Canada

Complete Current Congress Listing

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