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Epigraph Volume 14 Issue 3, Summer 2012



From The Information Officer



Edward H Bertram

Epilepsy is frequently an invisible disease: ignored by health authorities, paid little attention by the general medical community and hidden by those who suffer from it. For these reasons in most countries the resources allocated to epilepsy care almost never approach the cost of the disease to the patients, their families and society. One of the goals of the League, the Bureau and the Global Campaign Against Epilepsy is that everyone who has epilepsy has access to good treatment. One of the first steps in reaching that goal is to educate governments and the public about the impact of epilepsy so that they recognize the value in assuring the availability of the necessary medications as well as in training professionals who understand the issues and the treatments. Removing social and psychological barriers is also a necessary step, as the stigma associated with epilepsy is often far more limiting than the disease itself.

In this edition of *Epigraph* you will find a number of different approaches that have been taken in different countries by our colleagues, all with the goal of making life better for people with epilepsy. Two of the articles from Colombia and the Philippines emphasize the importance of working with government agencies in changing laws and policies that will protect the rights of our patients as well as increase access to treatment. An important point these articles make is that the process takes time (in the case of Colombia, 40 years) and dedication to overcome the obstacles that will almost certainly appear along the path. In both countries the efforts have been rewarded. Our colleagues in South Korea recognized that the terms used for the disease had negative connotations, so they spent several years working through the system to find a new set of terms that are more scientifically based and suggest a disease of brain physiology rather than possession or insanity. As they suggest, there really is much in a word. There is an article about the efforts to continue epilepsy care in Haiti which was devastated several years ago by an earthquake. We also take time in this edition to honor a number of our colleagues from the Asian and Oceanian Region who received the Asian Extraordinary Achievement Award for contributing to improved epilepsy care in the Region. Finally, the League is pleased to announce the recipients of the first North American Commission – Commission on African Affairs Visiting Professor Awards. Like the North American – Latin American awards, the goal of this program is to develop inter-regional cooperation to improve epilepsy care.

There are two messages to take from these great contributions from our colleagues. The first is that we can accomplish much with a sustained effort. The second is that it can often take a long time, but the results are worth the time. We can all take inspiration from the successes of our colleagues and stand up for epilepsy.

Edward H Bertram
Information Officer

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Message From The President



Solomon L Moshé, MD

The year 2012 marks the third year of the current executive term, and what a ride this has been. During this year we will have our Regional Congresses. The Asian and Oceanian Congress in Manila in March was a further testament to the growing strength of our Regional Commissions. There was an impressive number of participants from throughout the Region and, although I was impressed by the high quality of presentations that provided great insight into the issues faced by people with epilepsy in the Region, I was even more impressed by the level of collaboration across the Chapters as well as the commitment to improving the status of epilepsy. All of us are excited about the 1st African International Congress in Nairobi in June which will jump start the process of regional collaboration in our newest Region. The European and Latin American Congresses are following in the next months. We also look forward to the resumption of the Eastern Mediterranean Congress, hopefully in 2013. The organization of these Congresses brings together all components of our constituency with a very active role in research, education, and advocacy, and renews our sense of purpose.

Together with IBE we have been striving to improve the delivery of care worldwide. Through an extremely successful collaboration with WHO, we have developed new demonstration projects in Ghana and Karnataka State (India), where we hope to upscale our activities in order to augment the availability of treatments and access to care in these Regions. This success would not have been possible without the work and commitment of all our partners, including industry, which is also working to reverse the downward spiral of lack of access to care in many countries. This process has been helped by the publication of the Institute of Medicine Report on epilepsy as well as signing of the European Declaration, and the PAHO Strategic Plan, all of which converge to form the blueprint on how we can move forward in the coming years.

We also had our first round of elections, and I congratulate Dr. Emilio Perucca, who is our new president-elect. The elections for the additional members of the Management Committee and the Regional Chairs will be completed by the fall.

We are looking forward to seeing you at the upcoming Congresses. The feedback we receive from all of you will help mold our International Congress in 2013. The strength of this organization is the product of the inspiring team work across our Regions to improve the care of people with epilepsy everywhere. Keep up the great work!

Solomon L Moshé, MD
 President

Message from the President-Elect



Dr Emilio Perucca

Dear Colleagues and Friends,

It is a great honor to have been elected as the League's president for the 2013-2017 term. I wish to express my deep gratitude to all the Chapters and individuals that endorsed my candidacy. Your support reinforces my commitment to serve our constituency to the best of my efforts and capabilities.

Since its founding in 1909, ILAE has worked tirelessly to improve epilepsy care all over the world. Through teamwork, we have advanced our historical roles in education, training and research, disseminated knowledge with our Congresses and prestigious journal *Epilepsia*, and spear-headed novel ventures with our partners - such as WHO and IBE. As a result, ILAE is recognized as the leading society of medical professionals devoted to improving the lives of persons with epilepsy.

It is my view that in the coming years we will have an unprecedented opportunity to advance our mission more than ever before. My specific priorities as ILAE president will include:

1. **Access to Care.** A majority of people with epilepsy live in the poorest regions of the world and have little access to a sustainable supply of medications. The League has the duty to address this unacceptable treatment gap and I will therefore make this a major focus of my presidency. This will have many components, including public outreach, education, ensuring availability and distribution of medications, and support for the development of Centers of Excellence in Epilepsy Care. Sustainability will be a prerequisite and all stakeholders, starting with local Chapters and governments, must be involved. I am aware of the difficulties, but I believe we can make major advances using the experience acquired in successful initiatives, such as those conducted in China and Brazil in partnership with local Chapters, IBE and WHO.
2. **Promote optimal epilepsy care worldwide.** This initiative parallels Access to Care. With 15,000 members in 109 Chapters, we

are in a unique global position to impact government policies addressing epilepsy care. Having been personally involved in the approval of the European Declaration of Epilepsy, I appreciate the tremendous potential that we and our partners have in influencing the political agenda for the good of people with epilepsy. Similar initiatives have flourished in the Americas through the Pan American Health Organization Action Plan for Epilepsy and in the United States through the Institute of Medicine Report. I see opportunities in other regions of the world. We must build on existing momentum to motivate governments to take concrete actions for epilepsy care. To achieve this goal, ILAE will work closely with WHO, our Regional Commissions, Chapters and like-minded public partners.

3. **Advance knowledge on epilepsy.** Epilepsy research is grossly underfunded. We will miss no opportunity to emphasize the need to allocate greater resources for epilepsy research from governments and private institutions. The ILAE contributes to advances in epilepsy knowledge through its network of Commissions and Task Forces. These activities will be refined and coordinated to support our Strategic Plan. I will also ask Commissions to help us with another important mission, i.e. the identification and mentoring of the next generation of leading epileptologists.
4. **Education.** No improvement in epilepsy care can be achieved without an adequate supply of epilepsy professionals. Education remains a major focus of the League's mission. We currently sponsor a wide array of activities, including Congresses, courses, summer schools, workshops, distance education programs, fellowships and visiting professorships. These activities need to be appraised to enhance their merit, improve their cost-effectiveness and identify areas for more effective dissemination. This may include the broadening of our publication and web platforms. Educational activities must be adapted to local needs and cultures, and our Regional Commissions and Chapters should be involved closely in this process. The ILAE Regional Commissions contributed greatly to educational programs over the years, and I look forward to similar advances for our youngest Region, Africa, through our newly formed African Commission.
5. **Protect the League's long-term financial viability.** To maintain and expand our activities, long-term financial sustainability is essential. In the last few years, the Executive Committee took effective action to reduce administrative costs, increase revenues and diversify investments. However, there is no room for complacency. Our sources of income from Congresses and publications are under continuous threat, and the next Executive Committee must be vigilant and prepared to work with new paradigms to adjust to the ongoing changes.

I very much look forward to working together with the next Executive Committee, our Chapters, the IBE and all our members toward achieving these goals. By joining forces we will be able to make progress and with your help much can be achieved. A crucial component of teamwork is communication – I encourage all of you to feel free to contact me starting now and contribute with your ideas and suggestions as we develop the agenda of the League for the next term.

I look forward to working with you towards the fulfilling of our vision – a world in which no person's life is limited by epilepsy.

Emilio Perucca
Treasurer and President-Elect

Asian and Oceanian Extraordinary Achievement Award Winners for 2012



John Dunne, M.D., Australia
Co-Chair, Scientific Consultative Committee

At the Epilepsy Congress in Manila, the Commission on Asian and Oceanian Affairs recognized five colleagues for their exceptional contributions to epilepsy care, education and research as well as for demonstrated leadership in the Region. Their actions have had a significant impact on improving the conditions for people with epilepsy and serve as an example on what can be achieved. This award is the highest honor given by this Commission and is presented every two years at the Asian and Oceanian Epilepsy Congress.



Pictured
above

are awardees: Liwen Wu; Pongsakdi Visudhipan; Kurupath Radhakrishnan; Sunao Kaneko; Yushi Inoue; and Leonor Cabral-Lim who received awards from Byung-In Lee, Chair, Commission on Asian & Oceanian Affairs; Josephine Casanova-Gutierrez, President, Philippine League Against Epilepsy; and Robert Cole, Co-Chair, Scientific Organizing Committee.



Dr Leonor Cabral-Lim is from the University of the Philippines and works at the Philippine General Hospital in Manila. She was recognized for being an inspiring mentor, an excellent clinician and a visionary leader. She has trained a new generation of health workers and neurologists in epilepsy care and is respected broadly by her patients, students and colleagues. She was the moving force behind the Philippine League Against Epilepsy (PLAE) and initiated the first National Epilepsy Congress, now a regular bi-annual event. She was also responsible for securing the Presidential Decree declaring the first week of September of every year as National Epilepsy Awareness Week. Further, she initiated the BRIDGES project (Bridging Referrals to Improve Delivery of Grassroots Epilepsy Services), a project bringing medical epilepsy care to the grassroots, and she continues to work training rural physicians in epilepsy, which is where most epilepsy care is delivered in the Philippines.



Yushi Inoue is the Director of the National Epilepsy Center at the Shizuoka Institute of Epilepsy and Neurological Disorders in Japan. He was recognized for his leadership in advocacy, his educational and mentoring efforts and his many research contributions. He has made major contributions to patient care in Japan, not only at the National Epilepsy Center but also by supporting the Japan Epilepsy Association with his wife in many educational initiatives. He has guided public policy areas including driving legislation. In the Asia Pacific region, he has been a main organizer of the ASEPA epilepsy surgery teaching courses since 2006, and has led many other ASEPA teaching courses in numerous countries, including raising substantial funds annually to support these activities. He has played a key role in epilepsy training for overseas fellows from China, India, Indonesia, Hong Kong, Malaysia, Mongolia, Myanmar, Thailand, and Vietnam. In addition he is the author of more than 100 original scientific papers in English, and 300 in Japanese.



Sunao Kaneko is the Professor and Chairman of the Department of Neuropsychiatry, Hirosaki University Graduate School of Medicine in Japan. Dr Kaneko is recognized for extraordinary leadership, innovations, commitments to education and public service. He is currently president of the Japan Epilepsy Society and the Japanese Society of Clinical Neuropsychopharmacology. He has served as a core member of the ILAE Commission on Genetics, Pregnancy, and the Child. He introduced blood antiepileptic drug concentrations in clinical settings in Japan and played a key role in delineating the teratogenicity of AEDs. In genetic research, he organized a study group on the genetic study of epilepsy that has identified many epilepsy-related genes. He created the first genetic diagnostic chip in the world and applied it to clinical use. He currently serves as Information Officer in the CAO and manages the official CAOC website. In addition he developed the Japanese Epilepsy Society Scholarship system, by which two to three young researchers from the Asian and Oceanian Region receive training in Japan. From 2008, he has been involved in the annual Korean Epilepsy Society – Japan Epilepsy Society Joint Symposium held alternately in Japan and Korea. Finally, in the aftermath of the Great East Japan Earthquake in March 2011, while he himself was also affected by the disaster, he worked tirelessly to send large quantities of antiepileptic drugs to the disaster areas, and also launched the Reconstruction Headquarters.



Kurupath Radhakrishnan is the director of the Sree Chitra Tirunal Institute for Medical Sciences & Technology in Trivandrum, India. Dr Radhakrishnan is recognized for his leadership in clinical care, his effective advocacy, his educational and mentoring efforts and his research. In 1995, he established the R. Madhavan Nayar Centre for Comprehensive Epilepsy Care (RMNC) in Trivandrum, Kerala, India. This advanced tertiary center cares for patients from all over India and neighboring countries, providing presurgical evaluation and epilepsy surgery. In addition to tertiary epilepsy care, under his leadership the center conducts epilepsy clinics regularly in rural areas, and he implemented a community-based epilepsy care in collaboration with the general practitioners. He has developed and supported awareness programs, with his team working hard to overcome the stigma of epilepsy in Asia. The RMNC is the only center in India that with ILAE support offers a post-doctoral fellowship program in epilepsy for Indian graduates and for three doctors from Bangladesh. He has assisted in establishing a Comprehensive Epilepsy Care Center in the National Hospital, Sri Lanka. The RMNC conducts sustained educational programs for general practitioners about basic epilepsy care, and for the school, children and general public. He has over 200 publications in scientific journals encompassing clinical research, epilepsy electrophysiology and molecular genomics.



Pongsakdi Visudhiphan is Professor in the Department of Pediatrics, Ramathibodi Hospital in Bangkok, Thailand. He is recognized for his remarkable impact on the development of epilepsy care and well-being of patients with epilepsy in Thailand through his leadership, innovative skills, clinical research, teaching and mentoring. He is the founder and first president of Thailand Epilepsy Society, established in 1996. He was appointed a commission member on the CAO from 1998-2005. He was co-chairman on the Organizing Committee of the 5th Asian and Oceania Epilepsy Congress and president of the Asian and Oceania Epilepsy organization during the period of 2001-2004. He has written numerous publications, including the first descriptions of surgical treatment of epilepsy in Thailand. He is a great clinician with a warm heart who devotes his life to the care of patients with epilepsy and a great mentor who inspires all who work with him.



Liwen Wu is Professor of Neurology at the Peking Union Medical College Hospital in China, and he is received the award for his extraordinary leadership, clinical care, research and mentorship. In 1995, Dr Wu founded Hakuai Epilepsy Center, the first epilepsy center in China at Peking Union Medical College Hospital. He introduced the use of video-EEG monitoring and WADA test in pre-surgical evaluation. He has served as a leading investigator of numerous clinical antiepileptic drug trials in China. He devotes most of his clinical time to provide services to adults and children, primarily patients with epilepsy, consulting for 4,000 patients annually. He is committed to scientific research, writing and publication. His epilepsy research encompasses genetics of epilepsies, medical and surgical treatment and quality of life, with more than 90 scientific papers in national and international journals.

He has mentored many pre- and post-doctoral fellows, including MD/PhD students and he remains dedicated to teaching and participates in medical student and residency programs, especially those from developing or rural areas. He authored *Atlas of Clinical EEG* (Chinese) in 2007 and contributes frequently to community education.

A new partnership between the International League Against Epilepsy, Partners in Health and Rotary International to improve neurological care in rural Haiti



Lionel Carmant, MD
Treasurer of the ILAE NAC

In 2008, the North American Commission (NAC) of the International League Against Epilepsy (ILAE) founded, with the help of local physicians, the first neurology clinic in Haiti called CLIDEP (Clinique d'épilepsie de Port-Au-Prince). The clinic was operated by Dr Elie, a neurosurgeon, (as there was no neurologist in Haiti at the time) and Dr Sévère, a pediatrician, who trained in electrophysiology at the Université de Montreal under the care of Dr Carmant (the third founding member). The clinic became an instant success providing quality EEG and nursing care to 400 new patients each year. The EEG technologist and nurse had been trained in Santo Domingo thanks to the generous collaboration of our colleagues from the Dominican League Against Epilepsy.

In 2010, CLIDEP survived the disastrous earthquake that afflicted Haiti. Thanks to the contributions from the North American Chapters of the ILAE and the donation of a portable EEG machine from Grass Instruments, the clinic had the opportunity to offer care to local hospitals in Port-Au-Prince. However, we were still disappointed by the few patients we were seeing from outside the capital city (less than 10% of the visits).

To expand epilepsy care to other areas in Haiti, additional resources were needed. With the help of his Rotary Club (Montreal Ville-Marie), Dr Carmant began to raise money to put together a mobile clinic similar to what had been done in other Regions. This effort was guided by the experience of Dr Gallo Diop of the Senegalese Chapter and Chair of the Commission for African Affairs of the ILAE. A Gala Evening fundraiser in Montreal in April 2011, was a huge success raising more than \$30,000 and this amount was matched by Rotary International and a partnership with Rotary Club of Delmas-Aéroport in Haiti. The combined \$60,000 was used to buy a mini-van equipped with a generator and basic seizure medications.

In November 2011, CLIDEP established a partnership with the organization Partners In Health (PIH), which operates in 12 villages in Haiti. The Mental Health Director of PIH, Dr David Grelotti and the CEO of PIH Haiti, Ms Cate Oswald, suggested two regions to visit because of the availability of local physicians to partner with, as well as family medicine residents who could benefit from our training. These regions are the cities of Saint-Marc and Cange. Once the sites to visit were established an appeal was sent to ILAE NAC members fluent in either French or Creole to participate in the mobile clinic. We were able to recruit four other neurologists to provide regular services: Dr Jeffrey Bigelow from the American Epilepsy Society (AES), Dr Stanley Elysée from the Canadian League Against Epilepsy, Dr Mill Etienne from the AES and Serge Pierre-Louis also from the AES.



Figure 1- The ILAE-Rotary sponsored CLIDEP mini-van is equipped with a generator to prevent electrical failure and as well as with generic carbamazepine, valproic acid and phenobarbital for those who have no access to seizure medication.

On March 25th, we began CLIDEP's first mission in our brand new vehicle (Figure 1). We headed to Saint-Marc. Upon arrival, we had an outdoor waiting area full of patients. As it was when CLIDEP began its activities in Port-Au-Prince, the first few consultations included a number of non-epileptic events with a diagnosis based on local EEGs of unacceptable quality (Figure 2). The team worked through lunch as a teaching session for the local team was scheduled for 1PM. By 4PM we had seen 10 patients and performed six EEGs. We left Saint-Marc at 5:30 PM and arrived in Canges at 8PM exhausted but satisfied with our effort.

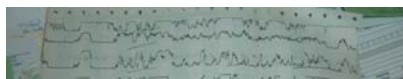


Figure 2- An EEG of unreadable quality and multiple artefacts interpreted as epileptic in a psychiatric hospital. The patient had pseudoseizures and was convinced that he was possessed by demons.

In Canges, clinic began at 8AM and included pediatric and adult neurology patients. Again, it was a very productive day with 14 consultations and seven EEGs. At the end of clinic, we had a briefing session with Drs Fils-Aimé and Grelotti to review all patients seen over the past two days after which the CLIDEP team returned to Port-Au-Prince (Figure 3). We were pleased with the results of our efforts, and we intend to revisit the same regions every other month for the next 12-24 months and then repeat the experience in other regions with the goal that all regions can get proper training of first-line health providers and more complicated cases can be referred to CLIDEP in Port-Au-Prince. We continue to seek funding to buy local equipment and train EEG technologists and nurses in each village.

Our efforts wer



Figure 3- The end of two days of mobile clinic. From left to right: Junior (driver), Dr Reginald Fils-Aimé (local physician and co-director of PIH Mental Health Section in Haiti), Dr Alix Elie (Director of CLIDEP), Dr Lionel Carmant (visiting neurologist), Ms Renée Hamilton (visiting occupational therapist) and Daphnée Verne (CLIDEP EEG technologist).

e greatly appreciated by our PIH partners who appreciated the new insights gained into epilepsy and its treatment, a thanks that went out to everyone from the ILAE and Rotary clubs who have supported this project directly or indirectly.

Epilepsy Gets a New Name in Korea



Byung In Lee, MD (Dept of Neurology, Yonsei University College of Medicine, Seoul)



Kyoon Huh, MD (Dept of Neurology, Ajou University College of Medicine, Suwon)



Sang Am Lee, MD (Dept of Neurology, Asan Medical Center of Ulsan University, Seoul)

NOTE: The Korean characters in this article are not viewable in Internet Explorer. They are viewable in other browsers or go to the PDF version posted on the website.

Gan-zil (간질: 癇疾: a convulsive disease) was the name for epilepsy in Korea, which has been replaced by a new name, Noi-jeon-jeung (뇌전증; 腦電症: cerebroelectrical disorder). The ‘Epilepsy Renaming’ has been the subject for many debates not only in Korea but also in East Asia because the Chinese name of epilepsy (jeon-gan; 癲癇 or gan-zil; 癇疾) implied the meaning of ‘crazy’, ‘mad’, or ‘divine punishment’. In Korea, the project of Epilepsy Renaming was officially launched in June, 2007, and successfully completed on 19 June 2011. In this article we wish to review the background and the process by which epilepsy got a new Korean name.

1. History of Epilepsy Care in Korea

Traditional Korean medicine was adopted from China starting in BC 3,000, and it was modified and reorganized by Dr J Huh (author of *Precious book of Eastern Medicine: 東醫寶鑑*) in the 16th Century. Western medicine was introduced to Korea in 1884 by Dr HN Allen who was a medical missionary from the US. He became a doctor of King Kojong of Chosun Dynasty and established a hospital (che-jung-won: 濟衆院) in 1885. This hospital ultimately became the Severance Hospital and the Medical College of Yonsei University in Seoul. Modern

epilepsy care in Korea was initiated by Dr L Robinson (1904-2009) in 1963, a medical missionary from the US, who used phenytoin supplied by the International Christian Board for the treatment of epilepsy. This action brightened the future of many patients suffering from epilepsy and triggered the foundation of "Rose Club", an NGO consisting of doctors, priests, social workers, patients and their families, and volunteers. Rose Club conducted two main activities, Christian charity activities and mobile epilepsy clinics. The epilepsy clinic of Rose Club registered more than 100,000 patients around the nation. The Korean Epilepsy Association (KEA) was organized as a branch of Rose Club in 1968, and it became a Chapter of the IBE in 1979. The rapid economical growth of Korea since the 1980s, which was called "the Miracle of Han River", rapidly promoted the standard of medical practice with major community hospitals being equipped with modern medical facilities. In 1989, a Comprehensive Epilepsy Care Program providing both medical and surgical treatment of epilepsy was established at the Yonsei University Hospital. The Korean Epilepsy Society (KES) was established in May 1996, and hosted the Inaugural Congress of Asian and Oceanian Epilepsy Organization (AOEO) 5 to 6 September, 1996. The KES was approved as the local chapter of ILAE in 1999.

2. The Korean Society: Concept and Stigma on Epilepsy

Korean traditional social concept was heavily influenced by Confucianism as in many countries in East Asia. Confucianism stresses a strict moral code for social and personal interactions and discourages any unexpected or deviant behaviors. Confucianism thus made epilepsy a forbidden disease that should not be exposed. In spite of the rapid modernization of Korean society, the traditional concepts are still deeply entrenched and make people with epilepsy (PWE) silent victims of strong social stigma. Several surveys of public awareness and attitudes toward epilepsy have been conducted in Korea and showed strong negative public attitudes toward epilepsy as expected. In a recent nationwide survey by Yoo et al. (2009), 27 percent of the control population thought epilepsy was a hereditary disease, 31 percent did not allow their children to associate with PWE, 64 percent objected to their children getting married to PWE, and 36 percent thought that PWE should not be employed like other people. It is also very intriguing to find out that a significant proportion of PWE carry a very negative view toward their own illness (table 1).

Table 1. Perception of Epilepsy in Patients and Healthy Controls

Q9*	PWE***	Controls	Q17*	PWE***	Controls
I would keep it as a secret from everybody.	103 (27.8%)	257 (17.4%)	1. Epilepsy	159 (47.3%)	241 (17.9%)
I would talk about it only to people very close to me.	174 (47.0%)	898 (60.8%)	2. Diabetes	36 (10.7%)	215 (16.0%)
I would talk about it freely with anyone.	65 (17.6%)	148 (10.0%)	3. Chronic respiratory problem	10 (3.0%)	65 (4.8%)
I don't know or don't wish to answer.	28 (7.6%)	174 (11.8%)	4. Chronic cardiac problem	9 (2.7%)	79 (5.9%)
			5. Psychiatric problem	119 (35.4%)	738 (55.0%)

*Q9: If you had epilepsy, how easily would you talk about it with other people?
 **Q17: If you were to have a disease, which one would you most "avoid" it to be?
 ***PWE: patients with epilepsy

More than 75 percent of PWE and controls wanted to hide the illness, and almost half of PWE regard epilepsy as the worst chronic disease, even worse than a psychiatric illness. On the other hand, the felt stigma study by SA Lee et al. (2005) revealed that only 31 percent of PWE in Korea felt stigma, which was unexpectedly much lower than the average of European countries (51 percent of PWE felt stigma) reported by Baker et al. (2000). Apparently there are complex relationships between "felt stigma" and "negative public attitudes", which may be influenced by different social traditions.

3. Project of "Epilepsy Renaming"

(1) First Phase

On the basis of accumulating evidence and experience, both KES and KEA agreed that Gan-zil (간질: 癇疾) represented a concept of "forbidden disease", thus Koreans don't want to talk about gan-zil. The joint symposium of KES-KEB on 8 June 2007, concluded that the most effective way of challenging the negative attitude toward epilepsy in Korea is to develop a new name for epilepsy that was neutral. The "Epilepsy Renaming Task Force" was organized (Chair: Professor K Huh, president of KEA) and it conducted a series of actions (table 2).

Table 2. Progress of the Project of "Epilepsy Renaming"

2007.06.08	Korean Epilepsy Association proposed the Project of "Epilepsy Renaming"
2008.08.28	Organize "Epilepsy Renaming Task Force"
2008.09.01	Appeal to members and patients for submission of New Names to replace 癇疾 through news papers, mails, home pages, and Epilia (Internet website of NGO)
2009.06.04	A ballot at the General Assembly of KES 뇌전증(腦電症: Cerebro-electric Disorder) was chosen as the new name of epilepsy
2009.10	Official request of opinions about the "New name of Epilepsy: Cerebro-electric disorder" to seven relevant Academic Societies
2010.05.03	Korean Medical Association officially approved "뇌전증(腦電症)" as the new name replacing 간질(癇疾)
2011.06.24	Officially changed the name of KES and KEA as 大韓腦電症學會 and 大韓腦電症協會
2011.06.29	뇌전증 (noi-jeon-jeung) become a "Legal Language" by the approval at the General Assembly of National Parliament(Dr. SJ Shin proposed a reform)

The guidelines for the new name were terminology that (i) was neutral, (ii) implied a scientific basis, (iii) was easily differentiated from

epilepsy-related words (eg, convulsion, fits, spasm, etc), (iv) was easy to use as both a noun and an adjective, and (v) was likely to be acceptable in global epilepsy communities. "Epilepsy Renaming" Task Force appealed to the public for new names to replace gan-zil (간질) on 1 February 2009, through newspapers and the Web. More than ten names were submitted and the Task Force chose four: (1) 뇌신경경련증 (noi-shin-gyung-gyung-ryun-jeung; 腦神經痙攣症; cerebral convulsive disorder), (2) 뇌진증 (noi-jin-jeung; 腦震症; brain quake disorder), (3) 뇌전류장애증 (nai-jeon-ryu-jang-ae-jeung; 腦電流障礙症; abnormal cerebroelectrical current disorder), and (4) 뇌전증 (noi-jeon-jeung; 腦電症; cerebroelectric disorder). Through an official ballot at the General Assembly of KES on 16 June 2009, 뇌전증 (nai-jeon-jeung; 腦電症; cerebroelectric disorder) was selected as the New Name for Epilepsy replacing gan-zil. 뇌전증 (noi-jeon-jeung) fully satisfied the proposed guidelines for being neutral, reflecting the scientific basis of epilepsy, clearly distinguishable from many words of resemblance, and easy to use as a noun and an adjective; e.g. 항경련제 (抗痙攣濟; anticonvulsive drugs) to 항뇌전약물 (抗腦電藥物; anticerebroelectric drug), 간질성발작 (痙攣性發作; epileptic seizure) to 뇌전성발작 (腦電性發作; cerebroelectric seizure). Finally it can be promoted internationally, comparable to "Cerebrovascular disease" or "Neuromuscular disease".

(2) Second Phase

Immediately after the adoption of 뇌전증 (noi-jeon-jeung) as the new name for epilepsy, the project entered into the second phase of three steps of promotion: (i) medical terminology, (ii) legal terminology, and (iii) public terminology. In October 2009, KES sent a letter to seven related academic societies (eg, Korean Neurosurgery Society, Korean Psychiatry Society, etc) asking their official opinions about the new name. All societies approved the use of the new name, which was followed by the submission of "Request for Approval of New Name" to the Korean Medical Association (KMA). KMA approved the new name in May 2010, and the National Institute for Korean Language approved the decision of the KMA. In the Korean Language Dictionary 간질 (gan-zil) has been replaced by 뇌전증 (noi-jeon-jeung). Subsequently, KES and KEA officially changed their names from 대한간질학회 (大韓痙攣學會; dae-han-gan-zil-hak-hoih) and 대한간질협회 (大韓痙攣協會; dae-han-gan-zil-hoep-hoih) to 대한뇌전증학회 (大韓腦電症學會; dae-han-noi-jeon-jeung-hak-hoih) and 대한뇌전증협회 (大韓腦電症協會; dae-han-noi-jeon-jeung-hoep-hoih), respectively in June 2010, which was the starting point for the formal change from "gan-zil" to "noi-jeon-jeung" in all medical or academic publications. The next step was the promotion of noi-jeon-jeung as the "Legal Terminology", which required the approval of the Korean National Parliament. Dr SJ Shin, a doctor and a congressman from the Hannara Party, who was a strong advocate for the project, submitted a reform containing the word of "noi-jeon-jeung" instead of "gan-zil" to the National Parliament and it was fully approved at the General Assembly on 29 June 2011, which has concluded the official process of "Epilepsy Renaming".



4. Future Strategy for Epilepsy Renaming

The final stage of the promotion of "noi-jeon-jeung" into public use has just started but requires intense and continuing long-term efforts. They will include social campaigns, public education, and support from many advocacy groups. The KES and KEA held a ceremony celebrating "Declaration of Noi-jeon-jeung", on 7 June 2012, which will be followed by the 17th Annual Congress of the KES and KEA which is an International Congress for this year. Leaders of ILAE-IBE are going to participate in the ceremony and many international and regional speakers are invited to the Congress. The final step of "Epilepsy Renaming" can be achieved only by the joint effort and support from the international epilepsy community.

Protecting the human rights of people with epilepsy: The long path to the landmark law in Colombia



Jaime Fandiño Franky, MD
Past-President and founder Colombia League Against Epilepsy Executive Director FIRE

The story begins in 1964 with the founding of the Colombian League Against Epilepsy which was made possible by the generous help from a number of people from Cartagena, Colombia (ILAE). This important step was followed by another: the creation of the Foundation for the Rehabilitation of People with Epilepsy in 1970 (IBE). Soon, we realized that without the involvement of the state, the battle for improving the lives of people with epilepsy would be very difficult even with the dedication of the professionals to the care of patients and families. So, the next step was to obtain a law protecting the human and civil rights for these abandoned people. These goals aligned the Colombian groups with the principles of the ILAE and IBE.

In the first almost 40 years of trying to convince members of the Colombian Parliament of the need for rights protection, specifically for people with epilepsy, we made no progress. Tired of pleading, we designed a new strategy to reach our goal. The first step was to find a senator who was sympathetic toward the suffering of people with epilepsy. We invited him to see the patients and clinics of the Colombian League Against Epilepsy in which we cared for many poor people, some of whom came from very far away. His visit completely changed his view about epilepsy, and he became deeply touched when he saw the reality of what it is like to be afflicted by this disease. Following his visit, he promised to help write a law that would protect the rights of people with epilepsy. We were asked to identify the essential issues and examples that would demonstrate to the parliamentarians that legal protection was needed. The politicians would take responsibility for the drafting of the law. During the next six months, we met many times until we got the definitive text that was entered in the first Commission of Parliament. In order to establish a personal dialogue with every parliamentarian about the needs of people with epilepsy our presence was of utmost importance in every session. So, we had 230 meetings with different legislators in order to explain what epilepsy is, and what problems the people and their families have.

As the law was progressing through the legislature the proposed legislation was sent to the Ministers of Treasury and of Social Protection

for comments. Both attacked the project by indicating that there was a lack of resources to support the requirements of the law. We fell into the depths of despair over the possible defeat of this critical law, so we called on the help of two of the epilepsy community's greatest friends and supporters: Hannecke de Boer and Carlos Acevedo. We asked both of them to speak to the entire Colombian Parliament to explain the need for the law and to encourage passage of the law. Their presentation at a regular session was transmitted by TV to the entire country. The godfather and sponsor of the law, Senator Manuel Virguez, made all of the arrangements for the session, which was an enormous success as well as a highly emotional event.

Soon after the presentations, the Parliament approved the law. We were looking with great anticipation to the final step, the signature of the President of Colombia which would make the law official. To our great surprise the President vetoed the law, adducing unconstitutionality and returning the document to the Parliament. In a final attempt to make the law a reality we appealed to the Constitutional Court, which unanimously obliged the President to sign the Law. In its opinion the Court clearly stated, "**People with epilepsy need a reinforced legal protection.**"

The passage of the law is only the first step in making sure patients with epilepsy have legal protection and access to care. The next important step is for every patient and his family to realize the marvelous rights that have been won. It was four years of full time effort, but the wonderful results will open many doors that were previously closed to people with epilepsy.

Signing of the Memorandum of Understanding between the Department of Health and the Philippine League Against Epilepsy



Hazel Paragua
President



Jean Marie B. Ahorro
First Vice President

The Philippine League Against Epilepsy (PLAE) was founded in 1997. From its beginning it has been active in improving access to care for patients and in advocating for recognition by politicians and policy-makers for greater support for epilepsy in the national health agenda. Early in the history of the PLAE, the organization succeeded in having President Gloria Macapagal-Arroyo decree that the first week of every September would be National Epilepsy Awareness Week. This week has been used by the PLAE and other epilepsy supporters as an opportunity to educate and lobby, but little progress was made in including epilepsy in the broader national health agenda.

The absence of support for epilepsy at the national level did not deter the PLAE from working to improve access to care. In 2004, Dr Maria Felicidad Soto started the Epilepsy Manager Project, which brought epilepsy specialists from major hospitals to start training government doctors and other rural health physicians in remote areas of the country in the diagnosis and treatment of epilepsy. The training consisted of didactic lectures as well as monthly visits by the epilepsy specialist to the local health clinics. The goal of the program was to have basic epilepsy care within one hour of each patient's home.

In spite of these successes, epilepsy remained outside of the Department of Health, and there were few health system resources available for people with epilepsy. In 2011 things began to change. A formal request was made to the Department for assistance in the implementation of PLAE programs. The initial response was to ask for a list of what the PLAE had accomplished and what it viewed as the important next steps. On 1 March 2012, Dr Teodoro Herbosa, the Undersecretary of Health and a trained Emergency Medicine specialist, met with three of the national epilepsy leaders, Drs Hazel Paragua, Josephine Casanova-Gutierrez and Leonor Cabral-Lin, and together they discussed the critical needs of people with epilepsy. After that single meeting a Memorandum of Understanding was drafted.

The 2nd of March 2012 marked a milestone in the history of the PLAE. On this day, a partnership between the Department of Health was solidified with the signing of the Memorandum of Understanding that recognized epilepsy as one of the mental health disorders that will be given priority in terms of programs and legislation by the Department of Health. Dr Herbosa, who currently heads the Public-Private Partnership program of the Department of Health signed the memorandum with Dr Hazel Paragua, President of the PLAE. The event was also witnessed by Prof Solomon Moshe, President of ILAE, Prof Emilio Perucca, ILAE Treasurer and Prof Samuel Wiebe, ILAE Secretary-General. The Executive Committee and other members of the PLAE were also present.

At the signing, Dr Herbosa said that the Department of Health would maximize this partnership to help in the care and awareness for persons with epilepsy. The ILAE President Moshe said that this endeavor will inspire member countries to create a stronger partnership with their own governments so that the ILAE programs can all be implemented even up to the grassroots level.

There is still much work to be done in support of this memorandum. There are three immediate goals for implementation. The first is to facilitate collection of data as to the incidence and prevalence of epilepsy in urban and rural health centers. The Department of Health regularly collects data through a computerized database system, and the PLAE hopes to add seizures and epilepsy among the list of disease conditions reported in the database. The second is to include anticonvulsants like phenobarbital, phenytoin, valproate and carbamazepine in the essential drugs list that the Department of Health regularly purchases and makes available in all government health centers and hospitals. The third goal is to have Department of Health workers help the PLAE with the lay education program to improve awareness of epilepsy.

Dr Herbosa also promised to create a Department of Health Task Force on Epilepsy in which PLAE representatives will be involved to develop policies and action plans specific for epilepsy. We look forward to reporting on the activities of this Task Force in the future.

The Philippine League Against Epilepsy is truly proud of this initiative.

The North American Commission–Commission of African Affairs Visiting Professors Program



Jo Wilmshurst
Cape Town, South Africa

The North American Commission and the Commission of African Affairs is pleased to announce the three projects that will be supported in the inaugural Visiting Professors program. The program supports the development of collaborations between a North American institution and an African one. There were eight applications and the primary selection criteria were the clarity of the goals and the likelihood that this project would be the beginning of a long-term relationship.

1. Mali-Montreal project

Principle investigators: Lionel Carmant / Yousseffa Maiga

This project is centered on a teaching meeting that will take place 26 to 28 September 2012, and builds on a collaboration that has developed between Dr Carmant and the members of the Malian League Against Epilepsy (MLAE). There are only five neurologists in this country with a population of 14 million. There are two main components of the project.

The first is teaching targeted at diagnosis and treatment of epilepsy by rural healthcare providers in Mali as well as by physicians from other French-speaking African nations: Côte d'Ivoire, Sénégal, Guinée, Centrafrique, Togo, Bénin, Niger, Mauritanie, Burkina Faso, Cameroun, RDC and Congo. Participants will include 50 healthcare providers and trainees from Mali, 10 Malian paramedics and 24 foreign healthcare providers. Speakers will include the five Malian neurologists, two members of the Commission of African Affairs and two visiting professors (one adult and one pediatric epileptologist). This session is also sponsored by the Health Minister of Mali and the WHO. Dr Carmant will be in charge of the pediatric sessions, which will include: pathophysiology of seizures and epilepsy in the developing brain, epileptic syndromes in children and teenagers, diagnosis and treatment of neonatal seizures, investigation of epileptic encephalopathies and an interactive video session.

The second aim will train urban interns and residents. Dr Carmant will visit the Bamako hospitals and neurology clinics to assess patients with refractory epilepsy and provide further training to interns and residents. Additional topics will include the ketogenic diet and epilepsy surgery in developing countries.

Dr Carmant will continue to visit Mali every other year on an exchange program between the University of Montreal and the University of Bamako. A telemedicine program will also be established with the help of two participating associations.

Finally, it is hoped that the involvement of the Malian government will improve access to care in Mali to patients with epilepsy, including access to medication, training of EEG technologists and providing larger rural centers with an EEG machine. NGOs such as Santé Sud are ready to help attain these objectives.

2. Calgary-Tanzania

Principle Investigator: Laura Jurasek, Stollery Children's Hospital, Alberta / Tanzania Training Centre for International Health, Ifakara, Tanzania

The theme for this interaction is a nurse-led teaching program on epilepsy and epilepsy management to healthcare professionals and students in collaboration with the Tanzania Training Centre for International Health and the Tanzanian National Nursing Association. Following the formal teaching, practical clinical teaching will be undertaken in the community to enable the healthcare professionals and students to become confident in history-taking from caregivers or patients with epilepsy and in examination and management approaches. The concept will be to "train the trainers" whereby the knowledge is disseminated to other colleagues and elsewhere in the community. Community healthcare workers and traditional healers will be targeted, home-based care encouraged and early intervention with appropriate referral to the hospital for emergencies. Teaching will also address the stigma of epilepsy, the need for inclusion and "normalization" of people with epilepsy in the community.

The program will begin in 2012 and have a follow-up review in 2013 which will focus on the number of teaching sessions held and the number of trainees completing the course. There will be a pre- and post-questionnaire of the epilepsy knowledge gained. Some of these evaluations will be undertaken in the communities that are part of the program (Ulanga and Kilombero regions – 56 villages). These villages will be randomized to being either part of the education program or not, and the knowledge pre- and post-compared. The research in this project is supported by the Canadian International Development Agency (CIDA).

3. USA-Zambia

Principle investigator: NIH Dr William Theodore / Lusaka, Zambia

The primary theme of this project is training key personnel in major EEG features. It will target the neurophysiology staff and doctors to ensure that they understand basic EEG. Dr Theodore has visited the center and already commenced training and identifying the key needs for the area. The local center has built a neurophysiology laboratory and Dr Theodore has arranged for EEG equipment to be donated. The donation allowed the Neurologic and Psychiatric Society of Zambia (NPSZ) to leverage additional resources to renovate space for the laboratory, to replace consumables associated with the EEG and to fund sending a Zambian abroad for training as an EEG technician.

To optimize the rational use of EEG in the Zambian environment in which EEG is an extremely limited resource (ie a single EEG machine in a country of more than 12 million people), in 2011 NPSZ developed guidelines for EEG use 1. While the clinical benefits of a single EEG machine are limited, such technology has offered important opportunities for expanding education in epilepsy care and has fostered increased interest among medical students and registrars. The University Teaching Hospital (UTH of Lusaka) EEG laboratory also provides support for the CHASE study (a Cohort study of HIV-Associated Seizures and Epilepsy), an NIH-funded study that developed in collaboration with Dr Theodore following his initial visit.

Dr Theodore will attend morning report daily to review neurology cases and offer bedside teaching. He will also provide instruction in EEG for MMeds, registrars and medical students to evaluate and identify ominous EEG patterns that require acute intervention. The trainees will also learn to review EEGs as part of an NIH-funded study of EEG in coma at UTH. One of the key outcomes will be the development and submission of an original research manuscript that details the EEG patterns of 50 to 100 consecutive adults with coma.

At the same time a candidate will spend one month at NIH with Dr Theodore to enhance their skills at EEG interpretation and to gain insights into recent advances in epilepsy research and clinical care. They will also develop didactic presentations regarding these advances that are appropriate for dissemination in Zambia.

In addition to the grant funding, and the \$2,000 pledged from other available epilepsy capacity funds, Dr Theodore will obtain travel funding from NINDS, if needed.

Priscilla Shisler to assume ILAE Administrative Director Position



Priscilla Shisler will assume the top ILAE staff position. She succeeds Peter J. Berry, CAE, who has served in the position for the past 15 years.

Berry said he was ready to shed his management responsibilities and move into more of a support role and to work on specific League projects as determined by the Management Committee. He added that he also wanted to give Shisler the opportunity to grow professionally. Berry will have the title of Advisor.

Shisler has worked with ILAE for the past two years and she has 20 years of experience in the education field. She currently serves as Leadership Liaison, supporting the Leagues' Executive Committee, education activities, and other projects.

In addition to the work she is already doing for the League, Shisler will become the second VIREPA Coordinator to Verena Hezser-v. Wehrs. VIREPA is ILAE's virtual epilepsy academy. With the expansion of the distance education program, Shisler will moderate three courses and Hezser-v. Wehr will assist in the development of

new courses.

Shisler earned a bachelor of science degree in secondary education and a master's degree in educational psychology from Baylor University. She is a member of the American Society of Association Executives (ASAE).

North African and Middle East Epilepsy Journal

The inaugural issue of the new *North African and Middle East Epilepsy Journal* (NAMEEJ) was published in May. This journal is the voice of the East Mediterranean Region of ILAE and IBE and welcomes articles, case reports and book reviews. Send articles to Mr Chahidi Abderrahmane, Professeur d'EP, Délégation de Beni Mellal and Vice President, Moroccan Association IBE Chapter at chahidi12@yahoo.fr.

Bookstore on the ILAE Website

There has been a steady increase in the number of books published that are relevant to epilepsy that members of the League will likely find useful for their practice or research. However, keeping up with the books that are available is no easy task. To help make the job easier we have created this Bookstore as a service to our membership. In it publishers can provide information on their epilepsy-related books. They may also provide information on where and how to purchase the books. The League does not sell the books. <http://www.ilae-epilepsy.org/booksales/index.cfm>.

The Bookstore is in the early stages of evolution, and we expect to add new titles and publishers on a regular basis, so please check back frequently for new additions.

There are currently seven books listed. If you have authored a book, please encourage your publisher to list their book on this website. The cost is minimal.

Farewells Listing on Website

ILAE hosts a 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. <http://www.ilae-epilepsy.org/visitors/farewells>.

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 as well 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 will depend entirely on your efforts to help preserve the memories and the accomplishments of our friends and colleagues.

Upcoming Congresses and Educational Events (www.epilepsycongress.org)

6th Baltic Sea Summer School

8–13 July, 2012 in Rostock, Germany

Deadline for applications: 15 April 2012

More information: Petra Novotny, Prof Peter and Jytte Wolf Foundation for Epilepsy, petra.novotny@wolfstiftung.org, or under BSSSE6 on <http://www.epilepsiestiftung-wolf.de/7.html>.

Second Advanced International Course: Clinical Epileptology

12–18 August, 2012 in Chengdu, Sichuan Province, People's Republic of China

To apply, contact Jie Mu, Department of Neurology, mujie2010@foxmail.com

16th Congress of the European Federation of Neurological Societies (EFNS)

8–11 September, 2012 in Stockholm, Sweden

<http://www2.kenes.com/efns/pages/home.aspx>

XXIst World Congress of Neurology

21–26 September, 2013 in Vienna, Austria, focusing on Neurology in the age of globalization.

http://www2.kenes.com/wcn/congress/Pages/Welcome_Message.aspx

10th European Congress on Epileptology

30 September–4 October 2012 in London, UK

<http://www.epilepsylondon2012.org>

25th ECNP – TEM Neurology 2012 – Epilepsy and Psychiatry

12–13 October, 2012 – Application Deadline: 13 April 2012 in Vienna, Austria

<http://www.ecnp.eu/en/meetings/tems/tems2012.aspx>

Canadian League Against Epilepsy 2012 Biennial Meeting

19–21 October 2012 in Calgary, Alberta, Canada

www.clae.org

7th Latin American Congress on Epilepsy

14–17 November 2012 in Quito, Ecuador

<http://www.epilepsiaquito2012.org>

American Epilepsy Society Annual Meeting and

4th Biennial North American Epilepsy Congress

30 November–4 December 2012 in San Diego, California

www.aesnet.org/meetings-and-events/annual-meeting

23rd Meeting of the European Neurological Society

8–11 June, 2013 in Barcelona, Spain

www.ensinfo.org; Preliminary program available in October 2012

30th International Epilepsy Congress

23–27 June 2013 in Montreal, Quebec, Canada

<http://www.epilepsycongress.org>

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