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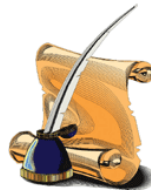
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Epigraph Volume 13 Issue 1, Winter 2011

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From The Information Officer



Edward H Bertram
Information Officer

For all who are involved in working with patients with epilepsy and their families, it is well recognized that access to the therapy and social support that are needed for a reasonable quality of life is often difficult. The critical needs vary from country to country, and, within countries, from region to region, but wherever one travels the comments remain the same: the necessary resources don't exist. Part of the problem arises because epilepsy is rarely viewed as a major public health issue so that other medical problems receive more attention and support. Another cause is the small numbers of professionals with an interest in epilepsy, a problem that affects all countries. One of the League's goals is to improve access to care and to encourage that the resources needed to address the many problems of epilepsy are made available. Although one's view about the state of affairs is often pessimistic, from time to time there are stories that inspire hope for the future. In this edition of *Epigraph* there are several articles that make us think that the future is bright.

Two of the critical factors in assuring that there is access to care are the presence of knowledgeable caregivers and a steady supply of medications. In many regions of the world, both are in short supply, and potential solutions are elusive. Two articles in this issue suggest that with dedication and ingenuity it may be possible to build an effective system for epilepsy care. The histories of the Chilean and Chinese Chapters provide some important lessons. Both started from almost nothing other than a few professionals who wanted to improve the lives of patients with epilepsy. The situations in the two countries were very different, as were the solutions. Key to success was the ability of the epilepsy groups to work with private and public organizations to find ways to move forward. Although in some cases, there were collaborations with international organizations, the drive, work, ingenuity and resources were local.

The lessons learned from the experience in China and Chile are especially important as we welcome our newest Regional Commission to the League's family. As reported below by Birinius Ezeala-Adikaibe, the Commission on African Affairs was inaugurated in November at a meeting in Dakar, Senegal. At that meeting the Chapters outlined the many challenges that are faced in each country as well as across the entire region. In many of the countries the situation is similar to the conditions in Chile and China before those Chapters became proactive in developing sustainable epilepsy care. The solution for each country will be as unique as each country's history, culture and system of healthcare. However, there is much to learn from one another and our collective experience as we move forward. As shown in Dr. Hecimovic's report from Croatia, sometimes the first step is determining the obstacles that we face.

In Nico Moshé's report, he emphasizes that the League has many goals, but perhaps the most important is strong and effective Chapters in all countries, Chapters that become the driving force for better epilepsy care. The message in this edition of *Epigraph* is that there are many ways that we can work to eliminate the fear associated with epilepsy.

President's Message



Solomon (Nico) L Moshé
President

During the past year the League has continued its worldwide campaign aimed at improving epilepsy care by emphasizing education and research. At our Centenary Celebration in Budapest, we set an aggressive agenda in a broad strategic plan. Although it is still early, we have made good progress which is outlined in the article entitled: "The ILAE at the Threshold of Its Second Century: Year 1" (*Epilepsia* 52: 185-87; <http://www.epilepsia.com>). Since the report was written in September 2010, here have been a number of additional achievements that are noteworthy.

- In November 2010 the League met with representatives of the African Chapters in Senegal (see the accompanying article), and the meeting resulted in the much anticipated formation of the Commission on African Affairs (CAA) which is now chaired by Dr Gallo Diop. The CAA will promote issues related to epilepsy in the Region, improve our educational agenda and work for solutions to the problems that are most pressing in Africa. The birth of the CAA is a critical step in achieving our ultimate goal of having active ILAE Chapters in all countries in Africa. We look with great anticipation to the great progress that our colleagues will bring to the cause of epilepsy in the League's newest region.
- The League was one of the charter members invited to participate at the WHO-organized meeting entitled "Mental Health GAP Forum" held in Geneva on 7 October 2010. We wish to express our deepest appreciation to Dr Shekhar Saxena, Director of the Mental Health and Substance Abuse Department, for all his efforts in support of epileptology worldwide (see photo below).
- A landmark publication was the launch of the **EURO GCAE Report** in Porto in August 2010. This report outlines the status of epilepsy care within the European region and provides a common basis for working toward broad solutions to the many problems that vex our patients. Editorials and commentaries were published in major journals, and the report was widely disseminated to all our Chapters.
- Together with the IBE we have formed a joint Task Force to address issues relating the support of epilepsy care and research within the European community. Our goal is to enlighten health officials and ministers of countries comprising the European Union, as to how we can augment epilepsy research and provide improved care which is often lagging even in the more developed countries.
- The League recognized the urgency to develop a Task Force addressing the worldwide impact of epilepsy on tropical diseases. Dr Pierre Marie Preux, Professor of Epileptology and Head of the Clinical Research Unit at the University of Limoges, France, has been designated to lead this initiative.
- In December 2010, the League and Autism Speaks held a very constructive workshop under the expert guidance of Drs Roberto Tuchman and Andy Shih. We developed a very ambitious agenda aimed at scientific research synergies from a global perspective. Among the goals that were discussed was the identification of infants with seizures at risk for autism, and those with autism at risk for epilepsy; the identification of risk factors common to epilepsy-autism; and the development of treatment models behavioral and pharmacological in infants with epilepsy-autism (or at risk for autism). The group included representatives from ILAE, Autism Speaks, Citizens United for Research in Epilepsy (CURE), American Epilepsy Society, National Institute for Neurologic Disease and Stroke and the National Institute of Child Health and Development.
- A significant initiative that we will continue to pursue for the next three years is the preparation and publication of the US Institute of Medicine Report on Epilepsy. The League is one of the sponsoring partners, and we are represented by Drs Gary Mathern, and Edward Bertram. We are hopeful that this venture will enhance the delivery of care not only in the US but also worldwide.
- A report from our Latin American colleagues is in preparation, and will address issues affecting the Americas in collaboration with the Pan American Health Organization (PAHO). We are grateful to Dr Jorge Rodriguez, Senior Advisor on Mental Health of PAHO as well as to Dr Carlos Acevedo, Secretary General of IBE, and Dr Marco Tullio Medina, Vice President of ILAE, for their vigorous efforts. The authors sought and obtained the input from the North American Commission, and thus are creating a powerful document that will bring to the attention of various ministers and high officials the plight of people affected with epilepsy in the Western hemisphere. We anticipate that within the next few years we should begin to notice dramatic and unprecedented changes in healthcare policies in all Western hemisphere countries.
- We anticipate that the new Constitution of the League will be ratified by the General Assembly during the Rome International Congress this coming September. This will enable all the Regions "to have a voice" in assessing how the League conducts its affairs.
- During this past year we have held four Regional Congresses which have yielded an astounding success. It is indeed invigorating to witness the collective dedication and passion shared by all our Chapters' members who participate actively in educational programs either as teachers or trainees, working from the ground up to provide services to people often with inadequate resources, striving to improve the healthcare system, and most importantly alleviate human suffering.
- In the year 2011 we will celebrate the 50th Anniversary of the IBE and the 75th Anniversary of the American Epilepsy Society. We congratulate both organizations for reaching these milestones, and look forward to a brighter future for people with epilepsy. As epilepsy has been a scourge for millennia, it is imperative that we continuously strive to develop more effective treatments with no side effects. I wish to reiterate how crucial it is to work together as a unified group representing all aspects of people with epilepsy, from professionals to lay people, and to raise awareness that epilepsy affects more than 50 million people, and is more common than multiple sclerosis, parkinson's diseases, cerebral palsy, and muscular dystrophy combined. We are looking forward to a very productive year and fruitful collaborations.



Dr Margaret Chan, Director General of WHO, discussing with Dr Mike Glynn and Dr Solomon Moshé, issues related to epilepsy (circle). The arrow points to the Epilepsy Poster, describing the WHO-related activities. This photo was taken at the launch of the "Intervention Guide" at the World Health Organization "MHGAP Forum" in Geneva, Switzerland on 7 October 2010. Attendance included 22 member states, 11 ambassadors, WHO Collaborating Centers and other international organizations, including ILAE and IBE, which contributed their strategic guidance to the WHO on raising the priority given to mental health.

The International Symposium on Epilepsy in Neurometabolic Diseases (ISENMD), Taipei, Taiwan



Kun-Long Hung, MD
Chairman, Scientific Committee
The International Symposium on Epilepsy in Neurometabolic Diseases (ISENMD)

The International Symposium on Epilepsy in Neurometabolic Diseases (ISENMD) was held at the Howard Plaza Hotel, Taipei, Taiwan on 26 - 28 March 2010. This symposium, incorporating the 13th Annual Meeting of the Infantile Seizure Society (ISS), was held in conjunction with the 14th Annual Meeting of Taiwan Child Neurology Society (TCNS). Since its formation in 1998, the ISS has held its annual meeting at different places within Japan. This year's meeting was in Taipei, Taiwan, the first time it has been held outside Japan.

The main theme of this meeting was "epilepsy in neurometabolic diseases". Owing to the rapid progress in this field, this Conference was dedicated to a better understanding of infantile seizures of neurometabolic origins, from basic to clinical aspects. With the help of modern advances, several kinds of neurometabolic derangements causing seizures in the infantile stage have been explored, and metabolic approaches have become a promising avenue for both research and therapy.

This three-day symposium attracted 387 pediatric neurologists and other experts in this field from 24 countries, gathering together in the dynamic city of Taipei. A total of 38 oral presentations were delivered, including 31 invited speeches presented by 29 speakers. The remaining seven oral presentations were chosen from free abstracts. On day one, two sessions were held, dealing with general aspects of neurometabolic diseases, including clinical/neurophysiological diagnosis, molecular basis, neuropathology, and neuroimaging. On days two and three, representative categories of neurometabolic diseases presenting with epilepsy were discussed, including aminoacidopathy, organic acid/urea cycle disorders, lipid metabolism/lysosomal storage diseases, mitochondrial diseases, peroxisomal disorders, vitamin/mineral metabolic disorders, neurotransmitter disorders, and miscellaneous diseases. Through these two-way approaches, the neurometabolic diseases causing infantile epilepsies were clearly demonstrated. In addition to the oral presentations, 56 abstracts were nominated as poster presentations. At the closing ceremony, the Organizing Committee presented outstanding awards to the presenters of the 9 best posters, who came from six countries.

Apart from the scientific program, the host Organizing Committee also arranged several social activities such as Welcome Party, Grand Social Party, Farewell Party and a post-conference tour for all participants. One of the highlights in the Grand Social Party was the choir of the Taiwanese pediatric neurologists, who wore traditional aboriginal head ornaments and bracelets to sing a Taiwanese aboriginal song. Furthermore, talent shows by volunteer participants added another surprise to all. Our invited speaker, Dr Philip Pearl, played Jazz piano as if it was his personal piano concert. Dr Seiji Yamaguchi presented a skillful magic show, which brought a lot of fun. The post-conference tour to the famous Palace Museum, the Chang-Kai-Shek Memorial Hall, and one local temple gave a perfect chance for the participants to learn about this city and her history from a different perspective.

For those who were unable to attend, or for those who want to view the entire scientific activities again, video-streaming DVD is available on the ISS and TCNS websites.



Professor Yukio Fukuyama
the founder of Infantile Seizure Society (ISS)
addressing the opening ceremony.

Taiwanese pediatric
neurologists wearing
traditional aboriginal head
ornaments and bracelets to
sing a Taiwanese aboriginal
song at the Grand Social
Party.



The History of the Chilean League

Excerpted from a full report by Carlos Acevedo

The Chilean League Against Epilepsy (LICHE) began quietly in 1953 when Dr Alfonso Asenjo started it at the Neurosurgery Hospital in Santiago, Chile where it remained for its first 30 years. It was run entirely by the volunteer efforts of the physicians' wives, with the primary goal of delivering antiepileptic medicines to the hospital's patients, because, at the time, epilepsy-related treatment in Chile was located solely at that one hospital. It operated out of a small building next to the hospital until 1982, when the host of a television show donated a small house in downtown Santiago, at some distance from the Neurosurgery Hospital. This small but generous donation proved to be a key step for the future of LICHE.

Because of its new location, the previous physician members could no longer participate regularly, so a new Board of Directors consisting of six physicians and six volunteers was established with the primary goal of expanding the reach of operations. Very quickly the Board decided that a major effort should be made to get antiepileptic therapy to all Chileans in need. They used the non-profit status of the organization to develop a unique Drug Bank to sell antiepileptic drugs at a discount to those who could afford them and to use the profits to subsidize the costs to patients with limited or no financial resources. They obtained drugs at reduced cost or donated from pharmaceutical companies and sold them to patients with insurance or financial means at a discount of 20% below what they would pay at a standard pharmacy. Initially there was only one drug provided, but with time, as the demand grew, more drugs were added, until all became available. To make this plan work, physicians referred their patients to the Drug Bank, and, over time, it has become the primary source of medicine for patients with epilepsy. Social workers have been involved from the early stages, as they evaluate patients for their financial means and needs and determine what an appropriate contribution is from the patient for the medicines received. In 2009, the Drug Bank provided \$894,000 in subsidies to its clients for the purchase of medications, and the number of visits had grown to 533,000, an increase from 360,000 in 2005.

The growth in the Drug Bank has been spectacular. Starting from a single house in downtown Santiago, it expanded to seven Drug Banks within the city, and there are now Drug Banks in the country's major cities, serving 90% of the population in Chile. The success of the Drug Banks and the hard work and commitment of the volunteers has allowed LICHE to expand its services. First, it created a social work system that advised people on issues involving family, education and work. Next to come were two educational centers, one to work with children with epilepsy and learning difficulties, and the second for adolescents and adults with epilepsy and mental disabilities to train them to work and to provide a sheltered work environment. Finally a free standing clinical center was established to diagnose and manage epilepsy of varying complexities. This center includes a laboratory for following blood levels of drugs and for recording EEGs.

The creation of the Drug Bank was not something done on a whim. There were a number of legal and regulatory issues that had to be resolved, and LICHE worked closely with the authorities in assuring that all requirements were met. With each new drug added, there were regulatory steps that had to be taken. As the program grew and was successful, it was also recognized that patients with epilepsy had other comorbid conditions that needed treatment. As a result, drugs for psychiatric issues were added to the list of medicines provided by the Drug Bank. Psychiatrists and neurologists routinely send their patients with epilepsy to the Drug Bank for their medicines and in 2009, there were over 533,000 visits to LICHE's facilities. This volume of activity cannot be supported by volunteer efforts alone, so over the years a group of professionals, including business managers have been employed to assure that operations run smoothly and meet regulatory requirements. They also make sure that the program appears in the media from time to time so that the efforts of LICHE are more widely recognized and that public support continues.

The success of this program, which has quietly been delivering high quality services to patients for decades, has been the result of a very original idea on how to assure that patients with epilepsy can obtain their medications, the hard work of many volunteers, and the commitment of patients, physicians, social workers and teachers among many others, to a common cause of helping one another. This outstanding example of an epilepsy success story began in a small room next to a hospital almost 60 years ago, and received the essential boost from the gift of small house that became the center a national effort driven by the energy of many.

To read further details about the history and how the Drug Bank operates, please visit the ILAE website <http://www.ilae-epilepsy.org/visitors/initiatives/>.

Inauguration of Commission for African Affairs (CAA)

Birinius Ezeala-Adikaibe, Nigeria. Information Officer for the CAA



Delegates of the Dakar Conference on the formation of CAA.

The official inaugural meeting of the African Commission of ILAE took place in Dakar, Senegal from 19-20 November 2010 at Hotel Ngor-Diarama Dakar. The meeting was declared open on the 19th by Prof

Amadou Gallo Diop of Senegal. This was followed by personal introduction of each of the representatives of each Chapter, observers and delegates from ILAE.

Of all African Chapters, Tanzania, Zimbabwe and Algeria were not represented. Present were Dr Calixte Kuate-Tegueu, Cameroon; Dr Sammy Ohene, Ghana; Prof Amara Cisse, Guinea; Prof Paul Kioy, Kenya; Prof. Baba Koumare, Mali; Dr Birinius Ezeala-Adikaibe, Nigeria; Prof Amadou Gallo Diou, Senegal; Dr Brian Kies, South Africa and Dr Angelina Kakooza, Uganda. Observers invited were Prof Njamnshi of Cameroon (Pan African Association of Neurological Sciences), Prof Pierre-Marie Preux of France (Tropical Neurological Institute of Limoges,), Dr Anthony Zimba (IBE Africa Commission) from Zambia. ILAE delegates were Prof Nico Moshé (USA); Prof Emilio Perucca (Italy); Prof Sam Wiebe (Canada); Prof Michel Baulac (France); Prof Lionel Carmant (Canada).

A welcome address was read by Prof Monsour Ndiaye, head department of Neurology of the University of Senegal. This was followed by a brief remark by Prof Moshé who talked about the history of African Commission, failures and challenges so far. The later part of the morning and the afternoon were dedicated to presentations of each Chapter on its activities, challenges and prospects. Prof Lionel Carmant, Prof Wiebe and Prof Jean-Marie Prieux made presentations, all targeted to show the great opportunities and prospects in working as a team to develop the African Commission. It was noted that a lot of work has been done or is presently going on in various parts of the continent, but there is a need for proper coordination and collaboration.

The second day of the meeting was dedicated to the formation of the Commission (ILAE-CAA). The executive members of ILAE all contributed by telling us how the Commission works and the successes achieved in other regions of the world and the scope of the future CAA based on ILAE Bylaws. The President Prof Nico Moshé, encouraged the African Commission to move forward and work as a team despite the envisaged challenges and always call on the parent body for help when the need arises. He stated that the North American Commission is waiting for us in Africa for partnership in promoting the treatment of epilepsy and research into newer epilepsy syndromes which may exist in Africa but are not yet recognized.

Later in the day the potential members of CAA met to discuss and elect the officers that will run the Commission until 2013. The officers were selected (see photo below) and were later endorsed by the International Executive Committee. Further work was done in setting out the Commission's Action Plan for 2011-2015. The major aspects of the action plan were updating the existing database of neurologists, psychiatrists, neurosurgeons, neuroscience training centers, present and previous research works and setting up a time frame for an African Congress on epilepsy. Issues concerning access to care were also raised and included in the action plan. Chapters were encouraged to participate more actively in international Conferences/Congresses and look for ways of expanding the number of African Chapters and their membership by reaching out to teachers, social workers and other lay people. The implementation of the various aspects of the action plan are to be carried out by local Chapters. However, the CAA is to coordinate the work. Each action plan was delegated to the various offices of the Commission.

The meeting ended 7:00 p.m. on Saturday, 20 November 2010.



Executives of the new Commission on African Affairs (CAA)

Chair: Pr Amadou Gallo Diop, Sénégal
Secretary General: Dr Calixte Kuate Tegueu, Cameroon
Treasurer: Dr Angelina Kakooza, Uganda
Education: Pr Bryan Kies, South Africa

Research: Pr Paul Kioy, Kenya
 Communication: Dr Birinus Ezeala Adikaibe, Nigeria
 Liaison to GCAE: Pr Baba Koumare, Mali
 Task Force on Access to Care:
 Dr Sammy Ohene, Ghana
 Pr Amara Cisse, Guinea
 Tanzania
 Zimbabwe
 Algeria

Moving Epilepsy Treatment in China into the Modern Era

The following is excerpted from a report by Shichuo Li, Wenzhi Wang, Jianzhong Wu and Hongchao Yang.

Epilepsy has been recognized in Chinese medical texts for at least 2,200 years, and over the centuries it has been treated with a variety of traditional Chinese medical practices including herbal preparations, acupuncture and moxibustion among many folk therapies. It is questionable how effective treatments were, and better results started to appear in the 1950s with the introduction of modern medicines and surgery. However, there wasn't much information on the impact of epilepsy on public health. In addition there wasn't much priority given epilepsy in the national health agenda with only a few healthcare workers who had a focus on epilepsy.

The epilepsy movement got a major boost in 1983 when Chinese epileptologists and other interested healthcare workers held the first National Epilepsy Congress in Yichang on the Yangzi Riven in central China. These Congresses have been held every two years since. To start building international professional ties, three additional Congresses were held under the name of World Association of Chinese Epileptologists, in turn, in Taipei, Hong Kong and Guangzhou. Although this organization never achieved official recognition, the meetings fostered broader ties for the national group. In the 1990s local epilepsy groups were organized under the umbrella of local medical associations, but the formation of the national organization didn't begin until 2002 when Dr Shichuo Li started to organize interested neurologists, neurosurgeons and other interested professionals into the China Association Against Epilepsy (CAAE) which was approved by the Ministry of Health of China in 2004. At the official inauguration in the Great Hall of the People in Beijing leaders from the IBE, ILAE and WHO joined national leaders and almost 1000 epilepsy health workers in celebrating the event. This celebration was followed in short order by the CAAE joining the ILAE as an official Chapter.

Even before the official formation and approval of the CAAE, Chinese epileptologists were busy working with international colleagues on improving epilepsy care across China. Perhaps the greatest challenge facing these efforts was a lack of knowledge about the number of people who were affected by epilepsy. The Global Campaign Against Epilepsy (GCAE), under the auspices of WHO and the Ministry of Health, began a four-year demonstration project in 2000 under the title of Epilepsy Management at the Primary Health Level in rural areas of six provinces. There were four components to the project: two epidemiological surveys, a phenobarbital treatment intervention trial, and the creation of an educational program. The overall goals were to improve the identification of people with convulsive forms of epilepsy within the existing local health care system and to develop a model of epilepsy treatment at the primary care level that could be applied nationally. In the course of the project it was hoped that an accurate determination of the prevalence of active convulsive epilepsy could be obtained as well as an estimate of the number of people with convulsive epilepsy who were not being treated (the treatment gap).

This collaborative project had a number of important results. The survey in the project areas found the prevalence of active convulsive epilepsy was 4.6/1000 and the adjusted mortality rate for people with epilepsy was almost four times that of the general population. The study enrolled over 2,400 patients with convulsive epilepsy into a trial of phenobarbital therapy. Two-thirds of the patients who completed 12 months of treatment had a better than 50% reduction in seizure frequency and one-third were seizure-free. At two years almost 75% of the patients had a reduction in seizures of at least 50% and a quarter remained seizure free. Only 1% of the patients stopped the phenobarbital because of side effects. The availability of treatment reduced the numbers of patients not taking medications (the treatment gap) significantly. Also of great importance, the cost of providing medical care to these patients once they were on phenobarbital was reduced to less than 20% of what it had been before phenobarbital. The results of this project were so convincing that the Ministry of Health has expanded the project so that more than 39,000 patients are receiving treatment, and a model is being developed for the treatment of epilepsy in rural areas where there are no neurologists.

This project has clearly demonstrated the public health and economic benefits of treating epilepsy, and the data that were generated played a major role in convincing the national authorities to support better access to treatment for patients with epilepsy. The results of the project also demonstrate the benefits of the drive and hard work of local epilepsy specialists who wish to improve epilepsy care. For a full and detailed report of the development of the CAAE and the ongoing Demonstration Project, please see the website <http://www.ilae-epilepsy.org/visitors/initiatives/>.

Asla Pitkanen, MD, PhD, DSc, Recipient of 2011 ASPET-Epilepsy Award



Dr Asla Pitkanen, Professor of Neurobiology, University of Eastern Finland is the recipient of the 2011 ASPET-Epilepsy Award. The Award is sponsored by American Society for Pharmacology and Experimental Therapeutics/Experimental Biology (ASPET) and the International League Against Epilepsy. The award is to recognize and stimulate outstanding research leading to better clinical control

of epileptic seizures.

Dr Pitkanen received her masters in biochemistry and medical degree from the University of Kuopio in Finland. She began her career in neuroscience as a first year medical student, working with patients with multiple sclerosis and then Alzheimer's disease. She began her research career in epilepsy by investigating GABA-A receptors in cortical cobalt models of epilepsy in the rat.

Among Dr Pitkanen's many contributions to the study of epilepsy are her seminal contributions to our understanding of the molecular mechanisms of epileptogenesis, the process by which a normal brain becomes epileptic. She has developed novel models of epilepsy induced by brain trauma and stroke. She has pioneered use of magnetic resonance imaging in characterizing these and other models. These models provide a valuable framework for assessing efficacy of novel therapeutics aimed at prevention of epilepsy.

Dr Pitkanen is also active internationally in increasing the visibility of epilepsy research. She was one of the organizers of a 2008 workshop on "Research Priorities in Epilepsy for the Next Decade." This workshop detailed epilepsy research priorities that should be investigated and funded in Europe. She has served as Secretary General of the Federation of European Neuroscience Societies, Vice President of the Epilepsy Society of Finland, and as a Member of the Scientific Advisory Board of the European Epileptology Meeting in Finland.

Dr Pitkanen will be presented the 2011 ASPET-Epilepsy Award on Saturday, 9 April at 7:00 p.m. at the ASPET Business Meeting Awards Reception of the American Society for Pharmacology and Experimental Therapeutics/Experimental Biology (EB) 2011 Meeting in Washington, DC. The Awards Ceremony will take place at the Washington Convention Center, Ballroom A.

National Epilepsy Day in Croatia



Hrvoje Hecimovic
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Based on the mission statement and the "Global Campaign Against Epilepsy – Out of the Shadows", which has been a joint project of the ILAE, IBE and WHO since 1997, the Zagreb Epilepsy Center initiated the creation of a National Epilepsy Day in Croatia. In this initiative we were joined by Ms Vita Loncar (shown in photo at right), a very successful Croatian actress who has epilepsy and openly talked about living with the disease.

National Epilepsy Day was first approved by the Government of the Republic of Croatia and then unanimously accepted by 113 votes by the Croatian Parliament who proclaimed National Epilepsy day on 17 October 2008. The Croatian Parliament statement expresses appreciation and understanding towards persons with epilepsy: "The National Epilepsy Day will help change attitudes towards persons with epilepsy, but also to change perception of the Society towards this disorder . . .".



At the first celebration of the National Epilepsy Day in 2009, the Zagreb Epilepsy Center decided to help other countries in the Region for the same cause. Thus we organized a Regional Round Table and invited ILAE representatives from six neighboring countries: Austria, Slovenia, Bosnia and Herzegovina, Serbia, Montenegro and Macedonia. The topic was "Quality of life of persons with epilepsy in my country". This first meeting has resulted in the group's meeting yearly in a different country. The second took place in Montenegro (Prof Vujisic, 2010) and this year it is in Bosnia and Herzegovina (Prof Kapidzic, 2011). Another important goal of these meetings is to improve care for persons with epilepsy in these countries. Results are already visible, as since our first meeting four countries – Bosnia and Herzegovina, Macedonia, Montenegro and Kosovo bought their first video/EEG machines for long-term monitoring. In addition Zagreb Epilepsy Center developed a comprehensive epilepsy surgery program.

Nationwide Survey on Public Knowledge of and Attitudes Toward People with Epilepsy

Prior to starting this initiative, Zagreb Epilepsy Center performed a nationwide survey to assess the level of stigma towards persons with epilepsy among citizens of Croatia. In the survey we randomly interviewed 1500 participants. The survey consisted of 14 questions, previously used in other similar studies. The results were very interesting. Almost half of the respondents treat persons with epilepsy differently (48%). The results also show that 91% of respondents have heard or read about epilepsy, 57% of them are familiar with a person with epilepsy and 55% have witnessed a seizure.

We have found two main predictors for stigmatizing persons with epilepsy. This was an assumption that epilepsy is a mental illness (41%) and that it is an infectious, contagious disease (17%). Every third participant suggested that people with epilepsy should work at lower quality jobs, despite their education and 17% do not want their son / daughter to live with a person with epilepsy. A surprising number (17%) believed that people with epilepsy should not have children and 12% that they should attend special schools because of their disease.

This was the first study assessing public knowledge of and attitudes toward people with epilepsy in the Croatian population. We showed that public knowledge of epilepsy is similar to other countries, and we defined predictors for negative attitudes. Future educational campaigns on epilepsy should improve attitudes toward epilepsy mainly by targeting misconceptions about epilepsy and by offering opportunities for personal acquaintance with people with epilepsy. Our plan is to repeat the survey five years later, in 2013 to determine if our educational efforts have been successful.

Chapter Meetings Available On [ILAE-epilepsy.org](http://www.ilae-epilepsy.org)

Chapter meetings can now be posted on www.ilae.org. Chapters can log in to the Chapter page and add their meeting dates or contact the Chapter Services office (gegan@ilae.org) to get the information posted. The information will appear under your Chapter name and website on your Chapter page.

Example:



Maintaining this information will help publicize your meetings as well as help leadership understand local Chapter activities.

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 six 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 will be 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 will be publically available to allow League members to learn about those who have gone before and the contributions they made as well as to act 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)

The London-Innsbruck Colloquium on Status Epilepticus 2011
7 – 9 April 2011 in Oxford, UK
<http://www.statusepilepticus2011.eu>

14th Annual Meeting of the Infantile Seizure Society – International Symposium on Neonatal Seizures and Related Disorders (ISNS)
9 – 10 April 2011 at Juntendo University Auditorium, Tokyo, Japan

<http://www.iss-jpn.info>

9th Congress of European Paediatric Neurology Society (EPNS)
11 – 14 May 2011 in Cavtat/Dubrovnik, Croatia
Sponsored by Croatian Child Neurology Society
<http://www.epns2011.com>

5th Migrating Course on Epilepsy
28 May – 4 June 2011 in Rome, Italy
Sponsored by Commission on European Affairs/ European Advisory Council and Lega Italiana Contro l'Epilessia
Please send **application form**, attachments and case reports by 1 March 2011, to Manuela Morandini: manuela.morandini@ptsroma.it; Nebojsa Jovic: njjovic@eunet.rs and Federico Vigevano: federico.vigevano@opbg.net

8th Annual World Congress on Brain, Spinal Cord Mapping & Image Guided Therapy
8 – 10 June 2011 in San Francisco, CA, USA
<http://www.worldbrainmapping.org/>

5th Baltic Sea Summer School on Epilepsy
19 – 24 June 2011 in Sopot, Poland
More information and online application: <http://www.wolfstiftung.org>.

ASES - Adriatic Summer Epilepsy School, International Epilepsy Teaching Course
22-26 June 2011 in Dubrovnik, Croatia
For more information, including speakers and registration form, please visit <http://www.zagrebepilepsycenter.hr>.

San Servolo Summer School
Advanced International Course: Bridging Basic with Clinical Epileptology 4
Sponsored by ILAE and the Fondazione Istituto Neurologico C. Besta
17 - 29 July 2011 in San Servolo, Venice, Italy.
Application form must be submitted by 1 March 2011.
For more information go to <http://www.epilearn.eu>.

First Epileptologists' Summer School in China
7 – 14 August, 2011 in Chengdu, Sichuan Province, People's Republic of China
Application deadline 20 March 2011
<http://www.ilae-epilepsy.org/Visitors/Centre/OtherILAEMeetings.cfm> or Email: leilei_25@126.com

XI Workshop on Neurobiology of Epilepsy (WONOE 2011): Finding Novel Mechanisms for Epilepsy Therapy
23 – 26 August 2011, Park Hotel Villa Grazioli, Grottaferrata, Italy
Organized by the Commission of Neurobiology of ILAE
Contact: segr.decurtis@istituto-besta.it

29th International Epilepsy Congress
28 August - 1 September, 2011 in Rome, Italy. Registration opens in December.
The abstract submission program will be available in November and will be open until March.
For more information go to <http://www.epilepsyrome2011.org/>.

4th Eilat International Educational Course: Pharmacological Treatment of Epilepsy
18 – 25 September 2011 at the Princess Hotel, Eilat, Israel
Sponsored by the ILAE Commission on European Affairs and the Hebrew University of Jerusalem
For more information go to <http://www.eilat-aeds.com> under Forthcoming Conferences or contact the Secretariat at eilatedu@targetconf.com.

4th Beijing International Epilepsy Forum
22 – 25 September 2011 in Dalian City, Liaoning Province, People's Republic of China
Sponsored by the China Association of Epilepsy
Submit abstracts to caae2008@sina.com
For more information go to <http://www.caae.org.cn>.

XXth World Congress of Neurology
12 – 17 November 2011 in Marrakesh, Morocco
More information to come.

9th Asian and Oceanian Epilepsy Congress
21 – 25 March 2012 in Manila, Philippines
More information to come.

Eleventh Eilat Conference on New Antiepileptic Drugs (Eilat XI)
6 – 10 May, 2012 in Eilat, Israel
<http://www.eilat-aeds.com> under Forthcoming Conferences

10th European Congress on Epileptology
30 September – 4 October 2012 in London, UK
More information available soon.

7th Latin American Congress on Epilepsy
October / November 2012 in Quito, Ecuador
More information to come.

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Acknowledgment

This publication is made possible in part by an unrestricted educational grant from Pfizer Inc.

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