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Message From the President



Emilio Perucca President, ILAE

Only a few months have elapsed since the inception of the new leadership of the League. Not fully by coincidence, this issue of *Epigraph* highlights many themes which our leadership considers top priorities — if we want to summarize them in short, *reaching out* would be the magical words.

The previous term saw some remarkable successes in sensitizing the general public, institutions and governments about the need to improve the lives of people with epilepsy — examples include the Declaration of Epilepsy by the EU Parliament, the Institute of Medicine Report in the U.S., and the Pan American Health Organization (PAHO) Epilepsy Action Plan. We need to follow up on these initiatives to ensure that they are implemented in a timely manner.

Indeed, concrete actions have already materialized, most visibly in the EU through allocation of about 36 million euros to epilepsy research. As discussed in the Curing Epilepsy and Dublin Epilepsy Forum reports, additional actions to promote epilepsy research are under way in different parts of the world. To facilitate cross-fertilization among these initiatives, ILAE and IBE have now created a trans-regional Global Research Advocacy Task Force, being led by Dr Shichuo Li of China

There are unacceptable disparities in epilepsy care both within and between countries, with over 80% of people with epilepsy in the world not receiving appropriate treatment. *Reaching out* to them is a moral imperative. Every action counts, and there is much to learn from the work of some of our Chapters and many enlightened individuals — the stories about the epilepsy caravans in Senegal and the North to South collaborative program in Perú are great examples illustrated in this issue of *Epigraph*. Improving access to epilepsy care is a priority which the League is pursuing at global level in collaboration with our many partners, including IBE and WHO, but we are also eager to promote national and regional collaborations towards this goal. The most important resource to improve epilepsy care is knowledge, and through our Congresses, educational courses, journals and the work of our Commissions we are making significant investments to advance and disseminate our understanding of the epilepsies and their management.

People with epilepsy suffer not only from lack of appropriate care, but also from stigma and discrimination resulting from widespread prejudice and ignorance. To fight this plague, reaching out to the general public is as important as educating health personnel, a point nicely made in Dr Li Min Li's report on the "Scientjournalist" initiative. Our newly formed Communication Task Force, that includes representation from the lay associations, is fully aware of this and will use the opportunities offered by modern IT technology to promote effective dissemination of knowledge both to professionals and to the general public.

An important initiative that the League is currently bringing to completion is the operational definition of epilepsy, which complements the 2005 conceptual definition. The process of vetting the proposed definition, now being applied for the first time, is another example of *reaching out*, as it involves posting the document on the League's website, soliciting feedback from our constituency, and ensuring that all suggestions and criticisms received are duly considered in the finalization of the paper. The participation of our community in this exercise has been overwhelming (see **report**) and extremely gratifying for all of us. Ensuring optimal understanding and application of the operational definition will also require a major communication effort, which we plan to carry out jointly with lay associations and other scientific societies. It is only though *reaching out* that we will be able to move our mission forward effectively, and to achieve that goal, I look forward very much to working with all of you.

From The Information Officer

Access to care is the greatest problem facing the overwhelming majority of people with epilepsy.



Edward Bertram Information Officer

and removing barriers that prevent care is a major goal of the ILAE. Across the globe the barriers arise in many ways. In much of the world there is a lack of even the most basic services which include a healthcare provider with some knowledge about epilepsy and the consistent availability of effective medications. In other regions, basic care is more available, but the expertise to provide more advanced services is absent. Epilepsy has always faced the problem of resource allocation: most healthcare systems do not recognize the extraordinary burden the epilepsy places on people, their families and society. This failure to receive the appropriate priority and resources is also often the result of ignorance and bias about epilepsy, its causes and its serious consequences. One of problems in moving forward to achieving our goal of a world in which no one's life is burdened by epilepsy is the issue of where to start in dealing with a problem that is so multifaceted. Some answers are provided in the work that some of our colleagues describe in this edition of *Epigraph*.

Taking care to places where none exists is the topic of Gallo Diop's article on delivering care to remote regions of Senegal and providing some training to local healthcare providers. Developing expertise in technology and its application is the topic of Jorge Burneo's article on developing an advanced epilepsy center in Lima, Perú. These efforts in Africa and Latin America have been made by groups of dedicated and committed people over longer periods of times. Progress in both places was made because of long term committments to improve the lives of people with epilepsy. Those who have worked on these and similar projects should be proud of the results of their considerable efforts. However, to sustain and expand these efforts, awareness of the problems and needs of people with epilepsy has to be raised. Unfortunately the media has shown scant interest in epilepsy. To meet the challenge, Patricia Tambourgi, Vera Camargo and Li Min Li from Brazii write about a new program to develop better understanding and interactions between journalists and the research community. Understanding how each group thinks and developing good relations between the two worlds is essential to bringing greater visibility and urgency to the issues of epilepsy and the promise of research. Recruiting more professionals to the cause of epilepsy is also essential to meet the many needs that are left unaddressed especially in countries with few neurologists. The recent conference in Bangalore, India, which reached out to many centers in India through video links, is one means of using new technologies to bring the epilepsy message to people in the early stages of their careers so that they can see the many aspects of epilepsy treatment and the hope that they can bring to a group of people ignored too long by the medical system. We should take inspiration from these and the many other efforts that many of our colleagues are making to overcome the barriers that keep people with epilepsy from achieving their potential.

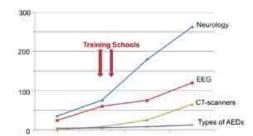
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Caravans for Epilepsy: Reaching People with Epilepsy in Rural Areas of Developing Countries



Amadou Gallo Diop Chair, Commission on African Affairs

Healthcare in Africa suffers from the lack of many of the resources that are taken for granted in other regions of the world, and the lack of trained specialists is one of the greatest deficiencies. Although infectious disease remains the major public health concern in most of the countries in the region, chronic non-communicable diseases are increasing in incidence especially as longevity increases across the region and the diseases of old age become more common. The Ministries of Health of Africa have not yet addressed the health issues of chronic disease with clear and visible policies for prevention and management of disorders such as diabetes, hypertension, vascular disease as well as chronic neurological diseases including epilepsy, dementia and Parkinsonism. What specialized expertise that exists is centered around the capital cities with almost no such care in the rural areas.



Growth of Epilepsy in Resources in Sub-Saharan Africa 1992-2012

The numbers make clear the problem for neurological and psychiatric diseases. In North Africa and the Republic of South Africa, there is one neurologist and/or psychiatrist for 200,000 to 350,000 people. For the rest of the continent the ratio increases to one for 1,000,000 to 4,000,000 people. The problem is further magnified when basic diagnostic resources are considered. There are approximately 180 EEG machines and 130 CT scanners to serve the 140 million inhabitants of the Maghreb region of North Africa. In South Africa there are about 100 EEG machines and 260 CT scanners for its 50 million citizens. For the rest of the continent's 540 million people there are 65 EEG machines and 45 CT scanners.

There are an estimated 10 million people in Africa with epilepsy, and 80% do not have access to meaningful care. The numbers do not favor access to knowledgeable care in most of sub-Saharan Africa where the needs may be greatest. Although the lack of treatment is mostly attributable to simple logistics and economics, there are cultural reasons as well, and many don't know that effective treatments are available.

In Africa a person with epilepsy is more likely to be treated if he/she has a high income, a higher level of education, lives in an urban area, has suffered from status epilepticus or encephalitis, or has suffered from cranial trauma with loss of consciousness. In most of Africa there are four main antiepileptic drugs available: phenobarbital, phenytoin, benzodiazepines, carbamazepine and sodium valproate. The annual costs for these drugs range from \$15 to \$500.

To improve the situation of people suffering from seizures in Senegal we have started the "Caravans for Epilepsy" initiative. The primary goals of these efforts were to diagnose and start treatment for people with neurological diseases and to train local healthcare workers to recognize and treat epilepsy. Over time, and because of our success, we have developed the concept of "Neuro-Caravans", extending our activities of care, training and communication to common neurological disorders, including stroke, Parkinsonism and the dementias.

Background and Procedures

In 2003, Senegal was chosen as a site of the Global Campaign Against Epilepsy's first Demonstration Project set up by WHO, ILAE, and IBE. Zimbabwe was also chosen, but the unexpected death of Professor Jens Mielke by air crash ended the project in Zimbabwe. Under this project different studies related to epilepsy have been conducted. The studies have included the ratio of health professionals to the general population, the quality of health services and facilities (including available AEDs) and the overall prevalence of epilepsy in the Pikine suburban area of Dakar. Following those steps, brand new initiatives have been set up, including a weekly consultation for people with epilepsy residing in this area, conducted by a specialist coming every Wednesday from Dakar (15 km, capital city of Senegal and hosting the unique Service of Neurology). In addition a nationwide public health action named "Caravans for Epilepsy" was created to bring knowledge about epilepsy and its treatment to areas where treatment did not exist.

Organization

Preparation of a "Caravan for Epilepsy"

Three months before the departure of the Caravan, a member of our team accompanied by a delegate of the supportive pharmaceutical company (Sanofi) visits the Region's administrative, medical and media leaders. The date, organization, program are discussed and the potential places for training and consultation are visited and evaluated.

A team of 12 to 15 people arrives on Thursday afternoon in the main city of the visited province. After installing the team, members of the Caravan's Social Education Commission meet with local media, while the rest of the team prepares the selected sites for training and consultation.

Activities

On **Friday**, the training session is held. For that purpose, weeks before, all of the medical officers and nurses of the province are informed and invited to attend this activity. That day, training on different aspects of epilepsy is provided: physiopathology, epidemiology, videos on the clinical aspects of seizures, and management of epilepsy. After each lecture, sufficient time is given for questions. At the same time, some members of the Senegalese League Against Epilepsy are meeting with primary school teachers and associations of women informing them about epilepsy. They discuss signs and factors contributing to epilepsy and they provide counseling about hygiene, social aspects and ways to support patients and families.

Saturday is reserved for consultation. Patients come from the districts of the province. Most of them have been previously selected by their local health staff. Many of them are seeking modern medical treatment for the very first time. After the clinical diagnosis, some selected cases can benefit from EEG recorded with a portable machine transported from Dakar.



Epilepsy Caravan Team by the military airplane preparing to depart for Casamance in southern Senegal. Professor Diop on far right foreground



Members of the Caravan on the Casamance River on the way to visit patients living on several of the river islands



People waiting for consultation with the Caravan team in Diourbel in central Senegal.

Results and Comments

From March 2005 to March 2012, 14 "Caravans for Epilepsy" have been organized in 12 cities of 10 provinces (twice in two cities). 2,312 patients have been examined, including 1,307 (62.5%) who were suffering from epilepsy. In addition, 175 MDs and 131 nurses have been trained about diagnosis and management of seizures and epilepsy. The number of patients suffering from other neurological conditions (37.5%) is due to the fact that such kinds of visits of professionals coming from the capital city is a unique opportunity for the local population to meet specialists.

This effort was started with support from the Global Campaign Against Epilepsy (WHO, ILAE, IBE), and it was been sustained in the development by the WHO, the National League against Epilepsy, a pharmaceutical company, our University Hospital and two NGOs for women. The long term success will depend on the Health Ministry and whether epilepsy will remain a focal point for the Ministry's effort. The project has shown the value of de-centralizing specialized activities to reach disfavored populations. We recognize that the short duration of these Caravans does not provide the ongoing care that is needed, but the Caravans demonstrate that need and benefit from local specialized care so that the Ministry of Health will provide more support for these efforts, because chronic neurological diseases require ongoing, sustained treatment.

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A Collaborative Effort to Establish a Comprehensive Epilepsy Program in Perú



Jorge Burneo University of Western Ontario, London, Canada

The International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE) and the World Health Organization (WHO) launched the 'Out of the Shadows' Global Campaign Against Epilepsy in Geneva in June 1997. Since then, efforts in different parts of the globe by these organizations and by local governments have been aimed at decreasing the burden of epilepsy by increasing awareness, creating acceptance and improving education.

In Latin America, The Declaration of Santiago in September 2000, and the subsequent demonstration project in Argentina, revealed a genuine interest to conquer epilepsy in this region of the world.

Perú is located in Western South America, and has a population of more than 29 million people, with an estimate of more than half a million of people with epilepsy (prevalence estimate of 17.8 per 1,000 people) (Burneo, Tellez-Zenteno et al. 2005). In the capital city Lima alone, with a population of 8.5 million, there is an estimate of more than 150,000 people with epilepsy and approximately 45,000 with medically-intractable epilepsy. Despite these large numbers, there had not been an established Comprehensive Epilepsy Programs until towards the end of 2011.

In 2008, the North American Commission of the International League Against Epilepsy (ILAE) launched a program call PECA: Partnering Epilepsy Centers in the Americas. This was done with the idea to pair a center from North America and a center from Latin America or the Caribbean. The North American center would be the one helping its counterpart to develop the existing program further, or if one did not exist, to create one.

With the support of the PECA Program, the Epilepsy Program at Western University (Canada) paired with the Department of Epilepsy at the Instituto Nacional de Ciencias Neurologicas (INCN) in Lima, Perú. Since 2008, these two institutions have been working together organizing workshops, visits to Perú and London (Canada), and online review of cases, among other activities.



Epilepsy workshop in Lima



David Steven and Jorge Burneo at the epilepsy surgery conference at the INCN

Collaborative Activities Perú-Canada

Timeline	Activities
August 2008	Workshop on Video-EEG in Lima
May 2009	Visit of Dr Jose C Delgado (neurologist) to London for 3 months
August 2009	Purchase of video-EEG unit
December	Prolonged Video-EEG monitoring starts

March 2010- Fellowship in Epilepsy Surgery carried away by INCN neurosurgeon in Mexico (under the March 2011 supervision of Dr Mario A Vanegas)

April 2011 Workshop on Epilepsy Surgery in Lima Rounds with Epilepsy Team in Lima

Aug-Dec Development of institutional guidelines on different aspects of pre-surgical evaluation, using Canadian model when possible

Canadian model when possible Training of neuropsychologist

Performance of a lesionectomy as Epilepsy Surgery with assistance from Dr Mario A

Vanegas

Early 2012 Performance of 2 more lesionectomies for the treatment of epilepsy

Online discussion and review of cases, with Canadian team, to assess candidacy for surgery

August 2012 Performance of first temporal lobectomy in a patient with medically-intractable epilepsy due to MTS, by Dr Carlos M Vasquez, with supervision from the Canadian team

The main objectives of this partnership have been realized, with the latest one being the performance of the first ever temporal

epilepsy due to hippocampal sclerosis in Perú in 2012 (Burneo, Delgado et al. 2013).

The Collaborative work between Perú and Canada has been successful and can be used as a model for the development of epilepsy programs in other countries in need of them. The success of this collaboration has been mainly based on the driving force and keenness of the young neurologists and neurosurgeon at the INCN. Due to it, the collaboration has been extended to the other health system that exists in Perú, called the Social Security System (ESSALUD), which actually has more advanced and equipped hospitals. One of the key aspects of the successful collaboration is that the partners keep the long term goals in mind while they focus on the first initial and necessary steps that will ensure the long term success. The table outlines the steady progress that was made, one step at a time.

lobectomy in a patient with medically-intractable temporal lobe



First temporal lobectomy in Perú

Finally, the work has not stopped, but will continue through continuous educational online activities, and more visits to Perú and Canada. In addition to Jorge Burneo key participants in the program include Jose Delgado, Carlos Vasquez, Lizardo Mija, Willy Zapata and Lucio Portilla all from the Department of Epilepsy, INCN in Lima, David Steven from the Epilepsy Program at Western University in London (Canada), Mario Vanegas from the Instituto de Neurologia y Neurocirugia in Mexico City and Jose Cavazos from the University of Texas Health Science Center in San Antonio,

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Dublin Forum Focused on Epilepsy Care and Research in Europe

The European Forum on Epilepsy Research took place in Dublin, Ireland, on 25-27 May 2013. It provided a platform for discussions on how to improve the lives of persons with epilepsy by influencing the political agenda in Europe and advancing epilepsy in Horizon 2020 (the 8th Framework Programme of the European Commission), which will run from 2014 to 2020.

The Forum's focus was to listen to patients and healthcare providers who deal with epilepsy-related issues; to define objectives and milestones for the epilepsy community; and to propose methods to strengthen epilepsy research and reduce the treatment gap, and the burden and stigma of epilepsy. 270 participants from 57 countries, including each of the 27 EU Member States, attended the Forum.

The Forum was an initiative of Epilepsy Advocacy Europe (EAE), a collaborative joint task force of the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) and was cofunded by the European Commission's 7th Research Framework Programme (2007-2013) and hosted in conjunction with the Irish Presidency of the Council of the European Union (EU).

Over the last three years there have been significant developments in promoting greater funding and awareness of epilepsy initiatives in Europe. The Written Declaration on Epilepsy was passed by a large majority of the Members of the European Parliament (MEPs). The MEP group European Epilepsy Advocates now has more than 30 active members and has played a major indirect role in the European Commission's recent 7th Research Framework call for funding for epilepsy-related research projects to the amount of up to €36 million.

Research

In discussions with policy makers, it was agreed that there is a need for further funding in epilepsy research within Horizon 2020. The following topics need extra resources:

- 1. Epilepsy in the Developing Brain
- 2. New Targets for Innovative Diagnostics and Treatment of Epilepsy
- 3. What is required for Prevention and Cure of Epilepsy?
- 4. Epilepsy and Comorbidities Special Focus on Aging and Mental Health.

Access to Epilepsy Care

Dr Christian Elger, University of Bonn, Germany, noted that there are on average 6,000 epilepsy patients per million population and one third of those are difficult to treat or untreatable. The density of neurologists across Europe is highly variable. Dr Elger stated the need for specialized epilepsy centers to provide services for 2-3 million inhabitants (4,000-6,000 patients). There was consensus that this course of action is highly desirable and requires support from politicians and decision makers at national and EU levels.

Burden and Stigma of Epilepsy

The need for a European-wide epilepsy awareness campaign, supported by the European Commission, was discussed, as a way to reduce the social burden of epilepsy. European Epilepsy Day, hosted on the second Monday in February for the last three years in the European Parliament, has been a major success. The European Commission plans to target stigma across all diseases and it is important that the epilepsy community contribute to the debate and participate in the ensuing initiatives.

Political Commitment

The Irish Minister for European Affairs, Lucinda Creighton TD, addressed the Forum and recognized the need for greater attention to epilepsy. This message was reinforced by Tonio Borg, EU Commissioner for Health, in a video presentation that demonstrated a spirited commitment to alleviating the burden of the disease.

John Ryan, Acting Director for Public Health in the European Commission's Department of Health, outlined five key areas where the epilepsy community can do more:

- 1. Fostering epilepsy patient and carer support
- 2. Training for health professionals
- Ensuring that epilepsy is included in the European Commission's programmes to reduce stigma in all diseases in 2014
- Highlighting the divergence in the treatment and care for epilepsy across Europe
- Assisting in the improvement of public health services in the developing world



ILAE Secretary General Helen Cross and Irish Minister for European Affairs Lucinda Creighton

Moving Forward

The Forum included a session entitled *Think Big – Aiming for the Horizon. No seizures, No epilepsy.* Its aim was to bring scientists, patient organizations, the European Commission Research Directorate, the United States National Institutes of Health/National Institute of Neurological Disorders and Stroke (NIH/NINDS), and industry representatives, including SMEs, to the same table, for the first time.

Philippe Cupers, Head of Neuroscience at the European Commission's Directorate General for Research and Innovation, outlined that the budget for Horizon 2020 could be in the region of €80 billion and that there are particular opportunities for epilepsy-related projects under the heading Health, Demographic Change and Well-being. Dr Vicky Whittemore, Programme Director, Epilepsy, National Institute of Neurological Disorders and Stroke (NINDS)/National Institutes of Health (NIH), United States, indicated the need for collaborative efforts with European partners.

The first European Forum on Epilepsy Research sat the whole epilepsy community around one table and was a tremendous success. It is hoped that its long-term effect will be to encourage all stakeholders into concerted action toward a world in which no person's life is hijacked by epilepsy. Presentations from the Forum are available at the EAE website www.epilepsyresearcheurope.org

The Forum identified the following principal needs:

- 1. Further funding in epilepsy research within Horizon 2020
- Specialized European epilepsy centers to provide services for 2-3 million inhabitants
- 3. Continuation of the annual European Epilepsy Day
- Contribute to the European Commission plans to target stigma across all diseases
- 5. Collaborative efforts with US partners



Participants in the European Epilepsy Research
Forum



Irish MEP Gay Mitchell speaking with Emilio Perucca, Mike Glynn, Nikki Saarsteiner (Barrister with Epilepsy) and John Ryan (Acting Director of Public Health at DG SANCO)

Organizing Committee:

Mike Glynn, Co-Chair, Epilepsy Ireland, Dublin, Ireland
Emilio Perucca, Co-Chair, University of Pavia, Pavia, Italy
Asla Pitkänen, University of Kuopio, Kiopio, Finland
Hanneke de Boer, Stichting Epilepsie Instellingen Nederland, Amsterdam, The Netherlands
Michel Baulac, Hopital de la Pitie-Salpetriere, Paris, France
Norman Delanty, Beaumont Hospital, Dublin, Ireland
Christian Elger, University of Bonn, Bonn, Germany
Reetta Kälviäinen, University of Eastern Finland, Kuopio, Finland
Janet Mifsud, University of Malta, Valetta, Malta
Ann Little, International Bureau for Epilepsy, Dublin, Ireland

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30th International Epilepsy Congress - Montreal



The 30th International Epilepsy Congress, held in Montreal, Canada from 23 to 27
June this year, was by all measures a great success. The Meeting also marked a time of transition as the new Executive Committees of the ILAE and IBE took office after the recent elections. The venue at the Palais de Congres in the heart of Montreal assured that meeting site was convenient to all of the delegates, and that convenience in turn ensured high attendance in the many sessions of the Congress. The attendance and the choices that the delegates made in which sessions to attend were carefully watched: all of the badges scanned (over 17,000) as one entered a

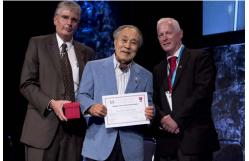
room let the organizers know which sessions were most popular and useful. The data generated will be used in planning the next Congress in Istanbul in 2015, as the organizers will now be equipped with a much better idea of the types of presentation and sessions that best serve the needs of the League's members in the most appropriate venue.

In addition to the installation of the new ILAE Executive Committee, there were several other notable events. At the Awards Ceremony, a number of our colleagues were recognized for exceptional service to the cause of epilepsy or for accomplishment in research with the Ambassador for Epilepsy Award, the Social Accomplishment Award and the Michael Prize (Read about all Award winners here). The highest award given at the meeting is the Lifetime Achievement Award which was presented to Juhn Wada (see picture) for truly outstanding and unique contributions to our understanding of epilepsy and its treatment. From the early clinical efforts, including the intracarotid amobarbital test that bears his name, to a later effort of examining the basis for the development of epilepsy and the key components of seizure circuits, Professor Wada's work has influenced our approach to the study of epilepsy. Without many of his pioneering efforts, we would not have made the progress that we have in the recent decades.

As the League moves forward with our partner, the International Bureau, in preparing future regional and international Congresses, we will use the Montreal experience to shape the sessions to meet the needs of everyone attending. The International Epilepsy Congress is a unique meeting that brings together clinicians, basic scientists, patients and people who provide the essential psychosocial services. It is the one place where the full spectrum of all of the issues, scientific, medical and social, are presented side by side so that we all understand the multidimensional aspects of epilepsy. Moving forward to improve the lives of people affected by the epilepsies really requires that we come together to share our experiences on a regular basis. Be sure to attend and bring your experiences to the next



Executive Committee (2013-17): Rear: Byung-In Lee, Chair - Commission on Asian and Oceanian Affairs; Tatsuya Tanaka, Vice President; Michel Baulac, France; Astrid Nehlig, Co-editor Epilepsia; Hasan Hosny, Chair - Commission on Mediterranean Affairs; Gary Mathern, Co-editor Epilepsia; Marco Medina, Chair - Commission on Latin American Affairs; Sheryl Haut, Chair - Commission on North American Affairs; Robert Cole, IBE Treasurer; Sam Wiebe, Treasurer. Front: Nico Moshé, Past President; Sari Tervonen, IBE Secretary General; Athanasios Covanis, IBE President; Emilio Perucca, President; Helen Cross, Secretary General; Meir Bialer, Chair - Commission on European Affairs



Juhn Wada accepts Lifetime Achievement Award from Nico Moshé and Mike Glynn



Ding Ding, 2013 Michael Prize recipient, presents her paper at the Awards Symposium



Participants in the 30th IEC in Montreal

In developing the Congress in Istanbul in 2015 we are encouraged by the comments we received from the delegates in Montreal:

"Very high innovative topics. Variable themes from basic sciences to social aspects. Highly qualified speakers."

"Caliber of presentations very high."

"There was a variety of topics and quality talks that I think fulfilled everyone's special interest."

"Everything is so organised and ran like clockwork. A great variety of topics too!"

"There were very interesting research related sessions. In particular, the platform sessions, 'Controversies' and 'What's new in diagnostics' were very interesting. In addition, the EpiQuiz was a nice surprise. The organisational aspects were splendid."

"I brought back with me everything that I could have hoped for."

"There were interesting forums with wide-ranging topics and styles which provoked discussion and were well-chaired. Choice available with most events including main symposiums. The location and facilities were ideal."

The feedback tells us that the epilepsy congresses are continuing to evolve to meet the changing needs of the international epilepsy community. We are looking forward to seeing everyone at next year's regional congresses and in Istanbul in 2015.

Congress highlights and more photos and testimonials

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Making Epilepsy Visible to the World: The role of the "Scientournalist"



Patricia Tambourgi, MSc and PhD Candidate – Journalist and International Relations Analyst, Graduate student, Science and Health Communication/Neuroscience of UNICAMP



Vera Regina Toledo Camargo, PhD Professor at Labjor of UNICAMP



Li Li Min, MD PhD Professor of Neurology of Faculty of Medical Sciences of UNICAMP

The Different Worlds of the Scientist and Journalist

One of the most difficult but important goals of a scientific or clinical expert is getting the latest information to the general public in a way that makes the importance of the topic clear. Getting the message out in a way that is understandable and interesting is not a skill that many scientists and clinicians have, but it is a skill of the journalist. However, in conversations with scientists, talking about how to talk to journalists about their findings, many wrinkle their noses and frown. Some say "What a waste of time!" Others answer "I have no interest in that kind of activity". Negative impressions like these concerning the relationship between scientists and journalists, are not rare, and these emotions often prevent important information from reaching the public.

Two problems emerge from this troubled relation. The first is that the journalist who seeks scientific information from the expert to write an article leaves the interview unsatisfied because the scientist does not always have time to explain their findings in an accessible way and often uses technical words unknown to the journalist. As a consequence of this poor communication between the two, the flow of information from the researcher to the public ends up being affected. Why does the relationship between scientists and journalists have to be so difficult?

Deconstructing this Relationship

If we look at the profile of the journalist and scientist, we find many different things, some diametrically opposite. Journalists are restless, seeking aesthetics behind the news, targeting the broadest audience possible, and searching to popularize science. In most cases they have no background in and little understanding of the scientific approach. In comparison scientists are methodical, looking for evidence behind a discovery while avoiding the popular press. They are skilled at communicating with their peers but not with the public. Despite differences between these professionals, they share a common trait: both of them are extremely curious.

It is evident that the appropriation of knowledge by scientists and its dissemination by journalists follow different paths. The challenge, however, is to make them tread a common path by working together. After all, society has the right to know about the state of the art scientific and clinical advances. How can lay people have access to information, if most of the people are not familiar with the intricacies of science and do not participate in the in academic and scientific meetings? Speaking to one another may require a skill that does not come naturally, so it may be necessary to train the two groups in communicating with each other.

Changing the Relationship: Epilepsy as the Laboratory for a New Collaboration

Epilepsy is a highly stigmatizing disease. The cause of stigma is beyond medical science. The ASPE (Assistência á Saúde de Pacientes com Epilepsia — Health Care of Patients with Epilepsy), executor of the Demonstration Project on Epilepsy of the WHO-ILAE-IBE in Brazil, demonstrated that media campaigns and appropriate use of language can change perception of epilepsy and reduce stigma. Thus, the Program CInAPCe (brand name of Interinstitutional Cooperation for Brain Research) funded by FAPESP (the São Paulo Research Foundation), brought together the leading educational institutions and sought an innovative way to publicize epilepsy through actions aimed at journalists. The basic idea was that, once sensitized, the journalist becomes a proponent for the cause of epilepsy.

However, we understand the problem in a more complex level, since the other variable is the scientist and clinician, who also need to know the aesthetic as means for effective communication. Moreover, this communion would be a statement that these two professionals can work together, bringing something more than journalism and scientific communication, but the science dissemination with capacity for social transformation.

The Laboratory of Journalism of UNICAMP (University of Campinas) – Labjor – is the arm of the CInAPCe program responsible for creating a graduate level program for fostering interaction between journalists and scientists with the goal of working together as a team for the greater benefit of creating accessible knowledge about epilepsy.

Labjor, in partnership with the Department of Neurology of the Faculty of Medical Sciences of UNICAMP, offered the first specialized graduate course "Science and Health Communication/Neuroscience" from 2009 to 2010. There were 26 candidates shortlisted after the first phase of examinations; 22 were accepted; and 15 people concluded the course. The participating students were from different backgrounds – journalists and scientists – which fulfilled the purpose of having both professionals in the same environment.

We are now in our second course cycle (2012-2013), and we have increased the number of course participants to 26, again with a balance between the number of scientists and journalists.

The program has 12 mandatory courses, which include both science and journalism, with a total of 360 hours distributed over three semesters. The course is free of charge and the program's aim is to prepare professionals with a global vision of sharing scientific knowledge in health sciences, with a special focus on neurosciences and its relation with science and technology systems.

And Results?



This sort of endeavor is directed to long term results with the goal of a society that is knowledgeable of the latest scientific advances. For the time being, we are sending the message that scientists and journalists can work together as a team to translate scientific findings into accessible and meaningful information. This exercise creates a full circle of communication among all stakeholders from the scientist to the lay public, who as tax-payers have the right to know about their investment in the scientific community.

This effort has had a positive effect for epilepsy in Brazil. Participants have developed books, e-books, podcasts, informative booklets, blogs, websites, social networks (Facebook, Twitter), several articles in magazines, talk shows, TV programs, interviews, and media desks. All these products have been used in local campaigns to raise awareness about epilepsy. This action is a good example of standing up for

epilepsy. The lessons learned in Brazil can be applied in any country. The key is for the local epilepsy experts to recruit members of the press to work together to improve understanding about epilepsy and the importance of making sure that people with epilepsy have access to care. Together we can make it happen.

International Epilepsy Colloquium in Bangalore

A Colloquium on Drug Resistant Epilepsy (DRE) was held at the National Institute of Mental Health and Neurosciences (NIMHANS) in Bangalore, India, on August 16 to 18, 2013. The Colloquium was a joint initiative of NIMHANS and the Association of American Epileptologists of Indian Origin. The Colloquium faculty included 14 epilepsy specialists from the United States, Canada, Japan and 24 speakers from across India. Three hundred and fifty participants attended the Colloquium at NIMHANS with another 450 participants participating on line through a live webcast of the Colloquium proceedings at 27 centers across India. Dr Vishwa Mohan Katoch, Directory General of the Indian Council of Medical Research and Secretary, Department of Health Research at the Ministry of Health and Family Welfare of the Government of India was the chief guest at the inaugural function of the Colloquium, which provided a comprehensive course in the management of people with drug resistant epilepsy.

By conservative estimates, there are ten to twelve million people with epilepsy and three to four million with DRE in India. These people have a many-fold increased risk of death and disability. During the three-day deliberations, participants learned about the underlying mechanisms of drug resistant epilepsies and the role of newer AED as well as the surgical interventions. On day one, the focus was on the evolution of concepts in drug resistance and the best medical management. On day two, the focus was on pre-surgical evaluation methods and surgical management for

people with drug resistant epilepsy. On day three, the focus was on the future developments and directions. A special session on the management of pediatric epilepsies and the training of video-EEG technologists and epilepsy nurses was also was included in the Colloquium. The research collaboration between American and Indian Institutions as well as opportunities for exchange fellowship for young neurologists and neurosurgeons was discussed. Two workshops on magnetoencephalography (MEG) for neurologists and surgical techniques for neurosurgeons were conducted.



Convention center at the National Institute of Mental Health and Neurosciences, Bengaluru



Dr P. Satish Chandra, Vice Chancellor of NIMHANS, together with organizers Professors Malla Bhaskara Rao, Sanjib Sinha and A. Arivazhagan of Bengaluru and Prof. Sanjay P. Singh of Creighton University, USA

On the final day an epilepsy awareness programme for people with epilepsy, their families, and public in general was organized. The public awareness programme was a joint initiative of NIMHANS, Association of American Epileptologists of Indian origin and Indian Epilepsy Association (Bangalore Chapter). This programme consisted of a play on epilepsy, and talk on recent advances in the management of epilepsy followed by question and answer session. It was well attended by people with epilepsy as well as their family members. Colloquium details and the commemorative photographs are available at www.iaes2013.com.

This programme reflected the significant progress that has been made in managing people with drug resistant epilepsy in India, and reflects the national and international scope of the Indian epilepsy efforts and successes. It also provided students and junior colleagues the opportunity to see the potential for a rewarding career in epilepsy and, because of the transmission of the colloquium to many institutions across the country, expanded the reach of the programme to many who wanted to know more about epilepsy but were unable to attend physically. One of the hoped for results is recruiting the next generation of epilepsy specialists into the community.

Malla Bhaskara Rao Professor, Department of Neurosurgery National Institute of Mental Health & Neurosciences (NIMHANS) Bangalore, India

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The National Institutes of Health Curing Epilepsy Conference







Edward Bertram

In April of this year the meeting "Curing the Epilepsies 2013: Pathways Forward" was held at the National Institute of Health in Bethesda, Maryland. This meeting was the third in a series of NIH meetings that started in 2000 following an initiative from the White House with the overall theme and goal "no seizures, no side effects." As a result of that first meeting, benchmarks were created in part to measure the progress we are making in achieving our goal and in part to emphasize to researchers what the critical steps are so that research can be better focused on what is needed to end the devastating impact of epilepsy. This year's meeting

was designed to review how far we have come and also to review and update the benchmarks. The two and a half day meeting included presentations from active researchers as well as from people whose lives have been affected by the disease. Topics included understanding the causes of epilepsy, the many paths that lead to epilepsy, the basis for comorbidites and SUDEP, what do we mean by an epilepsy cure and how we might get there. At the end of the meeting there was a prolonged discussion about the current benchmarks and how they should be modified.

The patient groups participated in the discussions and they strongly emphasized the importance of goals that can be realized and implemented. They referred to a Parkinson's disease survey about what patients viewed as the biggest problem, and the totally unexpected answer to clinicians and scientists was dyskinesia. The survey changed the focus of research and clinical emphasis. At this meeting many of the patient groups made the clear statement that seizure control and quality of life for everyone involved were the most important issues. The participation of patients, families and patient advocacy groups was essential to defining future goals. Because they live with the disease on a daily basis, our lay colleagues have a much better perspective on what it means to have epilepsy and what the priorities should be. Although all agreed that a cure would be ideal, there was also a clear statement that the prevention of seizures for all who suffer from epilepsy would have a major impact on quality of life.

One of the great roadblocks slowing progress in bringing new treatment to the clinic is the difficulty in finding people to participate in clinical trials. Part of the problem is the absence of readily accessible information about ongoing trials. To improve the low involvement, a website has been created (www.epilepsyhero.org) by Mylo Schaaf from the University of California San Francisco. Its purpose is to provide information about epilepsy clinical trials, and the site includes trial summaries, inclusion and exclusion criteria, trial location and contact information. Trial information is based on the NIH clinical trials site. It is a potentially very useful tool for increasing participation in important clinical research.

There were a number of presentations about the mechanisms of epilepsy including genetics, changes in ion channels, comorbidites, the meaning of a cure and the structural changes in the brain that may contribute to epilepsy, but there were several new topics. The growing importance of neural networks in understanding and treating epilepsy was made clear in several presentations in which new approaches to controlling system excitability were discussed. These approaches including targeting specific neurons in the seizure onset zone, defining local circuits that can be modulated and directing treatment at subcortical structures that are a component of the seizure circuit. The concept of connectomes or the map of neural circuits in the brain will become more and more of a focus of research to determine where and how to modulate system excitability and prevent seizures. In addition, there were two presentations about

causes of epilepsy that may give us new targets for therapy. Josep Dalmau added to his growing body of evidence that autoimmunity may lead to more types of epilepsy than previously thought. In addition Peter Crino presented the studies he and colleagues performed that created a strong link between human pappiloma virus and the development Type 2 cortical dysplasia. Both studies open up a new set of causes for the acquired epilepsies.

SUDEP and its causes was a major topic. No clear direction to pursue evolved, but it was encouraging that this terrible consequence of epilepsy is receiving more attention than before. Jack Parent from the University of Michigan presented his work using pluripotent stem cells from patients with Dravet's syndrome to understand the changes in physiology that may lead to seizures as well as underlie the associated cardiac problems. George Richerson of the University of Iowa presented data suggesting post-ictal apnea as a possible cause for SUDEP and drew parallels to Sudden Infant Death Syndrome and its possible serotenergic mechanisms. In the general discussion it was emphasized that there are likely a number of causes or contributing factors, but the new approaches and ideas presented clearly provide new directions for research as the community works to prevent sudden death.

Some cutting edge interventions were discussed. These ranged from an MRI guided laser ablation therapy to attack lesions that are not easy to reach otherwise, to a novel device consisting of electrodes implanted in the brain which detects seizures before they occur. While these interventions are in early stages of development and testing, they present hope for a new generation of surgical approaches.

On the last day there was an extensive discussion about the existing benchmarks and what new areas needed emphasis. Many central issues were raised, including understanding the epileptogenic processes for all forms of epilepsy, the need for better animal models, a new emphasis on the neural networks of epilepsy, a better understanding of the consequences of epilepsy and improving quality of life for all who are afflicted by the disease. After the meeting four areas for emphasis were chosen which covered these areas and more. These four proposed areas are 1) understanding the causes of epilepsy and epilepsy-related conditions; 2) preventing epilepsy and its progression; 3) improving the treatment options for controlling seizures without side effects and 4) limiting or preventing adverse consequences of seizures and their treatment across the lifespan.

For participants who had taken part in the first two Curing Epilepsy meetings it was gratifying to see how much progress has been made since 2000. As experience with the process and as new data appear, the areas for emphasis also change. There were many ways to pursue the neurobiology and clinical science of epilepsy. The value of the benchmarks is that they help us focus and allow us from time to time to take stock of the progress that has been made.

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Overwhelming Response to Request for Comments

In August, a request went out to the international epilepsy community to comment on the proposed definition for seizures and epilepsy that was prepared by an ILAE task force under the leadership of Robert Fisher. We had hoped that we would receive perhaps 100 comments, but when the comment period was closed at the beginning of October, we were amazed and gratified that we had received over 320 responses from across the globe. The nature of the comments made it clear that our members responded to the request with well-considered ideas. As the manuscript moves to the next stage in which the comments will be reviewed, the thoughts from the community will play a significant role in the final version, which will then become the League's definition.

This approach, in which there is member input, is a new initiative from the ILAE, under the newly adopted guidelines for League publications (www.ilae.org/Visitors/Documents/Guideline-PublPolicy-2013Aug.pdf). Under this policy, papers such as this one, which are intended to serve as a common language for the community, will be submitted to the League's members for comments. After a two-month period, a task force which consists of some of the authors of the document as well as new members, including individuals representing the Executive Committee and the editors of *Epilepsia*, will begin the review of the comments with a goal of weighing the members' thoughts and incorporating those thoughts, as appropriate, into the final document. The edited document will become the League's position and will be used in League publications thereafter. The primary goal in this effort is to provide everyone who works in epilepsy a common, agreed upon language. The task force will have six months to complete the task and produce this final document.

The League is truly thankful for the significant efforts taken by so many in responding to our request for your thoughts. The many comments represent the diversity of our members, and there have been many well considered recommendations made for changes to the definitions document. Your involvement and the many thoughts you offered are a very positive sign of a healthy organization in which differing points of view are aired openly and a resolution to provide a common ground is achieved.

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Obituary: Robert Stephen Burgerman, MD



Robert Stephen Burgerman, MD was an epileptologist and clinical neurophysiologist who was a long-term supporter of the epilepsy community. On July 12, 2013 he died suddenly, unexpectedly, and peacefully in his sleep. Born in Washington DC, he earned his undergraduate degree in electrical engineering and his MD at Washington University and did an internship at Barnes hospital in St Louis, Mo. He completed a Neurology residency at the University of Maryland and a two-year fellowship in epilepsy and clinical neurophysiology at the Graduate Hospital, affiliated with the University of Pennsylvania. He then moved to Sacramento, California where he was founder and medical director of the Sacramento Comprehensive Epilepsy Program at Sutter Medical Center. Bob served as the director of the adult epilepsy monitoring unit and neurodiagnostic laboratory for 21 years and was also Vice Chair of the Institutional Review Board. He was a consultant at the University of California, Davis and was an active member of the American Epilepsy Society, the American Clinical Neurophysiological Society, the Southern EEG Society, the American Academy of

Neurology, and the American Medical Association.

Bob remained committed to serving people with epilepsy throughout his career. He had special interest in functional brain mapping and the surgical treatment of epilepsy and served as an investigator for many new antiseizure drugs. He was distinguished by his attention to detail, an unquenchable thirst for knowledge, the ability to connect with patients, and the regularity with which he was involved in epilepsy educational venues both in the US and abroad. He had a kind and generous heart with unparalleled love and devotion for his wife Linda. Bob had a quick wit and great sense of humor. He was always supportive of others, sometimes at his own expense, and could be pointedly honest when

needed. He enjoyed windsurfing, skiing, and hiking, and found solace in nature and the arts — especially playing his saxophone. He will be greatly missed by his family, friends, and patients. His passing is a great loss. His family has asked that donations made on his behalf go to the Epilepsy Foundation of Northern California (www.epilepsynorcal.org).



Dr Burgerman with William Tatum when they were in training



Dr Burgerman with his saxophone

William O Tatum IV Michael R Sperling

Obituary: Cesare T. Lombroso, MD, PhD

A dedicated physician and AES leader will be missed.



Dr Lombroso was a dedicated physician who trained many doctors in his over 50 year career in medicine and was renowned for his ability to handle the most difficult cases of epilepsy. Dr Lombroso passed away peacefully on October 19, 2013 at his home surrounded by family.

Dr Lombroso was born in Rome, Italy, to a distinguished family that included numerous scientists and authors, many of whom achieved international recognition for their work. He received his M.D. degree in 1946 from the University of Genoa and then, in 1950, his PhD degree from the University of Rome. Later that year, Dr Lombroso began his long association with Harvard and The Children's Hospital.

In 1962, he succeeded Dr William G. Lennox as Chief of the Seizure Unit and EEG Laboratory at Children's Hospital, positions he held until he retired from the faculty of Harvard Medical School in

1988. Believing, as did Dr Lennox, that children with seizures do best when they are treated in a center that can address simultaneously the multiple interacting medical, psychosocial, behavioral and family issues that impact on their lives, Dr Lombroso succeeded in making the Seizure Unit at Children's Hospital a preeminent center for both treatment and clinical investigation.

There is scarcely an area of pediatric epileptology that has not been influenced by Dr Lombroso's contributions. He pioneered the concept that febrile seizures are usually benign and often do not require treatment. His studies of infantile spasms and other epileptic encephalopathies, breathholding spells and infantile syncope, idiopathic partial seizures, and neonatal seizures were major original contributions that remain classics in the field.

In electroencephalography, Dr Lombroso's work has hardly been less important. He helped define the normal paroxysmal changes that occur during drowsiness in children, clarified normal variants of EEG patterns that had previously been considered abnormal, and carried out systematic studies of EEG activity in newborns that helped make the EEG an indispensable diagnostic tool in hospital nurseries.

Dr Lombroso received the Ambassador for Epilepsy award from the International League against Epilepsy in 1981. He was the president of AES in 1986-87. He received the Distinguished Clinical Investigator Award given by the Milken Family Foundation in 1990. He was one of the original founders of the William G. Lennox Fund in 1962 which was combined with assets of his own trust in 2007. As a dedicated member of AES, he worked tirelessly on behalf of the Society for over 50 years. He was an ex-officio member of the board until recently. He will be greatly missed by both patients and professionals.

Dr Lombroso was the beloved husband of the late Irena (Kister) Lombroso, devoted father of Claudia G.C. Lombroso of Newton, MA, Anna C. Lombroso and her husband William Glynn of Sherborn, MA, and Paul Lombroso and his wife Jamice Naegele of North Haven, CT. He was the grandfather of Andrew and Amy Glynn, Christopher, Adam and Sonia Lombroso.

A Memorial Service is being planned for November 23 at Noon at **Harvard University-The Memorial Church**. Updated information will appear on the **AES website**, when available.

AES is accepting contributions, *in memory of Dr Cesare T. Lombroso*, to support critical epilepsy research: Lennox and Lombroso Trust for Research & Training c/o The American Epilepsy Society (AES) 342 North Main Street Ste #301
West Hartford, CT 06117-2507

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Farewells Listing on Website

The ILAE hosts a **Farewells** web page where we commemorate our departed colleagues in epilepsy and the contributions that they have made to the field. It is our intention that this section for memorials be open to obituaries for anyone who has been active in the field of epilepsy in any capacity: clinical, social, scientific, psychological, to name but a few. There are no academic, professional or geographical requirements to be considered for inclusion in this section. There are many great things that are done locally to improve the lives of people with epilepsy, efforts that are

critical in the battle against this condition. Unfortunately some of the most important contributions are done away from the limelight and may not catch the attention of the larger international community. It is the intention of this section that anyone who has been active in the field be included and have their efforts and successes more widely known. The only real criterion is that the individual worked to help relieve the burden of epilepsy somewhere in the world.

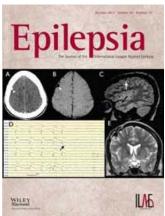
The memorial articles are written by those who knew the person. The goal is to tell your colleagues in epilepsy who this individual was and what the contributions were. Photographs are welcome.

There are two parts to this section: recent deaths and archives. The latter allows League members to learn about those who have gone before and the contributions they made. It also as acts as a resource for those who wish to look into the history of epilepsy and those who contributed to it. We look forward to your remembrances of our valued departed colleagues. Please send them or any comments or suggestions that you may have to farewells@ilae.org. We will also welcome multiple remembrances from our members. The success of this project depends entirely on your efforts to help preserve the memories and the accomplishments of our friends and colleagues.

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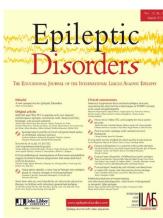
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Epilepsy Fellowship Bulletin Board



The ILAE website will offer the possibility for institutions to announce clinical and research fellowships in epilepsy-related disciplines (epileptology, neurophysiology, neurosurgery . . .). Institutions can describe their fellowship program in a few lines. The service is free of charge and announcements will initially stay posted for six months. For information, contact info@ilae.org.

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Upcoming Congresses and Educational Events

2013

9 - 13 November 2013 Society for Neuroscience - 43rd Annual Meeting San Diego, CA, USA Meeting Website

13 - 16 November 2013
Indian Epilepsy School 2013
8th National EEG workshop under ageis of IES- ASEPA
Delhi-India
Brochure | Program, venue and registration

21 - 23 November 2013 3rd International Congress on Neurology and Epidemiology (ICNE) Abu Dhabi, UAR

www.icne2013.com

6 -10 December 2013 American Epilepsy Society Annual Meeting Washington, DC USA www.aesnet.org | Congress Brochure

2014 Regional Conferences

22 - 24 May 2014 2nd African Epilepsy Congress Cape Town, South Africa www.epilepsycapetown2014.org

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

www.epilepsystockholm2014.org

7 - 10 August 2014 10th Asian & Oceanian Epilepsy Congress Singapore www.epilepsysingapore2014.org

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

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