

## Epigraph International Epilepsy Congress

Dear Friends and Colleagues,

On behalf of the Organising Committee, it is our pleasure to welcome you to the 32nd International Epilepsy Congress (IEC) in Barcelona, September 2nd – 6th, 2017. This congress is organised jointly by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE).

The International Epilepsy Congress is a major biennial event and a recognised landmark in the calendar of epilepsy specialists worldwide. The congress, which is held in the prestigious Palau de Congressos de Catalunya, gives delegates from all over the world the chance to come together with fellow researchers, clinicians and health care practitioners. The scientific programme is highly engaging, with a wide range of main and parallel sessions, as well as teaching sessions, debates, multidisciplinary conferences and video sessions.

Barcelona is one of the top cities in Europe and the world in terms of hosting international conferences. Visiting the different corners of Barcelona is an authentic journey through time – over 2,000 years of history, with Roman ruins, Gothic treasures, and surprises from the Renaissance age. The creative flair of Picasso, Miró, Dalí, Gaudí, and Tàpies is very much part of the city today and this is reflected in the buildings, exhibitions, and the design and art that are found in the most unexpected places. The city's character is truly Mediterranean, with a cosmopolitan and dynamic spirit and we hope you get to enjoy some of what the city has to offer while you are here.

We look forward to meeting you all in this wonderful city.

With warm regards,



Emilio Perucca



Athanasios Covanis



Antonio Russi

Co-chairs, 32nd IEC Scientific and Organising Committee





## Message from Current President

This issue of Epigraph is being released near the end of my term as ILAE President. It is appropriate, therefore, for me to look back at what has been achieved, and highlight a number of significant initiatives that have been undertaken by the League in the last 4 years.

### Improving epilepsy care on a global scale: The World Health Assembly Resolution

Because of its position as the leading professional organization in epilepsy, the League has a primary responsibility in advancing epilepsy care worldwide, in partnership with other key national and international stakeholders. Historically, the League has collaborated effectively with its sister organization, the International Bureau for Epilepsy (IBE), and with the World Health Organization (WHO). The ILAE-IBE-WHO Global Campaign against Epilepsy, established in 1997, has been invaluable in raising awareness and conducting several demonstration projects aimed at reducing gaps in diagnosis and treatment, particularly in low- and middle-low-income countries. The joint decision made by the League and the Bureau in 2014 to establish and promote an International Epilepsy Day, to be celebrated annually on the second Monday of February, represents an additional initiative to raise global awareness.<sup>1</sup>

Despite the success of these initiatives, the need for a renewed effort to raise the visibility of epilepsy and to trigger concrete actions on a planetary scale was broadly felt within our community. Based on these premises, as early as 2013 ILAE and IBE started to work with their



Emilio Perucca  
President

Chapters to sensitize national governments to the importance of bringing the many unmet needs of epilepsy to the attention of the World Health Assembly (WHA). It was in this context that, in late 2014, the People's Republic of China made a formal request to include a global

action on epilepsy in the agenda of the 2015 WHA. It was not by chance that this important step was taken by the Chinese authorities, because China had been the location of a highly successful Global Campaign project and there has been historically an excellent relationship between the Chinese Ministry of Health and the Chinese Association against Epilepsy, led by Dr. Shichuo Li. The preparation of a draft Resolution on Epilepsy by the People's Republic of China, jointly with the Russian Federation, for submission to the WHA led to an intensive action of the ILAE-IBE Global Outreach Task Force, chaired by Alla Guekht and Mary Secco, to sensitize our constituencies and national health authorities worldwide about the importance of supporting the initiative. The response from ILAE and IBE Chapters was overwhelming and partner organizations, including the World Federation of Neurology (WFN) and Health Action International, joined us in supporting the effort. The historical moment came on May 26, 2015 when the Resolution on Epilepsy was unanimously approved by the WHA.<sup>2</sup> In short, the Resolution urges WHA member States to (i) promote epilepsy awareness and education; (ii) establish national healthcare action plans for epilepsy; (iii) integrate epilepsy diagnosis and management into primary health care; (iv) implement strategies to prevent epilepsy and to improve access to medicines; and (v) allocate resources for epilepsy research. Concrete follow-up actions are already taking place in several countries, often in consultation with ILAE and IBE national constituencies. In many regions, these actions are facilitated by earlier national and international recommendations and guidelines, including the European Parliament's Written Declaration on Epilepsy, the U.S. Institute of Medicine Report, and the Pan American Action Plan on Epilepsy.

### New definitions and classifications of seizures and epilepsy

In 2013, the Executive Committee adopted a new procedure for the approval of papers that represent the 'official' position of the ILAE, i.e. documents that are intended to provide a common language or set of definitions for the international epilepsy community (<http://www.ilae.org/Visitors/Documents/Guideline-PubPolicy-2013Aug.pdf>). Prior to publication, these papers are placed on the web for a period of two months for public comment. All comments received are then addressed and incorporated as appropriate by an ad hoc Task Force before final approval by the Executive Committee as the ILAE position. This procedure ensures that position papers reflect not only knowledge of a selected group of experts, but also the input of our entire constituency worldwide. The first position paper approved through this process was the operational *clinical definition of epilepsy*, published in 2014.<sup>3</sup> This was followed in March 2017 by the position papers on the *classification of epileptic seizures*<sup>4</sup> and the *classification of the epilepsies*.<sup>5</sup> These landmark documents, which are available open access in the Epilepsia website (<http://onlinelibrary.wiley.com/doi/10.1111/epi.13709/epdf>; <http://onlinelibrary.wiley.com/doi/10.1111/epi.13670/epdf>) represent the culmination of a massive effort that has been ongoing within our community for over a decade, and provides a modern framework for terminology, definition and classification of epilepsy and seizure types. To assist the user in the application of these concepts, the ILAE Commission on Classification and Terminology has also prepared an instruction manual that includes a glossary and examples based on seizure descriptions from everyday clinical practice (<http://onlinelibrary.wiley.com/doi/10.1111/epi.13671/epdf>).<sup>6</sup>

### Diversifying the League's publication portfolio

The last four years also witnessed exciting developments in the League's *publication portfolio*, and I am grateful to the editors of our journals for making such developments possible. Epilepsia continues to be the most prestigious epilepsy journal for original research articles and scholarly reviews, and its impact factor has steadily risen from 3.91 in 2012 to 4.70 in 2017. In 2013, the League acquired Epileptic Disorders as its journal dedicated primarily to education. Finally, in September 2017, we launched *Epilepsia Open*. *Epilepsia Open* is a response to a call from our community, which believed that our pre-existing publication portfolio was insufficient to host the ever-

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increasing amount of high-quality epilepsy research being conducted throughout the world.<sup>7</sup> At the same time, with the ongoing shift from subscription journals to open-access journals, the League needed to invest in the open-access model to maintain its leadership in the epilepsy global publication arena. By publishing in *Epilepsia Open*, authors can ensure that their research is freely accessible to the entire scientific community, thereby enhancing the global visibility of their work and, ultimately, their citation index. As a further advantage, the new journal will make such research available to people with epilepsy, their families, and other lay readers who would otherwise have no means to access it freely.

#### Commission reports and an initiative to improve clinical guidelines

During the 2013-2017 term, a total of 33 ILAE Commission and Task Force Reports have been published in our journals and received with great interest, as testified by the high number of citations and downloads. At the same time, the League has taken steps to improve the quality of ILAE clinical guidelines, by developing standardized and rigorous procedures to be followed by Commissions and Task Forces involved in the production of guidelines.<sup>8</sup> Our Task Force on Guidelines has also conducted a systematic search of currently existing epilepsy guidelines identifying major gaps which, hopefully, we will be able to address in the near future.<sup>9</sup>

#### Expanding educational activities

In the last term, the League has gradually expanded its educational activities through our international and regional congresses, a greatly improved website, consolidation of Virepa (distant education) courses, and a broader range of courses and fellowships, run mostly through Regional Commissions. Access of our younger colleagues, and colleagues from resource-restricted countries, to educational activities has been supported by extensive bursary programs and highly discounted registration fees. In parallel, mentorship training programs have been established to promote career development for young leaders engaged in epilepsy care as well as research.

An important educational service provided freely by ILAE is the cutting edge online diagnostic manual of seizures and epilepsies, *epilepsydiagnosis.org* ([www.epilepsydiagnosis.org](http://www.epilepsydiagnosis.org)). Developed by a Task Force of the previous Commission on Classification and Terminology in partnership with eResearch at the University of Melbourne, *epilepsydiagnosis.org* was launched in September 2014 and is being constantly updated by Kate Riney and her team. The manual harnesses the power of the internet to present the large amount of new information about the epilepsies and their etiologies in a manner that is concise, current, and accessible to a global audience. It is as relevant to those in primary and secondary health care settings as it is to those in tertiary practices. As an indication of its popularity, in the last quarter of 2016 the manual had an average of 10,200 users per month engaging in 12,800 visits, for an average of 7.5 minutes per visit, with 44,000 page visits each month.

A new important educational initiative, spurred by Sam Wiebe and currently led by Guenter Kramer, involves ILAE

taking on the responsibility for the review and update of epilepsy-related content in Wikipedia. Wikipedia is by far the most widely accessed source of information on any aspect of knowledge and it is used not only by the general public, but also by medical students, primary care physicians and specialists. Ensuring that information on all issues related to epilepsy in Wikipedia is accurate and timely updated determines how epilepsy is perceived, diagnosed and treated in all parts of the globe.

#### Promoting research

The League is dedicated to promoting high quality epilepsy research. Over the last two terms, the joint ILAE-AES Task Force on Translational Research has produced several landmark guidance documents on methodology to improve standards of preclinical epilepsy research.<sup>10,11</sup> With respect to clinical research, a major effort is ongoing to stimulate multinational funding of ambitious research projects which could only be completed through large-scale international collaboration. Through its Regulatory Task Force, the League has also established an effective interaction with regulatory agencies across the globe, including the U.S. FDA, the European Medicines Agency and the Japanese PMDA. Communication of the Task Force with these agencies provides the opportunity to contribute expert advice on issues related to the development of drugs and devices and terminology to be used in regulatory documents, including prescribing information.

#### Strengthening alliances

The League welcomes collaboration with other professional societies. In the last term, our partnership with WFN has been strengthened through many initiatives, including organization of joint sessions at ILAE and WFN congresses; co-funding by the two organizations of epilepsy-related research projects; strong WFN support to the WHA Resolution on Epilepsy and the subsequent dedication of 2015 World Brain Day to epilepsy; excellent collaboration in finalizing epilepsy-related ICD codes; and the hosting of the General Assembly of WFN delegates at the venue of the European Congress of Epileptology in 2016. A strong collaboration has also developed with the European Academy of Neurology (EAN), including joint congress sessions, a memorandum of understanding on joint production of guidelines, and the publication of joint consensus documents.

#### Conclusions

My four years as ILAE President have been hectically busy, but immensely gratifying. The greatest source of gratification has been the continuous support of the hundreds of volunteers who dedicate their time in ILAE Commissions and Task Forces to advance our mission and, ultimately, improve lives of people with epilepsy. The League is blessed to be able to count on such people. I also wish to thank our staff and all members of the Executive Committee for their continuous support and inspiring collaboration, and the IDM team for their excellent work in the organization of our congresses and the running of the ILAE Chapter Services office. During my term, I was also fortunate to be working side by side with a highly dedicated IBE President, Athanasios Covanis, and a very supportive IBE team. Without the contribution from all

these colleagues and many other volunteers working in our Chapters throughout the world, none of the achievements listed in this report would have materialized. Very special thanks also go to my wife, Tita, who for many years tolerated patiently my being away from home for long periods of time, and my being always busy when at home to catch up with never ending work backlogs.

To my successor, Sam Wiebe, and to the 2017-21 Executive Committee, all my best wishes for a highly successful new term. With them, the League is in great hands, and surely will continue to thrive for many years to come.



Emilio Perucca

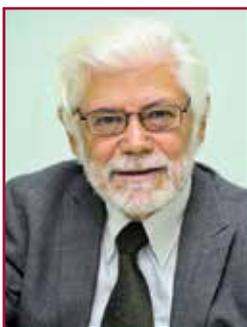
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# Perspective of the Past 4 Years as IBE President

*Athanasios Covanis, IBE President*

As the end of the current term of the IBE International Executive Committee draws to a close and with it the end of my four-year term as its President, it is a good opportunity to reflect on the challenges addressed and achievements enjoyed during this very busy period for the Bureau.



*Athanasios Covanis  
IBE President*

Almost immediately after I took office, I travelled to the WHO offices in Geneva, together with the new ILAE President, Emilio Perucca, in our roles as the new co-chairs of the ILAE/IBE/WHO Global Campaign Against Epilepsy. This would be the first of many meetings and events we attended jointly, recognising and cementing the joint working relationship between ILAE and IBE. We had very good discussions with Dr. Shakir Saxena and Tarun Dua and I was pleased to see that the future of the campaign was looking very exciting. Also at this time, the co-chairs of Global Outreach were named: Mary Secco, to represent IBE and Alla Guekht for ILAE.

The last four years did, indeed, turn out to be a very significant period in the life of the Global Campaign, with the WHA/WHO Resolution on Epilepsy approved at the World Health Assembly in 2015. But of course, this did not happen overnight or by accident and we must go back a year, to 2014, to see the initial efforts that would ultimately lead to this achievement. There was a considerable level of hard work involved in having the call for a resolution included on the agenda for the WHO Executive Board in late January 2015. But we were successful and so Monday 2nd February 2015 became a landmark day for people with epilepsy, as the WHO Executive Board approved a resolution on epilepsy that recognises the need for a coordinated effort at country level to address all aspects of epilepsy. The resolution calls on Member States of WHO/OMS to take action on a number of fronts in order to prioritise epilepsy care in a coordinated fashion around the world, placing equal weight on both the medical care and social aspects of the disease and recognising the importance of all stakeholders, including people with epilepsy and their careers.

The resolution also requests the WHO Secretariat to begin work on a framework program, which will include drafting of technical documents to assist Member States, particularly in low income countries, in implementing the actions stated in the resolution. What is particularly significant about the document is that it mentions, by name, both the International Bureau for Epilepsy and the International League Against Epilepsy. In terms of WHO resolutions, this is extremely rare.

The second hurdle was to have the resolution approved by the World Health Assembly (WHA) at its meeting in May. This required a huge level of effort by IBE, ILAE and by our respective chapters in encouraging member states to vote in favour of the resolution. But our efforts were successful and, on 26th May, the WHA unanimously approved the resolution, with 43 countries making statements in favour of the resolution, which was co-sponsored by 19 countries. This must count as the most significant achievement of this term of office.

The World Federation of Neurology recognised the significance of the WHA Resolution by dedicating World Brain Day on 22nd July 2015 to epilepsy.

The other major international activity that was introduced, by pure coincidence within days of the approval of the WHO Resolution, was the launch of International Epilepsy Day. Similar to the resolution, this did not come about easily and had taken many years of discussion and consideration. But, finally, following the very successful European Epilepsy Day, which had been running since 2011, the first International Epilepsy Day took place on Monday 9th February 2015, with celebratory events taking place around the world, as well as in the European Parliament in Strasbourg.

A joint initiative of IBE and ILAE, and developed in line with a strategy to advocate for appropriate legislation to guarantee human rights of people with epilepsy and to empower people with epilepsy to maximize their quality of life, International Epilepsy Day aims to highlight that epilepsy still remains a hidden disease due to the stigma attached; that it is treatable, yet 40% of people living with epilepsy in wealthier countries do not receive appropriate treatment, and over 70% of those living in low income countries cannot even access epilepsy medication regularly; that lack of treatment imposes a huge financial burden on national health systems; and that research and legislation remain key issues in improving the quality of life of persons with epilepsy. International Epilepsy Day was celebrated for the third time in 2017 and I look forward to watching this annual world day for epilepsy further develop in the coming years.

Great advances were made by the joint task force of IBE and ILAE in Europe – Epilepsy Alliance Europe – with registration in Europe to allow potential access to EU funding sources and with a number of events in the European Parliament. Co-chaired by Philippe Rylyn and me, Epilepsy Alliance Europe celebrated European Epilepsy Day (2014) and International Epilepsy Day (2015 to 2017) in the European Parliament in Strasbourg and Brussels. Epilepsy Alliance Europe is an important move that allows the task force to be involved in EU funded projects and, already, invitations have been accepted to participate in submissions to the EU under the latest call of the Horizon 2020 funding program. Important projects that IBE is involved in: E-PILEPSY, ESBACE, EpiCARE, the European Brain Council Value of Treatment project, EPITARGET and RADAR-CNS.

The European Advocates for Epilepsy group of Members of the European Parliament (MEPs) was established in 2011, thanks to the efforts of Gay Mitchell MEP. The task force continues to encourage the MEPs to join the Advocates Group which now has a membership of 55 MEPs and which is responsible for hosting epilepsy workshops, meetings and receptions in the parliament. A Global Research Initiative on Epilepsy Research was formed in 2016 with a view to joint European, North American and Asian research programs. As a consequence, a meeting took place on February 7th 2017 in Brussels hosted by Brian Hayes MEP, President of European Advocates for Epilepsy Group with the participation of ILAE, IBE, Epilepsy Alliance Europe, the European Advocates for Epilepsy MEP group, the US and Canadian National Institutes for Health, Epilepsy Foundation of America, American Epilepsy Society and representative of DG SANTE, the EU health commission. It was a very successful meeting with action plans to be accomplished in the future.

The other major joint activity of IBE and ILAE are the international and regional congresses. During the last four years, excellent congresses were held in Ljubljana, Dubai, Hong Kong, Singapore, Istanbul, Buenos Aires, Cancun, Cape Town, Dakar and Prague. I am also looking forward to Barcelona, which is expected to be one of the most successful international epilepsy congresses since Rome 2011.

At an internal level, in 2014, thanks to the support of Sari Tervonen, the Finnish Epilepsy Association and those members attending a workshop at the IEC in Istanbul, IBE the IBE strategy plan was reviewed, modified and approved, acting as our roadmap to 2018.

A revision of the Constitution & Bylaws, carefully carried out by the Governance Task Force over a period of three years, was also approved by the General Assembly in 2015, with one of the major changes being a return to the title of 'chapters' for our members. The Bylaws were also amended to encourage greater participation in IBE elections by relaxing the election procedures and shortening the process.

Communications play a major role in what we do, to ensure that we attract the biggest audience possible to see the work we are carrying out and the challenges we face. International Epilepsy News, first published in 1961, continues to be produced on a quarterly basis, although, for economic reasons, we moved to electronic format in 2013. But the newsletter is just one means of communication with our internal and external audience. The IBE website was redesigned in 2014 and for International Epilepsy Day we created a new website, epilepsy.org, which allows us to promote International Epilepsy Day activities and to share the stories of people living with epilepsy around the world.

We also use Social Media, in particular Facebook and Twitter, to advertise our work throughout the year. Social Media gives us instant access to people with an interest in epilepsy and will continue to play a major role in our communications package.

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IBE also continues to expand its partnerships, joining up with other NGOs and other groups with a common goal to share information, experience and best practice.

IBE Membership continues to grow and is now represented by Full and Associate Chapters in 104 countries around the world. Since 2013, we have attracted new members in Lebanon (associate chapter), Guyana, Luxembourg, Pakistan, Spain (associate chapter), Costa Rica, Moldova, Italy (associate chapter), UK (associate chapter) and Paraguay.

Our Promising Strategies program continues to provide funding to chapters in developing regions to support projects aimed at improving the quality of life of people

with epilepsy. IBE has provided more than US\$300,000 to over 70 projects since the program began in 2007, with the hope that it can be further developed and expanded.

It has been my great pleasure to visit IBE chapters and speak at meetings and congresses around the world since I was elected President in 2013. In the past few years, I have travelled to Argentina, Belgium, Bulgaria, Canada, China, Cyprus, Czech Republic, Dubai, France, Hong Kong, India, Iran, Ireland, Italy, Kazakhstan, Lebanon, Luxembourg, Mexico, Netherlands, Pakistan, Romania, Russia, Senegal, Singapore, Slovenia, South Africa, Sweden, Switzerland and Turkey. I would like to thank all those who invited me to speak at their epilepsy event for their generous hospitality.

Although my four-year term as President ends on 5th September, I look forward to serving IBE for a further four years in my capacity as Immediate Past President.



Athanasios Covanis  
IBE President

## Message from the President-Elect

*Samuel Wiebe, President-Elect*

This issue of Epigraph marks the transition to the new leadership team of the ILAE, which commences its work officially in September of 2017. As president for the period 2017-2021, I look forward with great anticipation and excitement to the next four years. Thank you for entrusting me to



Samuel Wiebe

serve our organization in this key leadership role. We have an outstanding leadership team which has been elected by you, and whose goal is to serve our constituency by improving education and care for people with epilepsy worldwide. The core group of elected officers constitutes the Executive Committee and the Management Committee.

### The New Leadership Team

The Executive Committee is the group in charge of deciding on all strategic aspects of the ILAE, and it consists of the elected Chairs of each of the six Regional Commissions, plus the Management Committee as voting members, as well as ex-officio and non-voting members from the International Bureau for Epilepsy and journal Editors. The six elected chairs are Roberto Caravallo (Latin America), Akio Ikeda (Asia-Oceania), Nathalie Jette (North America), Angelina Kakooza (Africa), Chahnez Triki (Eastern-Mediterranean), and Eugen Trinko (Europe).

The Management Committee is the group in charge of implementing the ILAE mission and dealing with day-to-day operations. This is composed of five people, which include myself as president, Ed Bertram as secretary general, Helen Cross as treasurer, Alla Guekht as vice president, and Emilio Perucca as past president. In addition, Jean Gotman will serve as strategic advisor.

### The New Working Groups – the engine of the ILAE

Although the new leadership team is not officially installed until September 2017, it is already hard at work assembling the new Commissions and Task Forces that will carry out the vision and goals for this term. To assemble these groups, I have consulted widely with individual Chapter Presidents and epilepsy leaders from around the world. The core leadership of as many as 25 new Commissions and Task Forces is now in place. These will eventually comprise about 400 top epilepsy professionals who will be the engine that propels us toward our goals by carrying out specific tasks and projects. The work to be accomplished in the first 100 days of this leadership team is well on its way.

### A Steadfast Course Toward our Aims

Our five global aims will be 1) to improve access to care, 2) create new knowledge, 3) translate knowledge into clinical care through education, 4) ensure financial sustainability and growth of the organization, and 5) increase collaborations. To achieve these goals we need to strengthen the core undertakings of the League through commissions such as diagnostics, medical and surgical therapy, paediatrics, psychiatry, neurobiology, epidemiology and genetics. In addition we need to develop and grow in new areas, such as guideline development, new education strategies, data sharing and big data models, addressing nosology and definitions in epilepsy, improving the standards of scientific research in epilepsy, developing leaders, engaging the next generation of epileptologists, and liaising with other international organizations. We also need to support the work of the teams that are responsible for the more pragmatic aspects of the League through committees such as finance, budget review, congress organization, publications, communication and administration. Finally, we must continually strive to improve the quality and service provided by our three main journals, *Epilepsia*, *Epilepsia Open*, and *Epileptic Disorders*,

and our nascent initiative in Wikipedia-Epilepsy.

### The League's Finances are in Good Order

During my current term as treasurer we have been fortunate to develop a strong financial base for the ILAE. This has been due in part to a strong performance of the financial market. But most importantly, to the adoption of fiscally responsible policies and sound business decisions with regard to our journals and investments. We have to thank our excellent team of finance advisors for their guidance and for embracing the mission of the League with such dedication. What this means for the new term is an outlook of cautious optimism. Our healthy financial situation will allow us to consider new possibilities for development, more effective work, and better education and care for people with epilepsy around the world.

### We Need to Hear from You!

As we ponder how to best serve our constituency and our community, we are keenly aware that we need to hear your voice. We need to hear from you directly so we can direct our efforts and support where they are needed. For example, we are prepared to look at how we support educational activities and to modify them according to our constituency's needs. Accordingly, we plan to launch a wide ranging consultation campaign to learn what aspects of our congresses, education, and publication we need to modify or strengthen to serve you better.

### There is Much to be Done – and we are Ready

I look to the tasks ahead with eager anticipation, but also with a good dose of realism. Achieving our goals will require energy and dedication, but especially collaboration and transparency. New ideas and new approaches are welcome. Making those new ideas a reality will require our collective effort. The new leadership team is energized and ready, and I look forward with excitement to the next four years.

# President-Elect, IBE

*Martin Brodie, President-Elect, IBE*

I am greatly honoured to have been elected as the next president of the IBE. My four year term begins at the General Assembly during the 32nd International Epilepsy Congress in Barcelona. Over the coming years I intend to respond to this responsibility by further developing IBE as a sustainable, proactive, forward thinking organization that is increasingly recognized as the voice of people with epilepsy and their care givers around the world. I believe that my training and experience in both the medical and social aspects of epilepsy have placed me in an excellent position to undertake this remit.

First something about myself! I've been caring for people with epilepsy since I set up my clinical and research services in 1982. In those days, we knew little and medical and social care for affected individuals was still rudimentary. I first became involved with epilepsy at an international level when I hosted the inaugural European epilepsy congress in 1992 in my home town of Glasgow in Scotland. I was subsequently appointed secretary and then chair of the European Commission of the ILAE from 1993 until 2001, during which time I helped establish the biennial European scientific meetings. From 2001 to 2005, I served as vice president of ILAE and was given the role of working on other regional agendas and setting up their congresses. Between 2005 and 2009, I became treasurer of ILAE and also sat on the IBE executive committee.

There is an old Gaelic adage that says 'praise youth and it will follow you'. While there is no doubt a great deal of truth in that saying, we must do more for young people with epilepsy if we are to help them grow and develop to their full potential. Not only must we recognise and laud their talents, efforts and abilities in life, but we must also encourage them to evolve into our future leaders, with sufficient confidence and knowledge to perhaps one day contribute to IBE's global agenda.

Throughout my career, I have always had a great interest in improving the lives of people with epilepsy and I recognized, in particular, the significant everyday problems faced by teenagers. Consequently, some colleagues and I set up the charity, Scottish Epilepsy Initiative (SEI), in 2003, whose major project is the TEA (Teenage Epilepsy Agenda) Room, a safe website for teenagers with epilepsy to talk among themselves and to share life experiences. Although initiated in 2010, the platform has recently been restructured and is attracting youngsters from around the world (<http://www.thetearoom.org.uk>). Discussions are by no means limited to health issues, but include a wide range of topics from sitting for a driving test to going to a



*Martin Brodie*

concert. This gives teenagers with epilepsy the chance of enjoying everyday conversations with supportive peers. My plan now is to extend our remit by providing education and training opportunities for the young users of our website worldwide, hopefully under the auspices of the IBE. All money raised in an individual country by an IBE chapter will be spent in that country. SEI will cover all the running costs of the project and all profits will go to the IBE.

In parallel with this initiative, I plan to expand our youth engagement across the regions. The initial template will follow that of the successful North American Youth Summit, which took place in 2015 in the USA. I believe that we can roll out this type of initiative in other parts of the world with equally positive results. This programme will be linked with the TEA room fundraising, education and training agenda.

A number of new IBE commissions are currently being set up. They will play an important role in focusing on particular areas of interest and will report back to the IBE executive on aspects of their work that we can roll out regionally and modify appropriately to meet the constantly evolving epilepsy climate. Each of these commissions will have ILAE representation.

The Research Commission, which will be chaired by Kheng-Seang Lim from Malaysia, will focus on psychosocial issues. The remit of all commissions will be drafted by its members, who will consider its aims and objectives and develop an action plan. I believe that there is the potential for synergy between the IBE Research Commission and ILAE's Advocacy for Research Taskforce, which I have been invited to join – an invitation I was pleased to accept.

With technology evolving at an ever-growing speed, telemedicine is now becoming a regular way of communicating on health and medicine, particularly in regions that are sparsely populated or difficult to reach. The care provided using modern communication technologies is both far reaching and broad in its range and includes not only medical diagnosis and treatment, but also more relevant to IBE's agenda, with the provision of support and information from social workers and other care-givers. Our Telemedicine Commission will be chaired by Najib Kissani from Morocco, who, together with a number of colleagues, will identify its direction and remit across the IBE regions.

The IBE Education Commission will be chaired by Margarete Pfäfflin from Germany, who has a vast and enviable expertise in education. As with the other commissions, I am planning a broad brush across the topic, but would like to see our IBE team look at all professional and lay aspects of epilepsy education. Specialist nursing is one area that could be further explored in different parts of the world. This initiative has been widely available in the UK for many years. Membership of the Education Commission will also be global so that we encompass programmes in all regions that have IBE representation, being mindful too of the issues that are specifically pertinent to each geographical area.

I look forward to continuing the close relationship that has been built up between IBE and ILAE and supporting the various programmes in which the two organizations will work jointly. These include the Taskforces on Global Outreach and the important World Health Assembly Resolution on Epilepsy, which will be updated by the WHO in Geneva next year. We will also continue to combine our efforts in the Epilepsy Alliance Europe and, of course, in our increasingly influential regional and international congresses.

There is much work to be done over the coming four years of my presidency if we are to modernise IBE's agenda with a proactive programme of effective initiatives. As a proud Scotsman, I echo the words of the great poet Robert Burns, I will 'dare to be honest and fear no labour.' My goal is to involve as many people as possible in helping to devise and contribute to our prospectus. I plan to invite every chapter and regional commission to provide suggestions for projects, fundraising initiatives and strategies relevant to their country and region. IBE must work hard to provide better support to assist its members in achieving their goals

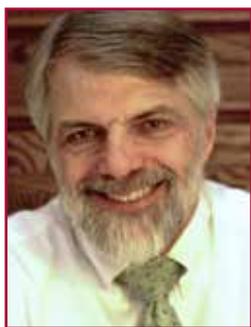
IBE must also play an active role in networking with other NGOs pursuing similar aims. As part of this exercise, greater effort will be made to support the agenda of the Global Campaign Against Epilepsy, particularly in resource poor countries. We will do our best to fight stigma and discrimination, wherever it appears around the world. No man is an island and I will be relying on the support of our international executive committee, particularly our new secretary-general, Mary Secco from Canada, and treasurer, Anthony Zimba from Zambia, together with our recently elected regional vice presidents and their teams, to help deliver services of the highest quality to our chapters.

Little can be done without money and I plan to appoint a finance committee to develop a global fundraising strategy aimed at raising an initial target amount of \$20 million. I hope that this project will develop its own momentum, not just over my 4-year term but for many years to come. In his poem Tam O'Shanter, Burns wrote that 'Nae man can tether time or tide' and I realise my four year term will pass all too quickly. I hope however, that when I step down in 2021, IBE will be in a healthier position, not only financially but also in terms of its range of programmes and activities. I'm looking forward very much to the challenges ahead!

# From the Secretary-General-Elect

*Edward Bertram, Secretary-General-Elect*

The ILAE was originally a forum for members from a handful of countries for discussing the treatment of epilepsy. Over the last century it has turned into an organization of over 110 chapters with a combined membership of more than 14,000 professionals. It started



*Edward Bertram*

out as a home for academic clinicians struggling with the issues of care in a world with limited treatment and diagnostic options, but since the founding of the ILAE, research has brought us undreamed of diagnostic and treatment options. The membership has shifted from predominantly clinical epileptologists to a much larger family of professionals with interests in neurophysiology, imaging, genetics, neurobiology, pharmacology and psychiatry among many others. Still, the goal is improved care of the patient, which most commonly takes place at locations quite removed, physically and psychologically, from the academic interests that predominate the League's activities and focus.

In the last twenty years the League and its partner the International Bureau for Epilepsy have become more focused on the issue of improved care delivery at the community level, where, in many cases, no care exists. The issues of poor access to medications, stigma and lack of knowledge about epilepsy have affected the majority of people with epilepsy across the world. Although these issues have been recognized for many years, the solution is complex, and involves economic, legal and social approaches. Providing better treatment has also been complicated by the more general belief that epilepsy, in terms of public health, is an unimportant disease. It is in this environment of a global lack of concern about the needs of people with epilepsy that the ILAE and the IBE developed the Global Campaign which has had as its goals increasing the visibility of epilepsy and the resources allotted to treat it while at the same time eliminating the prejudice against epilepsy and the people who suffer from it.

There have been a number of successes in the last two decades. There has been a growing recognition that epilepsy is a disease whose sufferers have unique needs such as uninterrupted access to medication and health care providers who know something about the disease. Most systems have been unable to support even the most basic resources. Several of our chapters, such as Colombia and Argentina, took the initiative to establish access to knowledgeable care a legal right. In Colombia, this policy was encoded in the national constitution after a multiple year effort on the part of several very dedicated individuals. In many cultures, the terms used

for epilepsy are derogatory and often suggest madness or an association with the dark side of the supernatural. The very name of the disease can place the person in a negative light. South Korea addressed this problem at its source. The written characters used for epilepsy translated to "mad pig." To eliminate this linguistically imposed negative image of epilepsy our South Korean colleagues worked to change the words that identified epilepsy from mad pig to electrocerebral disorder, a term that improves the image of epilepsy from a form of madness to one of abnormal electrical activity. In China, the demonstration project that involved the ILAE, the IBE, the WHO and the Chinese Association Against Epilepsy found that people with epilepsy in several provinces either had unrecognized epilepsy or had epilepsy that was not treated. Getting treatment to these people significantly improved quality of life and economic well being. These successes show us that a focused effort by the epilepsy community can have a major benefit.

The joint efforts by the League and the Bureau with its chapters have made several key steps in raising the awareness about epilepsy and the many unique unmet needs of people who have the disease. In the last 6 years, several major epilepsy agreements and publications from major international organizations have appeared. The Pan American Health Organization, the European Parliament and the World Health Assembly all passed resolutions in support of the special needs of people with epilepsy. The Institute of Medicine in the United States published a study outlining the many obstacles to appropriate care that are faced by people with epilepsy. These are important documents that confirm what we have known for years: epilepsy is a disease with needs that are largely unaddressed. However, these publications and agreements are just documents. The epilepsy community must bring these documents to life and develop a clear set of priorities. The authorities need direction on how to address the issues, direction that only our community can provide.

In this issue of Epigraph there are articles from members of the Executive Committee of the League, including the presidents (outgoing and incoming) of the ILAE and IBE that address the most pressing needs for the epilepsy community. Across the regions there are several common issues. The first is a general lack of knowledge about epilepsy, its causes and treatments. This knowledge gap is shared by patients and professionals alike. In much of the world epilepsy is still viewed as a spiritual disease by patients, families and the local healers. For this reason, they often do not know about or seek treatments that are considered standard by the medical community. Similarly, most training programs for medical professionals provide little if any education about epilepsy. As a result, patients understand little about the disease and most physicians know little about its diagnosis and treatment. Improving knowledge about epilepsy is a key goal for the League and Bureau, as it will help patients find the treatment they need.

The second major issue is access to therapy. In many countries the treatment gap is estimated as high as 80% for the number of people with epilepsy that receive no regular treatment. There are many reasons for this gap. One of the primary reasons is the absence of medications. In many parts of the world any medication is simply unavailable, or, available only intermittently. For many patients, the medications might be available but getting to a pharmacy requires an all day effort that is beyond the physical or financial means of the patient. Another reason for the treatment gap is the understanding among the population about the causes of epilepsy: it is widely believed in many cultures that epilepsy has a spiritual cause. As a consequence people affected by seizures seek a spiritual solution and have no faith that modern pharmacotherapy will have any benefit. In some cultures in which there are many prejudices against people with epilepsy, patients do not seek treatment, because they do not wish to be found by others to have the disease. Limited use of effective treatments therefore has economic as well as cultural causes, and our efforts to improve access will have to address all of the causes.

The third major issue that limits quality of life for people with epilepsy is the cultural prejudice and legal restrictions that have been present, in some cases, for centuries. These limitations have prevented people with epilepsy from leading normal lives by creating barriers to employment, education and marriage. These prejudices have marginalized epilepsy as a health care priority. As noted above, a number of our chapters as well as the League and IBE, have worked in the last decades to remove these restrictions and cultural prejudices. In some countries people are seeing an improvement in the ability to deliver appropriate care as a consequence of these new laws. This effort will continue.

In the next four years we won't solve all of the social, economic, medical and legal issues that limit the quality of life for people with epilepsy. However, the combined efforts of the epilepsy community at multiple levels can have an important impact. Each country has its own unique issues, and the League and the Bureau cannot address each local problem. We can be effective by supporting educational efforts for health care professionals and by advocating for epilepsy with health care authorities so that epilepsy's priority as an unmet public health need rises. This effort will require a greater interaction between the League, its chapter members and our partners in the IBE. I look forward to these discussions and developing plans to achieve our goal of a world in which no one's life is limited by epilepsy.

# From the Treasurer-Elect - Toward the Next Four Years

*J Helen Cross, Treasurer-Elect*

It is of course a great honour to have had the confidence of the community to have been re-elected to the management committee for the term 2017-2021, and particularly to serve as your treasurer. Over the past four years with care and attention to expenses, performance of our investments, and the continued success of the congresses and journals, we are happy as an organisation to be in relatively good shape with regard to our reserves. Our challenge as we enter the next term is to utilise the appropriate finances to serve the community, and to fulfil our mission; to ensure that all individuals world-wide have the educational and research resources that are essential



*J Helen Cross*

in understanding, diagnosing and treating persons with epilepsy whilst being aware of the fickle financial climate.

As we enter the next term we plan to regularly review our financial status and decide whether spending policies are warranted. Ultimately we need to listen to you, our community, and take into account your needs within the plan of resource allocation. However, we will continue to have clear accountability for expenditure with governance through the Executive and Finance Committees. Over the last term we have been fortunate to benefit from a fantastic team of financial advisors who will continue to work with us. We also acknowledge the work of the budget review committee, who have regularly reviewed allocation of resources to our Task Forces and Commissions, and whose role will be enhanced over this coming term. However we need to think beyond the governance of our existing finances, and look not only how we optimise use of our funds, but also how we may generate further monies through fundraising and collaboration with other organisations.

As a community, we look toward to the next four years with the commitment of individuals to new Commissions and Task Forces, and renewed enthusiasm for how we can make a difference. There is of course the expectation this will result in project proposals and budget requests. We still need to think creatively as to how we may utilise our resources, whilst retaining a buffer by which we can continue our operations for an extensive time in the future if our revenue sources were to decrease. However, we are aware of the educational needs worldwide as well as research gaps that remain, with education very much on our agenda acknowledging the differing requirements across cultures and communities. We need to commit resources appropriately to achieve our agenda in these areas. We can only do this through continuing to work as a team, transparency to decisions, collaborative working with other organisations, as well as integrated working across all areas of the community.

## Vice-President-Elect

*Alla Guekht, Vice-President-Elect*

I feel honored to be elected to serve in the Executive Committee of ILAE in 2017-2021 as the Vice-President. The accomplishments of the League for more than 100 years are tremendous; the great role of the ILAE as the leading multidisciplinary and multinational society of physicians and health professionals in all domains of epilepsy is well recognized.



*Alla Guekht*

resources to epilepsy research as an historic day in the fight against epilepsy. We wish to acknowledge the dedicated members of the current and past executives, chapters and associations who have worked tirelessly to improve the lives of people with epilepsy through their involvement with the ILAE, IBE and the WHO. The joint efforts of thousands of people all over the world, coordinated by the ILAE and IBE Presidents, were highly successful. Collectively their voice was recognized on May 26th, 2015 with the passing of an epilepsy resolution at the 68th World Health Assembly.

Following to the great success of the Resolution, we need to strive forward to ensure that the Resolution translates into effective actions, in particular:

- It is essential to continue and expand the key partnerships between the WHO, ILAE and IBE that was the prerequisite of the Resolution success.
- We need to build upon the global support of the Resolution and to engage the countries, which already expressed their commitment, to make the financial, human and other resources available for the improvement access to care, reducing stigma and increase funding for epilepsy research.
- It is important to strengthen the collaboration with the WFN, EAN and other professional organizations in neurology, psychiatry, pediatrics, and neurophysiology that will contribute to the improvement of care and raising awareness about epilepsy
- There is a need for the appropriate assessment of magnitude of the medical, social and economic burden of epilepsy to keep and further expand its role on the global agenda.
- It is strategically important to concentrate our collaborative efforts in joining WHO in the preparation on the Global Report on epilepsy

Our President-Elect, Professor Sam Wiebe, postulated five priority areas for the next term: Improving Access to Care, Knowledge Creation, Knowledge Translation and Education, Financial sustainability and growth, and Expanding boundaries.

According to the strategy outlined by the President-elect, the following directions should be prioritized: to address the treatment gap, promote epilepsy care, secure funding for research, foster education, and continue advocacy initiatives for people with epilepsy. Effective strategies to improve investment in epilepsy research and increase research capacity should be further developed. Epilepsy prevention, with the focus on unmet needs for evidence-based interventions targeting the epileptogenic processes, should be one of the key domains. More of ILAE's resources should be diverted to education (with implementation of new technologies) and outreach.

There are many challenges that face epilepsy care and research all over the world. It is essential to develop and strengthen solid international collaborations in education and research, enrich the teamwork with greater participation of all the ILAE Chapters, identifying priorities and needs at the global and regional levels and implementing successful initiatives. My commitment to the ILAE is long standing; I sincerely thank all the ILAE chapters that contributed to my election and I am inspired to work towards the world where no person's life is limited by epilepsy.

Alla Guekht, MD, PhD  
ILAE Vice-President –elect  
Professor of Neurology, Russian National Research Medical University  
Director, Moscow Research and Clinical Center for Neuropsychiatry

There were many outstanding achievements in the strategic activities of the League in the recent years. The fundamental progress in the domains of the definition and classification of epilepsy has been made. The concepts, definition, and classification of status epilepticus has been revised and the new conceptual definition of status epilepticus was proposed. The unprecedented development of the International Congress of Epileptology and the Regional Congresses in terms of scientific content, educational activities has been observed.

The historical event in the fight against epilepsy was marked by the unanimous approval of the World Health Assembly Resolution on the "Global Burden of Epilepsy and the Need for Coordinated Action at the Country Level to Address its Health, Social and Public Knowledge Implications". I have been privileged to be a part of the team working on the 68th Resolution of the World Health Assembly, which urges Member States to implement a coordinated action to address the health, social and public knowledge implications of epilepsy. The Resolution provides ILAE chapters with a powerful tool to engage governments into taking concrete action to improve epilepsy care, promote public awareness and allocate

# Epilepsy Care in Africa: Challenges and Suggestions for the Way Forward.

Angelina Kakooza-Mwesige<sup>1</sup>, Chair, Commission on African Affairs

In Africa, it is estimated that epilepsy accounts for about 0.26% of the total burden of disease as measured by the sum of life years lost due to premature death and disability (1). Africa bears the brunt of carrying the burden of the highest incidence and prevalence of active epilepsy compared to that of all other continents, with prevalence being highest in the rural areas compared to the urban areas (2) with variation in the different African regions due to the rich diversity of risk factors prevailing on the continent (3). On the whole, the risk factors for active convulsive epilepsy in children are more correlated to events occurring during the antenatal and perinatal periods, while those in the adults are linked to the presence of parasitic infections such as *Onchocerca volvulus*, *Taenia solium*, and *Toxoplasma gondii* (3). There is thus a potential likelihood of reducing the prevalence of epilepsy in SAA if the adverse perinatal complications are well managed through improved services in emergency obstetric and post-natal care, coupled with prompt treatment of the parasitic infestations (4).

Despite having a high epilepsy prevalence, the majority of people with epilepsy (PWE) in sub-Saharan Africa (SSA) do not receive appropriate treatment for their disease resulting in a high Epilepsy Treatment Gap (ETG), currently estimated at 80% (5). Epileptic seizures can be controlled successfully in about 70% of PWE using relatively inexpensive antiepileptic drugs (AEDs)(6). Notably, the ETG is greater in children compared to adults(5), which raises an important issue regarding the crucial need to rectify this disparity since complications such as convulsive status epilepticus commonly observed in children have grave consequences on the developing brain affecting their



Angelina Kakooza-Mwesige

chance of achieving their full developmental trajectory (7) and negatively impacting their health related quality of life (8). Irrespective of the reasons for this large ETG in SSA, there is need to urgently address this daunting challenge by clearly understanding the factors underlying treatment seeking in PWE, so as to develop and implement culturally appropriate interventions that can reduce its magnitude in SSA. In addition, efforts to explore ways of ensuring an uninterrupted supply of AED supply, committed involvement of the parents/caregivers in the supervision of the AED administration in their children and clinicians insuring that maximum tolerated and effective AED doses are prescribed, should be encouraged.

The dawn of the human immunodeficiency virus (HIV) infection being highly prevalent across SSA where an

and phenytoin) which have major interactions with antiretroviral therapy (ARV) (10). As the use of ARVs continues to escalate with the continual revision of the HIV/AIDS care guidelines and increasingly chronic nature of HIV/AIDS, there is need to study other feasible first-line AED-ARV combinations for use in SSA where second- or third-line AEDs may not be that readily available for the majority of the PWE.

The majority of PWE in SSA dwell in the rural areas with unevenly distributed health-care systems and limited resources for diagnosis and treatment. This scenario necessitates them time and again to travel vast distances to seek specialized epilepsy care from urban health-care facilities where the cost of the required medications and available investigations is often very prohibitive. Ironically,



Interviewing a caregiver about the care of their children.

estimated 25.5 million persons of all ages are living with HIV, further complicates the medical care of PWE (9). Most of the AEDs used in SSA are the older generation enzyme inducing drugs (phenobarbital, carbamazepine,

in the government units where these services may be obtained at no cost, most investigative facilities are often out of service, with frequently stock out of AEDs(11).

Furthermore, there is a lack of established standardized treatment guidelines for epilepsy and problematic or non-existent referral systems in many countries in SSA. The basic infrastructure for the supportive investigative tests like electroencephalography (EEG) and/or video electroencephalography (telemetry) is limited. Access to neuroimaging tests like, Computerized Tomography (CT) scanning, or Magnetic Resonance Imaging (MRI) may be offered in a few African countries but are not accessible for the majority due to the prohibitive costs. More advanced tests, for example, positron emission tomography valuable in localizing ictal foci, especially for the identification of potential candidates for surgery are rarely available. This situation implies that many PWE may remain undiagnosed or poorly managed due to the constrained diagnostic facilities at the health units. Worthy of note however, is despite the limited facilities in SSA to screen for possible candidates for surgery or perform surgical interventions, the advent of telemedicine has shown promising results (12).



A qualitative group discussion with caregivers to get their thoughts on health conditions afflicting their children.

(Continued on page 9)

Added to the infrastructure challenge are the restrictions in the number, availability and allocation of skilled health professionals trained to take care of PWE, such as neurologists, general practitioners, physicians, and epileptologists who are mainly concentrated in the urban areas. It is important that alternative, cost effective measures are developed to improve the access to care of PWE at the community level. Training of health workers with lower qualifications (e.g. nurses, community health workers, social workers) in epilepsy care and regularly updating them about recent advances in its management as well as the strategies to ensure adherence and follow-up care, would enable PWE to be managed at primary or secondary level care facilities. Each country is faced with its own peculiar challenges that have to be dealt with in-country, so the training should be advanced by Africans to ensure that the training is pertinent to the health care needs of the region.

By delegating and sharing health-care tasks with the lower qualified health staff (whose numbers are more than the skilled health professionals), means that only the very few with difficult-to-control epilepsies will be referred for specialist care at the tertiary epilepsy care facilities. There have been success stories registered with such efforts in dealing with mental health gaps in some low resource settings (13). In addition, technological innovations such as the mobile phone service which is popular in many African communities, may serve to improve access to epilepsy care by setting it up to provide patient reminders for medicine refills, appointments for specialist review or for the caregivers to record video clips of the seizure event at home and bring to the clinic for review (14).

In SSA, traditional healers (THs) have the advantage of being more accessible than biomedical health workers since they are found within the community (15), and it is estimated that there are 5 THs to 1,000 of the general population (16). PWE seek treatment from THs who play a prominent role in their care, being seen to offer a more holistic approach in line with their values and culture and often serving as the first point of contact in managing their disease (17). Regrettably, the majority of these THs are not conversant about epilepsy care, believing that supernatural events play a major causative role in most seizures. Secondly, for fear of being ridiculed and other private reasons, a number of PWE do not disclose to the biomedical practitioner that they are receiving traditional medicines (18). Such a scenario is potentially hazardous since the drug interactions of the AEDs with the active ingredients in the traditional herbal concoctions may prove fatal (19). Nevertheless, despite the controversial way that THs manage PWE, we need to recognize that they play a central role in epilepsy care in most health-care settings in SSA (20, 21). Therefore, in planning any medical interventions for PWE in SSA, it is important to appreciate the role THs play, dialogue with them and work out ways for possible cooperation.

Low community awareness and self-denial regarding a diagnosis of epilepsy is rife in SSA, and this is coupled with the tremendous associated stigma (22, 23), often arising from the way that epilepsy is viewed as being contagious and resulting from a curse, punishment for sins, or demonic possession (24). From the biomedical standpoint, epilepsy

is viewed in many African countries as a mental illness that requires psychiatric care which further compounds the stigma (25). These public misperceptions drive the stigma regarding epilepsy and contribute to increasing the social disability, which makes PWE less likely to be employed, get married or earn a living (23).

Raising epilepsy awareness through public education programs based on the information from qualitative and quantitative studies conducted to identify the causes of stigma basing on the social and cultural conditions in each region are recommended (23). Community intervention programs utilising education, communication, and social marketing avenues to achieve these aims have shown some success and should be created and grounded on the local perceptions of epilepsy and the community's needs (26-28). Efforts to integrate epilepsy care into existing health services, particularly mental health, may be another feasible option that could enable earlier intervention of PWE by having a more precise assessment. To ensure that these educational and care programs are sustainable, there is need for joint co-funding from the PWE with governmental and non-governmental partners (29).

Addressing the disease of epilepsy in SSA is of utmost importance due to the potential impact that can be created by the development of a comprehensive epilepsy care model for PWE that entails the implementation of a number of these feasible interventions that have been discussed.

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# Commission on Asian and Oceanian Affairs

*Akio Ikeda, Chair*

It is my great honor that I was elected as the next Chair of Commission on Asian and Oceanian Affairs (CAOA) between 2017-2021, and I am very pleased to thank all of the delegates in all the chapters in the CAO.



*Akio Ikeda*

CAOA consists of 20 chapters from East Asia, South East Asia, South Asia and Oceania region. As opposed to the other 5 regional commissions of ILAE, it is a heterogeneous region in many ways such as religions, economic status, geography and medical care systems. In spite of this great variability, the CAO in the last decades contributed to the cause of epilepsy in the region tremendously in a number of areas by the excellent leadership of chairs of CAO. These efforts include 1) EEG and epilepsy teaching by the Asian Epilepsy Academy (ASEPA), 2) intra-regional communication by means of the biannual Asian and Oceanian Epilepsy Congress (AOEC), 3) scholarships provided by several countries to the whole Asian area, 4) supporting quality care through the clinical competence endorsement system by means of ASEPA EEG Board System, 5) furthering the goals Global Campaign Against Epilepsy especially for stigma of epilepsy.

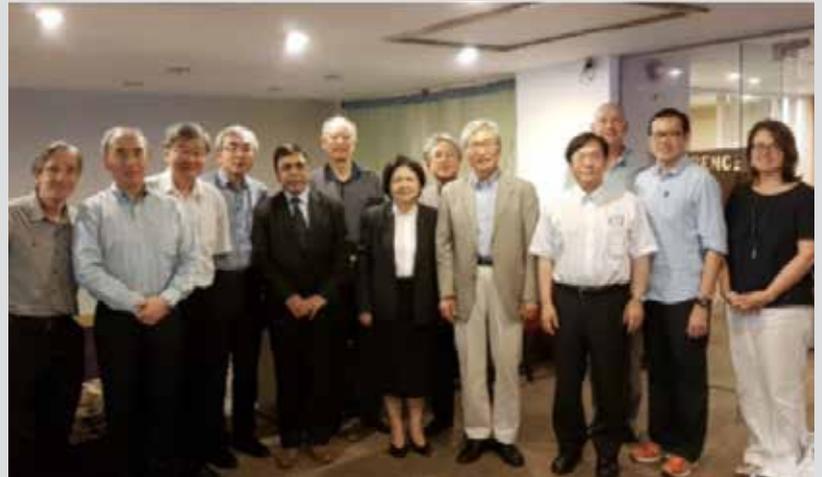
Among them, one of the most important and successful matters is the continuous teaching throughout the region, especially in the areas where specialized care for epilepsy is very limited. One of the most important steps in improving quality of care was the creation of the EEG certification system by ASEPA introduced by Prof. Seino and Prof. Lim. It started in 2006, and currently the certified delegates as

well as medical staff are in almost all the chapters in the CAO. Those teaching systems already established in CAO are a really important property, and continuous teaching will provide all delegates with the best opportunity to improve current unsolved problems by improving skills and knowledge of patient care, EEG reading and other clinical techniques, improving understanding of the epilepsy to combat the old stigma of epilepsy. Regional programs provide updated information of the newer drugs and the latest advances in social care against burden of epilepsy. Teaching also creates the new generation of medical professionals for all chapters, and provides the better understanding of the translatability between clinical practice and basic science of epilepsy.

Because of the vast geographical diversity within CAO, information technology such as remote digital EEG reading systems and other various types of remote medicine such as web-seminar would help and at least

complement face-to-face discussion and teaching. We are having the 12th AOEC at Bali in 21 – 24 June 2018, and the 33rd International Epilepsy Congress at Bangkok in 2019. Both of those largest, face-to-face meetings will facilitate and augment all of the ongoing activities in the CAO. It is very consistent with five priority areas presented by Prof. Samuel Wiebe, President-Elect, ILAE, 1) improving access to care, 2) knowledge creation, 3) knowledge translation and education, 4) financial sustainability and growth, 5) expanding boundaries.

The world of epilepsy is getting smaller and smaller, but the inner-space in the field of epilepsy is still vastly large. For the coming four years, I am very proud to say that CAO will conduct continuous teaching which will potentially open new windows for many areas. By adopting the latest information technology, we could make the geographical diversity much smaller. I greatly appreciate your help from CAO as well other regional commissions.



*A picture taken at CAO commission meeting held in June 8, 2017 at HCMC, Vietnam.*

# Commission on Eastern Mediterranean Affairs

*Chahnez Charfi Triki, Chair*

The Eastern Mediterranean Regional Commission (CEMA) of the ILAE was launched in 2004 and includes 12 countries from North Africa, Asia and the eastern end of the Mediterranean region. The total population of the region's countries is about 265 million



*Chahnez Charfi Triki*

composed of a diverse and varied population with a wide range of demographic profiles and incomes. In spite of the fact that this region includes populous countries, there are no epidemiological data which can provide understanding

about the incidence, prevalence and potential risk factors for epilepsy which can be used to assist in planning health services for people with epilepsy. The few studies conducted had heterogeneous methodologies which makes it difficult to compare results. These studies have determined that about 1.43 million people have been diagnosed with epilepsy at some time in their lives in this region, but only 56.0% of them require active therapeutic interventions for their epilepsy. These data lead us to consider that epidemiologic studies are a priority for our region.

In the last EMRO regional report, epilepsy is among the three most frequently encountered neurological disorders in primary health care settings in 20 of the 22 countries of the Eastern Mediterranean region. These data prompt us to consider that the epilepsy training of primary healthcare professionals as a necessity for our region especially since the number of neurologists is still insufficient. Indeed, the

number of neurologists varies from 1.2/100.000 in Qatar to 2.3/100.000 in Lebanon. This ratio is quite low when compared to other countries. Also, the number of people who have a special interest of epilepsy is unknown, and the majority of neurologists practice a general neurology. To increase the number of epileptologists in our region, several specific epilepsy teaching courses have been organized in several countries including Tunisia, Egypt and United Arab Emirates. These courses were organized in collaboration with many partners such as International Child Neurology Association (ICNA), World Federation of Neurology (WFN), Pan-African Association of Neurological Sciences (PAANS), Pan-Arab Union of Neurological Societies (PAUNS), as well as neurology subspecialty societies. Since the founding of the commission there have been four regional congresses – Luxor (2004, 2017), Dubai (2010, 2015) – and national annual meetings were held and were well

*(Continued on page 11)*



CEMA-CPE4



CEMA-épileptique et alors.

attended. The Epileptology certification program was started in 2000, in the medical school of Sfax (Tunisia) to improve the management of patients with epilepsy. This masters degree is dedicated for medical doctors who have a special interest for epilepsy and since 2005 it has become an elearning course (<http://www.uemv.net/campus-pu/>). The course lasts two years with 30 applicants per year. In addition to Tunisian neurologists, pediatricians, psychiatrists and some general practitioners, this course in French has trained neurologists and pediatricians from Algeria, Morocco and Sénégal. An epilepsy fellowship

program for young neurologists is currently present in Saudi Arabia, and more effort in order to set up a fellowship program in each country is necessary.

Despite the efforts of recent years, research in epileptology is still not very developed in our region and needs to be improved. Apart from some studies mainly on the genetics of epilepsy, the other aspects of epilepsy are little studied. Well-designed studies and multicentric studies on clinical, social, psychological aspects on a large scale and in the different countries of the region are a priority.

The person with epilepsy must also remain at the center of our preoccupations. In collaboration with the Eastern Mediterranean Regional committee of the IBE, a training and education program for people with epilepsy and nurses has been in place for some years in some countries This program should be strengthened and extended to all the countries of the Commission.

The Commission should also have the task of setting up a regional strategy and plan of action on epilepsy taking into account the specificities of each country and in accordance with the WHO Resolution on Epilepsy.

## Commission on European Affairs

*Eugen Trinkka, Chair*

The Commission on European Affairs of the International League against Epilepsy (ILAE-CEA) started in 1993 and now represents 46 chapters in 53 countries. The European Region embraces nearly 900 Million people in an area from the Arctic Ocean in the North to the Mediterranean Sea



*Eugen Trinkka*

in the South and from the Atlantic Ocean in the West to the Pacific Ocean in the East (Figure 1). The CEA supports all chapters in the region in developing their own policies, epilepsy programs and in advocating for improved public health activities, as well as setting research priorities.

The work of the CEA together with the ILAE and the International Bureau for Epilepsy (IBE) in the last 10 years has been a true success story. At first, the CEA started a comprehensive educational program and put forward an educational agenda for the next 10 years. Within these core courses several hundred young epileptologists have been trained. Furthermore, a collaboration of the CEA with the San Servolo Summer School in Venice has created a strong link with basic scientists. In 2009 a position paper setting out the research priorities in Europe was

published in *Epilepsia* (Baulac and Pitkänen, 50: 571–583). A joint taskforce involving the ILAE, CEA, IBE/EREC under the name Epilepsy Advocacy Europe has worked to bring epilepsy higher up in the political agenda of the European Union. Thanks to their work and the joint effort of all members, the EU – Declaration on Epilepsy was signed on the 9th May 2011. In this Declaration the EU acknowledges officially that epilepsy is the most common serious disorder of the brain in Europe and that although up to 70% of people with epilepsy could be seizure-free, 40% of people with epilepsy in Europe do not receive such treatment. The Declaration also acknowledges the difficulties in school and employment faced by people with epilepsy. It also recognizes the problems with stigma and prejudice, and how epilepsy severely reduces quality of life. Furthermore, the European Parliament declared epilepsy as a major disease and called upon the member states to take appropriate actions.

This major step assured epilepsy as a major non-communicable disease on the list for the European



Figure 1: WHO Region of Europe

Research Call FP7, so that research groups could apply for projects with up to 12 Million euros each. In 2014 another EU –activity driven by The Directorate-General for Health and Food Safety (DG SANTE) opened a call for European pilot reference networks for complex diseases, where interdisciplinary management is the key to the success. A group of clinicians and researchers led by Philip Ryvlin and Helen Cross have been selected as a pilot reference network (e-pilepsy group, [www.e-pilepsy.eu](http://www.e-pilepsy.eu)) with the aim to improve access to epilepsy surgery. One year later another major step forward has been achieved by the ILAE when the WHO signed the resolution on epilepsy on the 2nd February 2015, that declared that epilepsies are among

(Continued on page 12)

the most disabling and stigmatizing diseases globally and that national governments should take actions to improve healthcare, foster research and overcome the treatment gap between resource rich and resource limited countries. One year later the European Union launched the European Reference Networks (ERN) and accepted the reference network on epilepsy (EpiCARE, <https://www.epilepsyallianceeurope.org/programmes/epicare/>) as one of the reference networks in Europe on March 9th 2017 in Vilnius (Figure 2). The pilot ERN e-epilepsy has increased awareness and the availability of epilepsy surgery through the utilization of e-health and network collaboration. At the same time it became clear that there is an absolute need for a clinical network devoted to the rare and complex epilepsies.

EpiCARE will expand on this work to increase availability of specialist diagnostics and health care to the wider group of rare and complex epilepsies, incorporating E-epilepsy as one of several therapeutic networks (Figure 3). This network will shape future clinical care from precise diagnosis to better and eventually personalized treatments. Research driven industry and academia will embark on clinical trials only where high quality networks are functional in order to minimize the risk of failure of a trial due to poor governance and oversight. The major political achievement of the ILAE and the CEA have been made possible by setting up a strong advocacy organization, which started as a Joint Task Force and is now working and acting in a coordinated way as Epilepsy Advocacy Europe task force. It organized a European Forum on Epilepsy Research in Dublin 2013 (ERF2013), which revised the research priorities from 2008. The topics included: (1) epilepsy in the developing brain; (2) novel targets for diagnostics and treatment; (3) what is required for prevention and cure of epilepsy; and (4) epilepsy and comorbidities, with a special focus on aging and mental health. The ERF2013 report outlined how to (1) strengthen epilepsy research, (2) reduce the treatment gap, and (3) reduce the burden and stigma associated with epilepsy (Baulac et al. *Epilepsia* 2015; 56:1687-1695). This Group created a roadmap to reduce burden and stigma, improve access to care and outline research priorities of epilepsy in Europe.

So, there is much to do to help the approximate 6 million people with epilepsy in the European Region. There are large differences in the level of epilepsy care and management across Europe with a significant gap in access to care even in the highest income countries. A recent audit in the UK (NASH) revealed that a Neurologist saw only one third of people with epilepsy in the past year, 62.5% were not seen by any specialist doctor and a neurologist



Figure 2: Members of the EpiCare Network at the inauguration of the European Reference Networks in Vilnius, Lithuania, 2017

saw only 4.4% of patients after a first seizure. This makes clear that even in European countries with facilities for the highest levels of care, access to care is limited. The treatment gap within the European region is huge for EU member and non-member states alike. The European Study on Burden and Cost of Epilepsy will shed light on the health care across the European Union ([www.esbace.eu](http://www.esbace.eu)), but the situation in European countries outside of the EU will remain unknown.

#### What can the CEA affairs do to improve care and research in Europe?

First and foremost, all European organisations and forces must take coordinated action. These organizations include the CEA, the European Regional Executive Committee of the International Bureau of Epilepsy (EREC), Epilepsy Advocacy Europe, European Academy

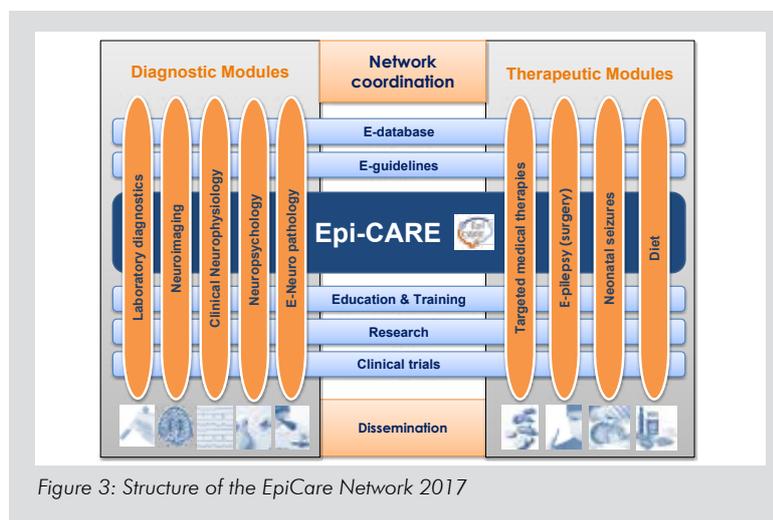


Figure 3: Structure of the EpiCare Network 2017

of Neurology, European Paediatric Neurology Society. Within the EU it is clear to whom the petitions should go, and the ILAE-CEA has already built excellent relationships with bodies of the European Union. One major challenge for the incoming CEA is to improve the dialogue between the epilepsy organisations and the national governments in non-EU countries, especially in the eastern European regions.

Secondly, education has to continue as a high priority. The CEA has always provided education, where it is needed,

but financial constraints have been a limiting factor. Strong efforts have to be undertaken to coordinate the educational activities of the major medical societies (EAN, EPNS and ILAE-CEA) to build up a comprehensive epilepsy curriculum, starting from basic education to advanced epileptology. New financial strategies have to provide a better support for these efforts.

Third, better understanding of the causes of epilepsies have increased the complexity of the clinical work up. Large European Reference Networks, such as the pilot network E-epilepsy and EpiCare are examples of how clinical pathways will be structured in the near future. It is our challenge to prove that these networks can improve care. We hope that these networks will provide a nucleus for larger networks extending outside the European Union. The incoming commission will work to support these networks and create affiliated networks to share the existing knowledge among larger centers.

After the period of successful European funding, first measures for the next steps have already been taken. The opportunity to work on large intercontinental research projects, funded by the major research organisations in Europe, USA and Canada, has the potential for major breakthroughs in antiepileptogenic treatments and cause specific therapies. The ILAE, with its regional commissions in all parts of the world, serves as an ideal organisation to support these global initiatives and eventually realize them by active advocacy.

Last, but not least, the CEA has organised the European Congresses on Epileptology, which is among the most appreciated epilepsy congresses in the world. They have been very successful in terms of scientific and educational content. However the challenge is to keep this high level by expanding educational courses to appeal to a broader audience. These conferences are the major source of income of the CEA which allows us to provide education in low-income countries. We should explore new avenues for financial support and for providing cost-efficient education. These goals can only be achieved when all people of good will keep on working together in the spirit and the

mission of the ILAE. I see the CEA fruitfully working with the other regional commissions. Indeed we should think globally and act locally or, better said, act regionally.

Let me take also the opportunity to sincerely thank all the chapters who took part in the elections, not only for their support, but also for the open communication with them. I will work with all my energy for the next four years to achieve these goals and help to improve the life of people with epilepsy.

# Commission on Latin American Affairs

*Roberto Caraballo, Chair*

Epilepsy is one of the most common chronic neurological disorders. In Latin America, with a current population of 640 million people, more than 5 million people suffer from the disease, posing a significant healthcare burden. It has been estimated that around 50% of the patients with epilepsy receive no treatment at all. Worldwide, mortality among people with epilepsy is two to three times higher than in the general population. In Latin America, the mortality index of people with epilepsy is 1.1 compared to 0.4 in the USA and Canada.



*Roberto Caraballo*

In Latin America, epidemiological and clinical characteristics of epilepsy and the treatment gap, i.e. the difference between the number of people with active epilepsy and the number of patients whose seizures are being appropriately treated, differ greatly by region. This heterogeneity found between and also within countries can be explained by population-specific risk factors and environmental factors. The most common causes of epilepsy in Latin America, especially in the tropical regions, are infectious and parasitic diseases (mainly neurocysticercosis), perinatal brain damage, vascular diseases, and head trauma, which are all preventable. The stigma associated with epilepsy may lead to underestimation of the prevalence of the disease. Typically, the lack of knowledge on the disease leads to prejudice.

Poverty and lack of education are the main problems in Latin America. Not only the general public but even physicians are sometimes unaware of epilepsy. Morbidity and mortality are increased because of the failure to identify cases, difficulties with infrastructure, and the unavailability of adequate antiepileptic drugs. People living in remote rural areas and indigenous communities frequently have limited access to conventional health systems and people with epilepsy often consult traditional healers.

In contrast, in certain areas, especially in large cities such as São Paulo, Mexico City, and Buenos Aires, epilepsy care is comparable to that of major North American and European cities, with access to epilepsy surgery, the ketogenic diet, and vagus nerve stimulation. Unfortunately, referral and counter-referral services are rare.

In Latin America epilepsy is generally not recognized as a public health priority. Budgets for health care are low and resources are scarce. Additionally, there are great differences between public health care and the private sector.

To improve the situation, the first steps to be taken are to identify the specific challenges that are encountered in epilepsy care, mainly based on the wide range of conditions under which epileptologists and other health care professionals in the field work in Latin America.

As systematic studies from Latin America were lacking, in 2008 the PAHO, WHO, ILAE, and IBE made a joint effort to identify the gaps in public knowledge, epilepsy care, and legislation in the region and published the first report on Epilepsy in Latin America and the Caribbean. A second epilepsy report was published in 2013, containing more extensive data on epilepsy care, programs, and services available in 25 of 33 Latin American countries.

A main pillar to achieve integral management of patients with epilepsy is the involvement of national governments through epilepsy laws regulating the care protection of people with epilepsy. Currently, in Colombia and Argentina legislation on epilepsy has been passed, serving as an example for other countries in the region.

Education on epilepsy for persons with epilepsy and their families, the general public, and primary care physicians, as well as neurologists and epilepsy surgeons remains a challenge. Supported by the ILAE, over the past years in the region training courses for relatives of patients with epilepsy and the general populations have been carried out using educational materials to reduce the stigma, discrimination, and social exclusion. Additionally, courses, workshops and pilot programs have

been organized under the supervision and with active participation of specialists from Latin America with a training abroad.

As the region still lacks specialized clinical epileptologists and neurosurgeons specialized in epilepsy surgery in most areas, training of specialists is highly necessary. A training program is in place providing 3 positions (2 for neurology and 1 for neurosurgery) each year. These professionals have the commitment to return to their country of origin and further teach their colleagues.

In Bolivia, a pilot project has been carried out with the opening of a referral center for the diagnosis and management of epilepsy for patients referred through the primary care network. Neurologists, pediatric neurologists, and EEG technicians have been trained in the diagnosis and protocolled management of epilepsy. The aim was to create a health care services network for epilepsy care with emphasis on primary care and provision of AEDs.

An important effort in education is the Latin-American Summer School on Epilepsy (LASSE), a pioneering education program that started its activity in 2007 and in the 11 previous editions has received around 1000 participants from almost all Latin-American countries under the supervision of the ILAE. The LASSE is addressed to young health professionals from throughout Latin America to deepen and update their knowledge on the epilepsies. In this 10-day course, 60-70 young professionals participate in lectures and case discussions. In addition, there is a special program for groups of 5-7 students who, accompanied by a tutor, prepare research projects.

Since 2011, the program of ALADE courses is in place. Generally 3 "migrating courses" are held each year in different places in Latin America. The courses are addressed to pediatric and adult neurologists as well as other professionals working in the field and encompass different topics, such as epileptic syndromes and type of epilepsies, treatment, including surgery, EEG and Video-EEG recordings, and others. The term "migrating" refers to the organization of the courses in different regions so as to facilitate easy accessibility by short travel distances.

In spite of these efforts, much remains to be done in Latin America. Taking into account that the majority of the people with epilepsy may be managed in primary health care, priorities need to be considered in this area. Education of professionals at this level, including online courses, is crucial to identify patients to diminish the gaps. Implementing programs considering their needs is fundamental.

To cover the needs of epilepsy patients, epilepsy services should be integrated in existing programs, such as those of mental health, and accessibility and affordability of safe antiepileptic drugs should be improved.

Often the lack of knowledge on epilepsy has a greater impact on persons with epilepsy than



*Latin America Region*

*(Continued on page 14)*

the disorder itself; therefore, awareness building through education programs in the general public, including key persons such as teachers, police, priests, and others, is crucial to reduce the stigma and false notions about the disease. The strategy of training the trainer programs is a cost-effective option to reach different levels of the society.

Recent developments in telemedicine may provide a solution especially in large countries, offering specialized consultation for patients and hospitals in remote places. However, given the lack of resources and the characteristics of the patients, even in smaller countries telemedicine may be an option, avoiding the need for patients to travel to specialized centers and supporting primary care hospitals that lack resources. In Argentina, a pilot project between a central tertiary pediatric hospital and provinces in the north-west of the country has shown promising results.

Considering the main causes of epilepsy in the region, prevention measures would have to be taken on a national level, involving the national ministries of health.



Latin America Clinic (Argentina)

Although much of the work required should be done at a primary level of health care, it is also important to support ongoing scientific studies and develop new research projects as well as participate in larger worldwide multicentre studies. Therefore, national data registries coordinated by Health Ministries are important for an accurate analysis of the situation and to provide information for research. Complete data facilitates the planning of interventions and evaluation of their impact. As many epilepsies are known to have a genetic component,

the identification of candidate genes is of great importance as it may influence choice of therapies and counselling for the family. Recently, a large multicentre study has been started for the whole exome sequencing to identify potentially pathogenic variants of epileptic encephalopathies in childhood in Latin America.

In conclusion, over the past years in the region the experience with training and pilot programs, workshops, and courses, as well as campaigns to inform the general public has greatly improved. In different countries epilepsy laws have been implemented. Our next challenge is to reach the many areas

in Latin America where adequate care and information is still not provided. Further work on the implementation of a regional strategy and plans involving governments, health-care policy makers, and epilepsy specialists is necessary. Priorities to be defined should be based on the local possibilities, preferably within national programs. National programs will provide the possibility of optimal and integrated management and will guarantee sustaining the goals achieved over time.

## Commission on North American Affairs

*Nathalie Jetté, Chair*

The North American Regional Commission (NAC) of the ILAE has continued to work towards its mission of improving the lives of persons with epilepsy across North America and the Caribbean, but also beyond, through education, advocacy, leadership and research.

Although our region is more homogenous than others as we are made up of fewer countries, disparities in care, stigma and knowledge gaps about epilepsy are still important challenges that affect us.



Nathalie Jetté

During the past term, the NAC has maintained previously successful programs in the region and has embarked on a highly successful multi-national leadership training program for rising stars in the field of epilepsy. Below are highlights of some of our accomplishments and ongoing activities.

### Knowledge Translation and Education Leadership Development Task Force

To achieve its mission, the ILAE needs strong leaders that can start and grow new chapters that engage members; lead global, national and local advocacy efforts; advance research agendas and clinical care for epilepsy patients and recruit young talent to the field. The skills required of these leaders are rarely addressed in graduate and medical training programs. To address this training gap, the North American Commission designed the ILAE Leadership

Scholarship Program under the direction of Drs. Sheryl Haut and Jaideep Kapur.

The first leadership course held in conjunction with the International Epilepsy Congress in Istanbul in September 2015 was a success. A class of 21 impressive participants representing every ILAE region enrolled in the 2-day training program that included a networking lunch with the ILAE Executive Team. There

were sessions on Strategic planning, Financial planning, Scientific communication, Electronic communication, Conflict resolution, How to run an effective meeting, and Personal leadership style among others. Evaluations and feedback from participants and faculty were incredibly positive. The second leadership course will be held in Barcelona in 2017, and the program will be expanded to provide more advanced applied learning and skill building sessions and networking and mentoring opportunities for ILAE's most prominent rising leaders.

### Education Task Force

The NAC (led by Dr. Sheryl Haut) partnered with the American Epilepsy Society (AES) as well as the Latin American Commission to expand epilepsy education across the region and jointly produced a comprehensive teaching slide set of epilepsy for the non-specialist. This material is geared towards general practitioners, general neurologists and pediatric neurologists, nurses, and other health care extenders. It was translated into Spanish by the Latin American Commission for use in the Pan American Health Organization (PAHO) epilepsy initiative.

### Intercommission Educational Outreach

The PECA program led by Dr. Jose Cavazos continued to support partnerships between epilepsy centers in the Americas to promote education and improvements in epilepsy care during this term. More than five programs were established or continued in Costa Rica, Panama, Peru, Ecuador and Mexico. Several of these programs were successful in obtaining funding from external sources to support or supplement these partnerships.

*(Continued on page 15)*



First ILAE leadership course participants, Istanbul, September 2015

A new collaborative global health program is expected to be created in the new term that will expand the scope of this initiative and provide a greater educational component to various regions rather than one-on-one ongoing collaborations to ensure sustainability of these initiatives.

**Improving Access to Care and Reducing Disparities and Stigma Caribbean Task Force**

The Epilepsy Society of the Caribbean (ESC) was ratified as a separate ILAE chapter in 2014, joining AES and the Canadian League Against Epilepsy as the third chapter of the North American Commission. This effort was led by Drs. Amza Ali and Dr. Dave Clark, whose vision towards this goal was unwavering. Progress in epilepsy care in the Caribbean has been rapid since the ESC was ratified, ranging from a highly successful and expanding biannual regional congress to significant progress towards an epilepsy surgery program for the region, based in Jamaica. Strong efforts in advocacy have included lobbying regional governments for new AEDs, and a social driving initiative created in collaboration with the International Foundation of Applied Disability.

The Caribbean Task Force, led by Dr. Dave Clarke, succeeded in obtaining an EEG machine (donated from Global Diagnostics) for St. Lucia during this term. They also implemented clinical care audits in a variety of centers. News and media initiatives took place in 2013-2014 to address epilepsy misconceptions with the general public. The task force also lobbied for new AEDs to be available at no cost to patients and they were successful in getting several AEDs on the formulary. A social driving initiative was also created in collaboration with the International Foundation of Applied Disability; the aim of this initiative is to go to government to lobby for new laws for drivers with epilepsy. The Caribbean Epilepsy Society also held Epilepsy Week in Antigua from November 9-13, 2015 with teams from the University of Texas (Austin) and New York University. During this week, along with educational sessions to various stakeholders, 106 patients were seen in clinics and this included neuropsychology assessments and plans for optimization of future clinics.

**Hispaniola Task Force**

In 2014-2015, the Haiti portion of this task force, led by Dr. Lionel Carmant, was highlighted by the opening of a third site in the city of Jacmel in the Southern portion of the island. A family physician and an EEG technologist/nurse were trained and



*Peru-Canada PECA Initiative: Epilepsy ward and first Peruvian video-EEG unit at Instituto Nacional des Ciencias Neurologica, Lima, Peru.*



*Peru-Canada PECA initiative: Drs. Mao Vasquez, Jorge Burneo and David Steven after the first ever temporal lobectomy in Peru.*



*The Clinical visits and educational efforts in the Caribbean 2015-2016.*

now run an epilepsy program under the mentorship of a neurologist. They also launched their website [www.clidep-haiti.com](http://www.clidep-haiti.com) or [www.clidep.org](http://www.clidep.org) and have recruited medical students to their program.

The most compelling story of this task force is that in the very short time since the epilepsy care centers were created, more than 5000 people living with epilepsy in Haiti have been seen and are now followed. The clinics continue to face serious treatment gaps issues because they do not have sufficient AEDs for everyone (many cannot even afford phenobarbital and therefore have breakthrough seizures when they run out of their medications). Only the Mirebalais site has free access to medication via the NGO Partners in Health. The PAHO program for access to medication is not in place in Haiti.

A group of colleagues of Dr. Carmant also planned a 3-day training session in the region (Drs. Anne Lortie, Dang Nguyen, Alexander Weil and Sylvain Chouinard) in 2016.

**Stigma Task Force**

The stigma task force led by Dr. Nathalie Jetté completed its work on synthesizing the worldwide evidence on stigma in epilepsy. Members of the task force worked on synthesizing the evidence from around 300 manuscripts. Four manuscripts were drafted addressing tools to measure stigma in epilepsy, interventions for stigma in epilepsy, frequency and factors associated with stigma in epilepsy and frequency and factors associated with attitudes in epilepsy. These manuscripts (under review) highlight gaps in the area of stigma in epilepsy research and provide recommendations for future research. The group will be meeting at the IEC meeting in Barcelona in September 2017 to discuss future directions of this task force.

**Research**

**Harmonization of Regulatory Activities**

The task force on regulatory activities was very productive during this term. This is a task force in collaboration with the European Commission. The goal of this effort is to identify and refine optimal clinical trial methodologies for new anti-epileptic drugs. The task force worked on three reports this past year including: (1) a paper on a unified indication (incorporating both monotherapy and polytherapy) for epilepsy; (2) The PEACE (pediatric extrapolation academic consortium in epilepsy) initiative has been working with the FDA and has been preparing a paper related to this issue; (3) A paper on time to baseline seizure frequency as an add-on study design was also drafted.

An AES town hall was held with many members of the FDA addressing the work of this task force, mostly focusing on time to baseline seizure frequency as an add-on study design. The FDA is still willing to

*(Continued on page 16)*

consider time to seizure as an outcome. The task force and relevant stakeholders met in Prague at the European Commission meeting and also met at the annual AED development meeting in May 2015. A joint US-European meeting also took place in Prague in September 2016 to continue the momentum of this important initiative.

#### Neurocysticercosis Study (Hispaniola Task Force)

In the Dominican Republic, the neurocysticercosis study was ongoing during this term. As of the end of November, 30 out of 100 patients were recruited and tested. Preliminary results are pending. In the first part of this study, more than 25% were affected by neurocysticercosis and those affected had a high family history of epilepsy. This led to the development of a parallel project funded by the Dominicans, where they are looking at the role



5th North American Caribbean Congress on Epilepsy, Barbados, March 2016.

of genetic markers of inflammation in the patients with neurocysticercosis and epilepsy. It is expected recruitment and analysis of this cohort will be completed by the end of this NARC term.

#### Conclusions

The NARC has accomplished much during this last term, but more work is still needed! We will continue many of our efforts but also create new opportunities to fill epilepsy care and education gaps through multidisciplinary collaborations and collaborations with our key partners (e.g. International Bureau for Epilepsy and its chapters, the World Health Organization, PAHO, etc.).

## How to Apply for Chapter Membership

The ILAE is a federation of 114 Chapters and a person can join the ILAE by becoming a member of their Chapter.

Benefits of Chapter membership include:

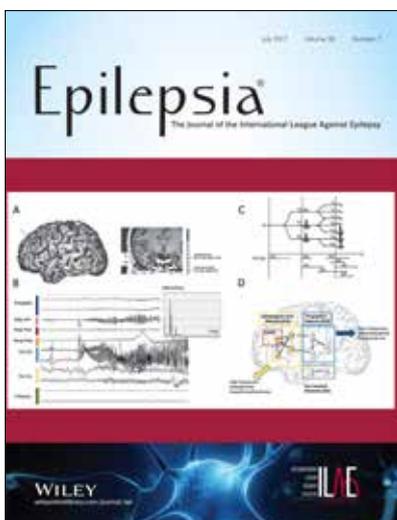
- Full participation in national and international activities of ILAE
- Heavily discounted subscription rates to *Epilepsia*, *Epileptic Disorders* and other epilepsy journals
- Chapter conferences and other benefits of individual Chapters
- Eligibility for membership of ILAE Commission / Task Forces
- Complimentary copy of *Epigraph*
- Access to the website features

Individual Chapters vary in the exact criteria for membership, but generally speaking, any doctor or health professional with an interest in epilepsy is eligible for membership. To join, write to the Secretary of your Chapter. You can find the contact addresses on the ILAE website at [www.ilae.org](http://www.ilae.org).

Your membership in the International League Against Epilepsy is vital. Of greatest importance is the fact that membership strengthens the authority of ILAE in its mission to influence and improve epilepsy care worldwide. Your membership counts; become part of the League!

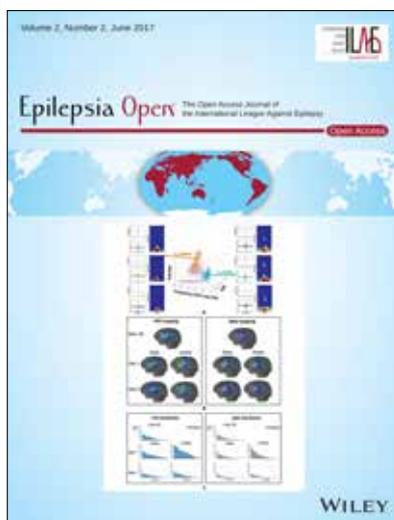
## ILAE Journals

### Research



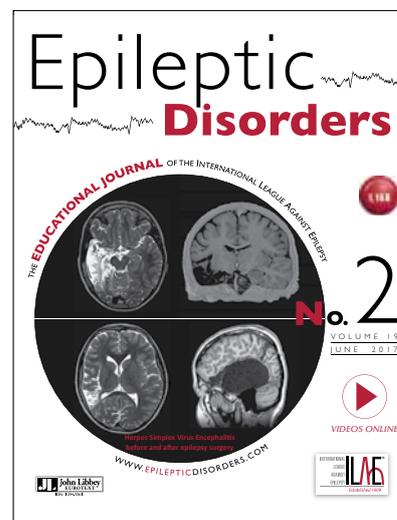
*Epilepsia*

### Open Access



*Epilepsia Open*

### Education



*Epileptic Disorders*

For subscription information, visit [www.ilae.org](http://www.ilae.org)

# An Introduction to ILAE

The ILAE is constituted as an international nonprofit organization and is registered in the United States.

The ILAE is the premier international professional association of physicians and other health professionals in the field of epilepsy. It was founded in 1909 and has grown greatly in size and influence in recent years. From its earliest years, it has been organized in the form of a federation of national Chapters. Currently there are Chapters in 114 countries with over ten thousand members worldwide.

The mission of the ILAE is to work towards a world where no person's life is limited by epilepsy. Its mission is to provide the highest quality of care and well-being for those afflicted with the condition and other related seizure disorders. For more details, readers can consult the ILAE website at [www.ilae.org](http://www.ilae.org).

## Executive Committee

The ILAE is overseen by an Executive Committee, currently 16 persons (current members in brackets). The President (S Wiebe), Secretary-General (E Bertram), Treasurer (H Cross), Vice President (A Guekht) and the Chairs of each ILAE Region are elected by the national Chapters for a four-year term. The Editors-in-Chief of *Epilepsia* (A Nehlig and M Sperling), *Epileptic Disorders* (A Arzimanoglu) and *Epilepsia Open* (A Gallinopoulou, D Schmidt, X Wang) are appointed by the President and the Executive Committee as non-voting members. The Past President (E Perucca) serves for a four-year term. The President (M Brodie), the Secretary-General (M Secco) and the Treasurer (A Zimba) of the International Bureau of Epilepsy (IBE), are Ex-Officio members of the Executive Committee.

## Constitution and Bylaws

The ILAE is governed by a written Constitution and Bylaws which are posted on the ILAE website. The Constitution covers the structure, objectives, membership, governance and the range of the ILAE activities. The Constitution can be amended at the General Assembly of the ILAE. There is a standing Constitutional and Elections Task Force to oversee changes in the Constitution. The Constitution was updated in 2011. The Bylaws were updated in 2017.

## Chapters

Each national Chapter has its own Constitution and Bylaws and officers elected by individual members. The constitutional and leadership arrangements as well as membership eligibility vary from Chapter to Chapter, within stipulations defined in the ILAE Constitution. However, membership is open to any doctor and health professional interested in epilepsy.

There are currently 114 Chapters in the ILAE, which is the greatest number in the League's history. National Chapters range in size from 3,000 to just seven voting members. The national Chapters establish and maintain good communication between persons active in the field of epilepsy, assist in the care of epilepsy and maintain standards of this care in their own countries. They may also promote publications in the field of epilepsy, organize or sponsor national meetings, appoint Commissions or individuals for specific problems, and develop or apply

other methods for the furtherance of the objectives of the ILAE.

## Regional Bodies

ILAE is divided into six Regions (North America, Latin America, Europe, Eastern Mediterranean, Asia and Oceania, and Africa). The largest region by number of chapters is Europe with 46 and the smallest is North America with three. Fully developed Regions have a Regional Commission a Regional Council, and regional epilepsy conferences are held every two years. Active Regions lead efforts in education and in influencing public policy in epilepsy.

## Commissions and Task Forces

In every four-year term, the President and the Management Committee appoint Topic-Oriented Commissions and Task Forces to carry out work for the ILAE. These bodies involve individuals from multiple regions. The assignments of each of these working groups is to provide advice and recommendations to the Executive Committee as well as to the broader community about issues that are of clinical, scientific, economic and political concerns for people with epilepsy. The active Commissions are listed on the ILAE web site ([www.ilae.org](http://www.ilae.org))

## Staff

ILAE Headquarters is located in West Hartford CT (USA). Headquarters staff performs services related to leadership support, financial and website management, and publications coordination. The League also provides services to its 114 Chapters from the IDM Office located in Dublin, Ireland. The following individuals serve on the staff of the ILAE: Priscilla Shisler, MEd, Administrative Director; Donna Cunard, MBA, Financial Manager; Deborah Flower, Web Content Administrator, Gus Egan, Chapter Services Coordinator and Finola Quinn and Niall Corcoran, VIREPA Coordinators.

## IDM Office

ILAE holds a global epilepsy congress once every two years. Each ILAE Region may hold a regional scientific conference every two years and every national Chapter holds national scientific conferences as well. The regional and international Conferences of the ILAE are organized by its own conference organizer (R Holmes, International Director of Meetings) and his office.

## Global Outreach

This is a joint ILAE, IBE and WHO initiative, launched in 1997. The first phase of the Global Campaign Against Epilepsy was devoted primarily to increasing public and professional awareness of epilepsy as a universal treatable brain disorder, and raising epilepsy to a new plane of acceptability in the public domain. The second phase of the Global Campaign Against Epilepsy was launched in 2001 and was devoted primarily to activities that promote public and professional education about epilepsy, identify the needs of people with epilepsy on a national and regional basis, and encourage governments and departments of health to address the needs of people with epilepsy. The third phase was launched in 2005 and is focused

on special projects in different parts of the world and on assisting healthcare authorities worldwide in the field of epilepsy.

## ILAE Journals

The ILAE publishes three peer reviewed journals: *Epilepsia*, *Epilepsia Open* and *Epileptic Disorders*.

### *Epilepsia*

*Epilepsia* is the scientific journal of the ILAE and the world's leading peer reviewed journal in the field of epilepsy. It has been the official journal of the ILAE since the founding of the League in 1909.

### *Epilepsia Open*

*Epilepsia Open* is the League's new open access peer reviewed journal that was started in 2016. It covers the entire breadth of basic, translational and clinical research in epilepsy and will include negative, failure to reproduce, and confirmatory studies. Because it is open access and freely available, *Epilepsia Open* will enhance the access to basic research findings for clinical scientists and health professionals.

### *Epileptic Disorders*

*Epileptic Disorders* is the League's educational journal. It publishes articles concerned with the clinical manifestations of epilepsy. The articles involve all aspects of the diagnosis, natural history and management of seizure disorders including neurophysiological, imaging and other ancillary techniques.

## Epigraph and the Website

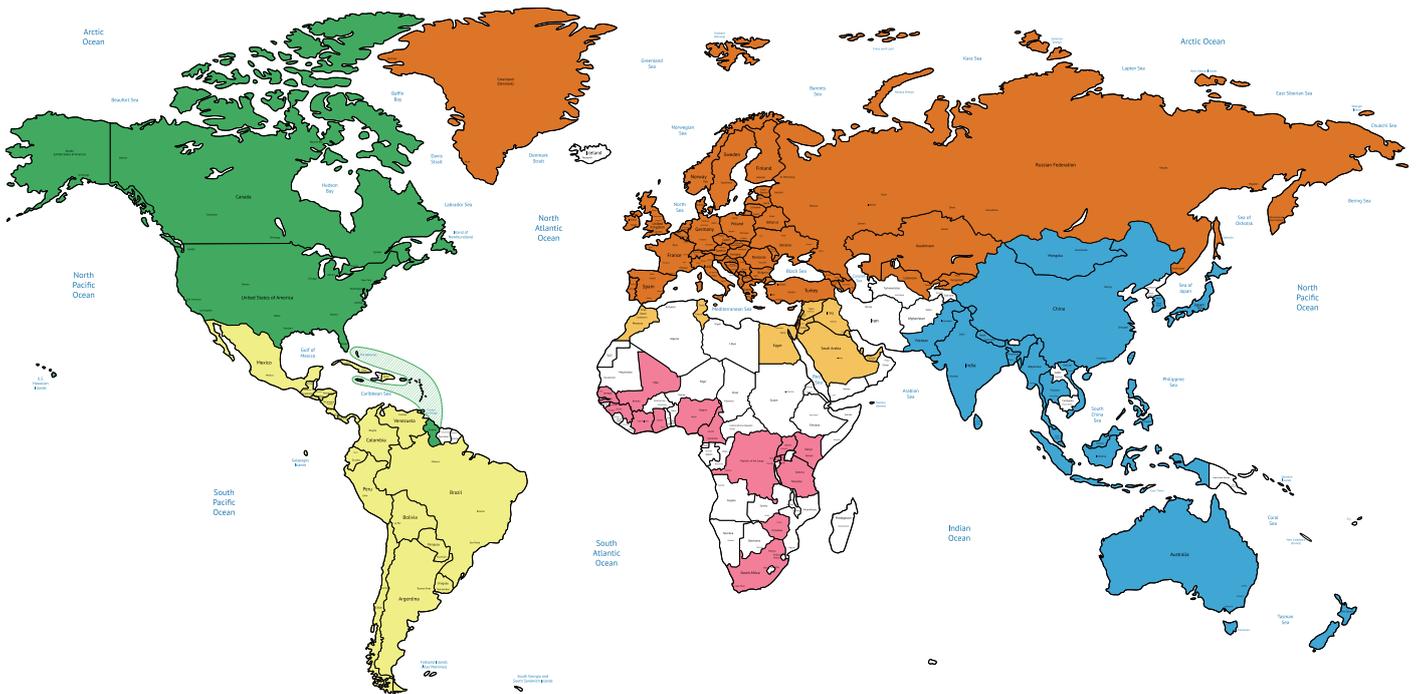
In 1994, the ILAE launched its own newsletter, *Epigraph*, sent to all members. The online version premiered in 2006. The newsletter is designed to facilitate communication of ILAE news to individuals in the greater epilepsy community. ILAE also has a website at [www.ilae.org](http://www.ilae.org). This has grown in size and complexity and in 2015 there were over 200,000 visits.

## Finances

With the assistance of the Headquarters Office, ILAE finances are overseen by the Treasurer, who reports to the Executive Committee on all financial and budgetary matters. Membership of the Executive Committee, Regional and Topical Commissions and Task forces is voluntary, and members are not paid for their work. Salaried staff is located in three administrative offices: Headquarters Office located in West Hartford, Connecticut, USA; Chapter Services Office located in Dublin, Ireland; and the Meeting Planning Office located in Dublin, Ireland. Income is derived from national chapter dues, sponsorships, *Epilepsia* royalties, international and regional Congresses, and investment income. The annual dues of each chapter to the ILAE are a minimum of \$10 per year per chapter, except for countries with low GDPs (World Bank categories low and lower middle) for whom membership may be supported by a solidarity fund.

# ILAE National Chapters

Albania	Denmark	Jordan	Paraguay	Turkey
Argentina	Dominican Republic	Kazakhstan	Peru	Uganda
Armenia	Ecuador	Kenya	Philippines	Ukraine
Australia	Egypt	Kosovo	Poland	United Arab Emirates
Austria	El Salvador	Kuwait	Portugal	United Kingdom
Azerbaijan	Estonia	Kyrgyzstan	Qatar	Uruguay
Bangladesh	Finland	Latvia	Romania	USA
Belarus	France	Lebanon	Russia	Uzbekistan
Belgium	FYR Macedonia	Lithuania	Rwanda	Venezuela
Bolivia	Georgia	Malaysia	Saudi Arabia	Vietnam
Bosnia Herzegovina	Germany	Mali	Senegal	Zimbabwe
Brazil	Ghana	Malta	Serbia and Montenegro	
Bulgaria	Greece	Mexico	Singapore	*Antigua, Bahamas, Barbados,
Cameroon	Guatemala	Moldova	Slovakia	Guyana, Jamaica, Martinique,
Canada	Guinea	Mongolia	Slovenia	St. Kitts, St. Lucia, Trinidad and
Caribbean*	Honduras	Morocco	South Africa	Tobago, US Virgin Islands
Chile	Hong Kong	Myanmar	South Korea	
China	Hungary	Nepal	Spain	
Colombia	India	Netherlands	Sri Lanka	
Costa Rica	Indonesia	New Zealand	Sweden	
Croatia	Iraq	Nicaragua	Switzerland	
Cuba	Ireland	Nigeria	Syria	
Cyprus	Israel	Norway	Taiwan	
Czech Republic	Italy	Pakistan	Tanzania	
Democratic Republic of Congo	Ivory Coast	Palestina	Thailand	
	Japan	Panama	Tunisia	



Commission on North American Affairs	Commission on Latin American Affairs	Commission on European Affairs	Commission on African Affairs	Commission on Eastern Mediterranean Affairs	Commission on Asian and Oceanian Affairs
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# Awards Presented at the 32nd International Epilepsy Congress

## 2017 Lifetime Achievement Award



Charlotte Dravet

Although especially known for the epilepsy syndrome that bears her name, Prof. Dravet made impressive contributions to our understanding of the clinical and electrophysiological correlates of epilepsy syndromes of childhood.

In addition to her clinical expertise and research achievements, Prof. Dravet is known worldwide for her humble attitude, tireless work and dedication to the epilepsy mission, including her support to the many lay associations, some made up of families of children with Dravet syndrome, which advocate for better care for children with epilepsy. She has produced many publications for the lay community, particularly parents of children with epilepsy, to help them cope with aspects of the disease.

## 2017 Social Accomplishment Award



Susan Axelrod

In 1998, Axelrod and two other mothers, frustrated with their inability to protect their children from the devastation of seizures and side effects of medications, spearheaded the search for a cure for epilepsy. Axelrod launched a nonprofit organization that has established a national and international presence in epilepsy awareness and research.

Under Axelrod's leadership, CURE has led a dramatic shift in the epilepsy research community from simply treating seizures to enhancing understanding of underlying mechanisms and causes, so that cures and preventative strategies can be found. CURE's research program is cutting-edge, dynamic and responsive to new scientific opportunities and directions through both

investigator-initiated grants and unprecedented scientific programs and initiatives and the exploration of new areas in the quest to find answers.

## 2017 Michael Prize Winner



Boris Bernhardt

The recipient of the 2017 Michael Prize is Dr. Boris Bernhardt from the Montreal Neurological Institute. His work over the last decade has focused on the neuroimaging of epilepsy in people. His work is helping to track the disease over time, and is providing new insights into brain plasticity, connectivity and cognition. He uses multimodal MRI combined with advanced statistical analysis to map the pathological changes associated with epilepsy.

Every two years, the Stiftung Michael from Germany awards the Michael Prize for outstanding epilepsy research performed by young investigators (under the age of 45). In addition to the recognition from the epilepsy community for their contributions to our

understanding of epilepsy, the awardees also received 20,000 euros. The Stiftung Michael (Michael Foundation) was founded in 1962 in Germany by Dr. Fritz Harzendorf who named the prize for his son Michael who suffered from epilepsy. His intent was to improve the care of patients with epilepsy as well as to encourage research in the field. Over the years, the foundation has supported the development of expertise in epilepsy in Germany as well as other countries through educational programs and other endeavors. The prize is supported, in part, by an unrestricted grant from UCB.

## 2017 Epilepsia Clinical Research Prize



Sarah Weckhuysen

*Epilepsia* is pleased to announce the winner of the 2017 *Epilepsia* Clinical Research Prize is Sarah Weckhuysen for her article, "Involvement of GATOR complex genes in familial focal epilepsies and focal cortical dysplasia" Sarah Weckhuysen, Elise Marsan, Virginie Lambrecq, Cécile Marchal, Mélanie Morin-Brureau, Isabelle An-Goufinkel, Michel Baulac, Martine Fohlen, Christine Kallay Zetchi, Margitta Seeck, Pierre de la Grange, Bart Dermaut, Alfred Meurs, Pierre Thomas, Francine Chassoux, Eric Leguern, Fabienne Picard and Stéphanie Baulac

*Epilepsia*. Version of Record online: 13 MAY 2016 | DOI: 10.1111/epi.13391

Sarah Weckhuysen is a neurologist with strong research interests in genetics of epilepsy. Following completion of her neurology residency, she has combined clinical epilepsy care with academic epilepsy research. As a clinician, she worked in the Epilepsy Center Kempenhaeghe in the Netherlands, in the Reference Centre of Rare Epilepsies of the Hôpital de la Pitié Salpêtrière in Paris, and since 2016, in the University Hospital of Antwerp, Belgium. In parallel, she obtained a Ph.D. on the topic of genetics of rare epilepsies while working in the Neurogenetics Group of Prof. P. De Jonghe at the VIB Center of Molecular Neurology in Antwerp, Belgium. She then moved to Paris for a postdoc at the Institut du Cerveau et de la Moelle Epinière in Paris, in the group of Stephanie Baulac, where the current study was done. In 2016 she returned to the Neurogenetics Group in Antwerp.

## 2017 Epilepsia Basic Science Prize



Tiwalade Sobayo

*Epilepsia* is pleased to announce the winner of the 2017 *Epilepsia* Basic Science Research Prize is Tiwalade Sobayo for his article, "Should stimulation parameters be individualized to stop seizures: Evidence in support of this approach" Tiwalade Sobayo and David J. Mogul

*Epilepsia*. Version of Record online: 9 DEC 2015 | DOI: 10.1111/epi.13259

Tiwalade Sobayo received his Ph.D. in biomedical engineering from Illinois Institute of Technology in January 2016 under the mentorship of Dr. David Mogul. His Ph.D. dissertation focused on understanding synchrony dynamics in brain networks (specifically the thalamus and hippocampus) as seizures evolve and leveraging this information to disrupt seizures with targeted electrical stimulation. In February 2016, he started his postdoctoral training where he is working to expand the range of the studied network to include additional relevant brain structures, investigate how well results in the animal studies translate to humans, and gain a better understanding of the mechanisms underlying the experimental results through the use of computational models.

## 2017 Epileptic Disorders Educational Prize



Hiroko Ikeda

Dr Hiroko Ikeda was awarded the Epileptic Disorders Educational Prize for her paper, "Characteristic phasic evolution of convulsive seizure in PCDH19-related epilepsy" by Hiroko Ikeda, Katsumi Imai, Hitoshi Ikeda, Hideo Shigematsu, Yukitoshi Takahashi, Yushi Inoue, Norimichi Higurashi, Shinichi Hirose, *Epileptic Disord* 2016; 18 (1): 26-33. The award will be presented at the 32nd International Epilepsy Congress in Barcelona, Spain (2-6 Sept 2017).

Dr Ikeda is a member of the Department of Pediatrics at the National Epilepsy Centre, Shizuoka Institute of Epilepsy and Neurological Disorders. She is a

pediatrician, child neurologist, and epileptologist, and a member of the Japan Epilepsy Society, Japanese Society of Child Neurology, and the Japan Pediatric Society.

Dr Ikeda was born in Hiroshima, graduated from Osaka Medical College, and pursued a career as a pediatrician and child neurologist at Osaka City General Hospital. She has devoted herself to daily practice and clinical research in epilepsy since 2008 at National Epilepsy Centre, NHO Shizuoka Institute of Epilepsy and Neurological Disorders, so that children with epilepsy could live better lives with better treatment.

## 2017 - 2021 ILAE Executive Committee Members



Samuel Wiebe  
President



Alla Guekht  
Vice President



Edward Bertram  
Secretary-General



Helen Cross  
Treasurer



Emilio Perucca  
Past President



Angelina Kakooza  
Commission on  
African Affairs



Akio Ikeda  
Commission on Asian  
and Oceanian Affairs



Chahnez Charfi Triki  
Commission on Eastern  
Mediterranean Affairs



Eugen Trinka  
Commission on  
European Affairs



Roberto Caraballo  
Commission on Latin  
American Affairs



Nathalie Jetté  
Commission on North  
American Affairs



Astrid Nehlig  
*Epilepsia*  
Editor-in-Chief



Michael Sperling  
*Epilepsia*  
Editor-in-Chief



Martin Brodie  
IBE President



Mary Secco  
IBE Secretary-General



Anthony Zimba  
IBE Treasurer

## Invitees



Jean Gotman  
Strategic Advisor



Alexis Arzimanoglou  
*Epileptic Disorders*  
Editor-in-Chief



Dieter Schmidt  
*Epilepsia Open*  
Co-Editor-in-Chief



Xuefeng Wang  
*Epilepsia Open*  
Co-Editor-in-Chief



Aristeia Galanopoulou  
*Epilepsia Open*  
Co-Editor-in-Chief



Shichuo Li  
Advisor on Public  
Health

## 2017 Ambassador for Epilepsy Award

The Ambassador for Epilepsy Award is given in recognition of outstanding international contributions to activities advancing the cause of epilepsy, either internationally or with international impact. The Award is given biannually at the International Epilepsy Congress.



*Michel Baulac  
France*



*Guiseppe Capovilla  
Italy*



*Nathalie Jetté  
Canada*



*Jaideep Kapur  
USA*



*Astrid Nehlig  
France*



*Terence O'Brien  
Australia*



*Makiko Osawa  
Japan*



*Galo Pesantez Cuesta  
Ecuador*



*Ivan Rektor  
Czech Republic*



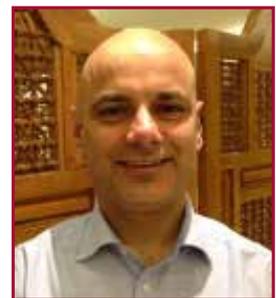
*Parthasarthy Satishchandra  
India*



*Eugen Trinka  
Austria*



*Sam Wiebe  
Canada*



*Sameer Zuberi  
UK*

# Meetings of Interest

## 13 – 18 September 2017

Eighth Caucasian Regional School of  
Clinical Epileptology (CRSSCE-VIII)  
Dilijan, Armenia

## 16 – 21 September 2017

XIII World Congress of Neurology  
Kyoto, Japan  
Website: [www.2017.wcn-neurology.com/](http://www.2017.wcn-neurology.com/)

## 23 – 25 September 2017

Cleveland Clinic Epilepsy Update & Review Course  
InterContinental Hotel & Bank of America Conference Center, Cleveland, Ohio, USA  
Program: <http://www.ilae.org/Visitors/Congress/congressinfo/ClevelandClinicEpiReview-2017.pdf>  
Website: <http://www.clevelandclinicmeded.com/live/courses/epilepsy-update/>

## 29 – 30 September 2017

3rd International Epilepsy Symposium: New Insights into Epilepsy  
Berlin, Germany  
Schedule: <http://www.ilae.org/Visitors/Congress/congressinfo/IntlEpSympos2017.pdf>

## 8 – 12 October 2017

ISPN 2017: 45th Annual Meeting of the International Society for Pediatric Neurosurgery  
Denver, Colorado, USA  
ISPNMeeting.org

## 9 – 12 October 2017

20èmes Journées française de l'Epilepsie (JFE)  
Palais du Pharo, Marseille, France  
Organized by La Ligue Française contre l'Epilepsie (LFCE)  
Website: <http://www.jfe-congres.fr/>

## 12 – 14 October 2017

International Workshop on Onchocerciasis-Associated Epilepsy (OAE)  
Antwerp, Belgium  
Website: <https://www.uantwerpen.be/en/conferences/oa-2017/>

## 13 – 15 October 2017

2017 CLAE Scientific Meeting  
Vancouver, BC, Canada  
Website: <https://canadianleagueagainstepilepsy.wildapricot.org/2017-Meeting>

## 15 – 17 October 2017

ANA 2017: American Neurological Association Annual Meeting  
San Diego, CA, USA  
Website: <https://2017.myana.org/>

## 15 – 20 October 2017

7th Eilat International Educational Course: Pharmacological Treatment of Epilepsy  
Jerusalem, Israel  
Website: [www.eilatedu2017.com](http://www.eilatedu2017.com)

## 25 – 28 October 2017

4th European Congress of NeuroRehabilitation (ECNR)  
SwissTech Convention Center, Lausanne, Switzerland  
[www.ecnr-congress.org](http://www.ecnr-congress.org)

## 26 – 28 October

2nd Moroccan Congress of Neurophysiology  
The First African and Middle Eastern Seminar of Clinical Neurophysiology and Movement Disorders  
Conference Center Mohammed VI, Rabat City, Morocco  
Website: [http://www.neuroafrikena.com/scientific-information/invited-speakers/Speakers\\_program\\_registration](http://www.neuroafrikena.com/scientific-information/invited-speakers/Speakers_program_registration)

## 1 – 3 November 2017

Epilepsy Society of Australia Annual Scientific Meeting  
Pan Pacific Hotel, Perth, Western Australia  
Website: [www.ivvy.com.au/event/ESA17/](http://www.ivvy.com.au/event/ESA17/)

## 23 – 24 November 2017

1st Regional Ukrainian Congress on Controversies in Neurology  
Kyiv, Ukraine  
Website: <http://www.rimon.in.ua/cony/2017/>

## 1 – 5 December 2017

AES Annual Meeting  
Washington, DC, USA  
Website: [https://www.aesnet.org/annual\\_meeting](https://www.aesnet.org/annual_meeting)

## 2018

### 22 – 25 March 2018

12th World Congress on Controversies in Neurology (CONy)  
Warsaw, Poland  
CONy 2018 Website: <http://www.comtecmed.com/cony/2018/>

### 15 – 20 April 2018

2nd International Training Course on Neuropsychology in Epilepsy  
Domaine de Châteauneuf, Provence, France  
Information <http://www.ilae.org/Visitors/Congress/congressinfo/Neuropsych-in-Epilepsy-2018.pdf>

### 1 – 6 May 2018

31st International Congress of Clinical Neurophysiology (ICCN) of the International Federation of Clinical Neurophysiology (IFCN)  
Washington, DC, USA  
Website: <http://iccn2018.acns.org/>

### 2 – 5 May 2018

4th International Congress on Epilepsy, Brain and Mind  
Hotel International, Brno, Czech Republic  
Abstract submission deadline: October 31, 2017  
Website: <http://www.epilepsy-brain-mind2018.eu/>



### 5 – 8 October 2018

6th Global Symposium on Ketogenic Therapies for Neurological Disorders: Embracing Diversity, Global Implementation and Individualized Care  
International Convention Center Jeju, Jeju, Korea  
Website: [www.ketoconnect.org](http://www.ketoconnect.org)