

INTERNATIONAL

# Epilepsy News

Reporting epilepsy news for 53 years

1963-2016

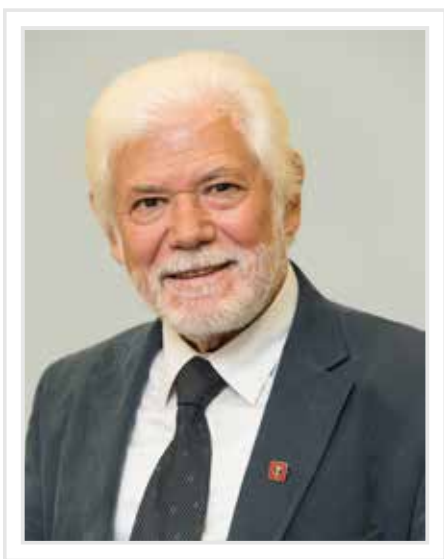
## Hong Kong Congress



**History of ILAE - Part 10**

***ERN - a new model of care***

# PRESIDENT'S LETTER



Dear IBE Chapters, Dear Friends

Since my last letter a lot has been happening and it has been a rewarding time. I attended the 3<sup>rd</sup> Eastern Mediterranean Epilepsy Congress/5<sup>th</sup> UAE Congress in Dubai in early March, which provided the opportunity to discuss various epilepsy issues pertinent to the region.

In May I travelled to Hong Kong for the 11<sup>th</sup> Asian Oceanian Epilepsy Congress, during which the very successful Epilepsy & Society Symposium took place. I was very pleased to be part of this meeting and I would like to commend the organizing committees for producing an outstanding scientific and social program, respectively, which covered a diverse range of topics in the field of epilepsy.

I also travelled to Beirut, Lebanon in late May to attend the official launch of the Stephany Epilepsy Centre and to present at the 3<sup>rd</sup> Epilepsy Congress organised by the Avance School and Association.

Later this year we will celebrate two further congresses, the 9<sup>th</sup> Latin American Epilepsy Congress, taking place in Cancún from 20<sup>th</sup> to 23<sup>rd</sup> August and the 13<sup>th</sup> European Conference on Epilepsy & Society in Prague from 15<sup>th</sup> to 16<sup>th</sup> September. This conference will have a half day joint program with the ILAE European Congress on Epileptology, which is a new event for the meeting.

As co-chair of joint task force of Epilepsy Alliance Europe, I attended a meeting in Brussels organised by Brain Hayes MEP, which was attended by DG Sante representatives, ILAE President Emilio Perucca,

## A lot of travel to important meetings

task force co-chair Philippe Ryvlin and ILAE Secretary General Helen Cross to discuss a European Reference Network (ERN) proposal that is built on the e-epilepsy pilot network.

In all those meetings and participation our main aim is to increase awareness and education about epilepsy, giving us the opportunity using specific regional/national evidence-based intervention to reduce prevalence and burden of epilepsy. Education at all levels is the best way to improve treatment issues and reduce preventable causes of epilepsy, particularly in resource poor countries.

We are running towards the end of our term in office and need to accomplish many tasks related to the WHA Resolution on Epilepsy. For this we work together with ILAE, WHO and the Global Outreach Task Force.

Among the items for discussion that need to be included in our future plans are: promotion of IBE/ILAE International Epilepsy Day by WHO, review of the WHO toolkit on epilepsy and identify ways for sharing this with IBE/ILAE chapters and regions, develop actions towards improving access to Antiepileptic Medicines in low and middle-income countries and also how to use new technology to improve epilepsy care of people with epilepsy.

I am looking forward to seeing many of you during the next Regional and/or International congresses.

With best wishes to all,

Athanasios Covanis  
President



International Epilepsy News  
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### INTERNATIONAL RELATIONS AND PARTNERSHIPS

#### WHO

IBE is in official relations with the World Health Organisation (WHO).

#### ECOSOC

IBE enjoys Special Consultative Status on the Economic and Social Council of the United Nations (ECOSOC).

#### CoNGO

IBE is a member of The Conference of NGOs in Consultative Relationship with the United Nations CoNGO.

#### EFNA

IBE is a member of the European Federation of Neurological Associations (EFNA).

#### EPF

IBE is a member of the European Patients' Forum (EPF)

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# In this issue



## Dear Readers

It's difficult to believe that, already, we have passed the halfway point of 2016 and are now racing towards, not only the end of another year but, also, the close of another decade.

When I began gathering news and stories for this issue of the newsletter I was reminded of the extent of activity

in the epilepsy world in the past few months.

Some things are coming to an end, such as the excellent series of articles written by Ted Reynolds telling the fascinating story of ILAE. The last episode can be found in this issue and on the IBE website you will find a compilation of all 10 articles.

Other events are about to begin - such as the EU European Reference Networks initiative, of which we hope epilepsy will be chosen as a standalone network. IBE is also involved in an IMI funded project looking at 'wearables' as a means of monitoring relapses in the health of people with epilepsy, MS or depression. We also share news of another new start - the third epilepsy centre and school of Avance in Beirut.

And, of course, some initiatives continue - such as the PAHO Strategic Plan for the Americas, which will continue to 2021. We bring you an update in this issue.

Ending on a sad note, we include an In Memoriam to Victoria Dimech who died tragically young in late June. As a former member of the European Regional Executive Committee, many readers will remember her with fondness.

Until next time - good reading.

*Ann Little*  
Editor

## Coming in the next issue



Don't miss the next issue of IE News, which will include very important information for all IBE chapters!



# EUROPEAN REFERENCE NETWORKS

A new model in healthcare



## What is an ERN?

Imagine if the best specialists from across Europe were able to combine their efforts and knowledge to tackle complex or rare medical conditions that require highly specialised healthcare and a concentration of knowledge and resources, and to have that service available to all patients, irrespective of where they lived in the European Union. If you can picture that, then you can see the potential of a European Reference Network (ERN).

In Europe, there are approximately 6,000 rare diseases, according to Orphanet ([orpha.net](http://orpha.net)). And, as the ethnic diversity in Europe increases, so too with the number of rare diseases.

Of course, providing highly specialized treatment and care for patients with a rare or complex condition can be hugely challenging. This is especially true when the prevalence of such conditions is low, as is the case for rare diseases, including some epilepsies. The problem is caused both to the scarcity of expertise and to the scattering of small patient populations across countries in the European Union (EU), sometimes in isolated locations where expertise does not exist or cannot be accessed.

However, collaboration between EU Member States can help to support the pooling of expertise in order to ensure that this expertise and knowledge is shared between healthcare professionals across national borders. By ensuring that healthcare professionals have the most up to date and expert knowledge available, they will be better informed to take decisions on treatment and care pathways for their patients. An added advantage will be improvements in clinical outcomes and, thereby, the quality of life of people living with a rare disease. ERNs will help to maximise the speed and scale of incorporating innovation in medical science and health technologies.

## Cross Border Directive

But how would this differ to the types of services already available for patients living

**75% of rare diseases diagnosed are in children**

with a rare and/or complex condition in the EU - you might ask?

At the present time, patients can avail of treatment and expertise, even when it is not available in their home country. It's called the Cross-Border Healthcare Directive (CBD). The CBD provides for the cost of publicly funded healthcare in one EU country to be availed of in another EU member state and for the costs to be reimbursed. But it's not so straightforward as it might seem. There are some issues:

- Payment is only made after the patient returns home, so the cost must be met by the patient and then claimed back. So the patient must have the ability to find the funds to pay for their treatment before they travel.
- Treatment will only be covered up to the cost of that treatment in the patient's home country. This can limit the countries in which the treatment can be sought.
- Travel and subsistence (including non-inpatient accommodation) are not covered. This can add up to a not-insignificant figure. And there may be regular travel for continued treatment or follow up.

When you consider that up to 75% of rare diseases diagnosed are in children, accessing Cross-Border Healthcare become more complicated and more expensive. Travel with children is never easy and even less so when a child is unwell; the parents travel and subsistence costs must be met and unpaid employment leave may be required;

those left at home must be cared for; etc.

## Pilot Studies

So, the introduction of ERNs will, hopefully, address all of these issues. Instead of the patients travelling to receive treatment, the treatment will come to them, through their consultant who will be able to access expertise through the appropriate European Reference Centre.

The programme is already underway with pilot programmes that began in 2012. One of these pilot studies is **e-epilepsy** ([www.e-epilepsy.eu](http://www.e-epilepsy.eu)) with the primary aim of improving the awareness and accessibility of surgery for epilepsy across different countries.

While epilepsy surgery is an established treatment in the management of individuals with drug-resistant focal epilepsy, there is still a lack of awareness of suitable candidates and possible benefits of epilepsy surgery amongst doctors and patients.

e-epilepsy established a consortium of 13 centres as associate partners, with a further 15 collaborating centres driving the project. The primary expected outcome of the project is to increase the number and proportion of European children and adults cured of their refractory epilepsy by improving delivery of optimal epilepsy surgery throughout Europe.

It is hoped that, if EpiCARE is chosen as one of the expected approximately 20 first phase ERNs, it will continue with its work through EpiCARE.

The e-epilepsy pilot study and the other pilot studies have shown that ERNs do work, are more cost effective, and can be very successful. So, there are great hopes for their continued contribution to improved access to treatment and care for people living in Europe with a rare or complex disease.



# EpiCARE - an ERN for epilepsy

Over the past few months, the EpiCARE group, with coordinator Prof J Helen Cross, Great Ormond Street Hospital for Children (GOSH), has been working long hours to complete a submission for a European Reference Network (ERN) on rare and complex epilepsies. This was in response to a call from the EU issued in March and which closed on 21 June.

Dissemination of activities will be core to the network, and will be the responsibility of the coordinator and Epilepsy Alliance Europe.

Over the coming months, all of the network applications submitted to the EU before the deadline will be reviewed but, in the meantime, there is the opportunity to promote to EU national members the tremendous benefits to patients, care providers and health departments that would be provided of an ERN dedicated to rare and complex epilepsies.

## WHY AN EPILEPSY ERN?

Traditional antiepileptic therapies will achieve seizure freedom in 60-70% of patients. In the remainder, who continue to have seizures, the clinical outlook is poor.

The EpiCARE network would develop and deliver highly-specialized diagnostics and care to improve interventions and outcome in individuals with rare and complex epilepsies, defined as those with incidence <5 in 10,000 population, either defined as an epilepsy syndrome or aetiologically driven epilepsy.

Traditionally treatments have been targeted at the seizures with little understanding of the underlying cause; advances in structural brain imaging, as well as molecular and metabolic diagnostics, have determined an increasing number of causes resulting in the description of in excess of 130 rare diseases. With an understanding of underlying cause, treatments can be more targeted.

The relative prevalence of each disease means a coordinated approach is required across key centres of expertise, with the development of e-tools to enable complex diagnostic and therapeutic interventions

in a wider number of patients across Europe. Only then can we increase the possibility for new treatments that can be integrated into the clinical care pathways.

## E-EPILEPSY PILOT NETWORK

One such example has been the advances in clinical assessment, neuroimaging and neurophysiology increasing the number of individuals proceeding to resective surgery, with resultant cure from otherwise drug resistant epilepsy. The pilot ERN e-epilepsy (EU EAHC 534055, 2014, Ryvlin & Cross, 3 years) has increased the awareness and availability of epilepsy surgery across Europe through the utilisation of e-health, and further demonstrated the absolute need for a clinical network devoted to the rare and complex epilepsies. Through EpiCARE it would plan to 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.

## NETWORK GOALS

The main goals would be:

- Full access and utilisation of presurgical evaluation and epilepsy surgery;
- An increase in diagnosis of rare causes of the epilepsies;
- Enhancement of identification of patients with treatable rare causes of the epilepsies
- Increase access to specialized care for rare causes:
- To foster research on innovative causal treatments in rare and complex epilepsies.

## ATTAINING NETWORK GOALS

With a strategy of collaborative work-



ing, sharing of expertise and access to advanced diagnostics EpiCARE anticipates an increased number of individuals with refractory epilepsy to have an underlying diagnosis as a cause for the epilepsy.

By collecting information about where such patients exist, the ERN would be able to collate information on clinical presentation and evolution across the life span, constitute cohorts of these rare conditions and advance the development of clinical trials, utilising innovative trial design for small select numbers of patients.

EpiCARE would also continue to increase awareness and accessibility of epilepsy surgery for carefully selected individuals through a continuation of the core network, the successful pilot ERN E-epilepsy. E-epilepsy has proven the ability to build a sustainable pilot network using e-tools and multidisciplinary team discussions. This would continue through the future EpiCARE network, increasing the number of resultant seizure free patients in the next five years.

By networking centres with expertise in diagnosis of rare and potentially treatable

causes of epilepsies, and the use of highly technological investigative tools and diagnostic investigation, a collaborative effort will be made at collecting and developing guidelines for diagnosis and treatment of rare and complex epilepsies within the first three years of the EpiCARE network. Collecting common outcomes through registries of specific diseases will enhance both experience and knowledge base as to optimal management in these rare conditions.

The participation of network members in virtual discussion utilising an existing IT platform, and the integration of expertise in teaching programmes, will also enhance the likely diagnosis of individuals in EU member and non-member states. This is specifically relevant to reducing the gap of knowledge on rare epilepsies in adult patients.

### REDUCING THE NEED FOR CROSS BORDER TRAVEL

Ultimately, such exchange of data will enhance local delivery of care and minimise the need for patients to travel to other centres, or indeed utilise the cross border directives, facilitating optimised care for all. This will enable a wider number of individuals to access better and safer healthcare care within the next five years, thus impacting positively on the quality of life of the patients and their families and also having a direct economic impact at family and societal levels.

### CAN YOU HELP?

While we believe that an ERN focussed specifically on rare and complex epilepsies could lead to enormous benefits for patients, care providers and national health departments, we are aware that there will be a significant number of other applicants who also believe their proposed network to be vital. For this reason, we need to persuade EU national members to look favourably on the EpiCARE submission. If you think you can help, by contacting your national health department, we would be happy to provide you with some information to help form your message.

### Members of the Network (Stage One)

1. Great Ormond Street Hospital for Children, London, UK
2. University College London Hospitals, UK
3. Queen Elizabeth University Hospitals Campus, Glasgow, UK
4. Oxford University Hospitals, UK
5. University Hospital Gasthuisberg KU, Leuven, Belgium
6. Motol University Hospital, Czech Republic
7. St Anne's University Hospital, Czech Republic
8. Kuopio University Hospital KUH, Finland
9. CHRU Lille Epilepsy Unit, France
10. GHE-HCL (Hospices Civils de Lyon), France
11. Hôpital Enfant Malade, Necker, Paris, France
12. Dept of Epileptology, University Hospital Bonn, Germany
13. Epilepsy Center, University Hospital Freiburg, Germany
14. RCCS Inst of Neurological Sciences of Bologna (INSB), Italy
15. Azienda Ospedaliero- Universitaria A. Meyer, Florence, Italy
16. Fondazione IRCCS Istituto Neurologico, C Besta, Milan, Italy
17. Fondazione Istituto Neurologico Nazionale Casimiro Mondino, Pavia, Italy
18. Ospedale Pediatrico Bambino Gesù, Rome, Italy
19. The Children's Memorial Health Institute, Warsaw, Poland
20. Centro Hospitalar e Universitario de Coimbra, Portugal
21. Centro de Referencia de Epilepsias Refractrias, Hosp de Santa Maria, Lisbon, Portugal
22. Centro Hospitalar do Porto, Portugal
23. Alexandru Obregia Clinical Hospital, Bucharest, Romania
24. Hospital Sant Joan de Deu Hospital Clinic, Barcelona, Spain
25. Hospital de Mar-Pare de Salut Mar, Spain
26. Hospital Universitario y Politecnico La Fe, Valencia, Spain
27. Sahlgrenska University Hospital, Gothenburg, Sweden
28. University Medical Center Utrecht (Brain Center Rudolf Magnus), The Netherlands

## REMEMBERING

**IBE was saddened to hear of the recent deaths of two of its former supporters - Dr Richard HE Grant and Dr Tim (Timothy) Betts.**



Dr Richard HE Grant (UK), pictured centre above, died in recent months. He served as IBE Secretary General for two terms 1977-1981 and 1981-1984. This was during the turbulent period when a merger of IBE and ILAE under an umbrella banner of Epilepsy International was being considered. It not to prove successful and the project was abandoned in 1985. Dr Grant received an IBE/ILAE Ambassador for Epilepsy Award in 1974.



Dr Tim Betts, who died in recent weeks, was a former consultant neuropsychiatrist specialising in epilepsy at the Queen Elizabeth II Hospital in Birmingham. He was also a clinical reader in psychiatry at the University of Birmingham. He led the Birmingham neuropsychiatry service through the 1980s and 1990s and was the medical director of the Birmingham University Seizure Clinic. A well-respected educator, he was awarded with an IBE/ILAE Ambassador for Epilepsy Award in 1987. He retired in 2003.

# In Memoriam

## Victoria Dimech 1960 - 2016

*Victoria and Mario Dimech, photo taken February 2016*



Victoria Dimech, Secretary of Caritas Malta Epilepsy Association (CMEA), passed away after a short illness on 28 June 2016, at the age of 55 years. Victoria was married to Mario Dimech, former President of the association, and had two children - Karl, 26 years and Claire, 24 years.

Mario has had epilepsy since he was 11 years old and, until adulthood, he had virtually lived in the shadows of this condition, believing that he was one of the few people to have it. His life changed completely when he met Victoria, who gave him the courage to come out of his shell, to realize his personal abilities and to fulfil his life, despite his condition. She used this personal experience to catalyse change in the understanding of epilepsy in Malta and for more social acceptance of persons with epilepsy in Maltese and European society.

Victoria was elected Secretary of CMEA in 2000, a few years after Mario was elected President, and they formed an excellent tandem ever since. Knowing how difficult it is to live in a society ignorant of this condition and its consequences in everyday life, Victoria incessantly worked in order that others did not go through the same experiences as Mario. She worked hard to promote independent living and empowerment of people with epilepsy and to encourage family members to have

confidence in their children/siblings: not to over protect them but to pull together for a better life for the person having this condition.

Victoria had been involved in voluntary organisations since childhood. She had a diploma in Education (Individual Educational Needs) and for the last 18 years had worked as a learning support assistant in schools supporting children with special needs. Her work as Secretary of CMEA was undertaken on a 100% voluntary basis, most times in the evenings, during holidays, or by taking time off from work in order to deal with the exigencies that might arise.

She was the main driver that led to an official inservice course for educators on epilepsy that was offered, for the past ten years, as an official inservice course organised in conjunction with the Ministry of Education for teaching staff. She was also on the organising committee of more than eight national conferences, organised every two years by our association. She was frequently invited to deliver talks on epilepsy and its management in public/private schools as well as to different associations in Malta and was invited to participate in TV and radio programmes to talk about epilepsy, its effect on people and society in general and how, with increased

knowledge, this condition can “come out of the shadows”. Her last TV appearance was as recent as early June, just before she became ill.

She was well known in the wider European epilepsy community since she was a member of the IBE European Regional Executive Committee (EREC) from 2009 to 2013 and regularly had attended and contributed to several Epilepsy & Society Conferences and International Epilepsy Congresses, including Paris 2005; Copenhagen 2006; Marseille 2008; Budapest 2009; Rome 2011 and Ljubljana 2013; as well as EREC meetings in Dublin and the launch of European Epilepsy Day in Strasbourg in

2012. She endeavoured to participate in these conferences in order to increase her knowledge of the condition and thereby enhance her contribution to the association and, especially, to people with epilepsy and their families. She also brought a unique insight to an understanding of epilepsy as a relative of a person with epilepsy and an educator in her own right.

She was active in EU projects in which the Maltese association was involved, such as the EU funded Grundtvig project “*Education for Professionals Allied to Medicine in Epilepsy*”, together with partners in Germany and Hungary; and a Leonardo da Vinci Project on the transition of persons with a disability from school to workplace, which took her to Ankara in Turkey and to Germany.

She was asked to contribute to various initiatives: in 2006 she was asked to join a panel of a European Epilepsy Advisory Board to discuss the video production “Brain Storm”. Victoria was also a member of the Malta Health Network and attended an EU Public Health Conference in Slovenia in 2007 as a Maltese representative.

Victoria will be greatly missed in Malta and Europe, especially by her CMEA colleagues and friends and by her family, who she loved so much. JM

# Have you visited the new IBE website yet?



Home About Publications Initiatives News Contact us Donate

We have a vision of the world where everywhere ignorance and fear about epilepsy are replaced by understanding and care.

*Image by Nurun Nahar Nargish*

## ibe-epilepsy.org

### NEW PROVISIONAL CHAPTERS

Since the beginning of 2016, IBE has received four new applications for membership. In line with the Constitutional changes approved at the last General Assembly, these applicants will be considered as Provisional Chapters, pending ratification at the next assembly, which will take place in Barcelona in September 2017. The applicant associations are:

- Asociación Internacional Bureau for Epilepsy Capítulo, Costa Rica (Full Chapter application)
- Asociación Paraguaya de Lucha contra la Epilepsia (ASOPALEP), Paraguay (Full Chapter application)
- Epilepsy Foundation of Guyana, Guyana (Full Chapter)
- Avance Association of People with Epilepsy and Special Needs, Lebanon (Associate Chapter application)

We are sure that you will join with us in welcoming these four associations to IBE.

# ANNUAL DUES 2016

Chapter dues for 2016 are now overdue. If your association has not yet paid, it is important to do so as soon as possible. Dues payments are important in funding IBE activities and, for the first time in 11 years, there is a small increase to the dues levels this year.

Another major change is the option to make dues payments in Euro and we would encourage as many chapters as possible, in particular chapters based in Europe, to choose this option in order to reduce bank charges. The new dues levels are:

- Chapters: US\$175/€160
- Associate Chapters: US\$125/€115
- Subsidised rate: US\$30/€28.

In addition, more than 30 chapters based in developing countries will continue to have their dues payments covered by the Solidarity Fund.

When settling your dues payment, we would earnestly ask that you consider a donation to the Solidarity Fund to help us to continue to support those chapters who have very limited financial means.

Please contact [ibeexecdir@eircom.net](mailto:ibeexecdir@eircom.net) with any queries on how to make your association's payment.





# Stephany Medical Clinic BEIRUT

With a young daughter with complex refractory epilepsy, Arlette Honein Neim experienced at first hand the social stigma and discrimination that exists in Lebanon for people with epilepsy. Some mothers did not wish their children to play with Stephany, and finding a school that would accept her as a pupil proved to be extremely difficult. It would have been easy for Arlette to become depressed but, instead, she decided to take action to make things better, not only for her young daughter, but also for families in similar positions.

So, in 1997 Arlette decided that she would establish a school for children with difficult epilepsy and with other medical issues, such as ADHD, who were also regularly refused admission to schools. Avance Association was born and received recognition by the Ministry of the Interior and the Ministry of Education in the Lebanon. With pupils ranging from kindergarten stage to almost 30 years of age, Avance provides personal development and education for students with special needs where regular schools cannot provide the required facilities for academic, professional or social integration. The goal is to allow the younger pupils to re-integrate into regular school programmes and the older students to be able to start a professional life.

By 2013, Avance was operating two schools in Beirut - one in Furn El Chebbak and the other in Aley. In addition to children from Lebanon, the school has also welcomed students who are refugees from Syria, Iraq and Palestine.

Fast forward to May 2016 and Avance is ready to launch a third centre - the Stephany Medical Clinic for Epilepsy - named for Arlette's daughter, Stephany. Inauguration of Avance Association's new centre was held under the patronage of his Excellency Rashid Derbas, the Minister of Social

***Above:** Group photo with, front row, from left - Representative of the military commander of the Armed Forces, Colonel Dr Melhem Haddad, Her Excellency Nayla Mouawad (First Lady, wife of former Lebanese President Renee Mouawad), Mrs Arlette Honein Neim and Dr Gurses (Turkey). **Right (top):** Her Excellency Nayla Mouawad, Colonel Dr Melhem Haddad, Dr Mikati (USA), Dr Covanis (Greece) and Mrs Arlette Honein Neim; **(middle)** cartoon character in one of the playrooms; **(bottom)** exterior view of the clinic.*

Affairs in Lebanon in the presence of several governmental representatives; neurologists from Lebanon, the US, Greece, Syria and Turkey; and families and friends of the association.

The Stephany Clinic is situated in the suburbs of Beirut, high up on a hill with wide terrace views out on to the city and the Mediterranean beyond. It is a renovated building that has more than a splash of purple for epilepsy in its decor. Cartoon figures abound and Spiderman climbs up the wall of one room. There are play mats, books and toys, and a children's bedroom good enough for a Hollywood set of Snow White. Young children will be enthralled. Adding to the Avance School and Association for Epilepsy and Special Needs, the Stephany centre will provide a clinic for epilepsy diagnosis and treatment, a nursery, a therapeutic boarding school, as well as an out-patients department offering services including psychomotor therapy, speech and occupational therapies, and family counselling. Well done, Arlette!





# Hong Kong 2016

11th Asian &  
Oceanian Epilepsy  
Congress  
13-16 May

## Epilepsy & Society Symposium in **HONG KONG** honours Golden Light awardees



Congratulations! to the 10 worthy recipients of the Golden Light awards, who were honoured in May during the 11<sup>th</sup> Asian & Oceanian Epilepsy Congress in Hong Kong.

The award winners, some of whom are pictured above, received their awards at the Opening Ceremony of the Congress and were honoured again at the start of the Epilepsy & Society Symposium. Each one had been nominated by an IBE chapter in the South East Asia or Western Pacific regions to reward their positive approach to a diagnosis of epilepsy or working on a voluntary basis to improve the lives of people with epilepsy

For people with epilepsy and non-medical professionals, the one-day Epilepsy & Society symposium programme provided an excellent opportunity to look at the social issues that affect their lives. A great deal





of gratitude are due to Anchor Hung and her hardworking team who prepared over several months to ensure a successful and interesting event!

With opening addresses by Dr Wing-man Ko, Secretary for Food and Health, and Dr PY Leung, Chief Executive, Hospital Authority, well over 150 people heard very interesting presentations on the background story of the renaming of the term 'epilepsy' in Hong Kong and Korea; How Technology Improves Diagnosis, Self-Management & Community Education; and Enhancing medical and nursing care for persons with epilepsy.

The event closed with an entertaining and educational puppet show by *The Kids on the Block*, using comedy to highlight how stigma and discrimination can affect a young person with epilepsy. The next Epilepsy & Society Symposium will take place

in Bali during the 12<sup>th</sup> Asian & Oceanian Epilepsy Congress in 2018.

#### PHOTOS

*Cover photo:* Dr Shichuo Li (China) and Dr Wing-man Ko (Hong Kong SARC). Both men had worked together at WHO some years ago

*Main photo:* recipients of the Golden Light Awards who had been able to travel to Hong Kong, with Dr Thanos Covanis and Dr Ko (third and fourth from left) and Mrs Denise Chapman (far right).

*Bottom from left:*

- Dr Vinod Saxena and Dr Ding Ding
- Selfie photo opportunity!
- Dr Covanis and Mrs Chapman
- Dr Derrick Chan, Prof Martin Brodie, Mrs Anchor Hung and Dr Muzhural Mannan.

#### GOLDEN LIGHT AWARDS

- M Amarjarga (Mongolia)
- Amrita Bhashyam (India)
- Rosalind Chee (Malaysia)
- Jeong-ja Jee (South Korea)
- Yin-chan Loke (Singapore)
- Kym Meers (Australia)
- Wai-hung Ng (Hong Kong)
- Kun-hoo Rhee (Korea - nominated by Nepal)
- Zhi-Gang Wang (China)
- Laura Liu Yi (Taiwan)





# SMART WATCHES



In mid-June, more than 80 people travelled to the pretty city of Brescia on Italy's Lake Garda, to attend the Kick-Off Meeting of an exciting new project, which will use smart phones and innovative technology in an observational study to establish the potential for wearable devices to make meaningful improvements to the well-being of people with a diagnosis of epilepsy, multiple sclerosis or depression.

RADAR-CNS is a research programme supported by the Innovative Medicines Initiative (IMI), which launched in April and of which IBE is a member of the Patient Advisory Board. The objective of the programme is to develop new ways of monitoring these three major disorder areas.

RADAR-CNS aims to improve patients' quality of life and, potentially, to change how these and other chronic disorders are treated.

Remote assessment using smartphones and wearable devices can provide a complete picture of a patient's condition at a level of detail that has not been possible before now. It might also allow treatment to begin before a patient's health deteriorates, preventing the patient relapsing or becoming more ill before they seek treatment.

RADAR-CNS is jointly led by King's College London and Janssen Pharmaceutica NV, funded by the IMI and includes 24 organisations from across Europe and the US. The programme brings together experts from diverse fields including clinical research, engineering, computer science, information technology, data analytics and health services.

Epilepsy, depression, and multiple sclerosis are distinct disorders, with different causes and symptoms, all of which can be severely detrimental to patients' quality of life and life expectancy. For all three disorders, patients often experience periods where their symptoms are manageable, followed by periods of deterioration and

acute illness (relapse). Patient surveys have repeatedly highlighted the need to predict when relapses will happen and to improve the treatments which are available to stop them from occurring.

According to co-lead of the RADAR-CNS programme, Matthew Hotopf, Professor of General Hospital Psychiatry at the Institute of Psychiatry, Psychology & Neuroscience at King's College London, UK, "*In recent years, the quality and quantity of data that we can collect using wearable devices and smartphones has exploded. It may be that this sort of data can improve clinical care simply by providing more accurate information. Better still, it may be possible to spot when a patient is getting into trouble before their clinic visit.*"

*"For example, in depression, someone's behaviour may change even before they have noticed they are struggling – their sleep may get worse, or they may stop doing so much in the weeks leading up to a relapse. RADAR-CNS will exploit the huge potential of wearable technologies to improve the lives of the millions*



# telling more than the time!

*of people worldwide with chronic illnesses like epilepsy, depression and multiple sclerosis.”*

What is most significant is that patients, from a number of countries in Europe, will be involved in RADAR-CNS from the start, helping to identify the most important symptoms to target. They will also advise researchers on how best to implement remote measurement technologies in a way that is acceptable and engaging to patients, including accounting for privacy and security. It is expected that up to one thousand patients across the three disorder areas will take part in the programme, providing vital input from the best source of information - the patient him- or her-self.

Wherever possible, RADAR-CNS will use inexpensive and widely available technology, so that the end results can be made available to as many patients as possible. The research will also be developed in a way that allows the results to be transferred to other diseases, potentially allowing the benefits of remote measurement technologies to become pervasive in medicine, and

transforming the way we think about prevention and cure.

According to co-lead of the RADAR-CNS programme Vaibhav Narayan, PhD, Head of Integrated Solutions and Informatics, Neuroscience, Janssen Research & Development, LLC, an affiliate of Janssen Pharmaceutica, *“Our goal is to improve clinical care and outcomes by using data generated by patients as they go about their daily lives to predict and pre-empt relapses and improve their quality of life. Such ‘predictive medicine’ solutions will be backed by scientific evidence and will meet regulatory standards. At the same time, the privacy and security of patients and their care-givers will be fully protected.”*

Running to 2021, RADAR-CNS is an example of new wave healthcare innovation - using the expertise of clinical researchers, engineers, computer scientists, data analysts and patients to forge the way forward.

<https://twitter.com/RADARCNS>

<http://www.radar-cns.org>

## LEGEND

**RADAR-CNS:** Remote Assessment of Disease And Relapse – Central Nervous System

**IMI:** Innovative Medicines Initiative - a Public Private Partnership established between EFPIA and the EU

**EFPIA:** European Federation of Pharmaceutical Industries and Associations

**EU:** European Union

## FUNDING SUPPORT

- Innovative Medicines Initiative grant agreement No 115902
- European Union Horizon 2020
- EFPIA.





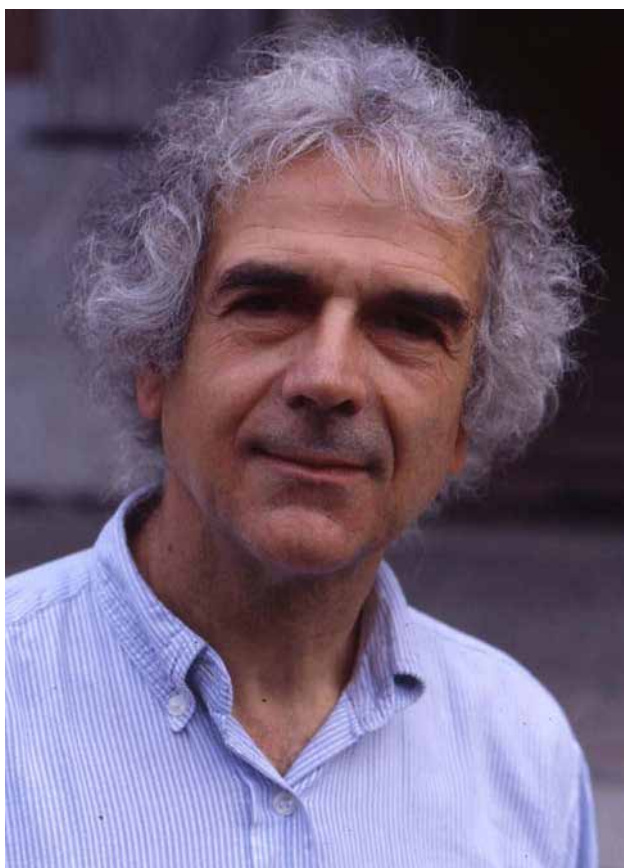
# THE HISTORY OF THE



## Part 10: 2001 – 2009: Accelerating towards the Centenary

In part 9, Ted described the administrative changes necessitated by the rapid growth of ILAE and the commensurate scale of its activities, including the launch of the second phase of the ILAE/IBE/WHO Global Campaign against Epilepsy in Geneva in February 2001. In this, the final article of the series, he takes us to 2009 and the celebrations to celebrate ILAE's centenary.

A compilation of the 10 articles that comprise the series are available on the IBE website <http://www.ibe-epilepsy.org/publications/other-publications/>



*Giuliano Avanzini, ILAE President 2001-2005*

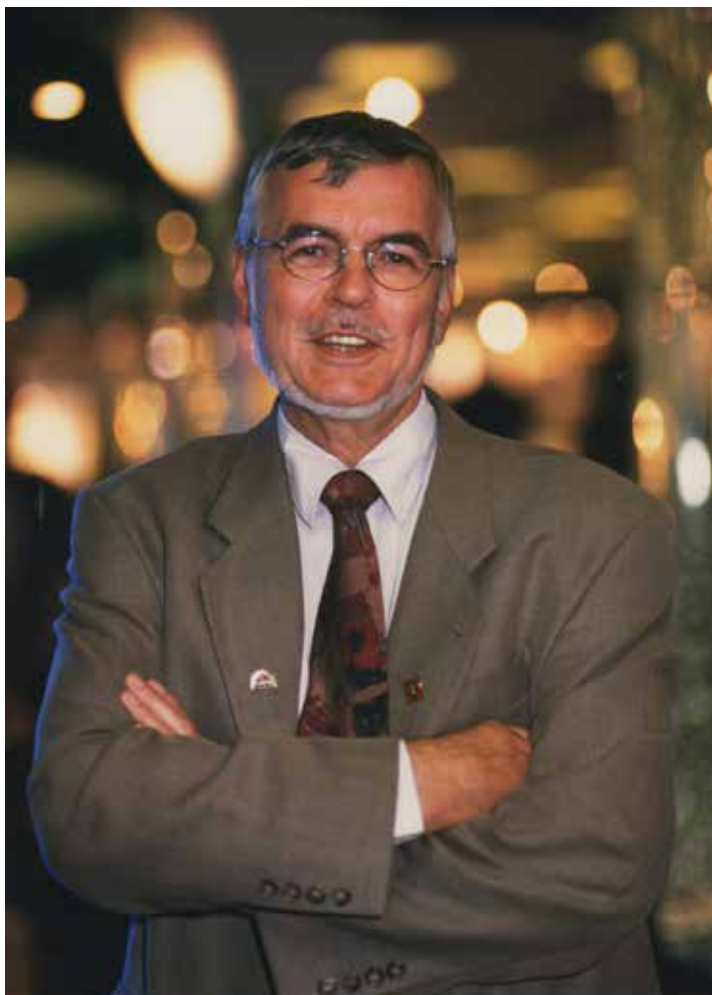
### 2001 – 2005

At the International Congress in Buenos Aires in May 2001, the new Executive was led by Giuliano Avanzini (Italy), with Natalio Fejerman (Argentina) as Secretary General and Ley Sander (UK) as Treasurer.

President Avanzini's priorities included developing and strengthening the regional activities of ILAE, to take account of differing cultural and socio-economic requirements, while at the same time improving communication and interaction between national Chapters, regional structures and the Executive, thus enhancing the Global Campaign. With this in mind he established Task Forces for regional, sub- and inter-regional organisation. Beginning at the ILAE European

Congress on Epileptology in Madrid in 2002, he also initiated annual Chapter Conventions at alternating Regional and International Congresses, which considerably increased the involvement of Chapters in the policy development and ongoing activities of ILAE at all levels.

A new administrative Headquarters of ILAE, with two permanent assistants under Executive Director Peter Berry, was now established in Brussels, because Europe had the largest number of Chapters. This Office supported Executive interactions with Chapters and Regions in all activities of ILAE except finance, which remained the remit of the Hartford, Connecticut Office. Communication was also improved by a new ILAE website, now under Information Officer, Simon Shorvon (UK), together with the continuing roles of *Epilepsia*, led by new editor, Robert Fisher (USA), and of *Epigraph* (Ley Sander, UK). Simon Shorvon also facilitated the establishment of an International Epilepsy Resource Centre at the Swiss Epilepsy Centre in Zurich, an idea promoted by past president, Pete Engel (USA). This also became the temporary home of the ILAE Archives.



*Peter Wolf, President 2005-2009*

By 2005, a further 16 Chapters joined the ILAE, of which China, representing about one fifth of the world's population, was a significant diplomatic achievement. The others were Bangladesh, Belgium, Costa Rica, Cyprus, Hong Kong, Kazakhstan, Kenya, Mongolia, New Zealand, Nicaragua, Pakistan, Singapore, South Africa, Tanzania and United Arab Emirates.

On a more negative note the decision to move, at short notice, the International Congress in 2003 from Tunis to Lisbon because of political considerations following the 9/11 attacks in the US, was a setback for ILAE relations with Africa. Plans for an ILAE Commission on Africa were again put on hold.

### **2005 – 2009**

At the AGM at the International Epilepsy Congress in Paris in 2005 new constitutional amendments, relating mainly to election procedures, were approved. Peter Wolf (Germany), who was the ILAE Constitutional expert during his 8 years as Secretary General, was now President, supported by Solomon Moshé (USA) as Secretary General and Martin Brodie (UK) as Treasurer. Peter Wolf prioritised the

Latin America, North America) and the ILAE/IBE/WHO leadership in advancing the Global Campaign.

The 2007 International Epilepsy Congress was held in Singapore, where Uganda was admitted as a Chapter. Throughout the period 2001 to 2009, ILAE/IBE Regional Epilepsy Congresses were held in each of the above regions alternating with the biennial International Congress, as ILAE accelerated towards its Centenary at the International Epilepsy Congress in Budapest in 2009. At Budapest six new Chapters i.e. Ghana, Guinea, Mali, Palestinian Territories, Uzbekistan and Vietnam, joined the League, bring the total past 100 to 103 in its Centenary year.

### **ILAE/IBE/WHO Global Campaign, Phase 2 (2001 - 2009).**

As described in Part 9, the success of the first four years of the Global Campaign led to a high profile launch of the 2nd phase in Geneva on February 12th 2001 led by the Director General of WHO, Dr Gro Harlem Brundtland. A central feature of phase 2 was Demonstration Projects, initially in regions of Brazil, China, Senegal and Zimbabwe. The methodology of these

development of regional educational structures and programmes. He had already established the European Epilepsy Academy (EUREPA) in 1996 and an Asian Academy (ASAPE) in 2003 and he advanced these models, in conjunction with the ILAE, in other regions with the help of a Global Education Commission, summer schools, residential courses, distance learning and fellowships. Other priorities included translational research and a new Epilepsy Care Commission to co-ordinate with the Regional Commissions (Asia/Oceania, Eastern Mediterranean, Europe,

projects included epidemiological assessment, case finding, educational and social intervention, and treatment by primary care workers. The ultimate objective was to examine the causes and to reduce the treatment gap; and to develop models of epilepsy treatment and care for integration into national health policies in nearby developing countries.

The largest and most successful project was in six provinces of China. In an initial survey of 55,000 people the lifetime prevalence of epilepsy was seven per thousand and the prevalence of active epilepsy was 4.6 per thousand (87% convulsive). Only 25% had had regular antiepileptic treatment. These findings led to a large community-based intervention trial of phenobarbitone in 2,455 patients with convulsive seizures (median frequency 10 per year and mean duration of epilepsy 15.5 years).

After two years of treatment one quarter were seizure-free and 72% experienced at least a 50% reduction in seizure frequency. So successful was this simple protocol, undertaken by specially trained primary care workers under the supervision of neurologists in rural communities with limited resources, that this approach was extended to 10 further locations in China and incorporated into a national programme (Wang et al, 2006).

Similar but smaller scale successful outcomes attended the Senegal and Brazil projects, but that in Zimbabwe was undermined by a deteriorating political situation. In the meanwhile several more developing countries initiated similar community-based projects, including Congo, Georgia, India, Indonesia, Maldives, Myanmar, South Korea and East Timor. Related global projects of the Campaign during this period included an Epilepsy Atlas describing epilepsy services available throughout the world; a study of epilepsy and stigma in China and Vietnam; and a global review of legislation related to epilepsy.

Finally, by 2009, 103 countries or chapters had initiated local or limited projects of various kinds under the umbrella of the Global Campaign. In view of the scale and success of the Chinese Demonstration Project, it was appropriate that China took the lead with the co-sponsorship of 17 other countries, in stimulating the General Assembly of WHO to unanimously approve in May 2015 Resolution WHA 68.20, which urges all member states to develop national healthcare plans for epilepsy management, particular in low and



Some of the present and past Officers and Commission Chairpersons of ILAE attending the 2009 Centenary gala event in Budapest

middle income countries, thus promoting the 5th and final objective of the Global Campaign (see Part 8, IBE Newsletter, Issue 2, 2015 and Covanis et al 2015)

### A century of achievement

Thus, stemming from small, mainly European, origins in Budapest in 1909, the leadership and membership of ILAE met again, together with IBE, at the International Epilepsy Congress in Budapest in 2009 to celebrate a century of achievement. Despite interruptions and setbacks, mainly due to two world wars, the League had grown into a truly global organisation with over a hundred national chapters, representing every continent. In partnership with the IBE, which it had spawned half a century earlier, and more recently with the WHO, ILAE has continued to

fulfil its founding fathers objectives at national, regional and global level i.e. “The League will devote itself to special projects on behalf of epileptics, and to finding a cure and means of prevention, as well as providing aid and social rehabilitation. Nor will the League neglect experimental research and comparative physiopathology, or laboratory work, which is essential for elucidating a series of problems as those raised by the origin, evolution and nature of seizure disorders, with their attendant range of somatic and psychic complications”. (see Part 1, IE Newsletter, Issue 3 - 2010). In the 1973 Constitution of ILAE these objectives were crystallised as:

1. the advancement and dissemination throughout the world of knowledge concerning the epilepsies;
2. the encouragement of research concerning the epilepsies;
3. the promotion of prevention, diagnosis, treatment and care for all persons suffering from these disorders;
4. the improvement of education and training in the field of the epilepsies.

While proudly acknowledging the progress of the first century of ILAE, all in ILAE, IBE and beyond will be aware that there are still enormous challenges in the century ahead to continue the promotion and fulfilment of these objectives on behalf of people with epilepsy throughout the world.

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# WE'VE MOVED



IBE has a new office. But we haven't moved far - just 3 doors from the current office - and phone and email addresses remain unchanged:

### NEW ADDRESS:

7 Priory Office Park,  
Stillorgan Road,  
Blackrock,  
Co. Dublin,  
A94 FN26,  
Ireland



# 3 for 2!

but time is running out...



The IBE Epilepsy & Society Conference introduced a special registration fee to help as many people as possible to attend the conference in September. This is proving to be particularly welcome for IBE chapters and small groups planning to attend.

The special fee provides an offer of 'three registrations for the price of two'. Early registration rates have now closed but a group of three people can making a saving of €200, with the single delegate of €200 or €400 for three.

These are exciting times for the Epilepsy & Society Conference, which will have a half-day joint session with the ILAE European Congress on Epileptology on the important topic of 'Outcomes in Epilepsy'. This is the first time that the congress programme will begin in this way.

On the programme for discussion at the conference are new developments in epilepsy treatment, associated cognitive dysfunction related to epilepsies, and the

psychosocial implications that derive from this common brain disease.

Outside the formal sessions, the aim is to facilitate communication and exchange of ideas among people with epilepsy, those who care for them and professionals in the field right across Europe.

The programme includes morning plenary sessions and afternoon discussion groups with as large as possible participation by delegates. The discussion group sessions will look at Epilepsy and Memory, Epilepsy and Employment and at Fundraising.

And all of this will happen in the beautiful city of Prague, Czech Republic. Located in the centre of Europe, Prague is very easily accessible from most countries in Europe and with many low-cost airlines offering frequent economic flights to the city. We'd love to meet you there! For more information visit

[www.epilepsyandsociety.org](http://www.epilepsyandsociety.org)

## 14<sup>th</sup> IBE EUROPEAN CONFERENCE ON EPILEPSY & SOCIETY



# Avances en el cumplimiento de la Estrategia y Plan de Acción sobre Epilepsia de la Organización Panamericana de la Salud (OPS) 2012-2021

Progress in implementing the Strategy and Plan of Action on Epilepsy of the PanAmerican Health Organization (PAHO) 2012-2021



## Actividades en el marco de la colaboración con OPS

Activities within the framework of collaboration with PAHO

### 2014-2016

#### 2014

**Septiembre:** Reunión conjunta OPS IBE ILAE, en 8° Congreso Latino-americano de Epilepsia, Buenos Aires - Argentina.

*September: PAHO/IBE/ILAE joint meeting during the 8th Latin American Epilepsy Congress, Buenos Aires, Argentina.*

**Diciembre:** Reunión estratégica OPS, en Reunión Anual AES - Washington.

*December: PAHO strategic meeting at the Annual AES meeting, Washington.*

#### 2015

Creación de red de Centros Colaboradores de OPS/OMS en Chile.

*Creation of a network of collaborating centres of PAHO/WHO in Chile.*

Reuniones sobre la Ley, su marco legal de las personas con epilepsia en Latinoamérica - Chile.

*Meetings on the legal framework for people with epilepsy in Latin America. Chile.*

**Junio:** Semana Boliviana de Epilepsia.

*June: Epilepsy Week in Bolivia*

**Agosto:** Taller Regional Tegucigalpa en Honduras.

*August: Regional Workshop in Tegucigalpa, Honduras*

**Noviembre:** Presentación Plan Estratégico sobre epilepsia para las Américas, durante el 22° Congreso Mundial de Neurología – Santiago de Chile.

*November: Presentation of the Strategic Plan on Epilepsy for the Americas during the 22nd*

*World Congress on Neurology - Santiago de Chile*

**Diciembre:** Reunión Técnica en Lima, Perú. Asesoramiento a Universidad de Salud Peruano para crear un programa nacional de epilepsia, coordinado por OPS Perú. Lima.

*December: Technical Meeting in Lima, Consulting with the Peruvian University of Health to create a national epilepsy program, coordinated by PAHO Peru.*

#### 2016

Libro Epilepsia en Latinoamérica OPS, Washington, USA.

*Publication of 'Epilepsy in Latin America, PAHO Washington DC, USA*

# La información sobre el Plan

La estrategia y plan de acción 2012-2021 se basan en una visión general de las Américas en el campo de la epilepsia; sin embargo, existen grandes diferencias entre los países y aún dentro de un mismo país. El documento recoge la experiencia alcanzada en nuestro continente, expresa el compromiso de los gobiernos y es compatible con el programa de acción mundial mhGAP.

Los enfoques de género, etnicidad y diversidad cultural, así como los abordajes de atención primaria de salud, promoción de la salud, derechos humanos y protección social, son ejes transversales de todas las áreas estratégicas. La atención a los grupos vulnerables o con necesidades especiales será priorizada.

Para apoyar esta estrategia y plan de acción, la OPS trabaja en colaboración con la ILAE, la IBE y otros asociados; asigna prioridades y moviliza recursos. Se alienta la cooperación entre los países.

## Principios y valores:

1. acceso universal;
2. equidad;
3. solidaridad panamericana;
4. respeto de los derechos humanos de las personas con epilepsia;
5. participación social;
6. uso de las mejores pruebas científicas disponibles;
7. protección de los grupos vulnerables;
8. respeto a los marcos históricos y culturales de las comunidades;
9. atención integral en materia de salud;
10. responsabilidad y rendición de cuentas.

## Information on the Action Plan

*The strategy and action plan 2012-2021 are based on an overview of the Americas in the field of epilepsy; however, there are large differences between countries and even within the same country. The document reflects the experience gained in the Americas, expresses the commitment of governments, and supports the global action program mhGAP.*

*Approaches to gender, ethnicity and cultural diversity, and approaches to primary health care, health promotion, human rights and social protection are keystones in all strategic areas. Attention to vulnerable groups with special needs will be prioritized.*

*To support this strategy and action plan, PAHO works in collaboration with the ILAE, the IBE and other partners; assigns priorities and mobilizes resources. Cooperation among countries is encouraged.*

## Principles and values:

1. universal access;
2. equality;
3. Pan American solidarity;
4. respect for the human rights of people with epilepsy;
5. social participation;
6. use of the best available scientific evidence;
7. protection of vulnerable groups;
8. respect for the historical and cultural frameworks of communities;
9. comprehensive care in health;
10. responsibility and accountability.



## VISION

La OPS encabeza los esfuerzos de colaboración para que los Estados Miembros logren que toda la población del continente americano disfrute de una óptima salud e impulsen el bienestar de sus familias y comunidades.

## PROPOSITO

Fortalecer la respuesta integrada del sector de la salud, mediante la ejecución de programas apropiados de atención a las personas con epilepsia a lo largo de la vida, que incluyan acciones de prevención, tratamiento y rehabilitación.

## VISION

*PAHO is leading collaborative efforts for Member States to achieve optimal health for the entire population of the Americas and to promote the welfare of families and communities.*

## PURPOSE

*To strengthen an integrated response in the health sector, through the implementation of appropriate programs of care for people with epilepsy throughout life, including actions for prevention, treatment and rehabilitation.*

# FUTURE CONGRESSES

[epilepsycongress.org](http://epilepsycongress.org)





**CANCÚN** 2016  
20-23 de Agosto




INTERNATIONAL  
LEAGUE  
AGAINST  
EPILEPSY  
Founded 1909

**IX** CONGRESO  
LATINOAMERICANO DE **EPILEPSIA**



**PRAGUE**  
14<sup>th</sup> European Conference on  
**EPILEPSY & SOCIETY**  
15-16 September  
**2016**  International  
Bureau  
for  
Epilepsy



2<sup>ND</sup> - 6<sup>TH</sup> SEPTEMBER  
**BARCELONA 2017**  
**32<sup>ND</sup> INTERNATIONAL EPILEPSY CONGRESS**

