

INTERNATIONAL

Epilepsy News

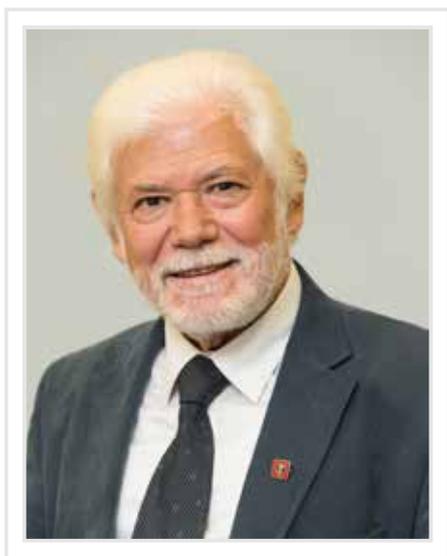
Reporting epilepsy news for 52 years

1963-2015



MIDTERM REVIEW
Istanbul Congress Issue

PRESIDENT'S LETTER



Dear Friends

Just over two years have elapsed since we took office in 2013. Two major activities occupied most our time with collaboration with our main partner, ILAE, being crucial. Both ILAE and IBE, as international bodies, have the following objectives: to increase public awareness and education; to fight stigma and protect human rights of people with epilepsy; to improve healthcare and access to medicines; and to increase investment in epilepsy research.

With our national, regional and international congresses we contribute to better education for all stakeholders involved in advocating epilepsy issues worldwide. Being invited to regional and national events as key speakers, we join forces to pressurise policy makers to improve health care for people with epilepsy and to apply or enforce human rights in social life, education and employment.

The main collaborative activities with ILAE have been International Epilepsy Day - a global event of epilepsy awareness - and our efforts to have the global burden of epilepsy and the need for coordinated action at country level on the WHO agenda.

The launch of International Epilepsy Day was realised in February 2015 and was celebrated by our members worldwide, as well as in the heart of Europe - the European Parliament. International Epilepsy Day will continue to grow in strength over the coming years. We recently have had the good news from our Italian member, that their national epilepsy day is

Two years of activities

being changed to coincide with the International Epilepsy Day in February.

The strongest part of our mission is to improve epilepsy care and quality of life of people with epilepsy and those who care of them. IBE, ILAE and WHO joined forces to have epilepsy on the agenda of the World Health Assembly for approval on May 26th, 2015 of a Resolution on Epilepsy. The support of 43 countries, many speaking on behalf of other countries in the Region, and the co-sponsorship 19 countries, shows the support we received worldwide. The resolution is now an official WHO document demanding a plan of action at national level. So Istanbul should be the start of the next most important step of our mission, which is to develop action plans for those countries where 80% of the people with epilepsy have no access to appropriate treatment.

As I write, I am preparing for the 31st International Epilepsy Congress in Istanbul, where I hope to meet many of you. The congress is an ILAE/ IBE educational event that gathers scientists and other professional and social advocates to exchange ideas, combine research projects, and develop networks of communication.

In this issue of International Epilepsy News you will have the opportunity to read many other activities that have taken place during the last two years.

To those of you in Istanbul, I wish you an enjoyable and very informative congress.

With best wishes to all,

Athanasios Covanis
President



International Epilepsy News
Issue 3 - 2015

EDITORIAL TEAM

Editor and Coordinator: Ann Little

Email: ibedublin@eircom.net

Regional Sub Editors:

- ⊙ Youssouf Noormamode (Africa)
- ⊙ Chahnez Triki (East Mediterranean)
- ⊙ Anastasia Vassou (Europe)
- ⊙ Tomás Mesa (Latin America)
- ⊙ Mary Secco (North America)
- ⊙ P Satishchandra (South East Asia)
- ⊙ Denise Chapman (Western Pacific)

Advisors:

- ⊙ Athanasios Covanis
- ⊙ Robert Cole
- ⊙ Sari Tervonen
- ⊙ Mike Glynn
- ⊙ Ding Ding
- ⊙ Philip Gattone
- ⊙ Najib Kissani
- ⊙ MM Mehndiratta
- ⊙ Janet Mifsud
- ⊙ Lilia Núñez-Orozco
- ⊙ Anthony Zimba
- ⊙ Emilio Perucca
- ⊙ Helen Cross
- ⊙ Sam Wiebe

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).

All rights, including moral rights, reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, without the prior permission in writing from the publisher. The Editor reserves the right to edit content for reasons of space or clarity. The views expressed in this magazine are not those of the publisher. Articles covering medical aspects of epilepsy are not intended to be taken as advice; they are not intended to replace medical care.

In this issue

Dear Readers



They say it is a sign of age when time appears to speed up, and it seems as though we have just returned from the last International Epilepsy Congress when already two years have flown by.

So, as we reach the mid-term of the current committees, I thought it was a good time to look back at what has happened since Montreal 2013, as it

can be easy to forget what we have achieved as we concentrate on our latest efforts. Yes, forgetfulness is another sign of age - you don't need to remind me of that either.

But this issue is not just a playback on past endeavours, it also focuses on the latest news and events and looks forward to the next few years as the new Strategic Plan 2015-2018 and the proposed changes to the Constitution and Bye-laws are put to the General Assembly for approval.

There is lots happening at the congress with an excellent programme, but we hope that you will also find time to visit us at the IBE Exhibition Booth, where you will have the chance to use our Selfie Spot to send a photo to family, friends and colleagues.

In the meantime, find a quiet spot to sit down, relax and enjoy this magazine. Above all, to all those in Istanbul - I wish you a wonderful congress!

Until next time - good reading,

Ann Little
Editor

Coming in the next issue



Getting ready for 2015

MEMBERS NEWS



from around the world



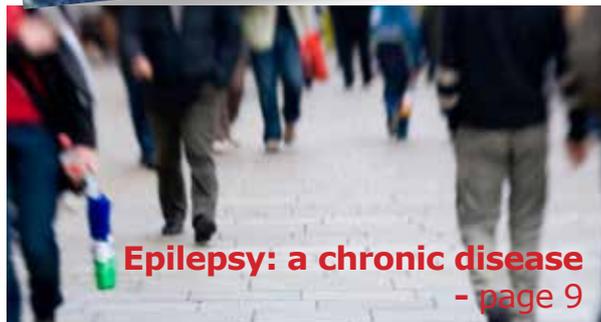
WELCOMING NEW MEMBERS
- page 7



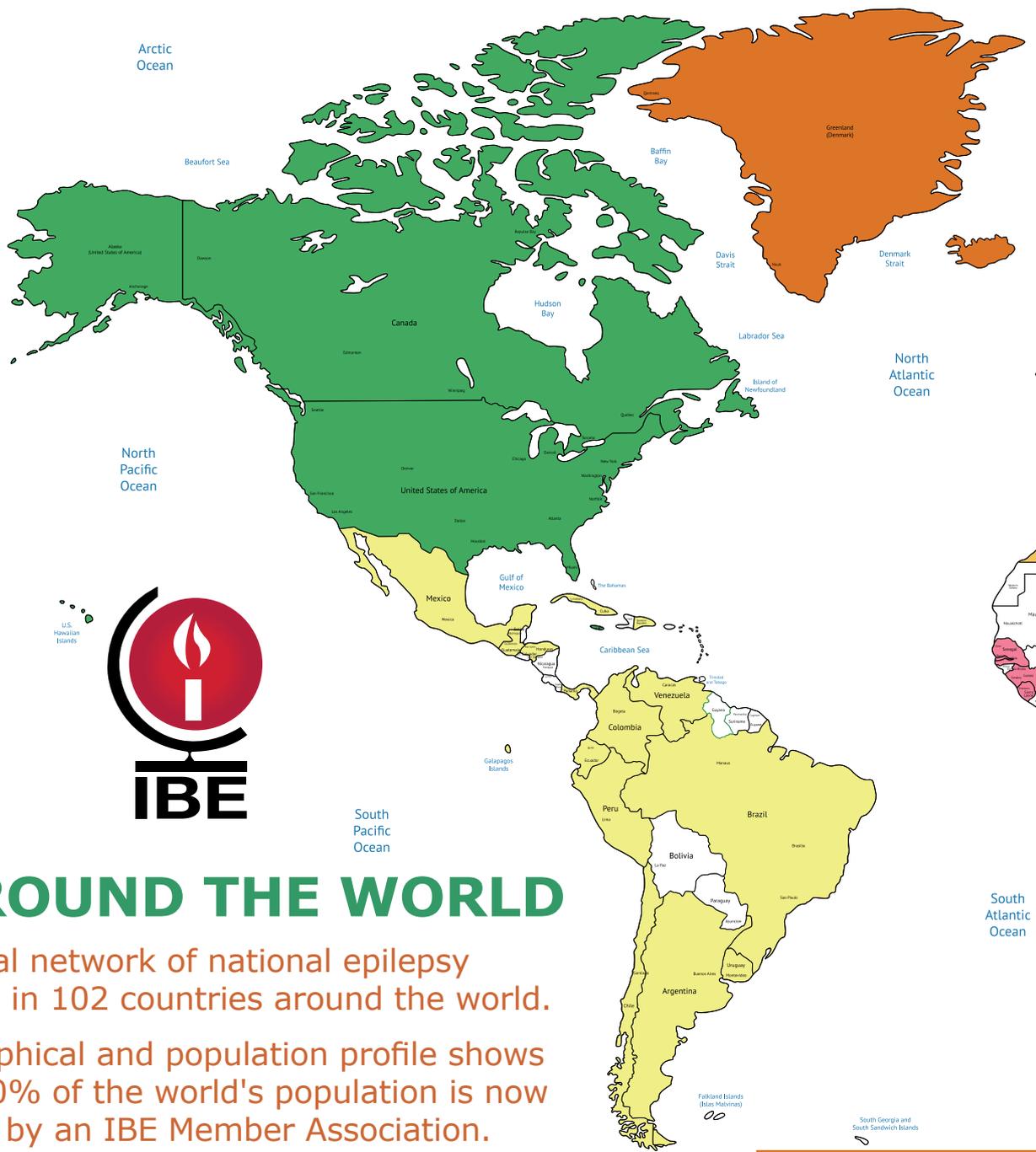
Regional Congress look-back-
page 12



REGIONAL COMMITTEE
MEETINGS - page 19



Epilepsy: a chronic disease
- page 9



IBE AROUND THE WORLD

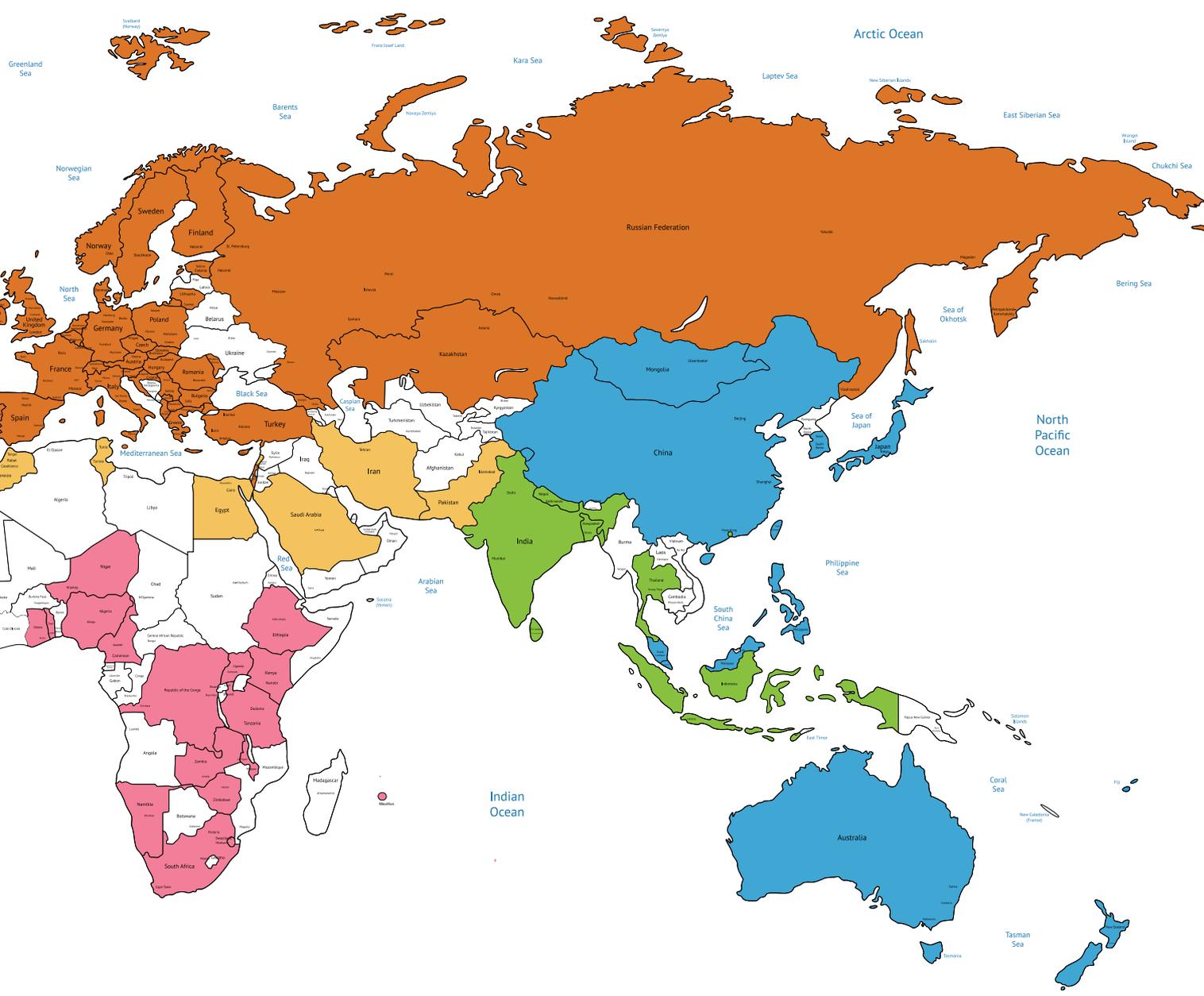
A global network of national epilepsy associations in 102 countries around the world.

Our geographical and population profile shows that over 90% of the world's population is now covered by an IBE Member Association.

- North American Regional Committee**
- Canada
 - Jamaica
 - USA

- Latin American Regional Committee**
- Argentina
 - Brazil
 - Chile
 - Colombia
 - Cuba
 - Dominican Republic
 - Ecuador
 - Guatemala
 - Honduras
 - Mexico
 - Panama
 - Peru
 - Uruguay
 - Venezuela

- European Regional Committee**
- Albania
 - Austria
 - Belgium
 - Bulgaria
 - Croatia
 - Cyprus
 - Czech Republic
 - Denmark
 - Estonia
 - Finland
 - FYR Macedonia
 - France
 - Georgia
 - Germany
 - Greece
 - Hungary
 - Iceland
 - Ireland
 - Israel
 - Italy
 - Kazakhstan
 - Lithuania
 - Luxembourg
 - Malta
 - Moldova
 - Netherlands
 - Norway
 - Poland
 - Portugal
 - Romania
 - Russian Federation
 - Scotland
 - Serbia
 - Slovakia
 - Slovenia
 - Spain
 - Sweden
 - Switzerland
 - Turkey
 - UK



- African Regional Committee**
- Cameroon
 - Congo, DR
 - Ethiopia
 - Gambia
 - Ghana
 - Kenya
 - Malawi
 - Mauritius
 - Namibia
 - Niger
 - Nigeria
 - Senegal
 - Sierra Leone
 - South Africa
 - Swaziland
 - Tanzania
 - Togo
 - Uganda
 - Zambia
 - Zimbabwe

- Eastern Mediterranean Regional Committee**
- Egypt
 - Iran
 - Lebanon
 - Morocco
 - Pakistan
 - Saudi Arabia
 - Tunisia

- South East Asian Regional Committee**
- Bangladesh
 - Hong Kong
 - India
 - Indonesia
 - Nepal
 - Sri Lanka
 - Thailand

- Western Pacific Regional Committee**
- Australia
 - China
 - Fiji
 - Japan
 - Korea
 - Malaysia
 - Mongolia
 - New Zealand
 - Philippines
 - Singapore
 - Taiwan

FILLING THE GAPS

Although IBE has members in 102 countries worldwide, there are a further almost 100 countries or states without an IBE association.

Can you help us fill the gaps? If you can help, please let us know.

AFRICA

- Algeria
- Angola
- Benin
- Botswana
- Burkina Faso
- Burundi
- Cape Verde
- Central African Rep
- Chad
- Comoros
- Congo
- Cote d'Ivoire
- Equatorial Guinea
- Eritrea
- Gabon
- Guinea
- Guinea-Bissau
- Lesotho
- Liberia
- Madagascar
- Mali
- Mauritania
- Mozambique
- Rwanda
- Sao Tome & Principe
- Seychelles

EASTERN MEDITERRANEAN

- Afghanistan
- Bahrain
- Djibouti
- Iraq
- Jordan
- Kuwait
- Libya
- Qatar
- Somalia
- Sudan
- Syrian Arab Rep
- United Arab Emirates
- Yemen
- Palestine

EUROPE

- Andorra
- Armenia
- Azerbaijan
- Belarus
- Bosnia & Herzegovina
- Kosovo
- Kyrgyzstan
- Latvia
- Monaco
- Montenegro

- Romania
- San Marino
- Tajikistan
- Turkmenistan
- Ukraine
- Uzbekistan

LATIN AMERICA

- Belize
- Bolivia
- Costa Rica
- Dominica
- El Salvador
- Guyana
- Haiti
- Nicaragua
- Paraguay
- Suriname
- The Caribbean

NORTH AMERICA

- Antigua & Barbuda
- Bahamas
- Barbados
- Grenada
- St Kitts & Nevis
- St Lucia
- Trinidad & Tobago

SOUTH EAST ASIA

- Bhutan
- Dem People's Rep of Korea
- Maldives
- Myanmar

WESTERN PACIFIC

- Brunei Darussalam
- Cambodia
- Cook Islands
- East Timor
- Kiribati
- Lao People's Dem Rep
- Marshall Islands
- Micronesia
- Nauru
- Niue
- Palau
- Papua New Guinea
- Samoa
- Solomon Is
- Tonga
- Tuvalu
- Vanuatu
- Viet Nam

Welcoming New Members 2013-2015

Epilepsy Fiji
Fiji
Western Pacific Region



Traditional home, Fiji

Georgian Society
of Young Epileptologists,
Tbilisi, Georgia,
European Region



Tbilisi, Georgia

Federazione Italiana Epilessie - FIE
Milan, Italy
European Region



Vittorio Emanuele
Gallery, Milan

Association d'Aide aux Personnes
Epileptiques
Luxembourg - European Region



Luxembourg
Old Town

Association Supporting
Children with Special Needs
Chisinau, Rep of Moldova
European Region



Chisinau, Moldova

SUDEP Action
Wantage, UK
European Region



Abingdon near Wantage

LI XUANLI - A Chinese girl told her story in September 2013

Interview with Sari Tervonen, CEO Finnish Epilepsy Association and IBE Secretary General

Photo: Ann Little



23 year-old Li Xuanli from Cheng du talked about her personal experiences at the 5th China International Epilepsy Forum in Chongqing. Li has had epilepsy since she was 19 years old, but is seizure free with medication.

She works for customer service in a company selling wedding dresses. She is involved in many QQ (Chinese Facebook) groups in which the members have epilepsy. There are around 150-200 members in each group she is attending.

Li was asked to speak about her epilepsy at the meeting. She wanted to encourage other people with epilepsy to trust in themselves, so that they can enjoy a better way of life. "Stay confident", she emphasised.

She advises people with epilepsy to be active in seeking informa-

tion about the disease and to share their thoughts with others in similar lifecycles.

IE News asked about her future wishes: "I would like to find a job that would involve the English language" tells Li. For that she is studying English. Maybe you will meet her in a Chinese Embassy one day when you are applying for a visa to travel to China!

IE News was very grateful to Li for having the courage to speak about her epilepsy, which does not usually happen in China. In China many people still hide their epilepsy because of the stigma they will face. But, of course, China is not alone in this.

It's a long way to a world without prejudice, but every step is important, both in large and smaller countries. Li is one brave person who is taking these steps.



13TH EUROPEAN CONFERENCE ON

Epilepsy & Society

LJUBLJANA, SLOVENIA

28TH - 30TH AUGUST 2013



LJUBLJANA 2013

In late August 2013, IBE celebrated the 13th Epilepsy & Society Conference in Ljubljana - one of Europe's smallest and prettiest capital cities.

The delegates enjoyed a programme that focused in the main on social issues but there were also some sessions, introduced for the first time, for professionals such as EEG technicians, epilepsy specialist nurses, paramedics and general practitioners.

A novel addition to the programme was a debate for and against the motion that 'representations of epilepsy in popular culture break down stereotypes'. This led to very interesting and heated discussion!

A highlight of the conference was a presentation on the European Union Written Declaration on Epilepsy, which was made by Jelko Kacin, a Member of the European Parliament (MEP) who addressed the meeting by video.

Salla Aatsinki, left, from Finland was interviewed by one of Slovenia's best known news presenters on her experiences of living with epilepsy. Her companion is Lipko, the mascot of the European basketball championships that took place in the city after the congress.

Outside the main congress programme, delegates enjoyed a special reception in the Town Hall, hosted by the Major of Ljubljana, Loran Janković.

The next Epilepsy & Society Conference will take place in Prague in 2016.

EPILEPSY: A chronic, life-long, non-communicable disease

A 19 Member Task Force spent 2 years in finalising the new operational definition of epilepsy. The results of their work were announced in mid-2014.

For people with epilepsy and their families, one of the most contentious aspects of the new definition was the decision, agreed by both IBE and ILAE, to refer to epilepsy as a 'disease'.

An article by Mike Glynn, IBE Immediate Past President, CEO of Epilepsy Ireland and a member of the ILAE Task Definitions Task Force, explaining why he was in favour of the new term, was published in IE News last year. An abridged version of his powerful argument, from Issue 3-2014, is published below.

At least 30% of people with epilepsy will continue to have seizures, rising as high as 90% in some developing countries. For these people epilepsy is an acute, chronic, life-threatening disease.

Many people, whose epilepsy is controlled, are very happy to refer to it as just a small "disorder" that upset their lives for a while. However, using mild terms, such as "disorder", to describe epilepsy undoubtedly contributes to this notion that it is benign. The "mistaken belief that epilepsy is a benign condition"¹ is almost certainly to have led to SUDEP being hidden for 80 years. It is now recognised as a leading cause of death in epilepsy.

American PR practitioner Lynda Resnick said that "when people affected by epilepsy are reluctant to expose their condition, the public remains in the dark about it – the tragic irony that has made patient care and raising funds for research more than challenging"². Prostate and breast cancer and heart traumas would not receive the same attention if those who suffered from them refused to call them diseases, but insisted they were just "disorders".

The general public does not recognise epilepsy as a serious problem³. As long as this situation continues, the search for cures for epilepsy will be stymied through lack of proper funding for research and care, and through a lack of support from the public.

There is a great, unresolved debate about whether epilepsy should be viewed as a separate symptom of underlying brain disease or as one or more idiopathic diseases or syndromes⁴. However there is no debate amongst epileptologists about whether or not epilepsy is a disease: only what type of disease or diseases it is. This debate has continued in some form from the time when the ancient Greeks called epilepsy the sacred disease, even while Hippocrates held



the view that it was a brain disease. As early as the 3rd century Galen classified epilepsy into three categories of disease⁴. These attempts to achieve a better form of classification of epilepsy as a disease continue to this day.

The new ILAE Definition of Epilepsy states that "Epilepsy is a disease of the brain"⁵. This is a very important step forward in ensuring that legislators, public health officials, media people and funders see epilepsy for what it is: a major serious health issue which can destroy lives.

The epilepsy community should now begin to build on this new start to create a future where no person's life is blighted by this chronic disease.

References:

1. Hanna, N.J. et al (2002) *The National Sentinel Clinical Audit of Epilepsy-Related Death: Epilepsy - death in the shadows*. The Stationery Office. p83.
2. Resnick, L. (2009) *Help us bring epilepsy out of the shadows*. [Internet], Huffington Post. [Accessed 1 October 2014]
3. Engel, J. (2009) *Do we belittle epilepsy by calling it a disorder rather than a disease?* *Epilepsia*, 51 (11), pp. 2363–2364.
4. Reynolds, E.H. and Rodin, E. (2009) *The clinical concept of epilepsy*. *Epilepsia*, 50(Supp.3), pp.2–7.
5. Fisher, R.S. et al (2014) *A practical clinical definition of epilepsy*. *Epilepsia*, 55(4), pp. 475–482.

Operational (Clinical) Definition of Epilepsy 2014

A person is considered to have epilepsy if they meet any of the following conditions:

1. At least two unprovoked (or reflex) seizures occurring greater than 24 hours apart.
2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years.
3. Diagnosis of an epilepsy syndrome.
4. Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or those who have remained seizure-free for the last 10 years, with no seizure medicines for the last 5 years.



EUROPEAN EPILEPSY DAY 2014

Organised by the ILAE/IBE joint task force Epilepsy Advocacy Europe, European Epilepsy Day was celebrated on 4 February 2014 in Strasbourg.

It was to be the final celebration of an annual European day for epilepsy and it was also to be the last European Epilepsy Day to be hosted by then Minister of the European Parliament, Gay Mitchell, who was retiring from political life a few months later. Gay Mitchell has since agreed to become a member of the joint task force (JTF).

Guest speaker at the event in Strasbourg

was EU Commissioner for Health, Tonio Borg. Members of the IBE European Regional Executive Committee also attended the event in the European Parliament and a large number of private meetings with MEPs took place.

European Epilepsy Day was also celebrated, across Europe, at national level by IBE and ILAE associations - from Ireland, at the most westerly of the continent, to the Russian Federation in its eastern extremity.

The theme for European Epilepsy Day in 2014 - Epilepsy is more than Seizures

- sent out a powerful message and has been used as the theme for other initiatives - including the first ever International Epilepsy Day in 2015.

While European Epilepsy Day has now been replaced by International Epilepsy Day, the first Monday in February is still a date in the calendar on which to bring epilepsy to the heart of Europe.

Photo: pictured outside the parliament building are, from left: Christian Elger (JTF), Meir Bialer (JTF), Gay Mitchell, Tonio Borg, Philippe Ryvlin (JTF) and Thanos Covanis (JTF).

Día Latinoamericano de la Epilepsia



Latin American Epilepsy Day is the oldest regional day promoting awareness and understanding about epilepsy. It dates back 15 years to 2000 and was officially launched at the 1st Latin American Epilepsy Congress, which took place in Santiago de Chile.

It is probably no surprise then that the

biggest celebrant of Latin American Epilepsy Day in 2014 was the Chilean League Against Epilepsy - ANCLICHE. Halting normal traffic, a Bikeathon attracted over 600 participants.

This was the first bike event in Santiago de Chile to be organised for a good cause. The initiative's aim was to show

that most people who have epilepsy can live a normal active life; that the real problems still existing for people with epilepsy are stigma and discrimination.

Latin American Epilepsy Day was also celebrated in Colombia, Guatemala, Honduras and Mexico.

WHO Regional Committee Meetings 2014

Representatives from IBE's Regional Committees in Europe, South East Asia and Western Pacific, attended the WHO regional meetings in 2014 to raise the profile of IBE



66th Session of the WHO Regional Committee for South East Asia

The meeting took place in New Delhi and was attended by Dr Man Mohan Mehndiratta IBE Vice President South East Asia



64th Session of the WHO Regional Committee for Western Pacific

Robert Cole, IBE Treasurer participated at the meeting, in Manila, calling for an Epilepsy Strategy for the region



63rd Session of the WHO Regional Committee for Europe

Michael Alexa, Vice Chair, IBE European Regional Executive Committee, attended the meeting in Izmir, Turkey

Regional Epilepsy Congresses 2014

2014 was the year of the IBE/ILAE congresses with the 2nd African Epilepsy Congress in Cape Town, 10th Asian Oceanian Epilepsy Congress in Singapore and the 13th Latin American Epilepsy Congress in Buenos Aires. For IBE, a highlight of these congresses was

the special programme for people with epilepsy, their families and caregivers. These programmes provide the platform for people with epilepsy and their families to share experiences, both good and bad, of lives lived with a diagnosis of epilepsy.

2nd African Epilepsy Congress CAPE TOWN 2014



"My goal is to inspire young people to never give up on their dreams"



This was the positive message from Nicola Laxton (pictured left with her mother Danica), a beautiful young woman from South Africa who, at the age of 9 was diagnosed with Absence seizures. Her story was an inspiration to many who attended the Epilepsy & Society Symposium at the congress in Cape Town.

Like many young people with epilepsy, she encountered problems when she was a teenager - being teased by her peers and missing days at school due to seizures.

But her determination to deal head-on with the challenges that life threw her way has seen her overcome these difficult times.

She won the Miss South Africa Teen competition and discovered her love for drama. At the time of the congress she was studying for a Performer's Diploma

through Trinity College, London. Her talent saw her being accepted to study an Honours Programme in Design at the School of Visual Arts in New York. She has modelling contracts in Johannesburg and with Topmodel in the UK. In her free time, she volunteers as a Youth Ambassador with Epilepsy South Africa. A true inspiration to others!

A very interesting presentation, which had delegates hanging on to every word, was on Traditional Healers. For many people, this was the first time to hear about efforts to educate traditional healers in modern approaches to epilepsy care. This was a truly fascinating session, presented by Johannah Keikelame from South Africa, who has been involved in this area for many years. Johannah was accompanied by two traditional healers in their colourful costumes (pictured left with Johannah standing centre).

The congress attracted a significant level of media interest. A local radio station devoted an hour long session to discussion on epilepsy, involving IBE President Thanos Covanis and Michael Alexa (a congress delegate from Austria), while the photo left shows Anthony Zimba, IBE Vice President Africa, being interviewed by the national TV station.



SINGAPORE 2014

Outstanding Persons Award

Recognising people with epilepsy who have made a difference

The Epilepsy & Society Symposium attracted 190 delegates from both Singapore and across the region. Recognizing that epilepsy is a condition that impacts the entire family, a family delegate rate was introduced to facilitate attendance by family units.

Topics ranged from anticonvulsants to stigma at work and school, and the truth about reflexology and stem cell therapy for epilepsy, as well as experience sharing by people with epilepsy and caregivers.

A special element of the symposium was recognition of the Outstanding Persons awardees, who had received their awards

during the congress Opening Ceremony.

Nominated by the national associations, the awards recognise people with epilepsy, or who play a special role in the care of people with epilepsy, who achieve great things despite having epilepsy in their lives.

The symposium closed with a Minifair. Booths showcased seizure first aid guidance, educational games stations (including the still popular IBE Action Zone! game), cognitive and behavioural strategies in epilepsy and videos from IBE groups around the region.

Many opportunities for discussion and

networking were made, friendships were renewed and new acquaintances made.

A highlight of the meeting was the evening of the 9th August. Delegates venturing to the quayside were treated to the fireworks display crowning Singapore's National Day celebrations.

Photos, from left:

- Enjoying Action Zone! at the Minifair;
- Ming Ying Goi (seated), a speaker at the Symposium, with Diana Koh and Sherman Goh, from Singapore;
- Shehaz Haveliwala, India and Robert Wierzbicki, Australia, both received Outstanding Persons with Epilepsy Awards.



Initiative and Strategic Plan for Epilepsy in the Americas

In addition to a very successful congress programme, an important meeting took place to discuss the Strategic Plan for the Americas. The plan has been in operation since 2011 and this was an opportunity to review progress to date and to plan for the coming years. Among the participants were Dr Devora Kestel, PAHO Department of Mental Health, Washington DC and Dr Viviana Venegas, Ministry of Health, Chile.

Dr Kestel presented an update on the Epilepsy Report for Latin America and the Caribbean and emphasised that the information in the report comes from ministries of health and is considered official data. The report is updated every

two years as new data are collected. Dr Marco Medina and Dr Carlos Acevedo, co-chairs of the Strategic Plan Task Force gave an update on activities for the previous 12 months while Dr Venegas gave an account of the main activities that the Chilean ministry of health has been engaged in in relation to the management of epilepsy in 2013, including the addition of Lamotrine and Levetiracetem to the national plan of epilepsy and the start of an educational plan for primary health team-care.

The meeting concluded by confirming the strong three-way relationship of ILAE/IBE/PAHO.



17-20 Setiembre 2014
BUENOS AIRES
 VII CONGRESO LATINOAMERICANO DE EPILEPSIA

Buenos Aires 2014

Considering, Addressing and Developing

During 2014 and 2015, IBE carried out three distinct activities but all with a common link - IBE's governance and future direction

MEMBERS SURVEY

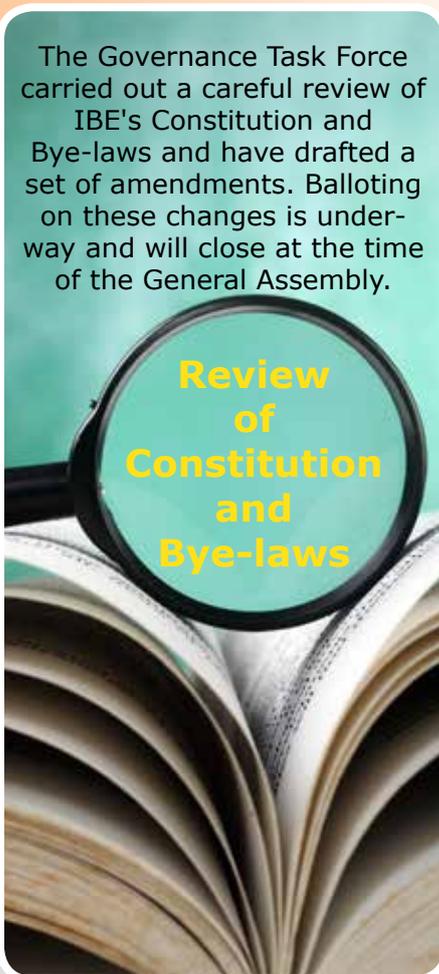
In planning for future activities and defining our aims and objectives, it is very important to have a good understanding of how our members operate. Of course, it is also vital to know our members views on how IBE is doing - what we are getting right, what we could do better and what we are getting wrong.

In early 2014, Secretary General Sari Tervonen facilitated a survey of IBE members with the aim of collecting data that would inform our future planning. Responses were received from 45 Member of a possible total of 132, with 76% of responses coming from Full Members. While the response rate was approximately 1/3 of all members, what was clear to see

was that our membership is hugely diverse. For example, 32% of the members who responded had no paid staff, while 14% had more than 20 salaried staff members. Size does count - 7% of members had more than 50 branches or affiliates, but 23% had just one office. The majority - 57% - had between one and 10 branches or affiliates.

The responses we received to questions on our future strategy were very important to us. For example, one comment was 'IBE needs to have 3-4 main goals that should be written clearly. The theme 'Epilepsy is more than Seizures' is a good starting point for clarifying a goal'. We agree - and we have taken that on board!

The Governance Task Force carried out a careful review of IBE's Constitution and Bye-laws and have drafted a set of amendments. Balloting on these changes is underway and will close at the time of the General Assembly.



Review
of
Constitution
and
Bye-laws

STRATEGIC PRIORITIES 2015-2018

Mindful of the views of the Members, the key strategic priorities for the next 3 years are clear, but powerful



Epilepsy is a health priority worldwide



Human and civil rights of people with epilepsy are enhanced and protected worldwide



People with epilepsy are empowered to maximise quality of life



Promotion of research into prevention, treatment, care and consequences of epilepsy

International Epilepsy Day is launched

- but not quite into outer space!

Around the world, on Monday 9th February 2015, people with epilepsy, their families, friends, work colleagues and caregivers, came out in force to celebrate the first International Epilepsy Day.

An initiative of ILAE and IBE - an International Epilepsy Day website epilepsy.org was also launched.

National associations and other stakeholders organised a great number of fundraising, awareness raising and educational activities on the day and everyone was invited to take part in the **#epilepsyday** Selfie photo event.

This brave man in Spain went to a whole new level to make his photo something special!

International Epilepsy Day 2015 will be celebrated on Monday 8th February 2016. Make sure to get involved!



RESOLUTION on global burden of epilepsy approved at World Health Assembly

Tuesday 26 May, 2015: the World Health Assembly approves a WHO Resolution on the global burden of epilepsy, calling on UN Member States to:

1. strengthen effective leadership and governance to address the specific needs of people with epilepsy, and make resources available as necessary to implement evidence-based plans and actions;
2. introduce and implement national health care plans of action for epilepsy management, aiming to overcome inequalities and inequities

3. integrate epilepsy management into primary health care where appropriate to reduce the treatment gap, by training non-specialist health care providers and by empowering people with epilepsy and their carers for greater use of specified self and home care programmes;
4. improve accessibility to and promote affordability of safe, effective and quality-assured antiepileptic medicines;
5. ensure public awareness of and education about epilepsy, in particular in primary and secondary schools, to

6. help to reduce the misconceptions, stigmatization and discrimination regarding people with epilepsy and their families;
6. promote actions to prevent causes of epilepsy, using evidence-based interventions;
7. improve investment in epilepsy research and increase research capacity;
8. engage with civil society and other partners in these actions.

Approval of the Resolution represents a major success for IBE, ILAE and their long-standing partnership with WHO. A special poster exhibition has been designed for the congress in Istanbul, which gives extensive information on this historic achievement.

IN REMEMBRANCE

Recalling colleagues who have left us



Mike Hill

Passed away May 2013

Mike Hills first took office as IBE Secretary General in 1993. He was to remain on the Executive Committee for 12 years, serving twice as Secretary General and a further term as Vice President.

Mike was a member of the Constitutional Review Task Force that drafted IBE's current Constitution, bringing his, not inconsiderable, knowledge in matters of governance to the table.

Mike was a member of the Election Task Force, first as its Chair and, more recently, as a Member - a position he still held at the time of his untimely passing.

He was awarded the IBE/ILAE Ambassador for Epilepsy Award in 1999 and the Social Accomplishment Award in 2009.



Harry Meinardi

Passed away December 2013

Harry Meinardi was a loyal supporter of IBE since he first took office as IE News Editor on the IBE Executive Committee in 1973. He went on to work on the IBE Executive Committee for 12 years, serving as President (1977-1981) and Past President (1981-1985). He was the only person to serve as both IBE President and ILAE President (1989-1993).

He was to remain involved in the work of IBE until shortly before his death, when he penned the last instalment of the terrific *Look Back with Pride* series of articles on the history of IBE, as catalogued through International Epilepsy News.

He received two IBE/ILAE congress awards - Ambassador for Epilepsy Award in 1971 and Lifetime Achievement Award in 2001.



Frank Gouveia

March 2015

Frank Gouveia first became involved in the work of IBE when he joined Epilepsy New Zealand as its Chief Executive Officer in 2006, after a successful commercial career.

Soon after, he began to support IBE in developing new members in less developed regions and, in particular, the Fijian Islands. It was unfortunate that he was to pass away just weeks before the Full Member application of Fiji was ratified.

In 2013 he was elected Vice Chair of the IBE Regional Executive Committee, a role he stepped in to with great energy and drive. His most recent involvement was at the Asian Oceanian Epilepsy Congress in Singapore 2014. It was with great sadness that IBE learned he had died just a few short months later.



Hello from ISTANBUL!

@IBESocialMedia



Photo Opportunity!



Make sure to visit us at the IBE Exhibition Booth where you will have the chance to take a Selfie shot, solo or with some colleagues, against our special Selfie Backdrop Wall. Then share your photo on IBE's Facebook Page @IBESocialMedia to let your friends see what they are missing!

International Epilepsy Day Souvenir

For the launch of International Epilepsy Day 2015, IBE and ILAE commissioned a souvenir screen cleaning cloth that features the International Epilepsy Day logo.

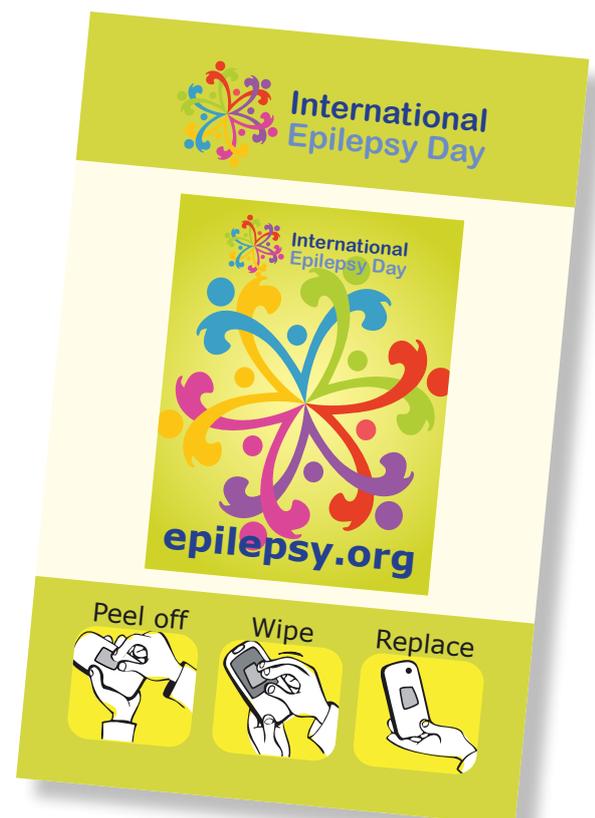
The cloths, which come on an instruction card, were presented as a small memento to each of the 751 Members of the European Parliament (MEP) when the first International Epilepsy Day was celebrated in the European Parliament last February.

We thought it would be nice to have a supply for IBE and ILAE supporters too, so we have brought a generous number with us to Istanbul.

Attaching easily to the back of a mobile phone, they can then be lifted off to clean the screen and replaced for further use. And they can be washed to keep them in perfect condition to leave your phone screen smudge free.

So, whether to act as a souvenir of International Epilepsy Day 2015 or to get you in the mood for the next celebration of International Epilepsy Day, on the second Monday of February 2016, why not come along to the IBE stand in the Exhibition Area and get your free cloth.

Available only while stocks last.



IBE General Assembly 2015

Marmara Room - Istanbul Lutfi Kırdar

Tuesday 8 September 2015

16:00 - 20:00

All IBE Members are invited to attend the assembly.

WE HOPE TO YOU SEE THERE!



AGENDA

Part One

Welcome Messages and Workshops

1. Opening Address
2. Greeting from ILAE
3. Discussion Workshops: three concurrent workshops in breakout sessions:
 1. IBE Strategic Plan
 2. WHO Resolution
 3. International Epilepsy DayCoffee break
Report back of workshops in Plenary

Part Two

Business Element

1. Minutes and Matter arising
2. Officer Reports: President, Secretary General and Treasurer
3. Executive Director's Report
4. Regional Reports
5. Task Forces
 - Legislation Task Force
 - Election Task Force
6. Governance Task Force: Approval of revised Constitution and Byelaws
7. Future Strategy
8. Joint Projects with ILAE: Global Outreach and Congresses
9. Presentation of New Members
10. Adjournment and Reception

Calling all IBE Members!

Don't miss the meeting of your
Regional Committee at the congress



WPREC
Western Pacific
Regional
Executive
Committee

WESTERN PACIFIC REGION

Sunday
6 September
Time: 13:00 - 15:00
Meeting Room:
Levent 3



EREC
European
Regional
Executive
Committee

EUROPEAN REGION

Tuesday
8 September
Time: 09:00 - 11:00
Meeting Room:
Levent 3



LAREC
Comité
Latino
Americano
del IBE

COMITÉ LATINO- AMERICANO

Martes
8 Setiembre
Hora: 13:00 - 14:30
Sala de Reunión:
Levent 3



SEAREC
South East Asian
Regional
Executive
Committee

SOUTH EAST ASIA REGION

Tuesday
8 September
Time: 14:30 - 16:00
Meeting Room:
Levent 3



FUTURE CONGRESSES

epilepsycongress.org



32nd International Epilepsy Congress BARCELONA 2017

