

# Annual Report 2014



International  
Bureau for Epilepsy



## Our Vision

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

## Our Mission

IBE exists to improve the social condition and quality of life of all people with epilepsy and those who care for them.

## International Executive Committee from July 2013 to 2017

**President:** Athanasios Covanis (Greece), **Secretary General:** Sari Tervonen (Finland), **Treasurer:** Robert Cole (Australia),  
**Immediate Past President:** Mike Glynn (Ireland)

### **Vice Presidents:**

**VP Africa:** Anthony Zimba (Zambia), **VP Eastern Mediterranean:** Najib Kissani (Morocco),  
**VP Europe:** Janet Mifsud (Malta), **VP Latin America:** Lilia Núñez (Mexico), **VP North America:** Philip Gattone (USA),  
**VP South East Asia:** MM Mehndiratta (India), **VP Western Pacific:** Ding Ding (China)

### **ILAE Ex Officio Members:**

**ILAE President:** Emilio Perucca (Italy), **ILAE Secretary General:** Helen Cross (UK), **ILAE Treasurer:** Samuel Wiebe (Canada)

## Partnerships

- Special Consultative Status on the Economic and Social Council of the UN (ECOSOC)
- Official working relations with the World Health Organization (WHO)
- Member of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO)
- Board Member of the European Federation of Neurological Associations (EFNA)
- Provisional Member of the European Patients' Forum (EPF)
- Close working partner with the International League Against Epilepsy (ILAE)



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IBE is a US registered not for profit organisation (Charter ID 721834-DNP) with tax exempt status 501(c)(3). EID 59:2606654

# PRESIDENT'S REPORT



**2014** was the first full year of the current term of office and was a busy year of activity and achievement.

One of the first activities of the year was European Epilepsy Day in February. This was also to be the last European Epilepsy Day as plans to supersede a European day for epilepsy with an international event were already underway. Similar to previous years, IBE associations across the region created a wide range of activities to create awareness about epilepsy and, at the same time, to raise funds for their work. At European level, once again we were hosted in the European Parliament in Strasbourg, meeting with Members of the European Parliament and with a poster exhibition on the theme *Epilepsy is more than Seizures*.

During the year, together with our partners, the International League Against Epilepsy, we also organised three regional congresses. The first of these was the 2nd African Epilepsy Regional Congress, which took place in Cape Town in late May. A highlight of the congress was the special IBE programme 'Epilepsy & Society', which had a high attendance of delegates including people with epilepsy, their families and care-givers.

The 10th Asian & Oceanian Epilepsy Congress, in Singapore in early August, also had a very successful and well attended 'Epilepsy & Society' programme in addition to the presentation of the Outstanding Persons with Epilepsy awards, which have become a special feature of the Asian congresses. The good news is that the awards may also be introduced by other IBE Regional Committees. This is a tremendous way of spotlighting those people with epilepsy who overcome their epilepsy to achieve great things.

The third regional congress, the 8th Latin American Regional Congress, took place in Buenos Aires in September with an excellent number of delegates attending. During the congress, an important meeting on the PAHO Strategic Plan for the Americas took place. Launched in 2011, the plan will run for 10 years and the meeting in Buenos Aires was to review progress to date and plan for the future.

In early 2014, the term of the European Parliament came to an end and ballots took place in each Member State to elect MEPs to start for the term 2014-2019. This provided the opportunity to advocate for epilepsy among delegates standing for election through the creation of a Manifesto, which was widely circulated in many of the languages of the EU. Following the elections, we began to renew the European Advocates for Epilepsy MEP group, with its new President, Brian Hayes MEP.

Our Secretary General, Sari Tervonen, facilitated a Members Survey, which has since been used in developing the IBE Strategic Plan for 2015-2018 and I would like to thank all of the members who participated. Linked to the Strategic Plan was the ongoing work of the Governance Task Force, in reviewing the Constitution and Bye-laws. To this end, the task force met in Stockholm in mid-2014 and work on drafting the new text got underway.

After two years of hard work, the ILAE Definitions Task Force produced the Definitions of Epilepsy 2014, which IBE has endorsed. The Task Force membership included two IBE representatives - Mike Glynn and Carlos Acevedo.

2014 was also a year of planning for the future and, in particular for the launch of the 1st International Epilepsy Day, that would take place in February 2015. A new dedicated website [epilepsy.org](http://epilepsy.org) was created and a competition was held to find the perfect logo. A range of materials was also developed to support members in celebrating the event at national level right across the world. A joint initiative of IBE and ILAE, over the years International Epilepsy Day will develop into the preeminent day for raising epilepsy awareness at global level.

Following some quiet background efforts, and thanks in particular to our friends in China and Russia, towards the end of the year we found that our efforts had borne fruit and that epilepsy would be on the agenda for the WHO Executive Board meeting in January 2015, with the exciting prospect of having a Resolution on epilepsy approved by the World Health Assembly. This would be a mammoth task, and would require much hard work and dedication, not only by the IBE and ILAE boards, but by IBE and ILAE chapters around the world. Little were we to know, as the year came to a close, just how well these efforts were to pay off! But that is for next year's report!

In closing I would like to thank to all those who have supported me over the last twelve months - my fellow members of the IBE Executive Committee, Regional Committees, Task Forces, Chapters and, in particular, Ann Little at the office. I would also like to mention the importance of the continued joint working relationship that IBE has with our partners in the International League Against Epilepsy. Together we can achieve great things.

With best wishes to all!

A handwritten signature in blue ink, appearing to read 'Athanasios Covanis'.

Athanasios Covanis  
President

# FINANCIAL REPORT

## Income and Expenditure Account

Year ended 31st December 2014

With comparative totals for 2013

	2014 US\$	2013 US\$
INCOME	811,656	1,654,938
EXPENDITURE	(1,407,579)	(1,564,009)
OPERATING (DEFICIT)/SURPLUS FOR YEAR	<u>(595,923)</u>	<u>90,929</u>

## Balance Sheet

Year ended 31st December 2014

With comparative totals for 2013

	2014 US\$	2013 US\$
CURRENT ASSETS		
Debtors	63,129	237,959
Cash in hand and at bank	2,474,325	3,173,786
Amount held on behalf of the IBE/ILAE Joint Task Force	152,760	200,661
	<u>2,690,277</u>	<u>3,612,406</u>
CREDITORS (Amounts falling due in one year)	(339,094)	(665,300)
NET CURRENT ASSETS	<u>2,351,183</u>	<u>2,947,106</u>
NET ASSETS	<u>2,351,183</u>	<u>2,947,106</u>
CAPITAL AND RESERVES		
General Reserve	2,321,824	2,921,736
Restricted and designated funds	29,359	25,370
	<u>2,351,183</u>	<u>2,947,106</u>

The financial statements were approved on 29 September 2015 and signed by:

Athanasios Covanis, President

Ann Little, Executive Director

## Statement of Income and Expenditure

Year ended 31st December 2014

With comparative totals for 2013

	2014 US\$	2013 US\$
<b>INCOME</b>		
Congress income received	520,883	1,549,202
Congress income receivable	205,318	-
Corporate donations	-	51,024
IBE/ILAE JTF management fee	20,041	20,924
IBE/ILAE JTF reimbursement of expenses (IBE 50%)	13,406	10,366
Membership dues and solidarity fund	10,609	9,106
Investment income	14,000	14,316
EPICURE grants	-	-
Miscellaneous income	-	-
	<u>811,656</u>	<u>1,654,93</u>
<b>EXPENDITURE</b>		
Congress expenditure	716,842	1,191,750
Office expenses	21,230	18,664
Printing and postage	342	1,239
Printing and postage - International Epilepsy News	-	18,220
Travel	89,844	85,166
Global Campaign costs	22,500	4,923
Accountancy fees	4,937	2,762
Audit fees	7,213	16,609
Administrator costs	64,809	200,359
Staff costs	90,015	-
Bank charges	1,400	2,317
Rent	22,433	19,666
Promising Strategies	11,321	25,606
Website costs	1,860	(4,564)
IBE JTF expenditure	13,406	10,366
Professional fees	11,027	-
Task Forces	7,275	-
	<u>1,086,454</u>	<u>1,593,083</u>
Loss of foreign exchange	321,125	(29,074)
	<u>1,407,579</u>	<u>1,564,009</u>

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2014

### IBE/ILAE Joint Task Force

The IBE/ILAE Joint Task Force programme is a joint 50:50 initiative of the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE). Its aim is to raise the profile of epilepsy across Europe by undertaking new research and educational activities. The initiative received corporate sponsorship and the fund is jointly owned by IBE and ILAE. IBE administer the programme and the fund, and received a management fee of US\$20,924 (2012: US\$19,885).

	2014 US\$	2013 US\$
Opening balance	200,661	242,316
Bank interest received	1,493	3,868
Expenditure incurred	(49,394)	(45,523)
Closing balance	<u>152,760</u>	<u>200,661</u>

### Congress Financial Information

The International Bureau for Epilepsy and the International League Against Epilepsy (ILAE) engages the services of a contracted International Director of Meetings (IDM) under the terms of an Agreement dated 2 February 2010. The IDM is charged with the organisation of various European and International Congresses.

The 2014 financial statements reflect the portion of assets, liabilities, net revenues and expenses held by the International Director of Meetings on behalf of the International Bureau for Epilepsy. An analysis of the proportion of congress assets, liabilities, income and expenses applicable to the Bureau is as follows:

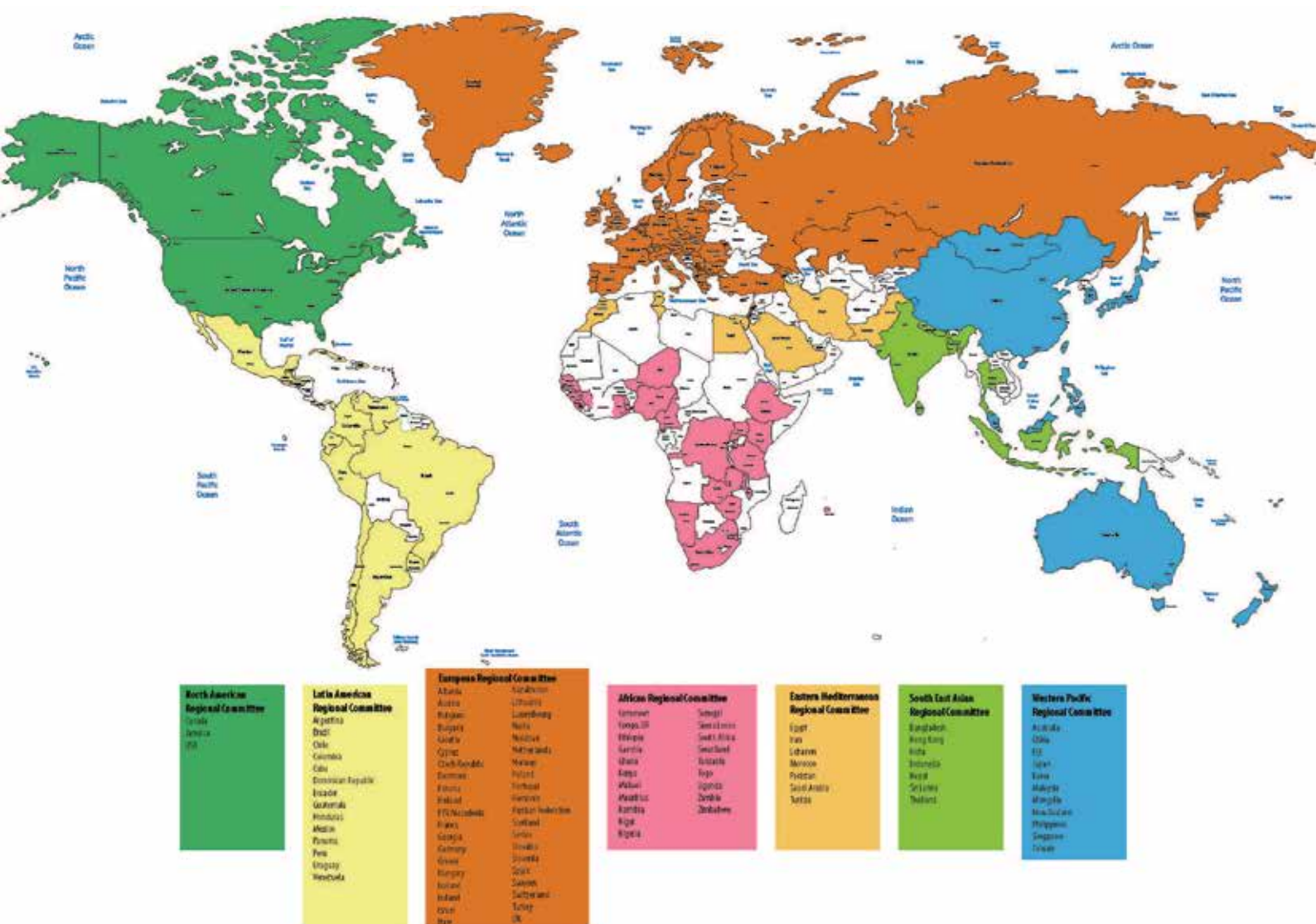
	2014 US\$	2013 US\$
Cash at bank	243,890	435,590
Debtors and prepayments	62,332	231,219
Creditors	(13,276)	(11,288)
Bank overdraft	(63,523)	(165,072)
Deferred income	(222,233)	(222,233)
IDM-Congress income received	520,883	1,549,202
IDM-Congress income receivable	205,318-	-
IDM-Congress expenses	(716,842)	(1,191,750)
	<u>          </u>	<u>          </u>

# SERVING PEOPLE WITH EPILEPSY IN EVERY REGION OF THE WORLD

Around the world IBE has 132 chapter members in **100 countries**

With an estimated total global population of 7.2 billion, **6.1 billion** people now live in countries with an IBE chapter

Which means that **85%** of the world's population lives in a country in which IBE is represented



# MEETING OUR MISSION AND VISION

## PROMISING STRATEGIES PROGRAM

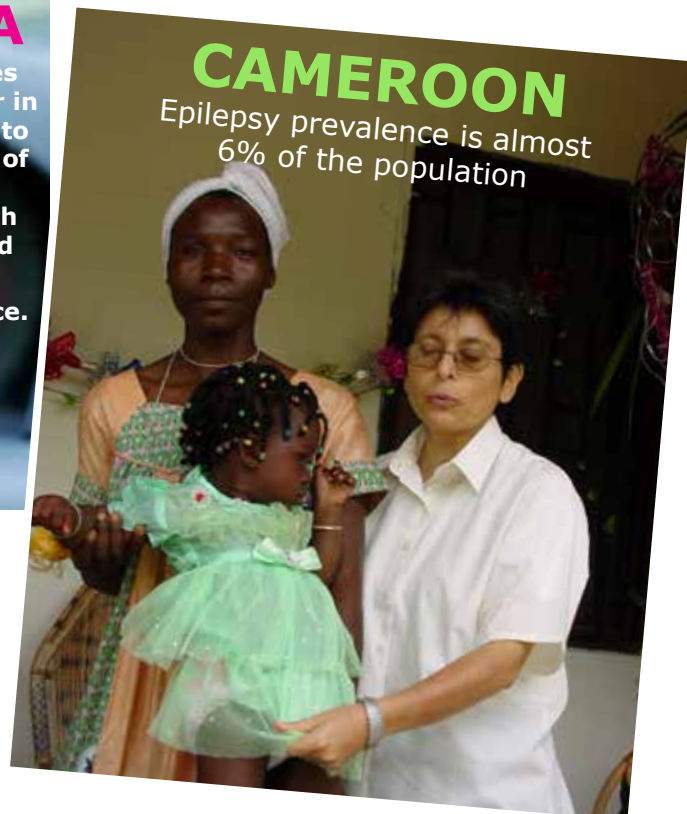
Promising Strategies was set up 10 years ago to support IBE chapters with financial funding for projects aimed at improving life quality for people with epilepsy. We have already given support to 81 projects in 38 countries, with total funding of US\$330,000. It is one of our most successful and rewarding projects helping hundreds of people with epilepsy in their struggle for a better life.

We have funded campaigns to inform and raise awareness about epilepsy in the general public, schools and government departments, and educated people with epilepsy about their condition. Skills training has formed a major element of the program, empowering people with epilepsy to become self-sufficient. Here are three of the many success stories from the program, which we are now working to further grow and develop.



### ARGENTINA

With Promising Strategies support, the IBE member in Argentina demonstrated to government the benefits of appropriate driving legislation for people with epilepsy, in reducing road accident mortalities. Legislation is now in place.



### CAMEROON

Epilepsy prevalence is almost 6% of the population

In CAMEROON, the stigma associated with epilepsy makes it impossible for a person with the disease to find employment. Our photo shows Christine, a young woman with epilepsy, who named her baby Franca de Simone, after Sr Franca de Simone (white blouse) who helped her create a life for herself, despite her epilepsy.

Promising Strategies support enabled the association, founded by the Italian nursing sister, to create employment opportunities by developing agriculture projects, such as crop growing and animal husbandry, in a remote and poor region of the country.

## UGANDA Non-profit Drugs Bank



90% of Uganda's population lives in rural areas, with poor roads and limited transport facilities. Obtaining anti-epileptic medication can pose severe problems. Add to that the cost of medication, with most people with epilepsy unemployed because of their seizures and the stigma surrounding their disease, and life becomes even more difficult.

In its efforts to meet these problems, Promising Strategies has provided support to Epilepsy Support Association Uganda for the development of a non-profit drugs bank.

The scheme allows ESAU to provide anti-epileptic drugs at low cost, on a strictly means-tested basis. The drugs are also made available to people living in remote areas of the country who would struggle to reach health clinics in urban areas.

In helping people with epilepsy to ensure continued access to their medication, seizure frequency is reduced and finding paid employment becomes a real possibility. Those receiving the drugs at reduced cost, and who find employment, will then pay a little more in order to supplement the cost for others less fortunate.



# Supporting, awarding, informing

## RECOGNISING ACHIEVEMENT

### Outstanding Persons with Epilepsy Awards

IBE celebrates the extraordinary achievements that people with epilepsy can attain, despite their diagnosis.

Overcoming difficulties such as recurring seizures, medication side-effects, and the problems that society imposes by way of stigma and discrimination, those receiving an Outstanding Persons with Epilepsy Award will have made an impact that will often improve the lives of others in society.

Shenaz Haveliwala, a young Indian woman, is a shining example of triumph over adversity. She has helped others through her voluntary tutoring at the Indian Epilepsy Society, fund raising to help finance epilepsy surgery for others without the means to pay, organising exhibition sales events for people with epilepsy to sell their handmade products, and creating the rent-by-day workspace called 'SoboConnect'.

And all of this despite the fact that she continues to have seizures, although she underwent temporal lobe surgery.



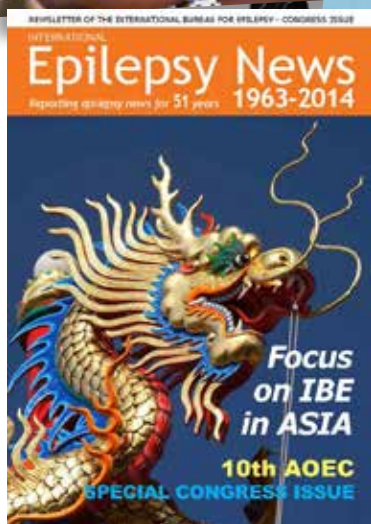
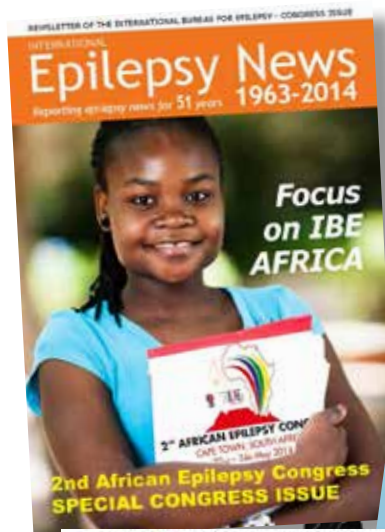
By showcasing those who rise above their epilepsy, IBE helps others with the disease to see that much is possible, even if the journey may be difficult.

More importantly, it sends a clear message to society that, in a large majority of cases, epilepsy is not a barrier to achievement, although stigma and discrimination often are.

## Newletters, Ezines and Websites

Our quarterly magazine – International Epilepsy News – together with special congress issues, regular Ezines and our websites: [ibe-epilepsy.org](http://ibe-epilepsy.org), [globalcampaignagainstepilepsy.org](http://globalcampaignagainstepilepsy.org) and [epilepsy.org](http://epilepsy.org) are the principal media organs of IBE. They

carry news of international events and information on IBE activities, while at the same time providing platforms to promote initiatives and achievements of IBE chapters. Our Facebook and Twitter accounts give instant news updates.



# MEETING OUR MISSION AND VISION



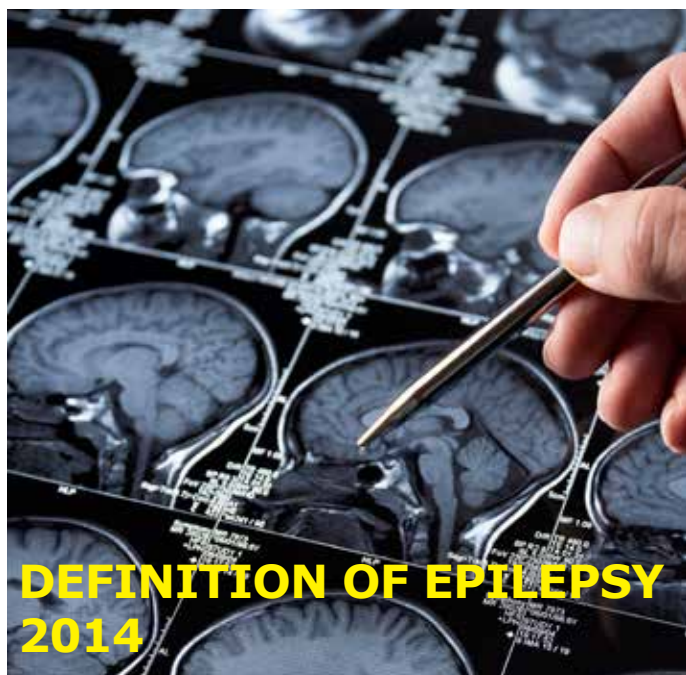
## Global Network

Our members are patient and family focussed organisations. Together we work to improve the social condition and quality of life of people with epilepsy and those who care for them.

We work collaboratively with professional and government partners world wide and support the development of new member organisations in underserved areas.

To ensure that IBE continues to best serve the broad international epilepsy community, in 2014 we undertook an indepth survey of our members, to obtain a detailed picture of their work and a clear understanding of how IBE could best serve them in achieving their objectives.

The results of the survey is informing the scope of our three-year strategic plan.



After two years of long and intense concentration by the ILAE Definitions Task Force, which included two IBE members - a new Definition of Epilepsy was produced in 2014.

For people with epilepsy, one of the issues that raised most debate was the decision to call epilepsy a disease. However, the reasoning behind this change has been carefully and sensitively explained, as best suited to describe a more lasting degramment of normal brain function.

After much debate and consideration, IBE was pleased to approve the new definition and to promote it widely to the lay epilepsy community.

## Working in collaboration with our Partners

Identifying areas of mutual interest, and sharing of information and experience, helps to build our knowledge base and discover new and innovative ways of supporting our members.

Throughout the year we continued to collaborate with our established partners and also developed new connections.

We are in official working relations with the WHO and, together with the ILAE have been developing the ILAE/IBE/WHO Global Campaign Against Epilepsy since 1997.

Together with our closest partner, the International League Against Epilepsy, we held congresses in Cape Town, Buenos Aires and Singapore where the congress programmes were specifically crafted to address issues of particular interest to those regions.

The IBE/ILAE joint task force on epilepsy in Europe - Epilepsy Advocacy Europe - organised the final European Epilepsy Day with celebrations in the European Parliament and at national level.

We have joined the board of the European Federation of Neurological Associations - EFNA - which further strengthens our networking opportunities.



# Setting direction for 2015

The most significant development, for people with epilepsy in 2014, came in late November with the important news that epilepsy would be on the agenda of the annual WHO Executive Board Meeting in January 2015.

At the meeting, a resolution calling on Member States of the WHO/OMS to take action on a number of fronts in order to prioritise epilepsy care in a co-ordinated fashion around the world, would be presented for approval.

The resolution was sponsored by the People's Republic of China, the Russian Federation and Maldives.

Working under extreme time pressure, the strong working relationship between IBE, ILAE, national patient associations and scientific epilepsy organisations was an impressive lobbying force in encouraging national governments to speak in favour of the resolution.

The concerted efforts of all would see no fewer than 28 countries speak in favour of the resolution, with the resolution approved for presentation to the World Health Assembly later in 2015.



## INTERNATIONAL EPILEPSY DAY

Announcing a global day focussed on epilepsy

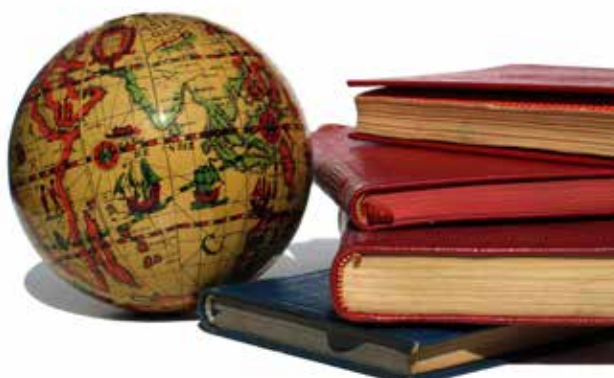


In mid-2014, with our partners ILAE, we announced the creation of International Epilepsy Day, which would launch on the second Monday of February 2015. This marked the culmination of a long held aspiration for an annual global awareness day for epilepsy.

Organised by the two largest and respected

epilepsy organisations, covering both the social and medical aspects of epilepsy, this annual day is set to grow and develop into a major event to highlight the need for improved services for people with epilepsy and increased research into the causes of epilepsy and the development of new and innovative treatments.

## CONSTITUTIONAL REVIEW



Changing times and a constantly growing organisation requires a regular review of how the organisation is governed. A Governance Task Force was charged to review the IBE Constitution and Bye-laws and to make recommendations for change. The highly qualified members of the task force worked throughout the year in drafting up amendments, which were circulated to the International Executive Committee for approval in September. The revised documents would be presented to the General Assembly at the time of the International Epilepsy Congress in Istanbul 2015.

## Strategic Plan for Epilepsy in the Americas

Launched in 2011, the 10-year PAHO Strategic Plan for the Americas has already resulted in significant initiatives aimed at highlighting the treatment gap and establishing ways to improve services. In late 2014, a meeting in Buenos Aires took stock of achievements to date and made plans for the future.

The Chilean League Against Epilepsy has been approved as a WHO Collaborating Centre; PAHO has completed a listing of essential antiepileptic drugs; and a number of educational workshops have taken place.

The three-way relationship PAHO remains a strong improve conditions for epilepsy in North, South America.

between IBE, ILAE and force in working to those living with Central and



# CONTACT DIRECTORY

## Offices, Committees, Task Forces and Networks

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#### Joint Task Force in Europe

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