

# Annual Report 2015



**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 September 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)

## Partners and Collaborators

- 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)



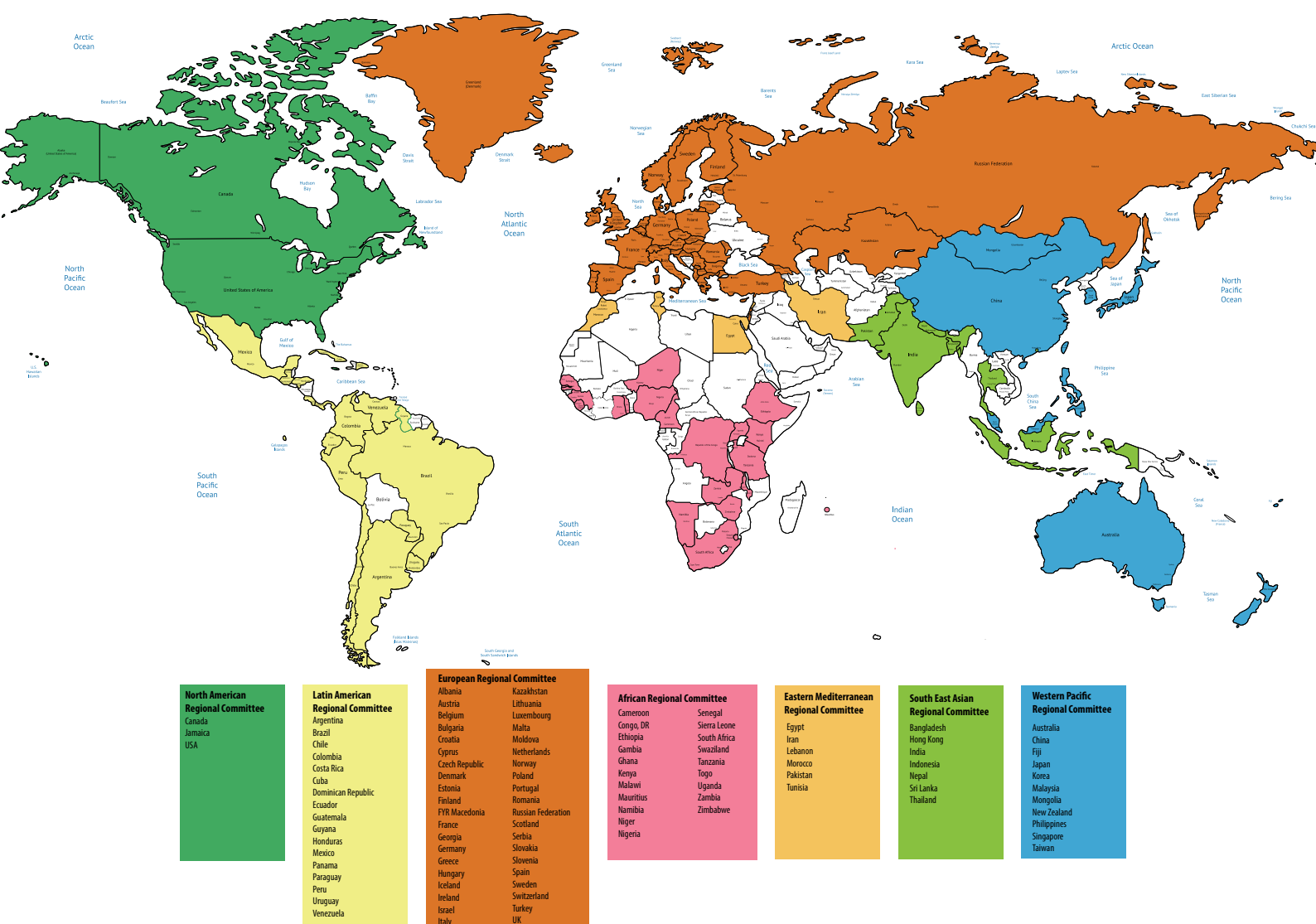
## Income sources

- IBE's activities are funded through membership subscriptions, congress income and grant funding from the pharmaceutical industry.
- In 2015, non-industry income accounted for 97.17% of all income.
- Industry funding amounted 2.83% of total income, with the highest contribution from a single company accounting for 1.91% of total income.

# Working for people with epilepsy and those who care for them across the globe

IBE now has 136 chapters in 103 countries

With the world population estimated at 7.1 billion,  
6.3 billion people or 89% of the world's population  
live in countries served by an IBE chapter







## PRESIDENT'S REPORT

It has been a very busy year, full of activities, challenges and achievements, most of which you will have heard about as they happened. However, this is the opportunity to have a brief review of what some of the activities that have taken place during 2015.

### Congresses

I was privileged to attend a number of congresses and conferences – both regional and national – organised by IBE, IBE/ILAE, by IBE member associations and by other supporters. These have included:

- 31st International Epilepsy Congress, Istanbul
- Adriatic Neurology Forum 2015 (ANF-2015), Opatija, Croatia
- 27th National Epilepsy Meeting Coimbra, Portugal
- Teaching conference in Russia-Kazakhstan
- ESBACE-Project, Kick off Meeting, Luxembourg
- China Association Against Epilepsy Congress, Shanghai, China
- Indian Epilepsy Association Conference, Udaipur, India: The role of IBE to close the treatment gap for epilepsy surgery in South East Asian Sub-continent

### International Epilepsy Day

The first celebration of International Epilepsy Day was on the second Monday of February and has already been seen to be a popular way of introducing awareness raising events as well as the opportunity to raise funds for national associations. The theme was *Epilepsy is more than Seizures* and we also continued to use this theme for International Epilepsy Day 2015.

In order to promote epilepsy vision throughout the world and increase awareness, IBE together with ILAE collaborated with the World Federation of Neurology in celebrating World Brain Day for Epilepsy on July and supported an event in Disneyland in November.

We would like to see International Epilepsy Day being celebrated by all IBE and ILAE chapters worldwide. By joining forces, we can make this a reality,

### Task Forces

The Governance Task Force had a final two-day meeting in Stockholm in 2014 to complete its work in reviewing the Constitution and Bye-laws. Their draft revised documents were then presented to the Full Members for balloting and I am very pleased that it was approved by the General Assembly at the International Epilepsy Congress in Istanbul in September 2015.

This marks some very positive changes to how we operate, and I hope it will encourage more of you to consider allowing your names to go forward to stand for positions on the Executive Committee in the coming years.

I would like to thank Johan Falk Pedersen, Chair of the Task Force, and the members – Susanne Lund, Sandy Finucane and Christopher Morris-Coole for their hard work over more than 3 years.

Following the sad death of Mike Hills in 2013, a vacancy arose on the Election Task Force and we were pleased that Shunglon Lai agreed to join the group. Since then it has overseen the election of the Vice Chair for the Western Pacific Region following the untimely death of Frank Gouveia. The Election Task Force, chaired by Susanne Lund and with members Shungon-Lai and Pete Engel, will oversee the International and Regional committees' elections in 2016.

The Legislation Task has encountered a number of set-backs in its efforts to make progress. The former chair, Hanneke de Boer, sadly passed away on 12th October 2015 and she was replaced by Sherman Goh from Singapore. Unfortunately, a serious family illness and bereaved meant that Sherman asked to step down for a while and Sherman has since been replaced by Stine Strømso from Norway. Apart from Stine and Sherman, the other members are Nikki Saarsteiner from Ireland, Silvia Kochen from Argentina and Caroline Morton from the Netherlands.

### Epilepsy Alliance Europe

In late 2014 a new entity Epilepsy Alliance Europe Ltd was registered in Europe. This was necessary in order for the Joint IBE/ILAE Task Force to play a partnership role in applications for

funding to the EU and also in promoting partnerships worldwide for research funds and collaboration.

The MEP interest group – European Advocates for Epilepsy – was reformed following the EU elections in early 2014. We are now in the process of building up the membership list of MEP supporters and had two meetings of the group – in September 2014 and March 2015. At the of 2015, there were 24 MEPs in the group but, thanks to a very successful International Epilepsy Day, by February 2016 the number had risen to 56 – but that is for next year's report!

The Joint Task Force was also invited to partner on a number of applications submitted for EU funding under Horizon2020 in early 2015. These funding opportunities are extremely competitive and with hundreds of applications for just one fund. Unfortunately, none of the applications in which we were involved were successful.

### **WHO Resolution**

Approval of the WHA/WHO Resolution on the global burden of epilepsy was the most important event to have happened in the last few years. With overwhelming support of national health ministries, the resolution was approved during the 68th World Health Assembly in Geneva in May 26th, 2015. I was honoured, together with the ILAE President, to attend and to speak to the resolution during the meeting.

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.

The resolution sends a strong message in the international community and its government across the world about the need to treat epilepsy as a major health priority and to establish specific actions to address the needs of people with epilepsy. The resolution provides our members with a powerful tool to engage governments into taking actions to improve epilepsy care, promote public awareness, improve diagnosis, access to treatment, medical and social services, removing disparities in epilepsy care, fighting stigma and discrimination and promoting research.

This success would not have been possible without the three-way partnership of IBE, ILAE and WHO in the Global Campaign Against Epilepsy and without the hard work of IBE and ILAE chapters across the world who were diligent in encouraging their ministries to make statements both during the WHO Executive Board meeting in February and at the World Health Assembly in May.

The resolution is the most challenging action of IBE, ILAE and WHO for many years to come. Improving health care, access to treatment and appropriate treatment is an initial challenge. Reducing the treatment gap and treating epilepsy effectively as a whole is an ultimate plan.

Following the approval of the resolution it was decided among other actions to produce an easy-to-understand information toolkit about epilepsy to key stakeholders groups.

Controlling all seizures and ultimately curing epilepsy is not IBE's and ILAE's dream but also that of all people with epilepsy in the world.

### **The Future**

One of the major obstacles that will face IBE – and I know that many other organisations are similarly challenged – is the increasing difficulty in identifying financial support. The lack of emerging new epilepsy drugs, coupled with the high number of drugs coming off patent and falling congress delegate numbers means that IBE is struggling to achieve year end surpluses.

We are working to identify new funding opportunities and to this end we contracted a consultancy firm to look at our present performance and to advise us on future direction. We hope that this will help us to ensure IBE's future health. Nevertheless, we should be prepared to sacrifice funds in order, not only to make plans, but also, to be able to execute our decisions.

### **Conclusion**

Building on previous IBE and IBE stakeholders activities we are looking forward for more successes in the future. On reducing the treatment gap several actions should be taken at regional and national level to improve care, appropriate care and quality of life of people with epilepsy. An additional effort should be made to protect their human rights based on international accepted standards.



Athanasios Covanis  
President

# FINANCIAL REPORT

## Income and Expenditure Account

Year ended 31st December 2015

With comparative totals for 2014

	2015 US\$	2014 US\$
INCOME	1,167,067	811,656
EXPENDITURE	(1,202,263)	(1,407,579)
OPERATING (DEFICIT)/SURPLUS FOR YEAR	<u>(35,196)</u>	<u>(595,923)</u>

## Balance Sheet

Year ended 31st December 2015

With comparative totals for 2014

	2015 US\$	2014 US\$
CURRENT ASSETS		
Debtors	143,122	63,129
Cash in hand and at bank	2,408,380	2,474,325
Amount held on behalf of the IBE/ILAE Joint Task Force	104,606	152,760
	<u>2,656,108</u>	<u>2,690,277</u>
CREDITORS (Amounts falling due in one year)	(340,120)	(339,094)
NET CURRENT ASSETS	<u>2,315,988</u>	<u>2,351,183</u>
NET ASSETS	<u>2,351,183</u>	<u>2,351,183</u>
CAPITAL AND RESERVES		
General Reserve	2,260,335	2,321,824
Restricted and designated funds	55,653	29,359
	<u>2,315,988</u>	<u>2,351,183</u>

The financial statements were approved on 14 September 2016 and signed by:

Athanasios Covanis, President

Ann Little, Executive Director

## Statement of Income and Expenditure

Year ended 31st December 2015

With comparative totals for 2014

	2015 US\$	2014 US\$
INCOME		
Congress income received	1,046,872-	520,883
Congress income receivable	-	205,318
Corporate donations	10,720	-
IBE/ILAE JTF management fee	16,720	20,041
IBE/ILAE JTF reimbursement of expenses (IBE 50%)	41,454	13,406
Membership dues and solidarity fund	13,832	10,609
Investment income	3,885	14,000
EPICURE grants	11,250	22,500-
Miscellaneous income		4,899
Restricted gifts and donations	22,334	-
	<u>1,167,067</u>	<u>811,656</u>
EXPENDITURE		
Congress expenditure	680,049	716,842
Office expenses	11,805	21,230
Printing and postage	347	342
Travel	30,834	89,844
Global Campaign costs	20,018	22,500
Accountancy fees	5,758	4,937
Audit fees	14,995	7,213
Administrator costs	26,138	64,809
Staff costs	140,094	90,015
Bank charges	1,207	1,400
Rent	17,913	22,433
Promising Strategies	6,732	11,321
Website costs	5,660	1,860
IBE JTF expenditure	40,032	13,406-
Professional fees	20,234	11,027
Task Forces	-	7,275
	<u>1,086,454</u>	<u>1,593,083</u>
Loss of foreign exchange	180,447	321,125
	<u>1,407,579</u>	<u>1,564,009</u>

# FINANCIAL REPORT continued

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2015

### 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\$16,720 (2014: US\$20,041).

	2015 US\$	2014 US\$
Opening balance	152,760	200,661
Bank interest received	781	1,493
Expenditure incurred	(48,935)	(49,394)
Closing balance	<u>104,606</u>	<u>152,760</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:

	2015 US\$	2014 US\$
Cash at bank	439,146	243,890
Debtors and prepayments	139,652	62,332
Creditors	(43,106)	(13,276)
Bank overdraft	(79,068)	(50,633)
Deferred income	(50,305)	(63,523)
IDM-Congress income received	1,046,872	726,201-
IDM-Congress expenses	(680,049)	(716,842)



# HIGHLIGHTS OF THE YEAR



## INTERNATIONAL EPILEPSY DAY is launched!

The launch of International Epilepsy Day in February 2015 marked the culmination of a long held aspiration for an annual global awareness day for epilepsy.

International Epilepsy Day is the opportunity for all stakeholders to join together and speak with one global voice. Organised by the two largest and respected epilepsy organisations, covering both the social and medical aspects of epilepsy, this annual day is already developing 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.

The objectives for International Epilepsy Day are:

- to raise awareness of the disease at international and government level as well as in the general public
- to strengthen the epilepsy movement by uniting epilepsy associations in a worldwide campaign
- to raise visibility on epilepsy and encourage discussion about epilepsy
- to provide epilepsy associations with a significant fundraising opportunity.

International Epilepsy Day was celebrated by IBE and ILAE chapter across the world as well as in the European Parliament in Strasbourg, with over 100 MEPs attending a special Reception to mark the event.



A 'selfie' campaign on IBE's Social Media streams with the hashtag #epilepsyday caught the imagination of people with epilepsy and those who care for them right around the world, with some stunning images uploaded to Facebook.

It was most significant that WHO also recognised the day with an important video on epilepsy placed on its website homepage.

International Epilepsy Day will continue to be celebrated each year on the 2nd Monday of February.

## 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), [epilepsy.org](http://epilepsy.org) and [epilepsy-allianceeurope.org](http://epilepsy-allianceeurope.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.

NEWSLETTER OF THE INTERNATIONAL BUREAU FOR EPILEPSY - ISSUE 4 2015  
INTERNATIONAL  
**Epilepsy News**  
Reporting epilepsy news for 52 years 1963-2015

Hanneke de Boer  
1946-2015



NEWSLETTER OF THE INTERNATIONAL BUREAU FOR EPILEPSY - ISSUE 3 2015  
INTERNATIONAL  
**Epilepsy News**  
Reporting epilepsy news for 52 years 1963-2015



NEWSLETTER OF THE INTERNATIONAL BUREAU FOR EPILEPSY - ISSUE 2 2015  
INTERNATIONAL  
**Epilepsy News**  
Reporting epilepsy news for 52 years 1963-2015



# RESOLUTION on Global Burden of Epilepsy approved at World Health Assembly



Tuesday 26 May, 2015, will be remembered as a historical date for all those working to improve the quality of life of people with epilepsy and those who care for them. On that date, the World Health Assembly approved the WHO Resolution on the Global Burden of Epilepsy, which calls for 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 in health, social and other related services;
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 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.

## How the resolution developed

Approval of the Resolution represents a major success for IBE, ILAE and their long-standing partnership with WHO. For some time, IBE, ILAE and their members have been working tirelessly to sensitize national governments about the need to set up a coordinated effort against epilepsy.

Responding to these calls, the People's Republic of China took the lead in late 2014 by drafting a Resolution calling for a global action to be implemented under the umbrella of WHO and in partnership with ILAE and IBE.

The draft received early co-sponsorship by

**Photo:** Thanos Covanis, IBE President; Shekhar Saxena, WHO; Shichuo Li, IBE/ILAE Global Outreach; Tarun Dua, WHO; Emilio Perucca, ILAE President; Brooke Short, WHO; Ann Little, IBE; Alla Guekht and Mary Secco, Co-chairs ILAE/IBE/WHO Global Campaign Against Epilepsy, at the WHO Building in Geneva.

the Russian Federation, and many other countries soon joined in expressing their support.

In February 2015, the 136th Executive Board meeting of WHO voted unanimously to recommend that the Resolution be approved by the 68th World Health Assembly. The level of support that the Resolution received at the World Health Assembly was overwhelming.

Between the meeting of the Executive Board and at the World Health Assembly, a total of 43 countries made strong statements in favour of the Resolution and expressed commitment to step up actions against epilepsy. Remarkably, 19 countries requested to be named as co-sponsors of the Resolution. Further supportive statements were made by WHO itself and by civil organizations accredited with WHO, including, in addition to IBE and ILAE, the World Federation of Neurology and Health Action International.



## Ensuring implementation of the Resolution?

The resolution provides a powerful tool to engage national governments into implementing effective actions to improve medical and social services for people with epilepsy, promote public awareness about epilepsy and allocate resources to epilepsy research.

The Joint ILAE-IBE Global Outreach Task Force has already worked on recommendations to assist all stakeholders, including IBE and ILAE Chapters, in ensuring the Resolution translates into effective actions.

Other activities include meetings and workshops to facilitate the involvement of stakeholders, including policy makers, and the engagement of national and interna-

tional institutions in order to achieve the goals of the Resolution. All these activities will be conducted in close partnership with WHO. Importantly, the Resolution calls for the WHO Director General to identify the relevant best practices to address the burden of epilepsy and to develop, in consultation with relevant stakeholders, a set of technical recommendations guiding Member States in the development and implementation of epilepsy programmes and services. The Resolution also requests WHO to provide technical support

to Member States in actions for epilepsy management, especially in low- and middle-income countries.

These are great times for all those who work towards ensuring better lives for people with epilepsy. The Resolution is just the beginning – it now our duty to exploit this unprecedented opportunity to its utmost potential.

By working together, there are no limits to what we can achieve!

### Co-sponsoring countries

1. Argentina
2. Australia
3. Canada
4. Ghana
5. Georgia
6. Greece
7. Islamic Republic of Iran
8. Japan
9. Italy
10. Malaysia
11. Maldives
12. Malta
13. Panama
14. People's Republic of China
15. Romania
16. Russian Federation
17. Thailand
18. United Kingdom
19. Venezuela

### Countries statements in support of the Resolution

- |   |                                |
|---|--------------------------------|
| 1. Albania  | 23. Malaysia                   |
| 2. Argentina                                      | 24. Maldives                   |
| 3. Australia                                      | 25. Malta                      |
| 4. Azerbaijan                                     | 26. Nepal                      |
| 5. Bahrain  | 27. Panama                     |
| 6. Benin (on behalf of 47 Members of AFRO region) | 28. Poland                     |
| 7. Brazil   | 29. People's Republic of China |
| 8. Canada   | 30. Republic of Korea          |
| 9. Czech Republic                                 | 31. Romania                    |
| 10. Democratic Republic of Congo                  | 32. Russian Federation         |
| 11. Egypt   | 33. Saudi Arabia               |
| 12. Georgia                                       | 34. Suriname                   |
| 13. Ghana   | 35. Swaziland                  |
| 14. Greece  | 36. Taiwan China               |
| 15. India   | 37. Tanzania                   |
| 16. Islamic Republic of Iran                      | 38. Thailand                   |
| 17. Iraq (on behalf of 21 Members of EMRO region) | 39. Timor-Leste                |
| 18. Indonesia                                     | 40. United Kingdom             |
| 19. Italy   | 41. United States of America   |
| 20. Japan   | 42. Uruguay                    |
| 21. Lebanon                                       | 43. Venezuela                  |
| 22. Lithuania                                     |                                |

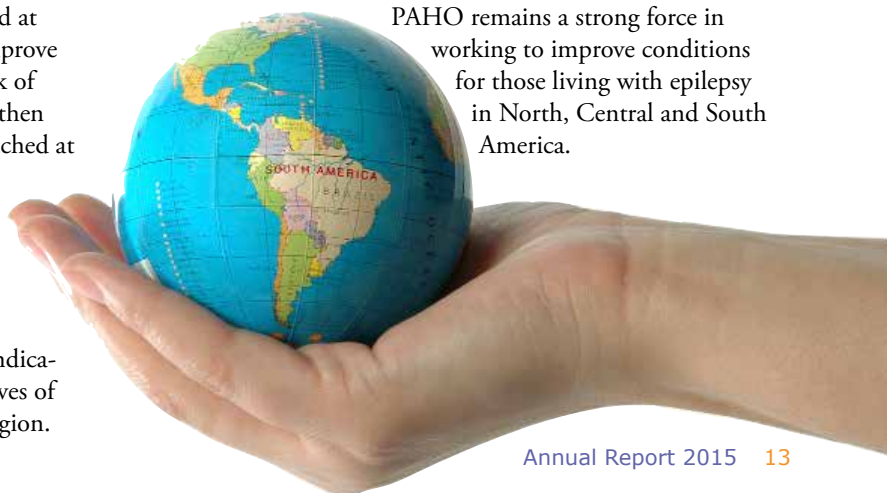
## PAHO Strategic Plan for Epilepsy in the Americas

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. Since then several other meetings have taken place and initiatives launched at the national level.

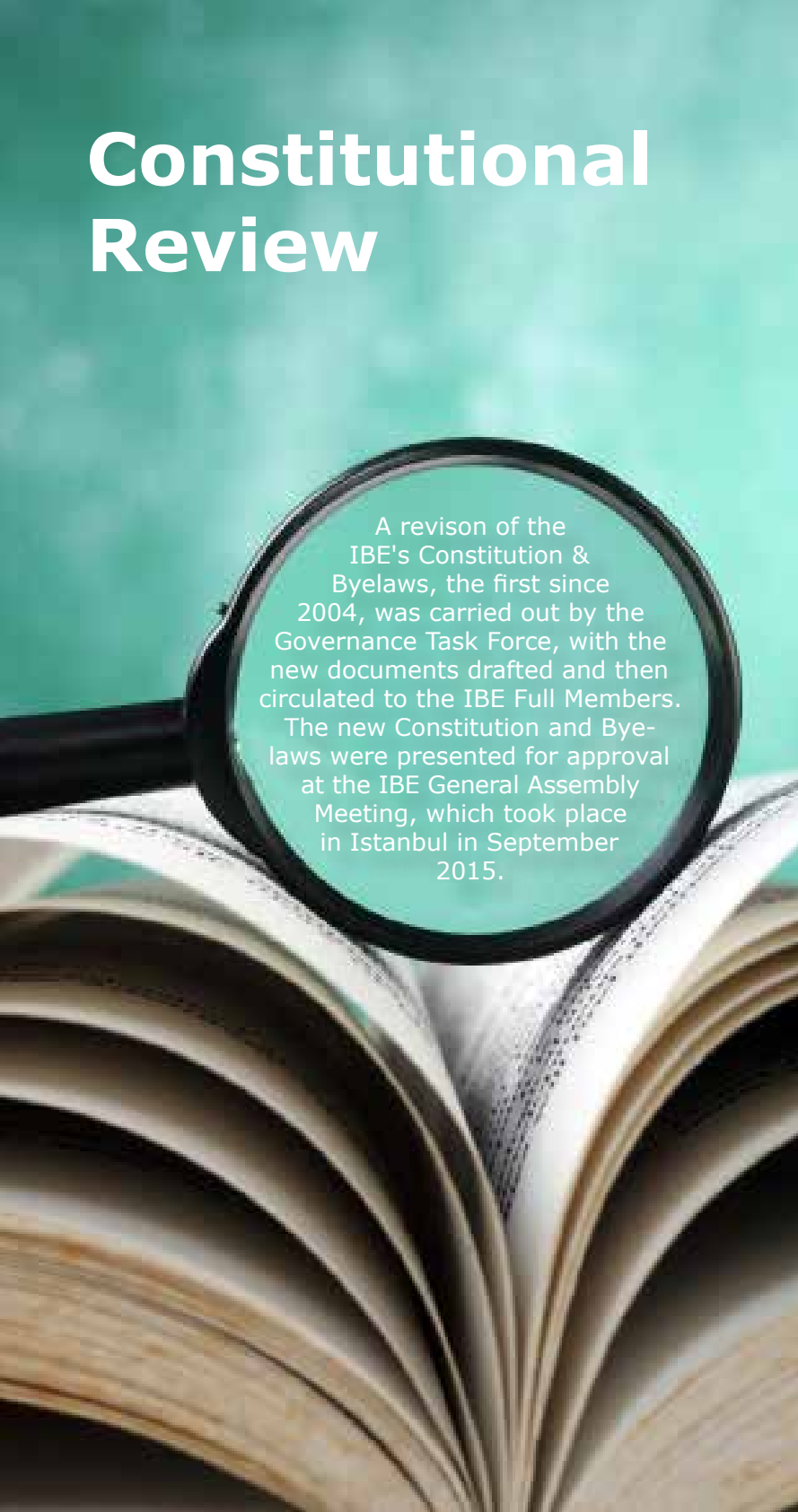
The Chilean League Against Epilepsy has been approved as a WHO Collaborating Centre; PAHO has completed a listing of essential antiepileptic drugs; and a number of educational workshops have taken place.

The 10-year plan has now reached it's midway point and indications are that it will continue to impact positively on the lives of people with epilepsy and those who care for them in the region.

The three-way relationship between IBE, ILAE and PAHO remains a strong force in working to improve conditions for those living with epilepsy in North, Central and South America.



# Constitutional Review



A revision of the IBE's Constitution & Byelaws, the first since 2004, was carried out by the Governance Task Force, with the new documents drafted and then circulated to the IBE Full Members. The new Constitution and Byelaws were presented for approval at the IBE General Assembly Meeting, which took place in Istanbul in September 2015.

The Governance Task Force completed a major review of the Constitution and Bye-Laws with amended text presented to the International Executive Committee and the Regional Committees for comment and approval. The documents were then circulated to the Full Members for balloting, with the final approval taking place during the IBE General Assembly Meeting in Istanbul, September 2015. The principal changes include:

## **Members become Chapters**

When the Constitution was adopted on 31 December 2004, one of the changes introduced was a change of title from Chapter and Friend to Full and Associate Member. Until then, both IBE and ILAE had used the term Chapter in referring to its voting membership. The Governance Task Force suggested that the Constitution and Byelaws revert to the old term Chapter, in relation to voting members, and to introduce the title Associate Chapter for non-voting members. Applicant associations, whose membership has not yet been fully ratified, would be described as Provisional Chapters.

## **Election Procedures**

The revised procedures deal, in particular, with the lobbying process, allowing a much greater level of lobbying by candidates. The Task Force also simplifies some of the procedures in order to encourage a higher level of participation in the election process by Full Members - from the nomination process, through to balloting and election.

The changes ratified by the then Full Members, (now Full Chapters) are in place for the elections beginning in late 2016, to elect the International Executive Committee and the Regional Executive Committees for the term 2017-2021.

## **Staggering of Board Terms**

Continuity of knowledge and expertise is very important for the smooth running of an organisation. To address this, the Governance Task Force recommended a staggering of the four-year term of office, beginning with the term 2017-2021. The Regional Vice Presidents will serve for a two-year term, while the positions will have a four-year term, in order to begin the staggering process.

There will be a further election in 2019 for a 4-year term for Vice Presidents. In addition, the elected Regional Vice Presidents will be deemed to be the Chair of their Regional Executive Committee.

# PROMISING STRATEGIES PROGRAM

Promising Strategies was set up 11 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. Preparations are underway to review the application process in advance of the call of the next round of funding.

# Strategic Plan 2016-2019

During the General Assembly in September, members were invited to discuss the new Strategic Plan for IBE that has been prepared by a small Task Force comprising Philip Lee (UK), Phil Gattone (USA), Sari Tervonen (Finland) and Ann Little (Ireland). In preparing the document, the group carefully considered the priorities that best reflected future direction for IBE and the goals that could be aimed for over the following years.

## CORE VALUES

- We are passionate about improving quality of life for people facing a diagnosis of epilepsy
- The person with epilepsy is our primary stakeholder and all we do is focused on helping that person
- We work collaboratively with our partner epilepsy related organisations, professional, lay and governmental
- We are transparent and democratic in our governance and decision-making

## OUR GOALS

### 1. Make epilepsy a worldwide health concern and priority

- To advocate with WHO and the UN to recognise epilepsy as a worldwide need and to develop a global action plan for IBE advocacy with WHO in collaboration with partner epilepsy organisations.
- To encourage each IBE member country to report on progress on strategic global outreach targets to IBE and to regularly share information with WHO and others on progress.
- To share and promote accurate, up to date information about the impact of epilepsy in different regions, through websites, social media, newsletters and conferences.

### 2. Advocate for improved human and civil rights for people with epilepsy worldwide

- Create and share model legislation and guidelines with IBE chapters, and offer mentoring to member countries from those who have successfully made impact.
- Encourage member countries to implement legislative changes to promote civil rights for people with epilepsy and encourage regions to identify epilepsy-focussed human and civil rights goals for their member organisations.

### 3. Provide resources for people with epilepsy and the families to maximize quality of life

- Provide accurate information exchange on evidenced based best practices in self-management of epilepsy, epilepsy in schools, youth and young adult programs, and other identified programs.
- Promote the use of electronic and social media to inform and exchange information and create communities among people affected by epilepsy.

The document was discussed as part of a special workshop held during the congress in Istanbul, prior to the General Assembly Meeting and comments and suggestions for change were brought back to the Task Force. The suggestions of the members (chapters) have since been incorporated in the document, which is currently in the process of electronic approval by the chapters.

Priorities, values and goals are as follows:

## STRATEGIC PRIORITIES

- 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

- Seek support to allow lay organisations and people with epilepsy to attend international and regional meetings.
- Assist with the development of new chapters in areas that are not currently served and encourage youth councils in member organisations.

### 4. Promote prevention and research focused on care and treatment of epilepsy and its consequences worldwide

- Encourage chapters to pursue awareness and education campaigns about current concerns of epilepsy, prevention, need for better treatment for those affected.
- Promote the prevention of epilepsy; access to currently available treatments and the value of research and new therapies to stop seizures and cure epilepsy.

### 5. Improve the unity, sustainability, and communication of the IBE

- Evaluate means of financial support for IBE and make recommendations for changes to improve IBE's financial status, sustainability and independence.
- Create representative inter-regional and cross-regional task forces for each IBE goal to foster inter-organisational mentoring, best practice exchange, and to support the development of action plans and recommendations on standards and strategies for action for regions, for countries, and for IBE.
- Utilize electronic platforms for meetings within regions and cross regionally to promote information exchange and to support the creation of collaborative learning groups.
- Establish a mentoring program where chapters offer to provide information exchange.
- Utilize all communications vehicles to implement goals.





# CONTACT DIRECTORY

## Offices, Committees, and Task Forces 2013-2017

### IBE HEAD OFFICE

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ibeexecdir@eircom.net  
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### CONGRESS OFFICE

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7 Priory Office Park  
Stillorgan Road, Blackrock  
Co Dublin, A94 FN26, Ireland.  
T: +353 1 205 6720  
info@epilepsycongress.org  
www.epilepsycongress.org

### INTERNATIONAL EXECUTIVE COMMITTEE

#### President

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