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 2017-2021
President: Martin Brodie (Scotland), Secretary General: Mary Secco (Canada), Treasurer: Anthony Zimba (Zambia)
Vice Presidents:
VP Africa: Jacob Mugumbate (Zimbabwe), VP Eastern Mediterranean: Hassan Hosny (Egypt), VP Europe: Natela Okujava (Georgia), VP Latin America: Tómas Mesa (Chile), VP North America: Philip Gattone (USA), VP South East Asia: Satish Jain (India), VP Western Pacific: Ding Ding (China)
Immediate Past President: Athanasios Covannis (Greece)
ILAE Ex Officio Members:
ILAE President: Sam Wiebe (Canada), ILAE Secretary General: Ed Bertram (USA), ILAE Treasurer: Helen Cross (UK)

Partners and Collaborators
• Special Consultative Status on the Economic and Social Council of the United Nations (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)
• Associate Member of the European Patients’ Forum (EPF)
• Close working partnership with the International League Against Epilepsy (ILAE)
• Observer status on the PCWP Committee of the European Medicines Agency (EMA)

Income sources
• IBE’s activities are funded through membership subscriptions, congress income and grant funding from the pharmaceutical industry.
• Industry funding amounted 3.7% of total income. IBE received industry-related income from two companies in 2017 - Shire International Gmbh and UCB Pharma. The higher contribution (82.2% of total) was received from Shire International Gmbh.
• In 2017, non-industry income accounted for 96.3% of all income.
Doesn’t time fly! It’s only just over a year since I took over the presidency of IBE. Although my official term of office began during the 32nd International Epilepsy Congress in Barcelona in September 2017, the previous President, Thanos Covanis, and his committee had kindly invited me to ‘shadow’ their work following my election in January and so I have taken part in many IBE activities during much of last year.

A very successful International Epilepsy Day was celebrated around the world on Monday 13th February, with IBE and ILAE chapters marking this awareness day with many local activities. In Europe, a significant global workshop took place in the parliament in Brussels, which was attended by representatives from Europe as well as from the US and Canada. This was the start of what has become an international effort towards a global alliance for epilepsy research. There was particular focus on including people with epilepsy and those who care for them as partners in the research agenda and not just as recipients of research activities, as was previously largely the case. A new animated video has been created, with Campi, the sea horse, and his parents visiting the doctor. As I write, we are preparing the fourth in this series in time for International Epilepsy Day 2019. These short videos have been translated and subtitled into a number of languages.

The Creating Artistic Waves competition received 140 entries from 25 countries around the world. February also saw the 4th East Mediterranean Epilepsy Congress take place in Luxor on the east bank of the Nile River in Egypt, an area steeped in ancient history. The congress attracted close to 400 delegates from 30 countries. Three months later, from 5th to 7th May, the 3rd African Epilepsy Congress took place in Dakar, Senegal with a similar number of delegates. These regional congresses, organised jointly by IBE and ILAE, play an important role in providing training opportunities and increasing knowledge about epilepsy for all those involved in the field in these regions.

Our Promising Strategies Programme continued apace with projects in Tibet, China and Colombia receiving funding in 2017. The Colombian project focussed on eliminating the worms affecting diseased pigs, which were responsible for spreading neurocysticercosis in one region of the country. Its success has led the government to consider rolling it out throughout the entire Caribbean coastal region of Colombia!

The official start of the 4-year term of office for myself and my colleagues began at the time of the General Assembly on 5th September in Barcelona. The remaining three months of the year was the opportunity to begin putting in place some of the new activities that I believe will help move IBE forward, with a particular focus on youth. The EpilepsyNext programme, with five modules already identified, was fine-tuned prior to its launch. This is a major global programme, that will require a major level of funding to fully implement. I believe that it is imperative for us to support young people with epilepsy by making available the tools and training that will provide them with the best opportunity to excel in their chosen paths in life. By the year end, plans were already in place for the first Latin American Young Adult’s Summit and the Golden Light Awards, to be held in Costa Rica in 2018. I also set up three new Commissions and identified their global membership. The Education Commission is chaired by Margarete Pfäfflin (Germany), the Research Commission by Kheng-Seang Lim (Malaysia) and the eSolutions Commission by Najib Kissani (Morocco). In next year’s report, I will have the opportunity to share their achievements with you. I warmly thank the new chairs and the commission members for giving their time and dedication to the global IBE agenda.

A new avenue to promote our work and that of its members came via the new monthly IBE platform in Epilepsy & Behavior. The journal provides IBE with access to a wider audience with which to share developments and initiatives as well as commentaries on personal issues. I hope that many individuals and chapters will take advantage of this opportunity! As the year drew to a close, I believe that we had placed ourselves in an excellent position to introduce a range of initiatives, and to further develop those already in place, to ensure that we can support our chapters around the world in their vital work for people with epilepsy and those who care for them. Keep up the good work!
### Income and Expenditure Account

**Year ended 31st December 2017**  
With comparative totals for 2016

<table>
<thead>
<tr>
<th></th>
<th>2017</th>
<th>2016</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>US$</td>
<td>US$</td>
</tr>
<tr>
<td><strong>INCOME</strong></td>
<td>1,550,009</td>
<td>649,269</td>
</tr>
<tr>
<td><strong>EXPENDITURE</strong></td>
<td>(941,659)</td>
<td>(916,059)</td>
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<tr>
<td><strong>OPERATING (DEFICIT)/SURPLUS FOR YEAR</strong></td>
<td>608,350</td>
<td>(266,790)</td>
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</table>

### Balance Sheet

**Year ended 31st December 2017**  
With comparative totals for 2016

<table>
<thead>
<tr>
<th></th>
<th>2017</th>
<th>2016</th>
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</thead>
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<tr>
<td></td>
<td>US$</td>
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<td><strong>CURRENT ASSETS</strong></td>
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<td>Debtors</td>
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<td>Cash in hand and at bank</td>
<td>2,720,460</td>
<td>2,288,511</td>
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<td>Amount held on behalf of the IBE/ILAE Joint Task Force</td>
<td>66,618</td>
<td>69,893</td>
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<td><strong>Net Current Assets</strong></td>
<td>3,083,678</td>
<td>2,533,096</td>
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<td><strong>CREDITORS (Amounts falling due in one year)</strong></td>
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<td>(483,899)</td>
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<td><strong>Net Current Assets</strong></td>
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<td>2,315,988</td>
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<td><strong>Net Assets</strong></td>
<td>2,657,547</td>
<td>2,049,197</td>
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<td><strong>Capital and Reserves</strong></td>
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<td>General Reserve</td>
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<td>1,993,544</td>
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<td>Restricted and designated funds</td>
<td>55,653</td>
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<td><strong>Total Capital and Reserves</strong></td>
<td>2,657,547</td>
<td>2,049,197</td>
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The financial statements were approved on 1 September 2018 and signed by:  
Martin Brodie, President  
Ann Little, Executive Director
# Statement of Income and Expenditure

## Year ended 31st December 2017

With comparative totals for 2016

<table>
<thead>
<tr>
<th></th>
<th>2017 US$</th>
<th>2016 US$</th>
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<tbody>
<tr>
<td><strong>INCOME</strong></td>
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<tr>
<td>Congress income received</td>
<td>1,436,373</td>
<td>536,491</td>
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<td>IBE/ILAE JTF management fee</td>
<td>16,173</td>
<td>16,450</td>
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<td>IBE/ILAE JTF reimbursement of expenses (IBE 50%)</td>
<td>12,889</td>
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<td>Membership dues and solidarity fund</td>
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<td>14,323</td>
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<tr>
<td>Investment income</td>
<td>14,617</td>
<td>9,518</td>
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<tr>
<td>Restricted gifts and donations</td>
<td>56,828</td>
<td>53,530</td>
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<tr>
<td><strong>TOTAL INCOME</strong></td>
<td>1,550,009</td>
<td>649,269</td>
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<table>
<thead>
<tr>
<th></th>
<th>2017 US$</th>
<th>2016 US$</th>
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</thead>
<tbody>
<tr>
<td><strong>EXPENDITURE</strong></td>
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<tr>
<td>Congress expenditure</td>
<td>810,258</td>
<td>543,720</td>
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<td>Office expenses</td>
<td>16,364</td>
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<td>Printing and postage</td>
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<td>Travel</td>
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<td>Global Campaign costs</td>
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<td>Accountancy fees</td>
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<td>Administrator costs</td>
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<td>Staff costs</td>
<td>115,254</td>
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<td>Employer’s PRSI</td>
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<td>Bank charges</td>
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<td>Rent</td>
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<td>14,725</td>
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<td>Promising Strategies</td>
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<td>Website costs</td>
<td>4,276</td>
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<td>IBE JTF expenditure</td>
<td>11,090</td>
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<td>International Epilepsy Day</td>
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<td>Professional fees</td>
<td>8,616</td>
<td>340</td>
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<td>Bad debts</td>
<td>-</td>
<td>35,880</td>
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<tr>
<td><strong>TOTAL EXPENDITURE</strong></td>
<td>1,081,291</td>
<td>873,772</td>
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(Profit)/Loss on foreign exchange

(139,632) | 44,287

**TOTAL EXPENDITURE**

941,659 | 916,059
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$16,173 (2016: US$16,450).

<table>
<thead>
<tr>
<th>Year</th>
<th>US$</th>
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<tbody>
<tr>
<td>2017</td>
<td>69,893</td>
</tr>
<tr>
<td>2016</td>
<td>104,060</td>
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</table>

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 2016. The IDM is charged with the organisation of various European and International Congresses.

The 2017 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:

<table>
<thead>
<tr>
<th>Year</th>
<th>US$</th>
</tr>
</thead>
<tbody>
<tr>
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<td>338,809</td>
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<td>2016</td>
<td>291,601</td>
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<thead>
<tr>
<th>Item</th>
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<th>2016</th>
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</thead>
<tbody>
<tr>
<td>Cash at bank</td>
<td>338,809</td>
<td>291,601</td>
</tr>
<tr>
<td>Debtors and prepayments</td>
<td>284,073</td>
<td>173,955</td>
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<tr>
<td>Creditors</td>
<td>(267,061)</td>
<td>(267,366)</td>
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<tr>
<td>Bank overdraft</td>
<td>(33,085)</td>
<td>(63,552)</td>
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<td>Deferred income</td>
<td>(1,436,373)</td>
<td>(536,491)</td>
</tr>
<tr>
<td>IDM-Congress income received</td>
<td>(810,258)</td>
<td>(543,720)</td>
</tr>
<tr>
<td>IDM-Congress expenses</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Working for people with epilepsy and those who care for them across the globe

In 2017, IBE had 137 chapters in 103 countries

With the world population estimated at 7.6 billion, 6.8 billion people or 89% of the world’s population live in countries served by an IBE chapter

<table>
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<th>Country</th>
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HIGHLIGHTS 2017

CREATING ARTISTIC WAVES
Art Competition
‘A whim of courage’
Artist: Lungelo Dube, Swaziland
Winner of the adult section and one of more than 140 entries received for the competition to celebrate International Epilepsy Day

International Epilepsy Day
Organised jointly by the International Bureau for Epilepsy and the International League Against Epilepsy, International Epilepsy Day provides the platform for people with epilepsy to share their experiences and stories with a global audience and to build a stronger epilepsy community. It has been developed to advocate for appropriate legislation to guarantee human rights of people with epilepsy and to empower people with epilepsy to maximise their quality of life.

Towards a Global Alliance on Epilepsy Research

Workshop in the European Parliament
hosted by Brian Hayes MEP

The workshop on 7th February, organised by the Epilepsy Alliance Europe task force, was attended by some of the most senior representatives of a number of agencies and associations from Europe and North America. The purpose of the meeting was to see how resources in the US, EU and possibly Asia, might be pooled so that each region was not working in a silo but as a joint collaborative unit.

The European Written Declaration on Epilepsy in 2011, supported with the signatures of 459 MEPs, and the more recent WHO Resolution on epilepsy, approved unanimously by the World Health Assembly in 2015, recognised the importance of the issue.

The workshop also demonstrated to the European Parliament “the quiet but deliberate work that has been going on since 2011”, Mr Hayes said in his opening address.

Campi visits the doctor

In the first episode of the Campi animated videos, introduced in 2016, we met Campi and his schoolfriends. In the second in the series of short animated films created especially for young children was launched to celebrate International Epilepsy Day 2017. In this episode, Campi visits Dr Christina Langoustina with his mother and father to find out what is causing Campi to have seizures.
International Epilepsy Day - Social Media

Surge in Social Media activity

Twitter [http://www.twitter.com/IntEpilepsyDay](http://www.twitter.com/IntEpilepsyDay)
@IntEpilepsyDay account performance, February 2017
Tweet impressions: 59.6k (+585.6%)
Profile visits: 4,265 (+499.9%)
Mentions: 247 (+1,664.3%)
Top Tweet: 9,137 impressions
Top media Tweet: 5,888 impressions
Total Followers Sep 2016: 557
Total Followers Feb 2017: 926 (+66%)

Facebook [https://www.facebook.com/epilepsyday/](https://www.facebook.com/epilepsyday/)
International Epilepsy Day Page performance, February 2017:
Page Likes: +522 (+358%)
Page Views: 1899 (+562%)
Post Engagements: 10,152 (+1,029%)
Reach: 36,403 (+731%)
(100% organically generated activity)
Total Page Likes Sep 2016: 5,556
Total Page Likes Feb 2017: 6,221 (12% increase)

Instagram [https://www.instagram.com/IntEpilepsyDay/](https://www.instagram.com/IntEpilepsyDay/)
NEW FOR 2017! Follow @IntEpilepsyDay on Instagram

World Health Organization

International Epilepsy Day is recognised annually by the World Health Organization (WHO).
WHO was Twitter’s top Health Influencer during the period, with 3.3 million followers of their account.
The most popular health-related URL in a tweet during the period was WHO’s epilepsy factsheet:
WHO’s factsheet Tweet was shared over 1,100 times and their Facebook post over 1,300 times.
They also shared a webpage dedicated to International Epilepsy Day featuring the artwork of W.M.M. Sanjana, a young person from Sri Lanka, who was one of the runners-up in the children’s category of the Creating Artistic Waves competition for International Epilepsy Day.

From February 11 to February 15, 2017
#EpilepsyDay was the most used hashtag on Twitter among the health community, being used 1,939 times*
Communication is essential to our work. It provides the platform to promote what we do, to encourage discourse with our chapters, and to inform the wider world about epilepsy and about the efforts we undertake to improve life quality for all those affected by epilepsy around the world.

Since IBE’s first printed newsletter, a one page letter, typed on a manual typewriter, copied and mailed out to chapters and supporters in 1961, how IBE communicates its message has taken giant steps forward. First came the electric typewriter, followed by the fax machine, the computer, email and the world wide web. IBE launched its first website in 2001 and now maintains 4 separate sites:

- ibe-epilepsy.org
- internationalepilepsyday.org
- epilepsyallianceeurope.org
- globalcampaignagainstepilepsy.org

The benefit of new technology has facilitated the creation of new communication streams including eZines and social media. In recent years, social media channels, in particular Facebook and Twitter, have been adopted, recognising the need in the modern era, for instantaneous delivery of news as it happens.

However, despite the marvels of modern technology, one-to-one communication - by email, phone and Skype - still remain important communication channels, used at chapter and committee levels. Improving how we communicate our message to our internal and external audiences, is an issue that is continually under review.

International Epilepsy News

Entering its 54th year of uninterrupted publication, the IBE news magazine continued to be published each quarter during the year. Following the start of the new term of the International Executive Committee in Barcelona, a redesign of the magazine was introduced, with Issue 4-2017 showing its new look.

Published online and distributed to a database of over 3,000, IE News provides the opportunity to report on IBE activities, on events and news from its chapters, updates on projects in which IBE is involved, as well as information on external issues that impact on people with epilepsy.

The newsletter is also available to download from the IBE website ibe-epilepsy.org, where an archive of previous issues is stored.

Communications strategy

Websites, e-Zines and Social Media
With our partner, the International League Against Epilepsy (ILAE), IBE organises biennial international epilepsy congresses as well as regional congresses in Africa, Asia Oceania, East Mediterranean and Latin America. In addition to the scientific sessions, epilepsy congresses now also include teaching sessions and leadership programmes, with dedicated Epilepsy & Society programmes created specifically for people with epilepsy, their families and those who care for them. In 2017, the Epilepsy & Society Programmes took place at the regional meetings in Luxor and Dakar, with the presentations focussed on issues particular to the region in which the congress was being held.

The 4th East Mediterranean Epilepsy Congress took place in Luxor, Egypt from 16th to 18th February. This was the second time this regional congress has been held in this city on the Nile, a place with a fascinating and ancient history with temples and tombs on either side of the river, and where every day more wonders are revealed by modern archeologists. Despite the fact that there had been a significant decline in tourist numbers to Luxor in recent years, the congress attracted close to 400 delegates from 30 countries.

Three months later, from 5th to 7th May, the 3rd African Epilepsy Congress took place in Dakar, Senegal with a similar number of delegates. The two previous congresses had been held in Nairobi and Cape Town.

These regional congresses, organised jointly by IBE and ILAE, play an important role in providing training opportunities and increasing knowledge about epilepsy for all those involved in the field in these regions. They also serve to enforce IBE’s mission to end stigma and discrimination through epilepsy education in every region of the world.

Barcelona proved to be a very popular venue for the 32nd International Epilepsy Congress in Barcelona, with one of the highest delegate numbers for an international meeting in recent years. Apart from the excellent congress scientific programme, the congress was also significant as it marked the end of the term of office for the 2013-2017 IBE board and the start of the term for the incoming International Executive Committee.

The General Assembly was the occasion to formally ratify new chapters approved by the International Executive Committee since the previous assembly, to hear on progress made in a number of IBE projects and initiatives, and for chapters and the committee to meet informally during the assembly reception.

Charlotte Dravet, France, receives a well-deserved standing ovation on being presented with the Lifetime Achievement Award at the Opening Ceremony in Barcelona.
Planning for an exciting new initiative to help young people to grow in independence and to develop the skills and qualities necessary for a happy and productive life began in the last quarter of 2017. The EpilepsyNext initiative will also challenge young people to use these attributes for the betterment of themselves and the global epilepsy family.

In the future it is hoped to develop and expand the initiative to introduce new modules to the programme but, as always, this will be funding dependent. As a start, five modules have been identified:

**The TEA Room:**
A safe online environment for teenagers with epilepsy to meet and discuss issues of relevance to them. This initiative was first developed by the Scottish Epilepsy Initiative charity and is now been expanded.

**Young Adult Summit:**
A coming together of young adults to share their experiences, identify challenges that prevent them from participating fully their community and develop projects to address these challenges. By the end of 2017, plans were underway for the first summit - to take place during the Latin American Epilepsy Congress in Costa Rica in October 2018.

**Leadership Training Programme:**
Offering tailored high-quality support to young adults (18-30 years), who have the motivation to learn about advocacy, and to maximise their leadership potential equip them with the skills to become future leaders of epilepsy associations.

**Golden Light Awards:**
Adapting an award program already in place for Asian & Oceanian Epilepsy Congresses to focus on young people and to award those personally affected by epilepsy whose efforts had made a significant impact on their own lives or on the lives of others.

**My story:**
Many people have powerful personal narratives that can inspire and inform about living with epilepsy. My story supports them in sharing their story in their own voice without stereotyping or victimising. These stories will let us, and the world, know that a person is more than their illness.

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**Programmes and initiatives**

**IBE’s focus on youth**

IBE is committed to finding new and innovative solutions to the problems impacting people with epilepsy and their families world-wide. As part of this commitment, under its Promising Strategies Program (PSP), IBE has been providing a limited amount of financial support to IBE chapters on a competitive basis for initiatives aimed at improving the quality of life for people with epilepsy in resource challenged countries or regions. In the 11 years since it was established, PSP has provided more than US$300,000 in funding to 83 projects in 38 countries. Two new projects were funded in 2017 in Tibet, China and Colombia.

**Neurocysticercosis** is the first cause of epilepsy in the Caribbean region. The Colombian project focussed on eliminating the worms affecting diseased pigs, which were responsible for spreading neurocysticercosis in one region of the country. One year on and already the project of FIRE, IBE’s chapter in Colombia, is making an impact in the eradication of neurocysticercosis in one rural town. Its success has led the government to consider expanding it across the entire Caribbean coastal region.

In Tibet, medical resources are highly insufficient in the Ganzi Tibetan Autonomous Prefecture. At county-level, hospitals have only 3 to 5 doctors, and only one with a practitioner's license. People living in Tibet have the shortest life expectancy and highest illiteracy rate in China. The epilepsy treatment gap has been shown to be as high as 97%. And 60% of people will choose traditional Tibetan medicine. In the program, GPs and patients are the targeted population. There is an urgent need to train the local doctors in proper epilepsy control; to educate people with epilepsy to adhere to appropriate treatment; and increase public awareness of epilepsy. This is done by doctors from Chengdu and Kangding who are supported by PSP and who travel to these remote regions.
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International Epilepsy Day
Celebrated annually on the
2nd Monday in February
www.internationalepilepsyday.org
EUROPE

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PRESIDENT
Annual Report 2017
INTERNATIONAL EPILEPSY DAY 2019
VIDEO COMPETITION

AS PART OF OUR INTERNATIONAL EPILEPSY DAY CELEBRATIONS FOR 2019, WE INVITE YOU TO ENTER OUR VIDEO COMPETITION WITH CASH PRIZES FOR THE WINNING ENTRIES!

The winning videos will be selected based on their success in telling an inspiring personal story or in using a novel means of increasing knowledge and awareness of epilepsy. In each category, there will be one 1st Prize of US$500 and five Runners’ Up prizes of US$100.

CATEGORY ONE: My Personal Story
People with epilepsy, their families, friends and carers, can create non-professional individual short videos, using a smart phone or personal camera, to inspire others or to highlight problems faced.

CATEGORY TWO: Educational Video
Open to organisations and support groups who have developed professionally produced videos to educate the public, policy-makers, and people with epilepsy themselves, about epilepsy during the past 3 years.

VISIT WWW.INTERNATIONALEPILEPSYDAY.ORG FOR MORE
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