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 Covannis (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 Mehdiratta (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 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 8.1% of total income. IBE received industry-related income from two companies in 2016 - Shire International Gmbh and UCB Pharma. The higher contribution (78% of total) was received from Shire International Gmbh.
- In 2016, non-industry income accounted for 91.9% of all income.
Dear Friends

2016 was a busy and productive period for IBE as we consolidated ongoing activities and developed new initiatives in our efforts to improve the quality of life of all those affected by epilepsy.

As an international organisation for national epilepsy associations, IBE exists to provide support for a strong global network of chapters, encouraging communication and collaboration between chapters and with all stakeholders in order to meet our mission and vision.

Our priorities are to promote access to care and appropriate treatment for people with epilepsy; to protect their human and civil rights and, as a consequence, to maximise their quality of life. Furthermore, by supporting and promoting research, we contribute to better treatment options and, by using the WHO Epilepsy Resolution, we strive to have epilepsy recognised as a health care priority by national governments in both developed and emerging economies. All our actions are developed with these priorities foremost in mind.

2016 began with the second celebration of International Epilepsy Day and it was heartening to see the number of countries recognising the day had risen to more than forty. A wide range of events were organised at a national level to address issues faced by people with epilepsy and their families at a local level and we were pleased to report on these in our newsletter and in social media. Our photography competition with the title ‘Yes, I can!’ attracted more than 200 entries and some of the wonderful photographs we received were used in a special exhibition in the European Parliament in Strasbourg. The positive message in most of the photos was the determination of people with epilepsy to live life to the full despite their diagnosis of epilepsy. Together with a second exhibition in Strasbourg, featuring the personal stories of people with epilepsy, the images brought epilepsy to the attention of the more than 700 MEPs from 28 countries and resulted in an increase in the membership of the EU Advocates for Epilepsy MEP group to 55.

The International Epilepsy Day event in the European Parliament was just one of the activities of the IBE/ILAE joint task force in Europe – Epilepsy Alliance Europe. The task force was also involved in a number of research projects in Europe including the Value of Treatment project of the European Brain Council, the European Reference Network pilot study - E-PILEPSY and EpiCARE, as well as ESBACE - which is looking at the costs and prevalence of epilepsy in a number of European countries.

2016 was also the year in which, together with our partners, the International League Against Epilepsy, we organised a number of regional congresses. The 11th Asian & Oceanian Epilepsy Congress took place in Hong Kong in mid-May and included a very successful Epilepsy & Society Day within the official programme. More than 200 people with epilepsy and their carers attended the day, and great thanks are due to Anchor Hung and her team for their tireless work in preparing an excellent agenda for the day. The Outstanding Persons with Epilepsy awards (now called the Golden Light awards) were presented to people nominated by the chapters in the region, to recognise their great efforts to overcome a diagnosis of epilepsy.

The 9th Latin American Epilepsy Congress was held in Cancun, Mexico in late August. This had another excellent Epilepsy & Society programme, organised by Dr Lilia Nuñez and with more than 300 participants, many of whom had travelled great distances by bus to attend.

In September, the 14th IBE European Conference on Epilepsy & Society took place in tandem with the 12th ILAE European Congress on Epileptology. This is the only congress that is not organised jointly with ILAE. Our congresses provide the opportunity to increase awareness and education of epilepsy, using regional/national evidence-based intervention to reduce the prevalence and burden of epilepsy. Education at all levels is the best way to improve treatment issues and reduce preventable causes of epilepsy, particularly in resource-poor countries.

Elsewhere, work continued apace on promoting the WHO/ WHA Resolution on epilepsy, which had been approved in May 2015. This is a major task to support chapters to work with national health departments and other stakeholders to encourage the adoption of the recommendations detailed in the resolution. In December 2016 I was invited to participate together with Shekhar Saxena (WHO), and Alla Guekht (ILAE) at the External Engagement Submit in Geneva organized by UCB to discuss how to implement the WHO Resolution Worldwide. At the same period together with the IBE Secretary General and Executive Director we were involved in producing the toolkit in the management of prolonged seizures at schools. Throughout the year, I was pleased to attend and speak at national meetings organised by IBE chapters and others, providing a platform to speak about the work of IBE and the efforts required to make a difference to the lives of those living with a diagnosis of epilepsy. I would like to extend my thanks to the warm hospitality I received on each occasion.

As the year came to a close, we looked forward to 2017.
Income and Expenditure Account
Year ended 31st December 2016
With comparative totals for 2015

<table>
<thead>
<tr>
<th></th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>INCOME</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>649,269</td>
<td>1,167,067</td>
</tr>
<tr>
<td>EXPENDITURE</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(916,059)</td>
<td>(1,202,263)</td>
</tr>
<tr>
<td>OPERATING (DEFICIT)/SURPLUS FOR YEAR</td>
<td>(266,790)</td>
<td>(35,196)</td>
</tr>
</tbody>
</table>

Balance Sheet
Year ended 31st December 2016
With comparative totals for 2015

<table>
<thead>
<tr>
<th></th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>CURRENT ASSETS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Debtors</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>174,692</td>
<td>143,122</td>
</tr>
<tr>
<td>Cash in hand and at bank</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>2,288,511</td>
<td>2,408,380</td>
</tr>
<tr>
<td>Amount held on behalf of the IBE/ILAE Joint Task Force</td>
<td>69,893</td>
<td>104,606</td>
</tr>
<tr>
<td></td>
<td>2,533,096</td>
<td>2,656,108</td>
</tr>
<tr>
<td>CREDITORS (Amounts falling due in one year)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(483,899)</td>
<td>(340,120)</td>
</tr>
<tr>
<td>NET CURRENT ASSETS</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2,315,988</td>
<td>2,315,988</td>
</tr>
<tr>
<td>NET ASSETS</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2,049,197</td>
<td>2,351,183</td>
</tr>
<tr>
<td>CAPITAL AND RESERVES</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General Reserve</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1,993,544</td>
<td>2,260,335</td>
</tr>
<tr>
<td>Restricted and designated funds</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>55,653</td>
<td>55,653</td>
</tr>
<tr>
<td></td>
<td>2,049,197</td>
<td>2,315,988</td>
</tr>
</tbody>
</table>

The financial statements were approved on 1 September 2017 and signed by:
Athanasios Covannis, President
Ann Little, Executive Director
Statement of Income and Expenditure
Year ended 31st December 2016
With comparative totals for 2015

<table>
<thead>
<tr>
<th></th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>US$</td>
<td>US$</td>
</tr>
<tr>
<td><strong>INCOME</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congress income received</td>
<td>536,491</td>
<td>1,046,872</td>
</tr>
<tr>
<td>Corporate donations</td>
<td>-</td>
<td>10,720</td>
</tr>
<tr>
<td>IBE/ILAE JTF management fee</td>
<td>16,450</td>
<td>16,720</td>
</tr>
<tr>
<td>IBE/ILAE JTF reimbursement of expenses (IBE 50%)</td>
<td>18,957</td>
<td>41,454</td>
</tr>
<tr>
<td>Membership dues and solidarity fund</td>
<td>14,323</td>
<td>13,832</td>
</tr>
<tr>
<td>Investment income</td>
<td>9,518</td>
<td>3,885</td>
</tr>
<tr>
<td>EPICURE grants</td>
<td>-</td>
<td>11,250</td>
</tr>
<tr>
<td>Restricted gifts and donations</td>
<td>53,530</td>
<td>22,334</td>
</tr>
<tr>
<td><strong>Total Income</strong></td>
<td><strong>649,269</strong></td>
<td><strong>1,167,067</strong></td>
</tr>
</tbody>
</table>

|                  |            |            |
| **EXPENDITURE**  |            |            |
| Congress expenditure | 543,720    | 680,049    |
| Office expenses   | 21,367     | 11,805     |
| Printing and postage | 215        | 347        |
| Travel            | 51,718     | 30,834     |
| Global Campaign costs | 16,433     | 20,018     |
| Accountancy fees  | 5,791      | 5,758      |
| Audit fees        | 5,186      | 14,995     |
| Administrator costs | 13,647     | 26,138     |
| Staff costs       | 107,627    | 140,094    |
| Employer’s PRSI   | 11,606     | 11,594     |
| Bank charges      | 1,342      | 1,207      |
| Rent              | 14,725     | 17,913     |
| Promising Strategies | -          | 6,732      |
| Website costs     | 10,129     | 5,660      |
| IBE JTF expenditure | 25,728     | 27,738     |
| International Epilepsy Day | 8,318     | 12,294     |
| Professional fees | 340        | 20,234     |
| Bad debts         |            |            |
| **Total Expenditure** | **873,772** | **1,021,816** |

|                  |            |            |
| Loss of foreign exchange | 44,287     | 180,447    |

|                  |            |            |
| **Total**        | **916,059** | **1,202,263** |
Notes to the financial statements
for the year ended 31 December 2016

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$13,948 (2015: US$16,720).

<table>
<thead>
<tr>
<th></th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>US$</td>
<td>US$</td>
</tr>
<tr>
<td>Opening balance</td>
<td>104,060</td>
<td>152,760</td>
</tr>
<tr>
<td>Bank interest received</td>
<td>25</td>
<td>781</td>
</tr>
<tr>
<td>Expenditure incurred</td>
<td>(34,737)</td>
<td>(48,935)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Closing balance</td>
<td>69,893</td>
<td>104,606</td>
</tr>
</tbody>
</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 2016 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></th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>US$</td>
<td>US$</td>
</tr>
<tr>
<td>Cash at bank</td>
<td>291,601</td>
<td>439,146</td>
</tr>
<tr>
<td>Debtors and prepayments</td>
<td>173,955</td>
<td>139,652</td>
</tr>
<tr>
<td>Creditors</td>
<td>(267,366)</td>
<td>(43,106)</td>
</tr>
<tr>
<td>Bank overdraft</td>
<td>(63,552)</td>
<td>79,068</td>
</tr>
<tr>
<td>Deferred income</td>
<td>(11,159)</td>
<td>(50,305)</td>
</tr>
<tr>
<td>IDM-Congress income received</td>
<td>536,491</td>
<td>1,046,872</td>
</tr>
<tr>
<td>IDM-Congress expenses</td>
<td>(543,720)</td>
<td>(680,049)</td>
</tr>
</tbody>
</table>
Working for people with epilepsy and those who care for them across the globe

In 2016, IBE had 137 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

Albania  Argentina  Australia  Austria  Bangladesh  Belgium  Brazil  Bulgaria  Cameroon  Canada  Chile  China  Colombia  Congo, DR  Costa Rica  Croatia  Cuba  Cyprus  Czech Republic  Denmark  Dominican Rep  Ecuador  Egypt  Estonia  Ethiopia  Fiji  Finland  France  Gambia  Georgia  Germany  Ghana  Greece  Guatemala  Guyana  Honduras  Hungary  Iceland  India  Indonesia  Iran  Ireland  Israel  Italy  Jamaica  Japan  Kazakhstan  Kenya  Korea  Lebanon  Lithuania  Luxembourg  Macedonia FYR  Malawi  Malaysia  Malta  Mauritius  Mexico  Moldova  Mongolia  Morocco  Namibia  Nepal  Netherlands  New Zealand  Niger  Nigeria  Norway  Pakistan  Panama  Paraguay  Peru  Philippines  Poland  Portugal  Romania  Russia  Scotland  Senegal  Serbia  Sierra Leone  Singapore  Slovakia  Slovenia  South Africa  Spain  Sri Lanka  Swaziland  Sweden  Switzerland  Taiwan  Tanzania  Thailand  Togo  Tunisia  Turkey  Uganda  UK  USA  Uruguay  Venezuela  Zambia  Zimbabwe
Organised jointly by the International Bureau for Epilepsy and the International League Against Epilepsy, International Epilepsy Day was launched in February 2015, building on the previously successful European Epilepsy Day and creating an international day focused on epilepsy. It provides the platform for people with epilepsy to share their experiences and stories with a global audience and, thereby, 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.

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

Already, after two years, the day is recognised and celebrated by chapters of IBE and ILAE, as well as by epilepsy centres, support groups and individuals, in more than 40 countries around the world. In both 2015 and 2016, the World Health Organization (WHO) recognised the day with special videos about epilepsy on its homepage.

We measured success by:
- increased activities to mark International Epilepsy Day, in more countries and by more chapters
- an increase in visitor numbers to the website epilepsy.org
- continued recognition of the day by WHO
- increased Facebook ‘likes’ and Twitter ‘followers’
- increased Social Media sharing and commenting - Facebook, Twitter, Snapchat, Instagram
- an increased level of media attention at local and international levels

We would like to thank all those who helped make International Epilepsy Day 2016 a great success. Thanks are also extended to Shire International and to UCB Pharma for their support.

PHOTOGRAPHY COMPETITION

With a prize fund of US$2,000, almost 300 photographs were received from more than 200 competitors for the Yes, I can! photo competition organised to mark International Epilepsy Day 2016. Using photography competition websites gave an opportunity to bring epilepsy into focus for many people who knew nothing about the disease. The competition also gave people with epilepsy and their carers the chance to demonstrate, through stunning and moving photos, that people with epilepsy can achieve great things despite their condition. A winning formula for raising awareness about epilepsy to a wide and varied audience.

The photos were showcased on a gallery featured on the International Epilepsy Day website - epilepsy.org - and were also used in a special poster exhibition mounted in the European Parliament in Strasbourg.

Photo left: young children in Chile enjoying handpainting - a photo entered for the Yes I can! photo competition.
Events in the European Parliament in Strasbourg

Hosted by Brian Hayes MEP, President of the European Advocates for Epilepsy MEP group in the parliament, a reception was held to launch International Epilepsy Day and to showcase the two poster exhibitions that were produced to celebrate the day.

One of the exhibitions told the personal stories of people with epilepsy while the second featured a selection of photos from the Yes, I can! Photography Competition.

Both exhibitions hung in a busy main walkway through which the more than 700 MEPs pass at least twice each day on their way to the plenary hemicycle and were in place for the parliamentary week.

We also had a Photo Opportunity for MEPs to have their photos taken for social media. Many MEPs uploaded the photos to their own platforms to demonstrate their support for people with epilepsy.

An important element of International Epilepsy Day in the parliament was the separate private meetings with 36 MEPs, all of whom demonstrated strong support for our cause.

The activities in the parliament resulted in an increase in the number of members of the European Advocates for Epilepsy group from 24 to 55.

MEET CAMPI: a seahorse who has epilepsy

Campi, the animated seahorse character was created for a new video for school children that was made especially for International Epilepsy Day and which featured on the website epilepsy.org. He was so named because the seahorse is genus Hippocampus and its shape resembles a part of the brain that has the same name and is important in producing seizures and epilepsy.

We also created a colouring page for teachers to download. This is the start of what we plan to build into a comprehensive school kit to teach very young school children about epilepsy in a fun and educational way.
Communications Strategy

Communication with our chapters, close working partners, other stakeholders and our external audience is essential to our work. Communication is an ongoing activity and encompasses all available avenues, including the International Epilepsy News, which has been in continuous publication on a quarterly basis for more than 50 years.

In more recent years, the benefit of new technology has facilitated the creation of new communication streams including eZines, social media and websites. IBE launched its first website in 2001 and now maintains 4 separate sites:

- ibe-epilepsy.org - the website of IBE, which was redesigned during 2016
- epilepsy.org - the website designated to International Epilepsy Day for 2016 celebrations
- epilepsyallianceeurope.org - the website of Epilepsy Alliance Europe and its task force
- globalcampaignagainstepilepsy.org - which works as a repository for materials connected to Global Outreach.

In recent years, social media channels, in particular Facebook and Twitter have been adopted. Nevertheless, 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.
IBE at Congress

IBE, together with its medical counterpart and partner, the International League Against Epilepsy, organises biennial International Epilepsy Congresses as well as regional congresses in Africa, Asia Oceania, East Mediterranean and Latin America. The regional meetings usually take place every two years. In addition, IBE and ILAE hold separate regional congresses in Europe. In 2016, regional congresses took place in Hong Kong (Asia Oceania), Prague (Europe) and Cancun (Latin America).

In addition to the scientific sessions, the regional and international 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 2016, the Epilepsy & Society Programmes took place at all three regional meetings, with presentations focused on issues particular to the region in which the congress was being held.

Golden Light Awards

HONG KONG

The Golden Light Awards, presented during the Epilepsy & Society Programme at the Asian & Oceanian congresses, recognise people who have made significant contributions to community service by providing longstanding support for people living with epilepsy, through individual achievement. It recognises their advocacy endeavours for epilepsy or for distinguished services to a local epilepsy support association.

The awards were presented at the Opening Ceremony of the 11th Asian & Oceanian Epilepsy Congress in Hong Kong in May 2016. IBE recognises the importance of awarding people with epilepsy and those who care for them, who demonstrate determination, tenacity and dedication in their work and everyday lives.

Photo: recipients of the Golden Light Awards who had been able to travel to Hong Kong, with Dr Athanasios Covanis, IBE President 2013-2017, Dr Wing-man Ko, Secretary for Food and Health (third and fourth from left) and Mrs Denise Chapman, Chair IBE Regional Executive Committee Western Pacific (far right).

Latin American Epilepsy Congress - Cancun, Mexico

More than 300 people with epilepsy, their families and carers attended the full day Epilepsy & Society program held during the Latin American congress in Cancun. This was the highest attendance at any of the regional Epilepsy & Society days. Many of the participants had travelled several hours, some in overnight bus rides, to be able to attend the sessions organised by the IBE Latin American Regional Committee.

The sessions, all in Spanish, provided a unique opportunity for many of the participants, to have their concerns aired and to learn about coping mechanisms to meet the lifestyle issues that affect people with epilepsy in their daily lives.

Epilepsy & Society Conference - Prague

The fourteenth IBE stand-alone European Conference on Epilepsy & Society took place in Prague in September, with a half-day of joint sessions with the International League Against Epilepsy. A highlight of the conference programme was the workshops on three popular topics: Epilepsy & Memory, Fundraising, and Epilepsy & Employment (overcoming stigma). All three were excellent interactive and stimulating presentations that gave food for thought to those attending.

Despite the popular programme, it is likely that this will be the last European conference to follow this model. IBE is now considering a new structure and a fresh approach for its conferences in the region. The first European Conference on Epilepsy & Society took place in Rome in April 1988 and now, almost 30 years later, now is a good time to look at modernising its content and outline to meet the current requirements of people with epilepsy and those who care for them, which have evolved over the intervening years.
Registered as an entity in 2015, Epilepsy Alliance Europe (EAE) is a joint organisation that brings together European professional and lay stakeholders associated with the International League Against Epilepsy (ILAE) and with the International Bureau for Epilepsy (IBE). Its main objectives are:

- the protection of the rights of people with epilepsy
- the improvement of epilepsy care
- the dissemination of awareness and knowledge about the complex spectrum of epileptic diseases
- the promotion of research in epilepsy and its comorbidities
- to establish epilepsy as a healthcare priority in Europe.

The activities of Epilepsy Alliance Europe are carried out by the joint task force that comprises four nominees each of the IBE and the ILAE.

One of the main activities of the task force in 2016 revolved around the call for European Reference Networks (ERN) on rare and complex diseases. Already, E-PILEPSY was running as a pilot ERN and there were concerted efforts to have epilepsy selected as a stand alone disease for the next phase.

To highlight that the need to have epilepsy chosen as a ERN in its own right, and not included with other neurological disorders, a special session was organised at the congress of the European Academy of Neurology in Copenhagen.

The EpiCARE submission was successfully approved late in the year as one of 24 ERNs that would get underway, officially, in early 2017.

The EpiCARE network will develop and deliver highly-specialised diagnostics and care to improve interventions and outcome in individuals with rare and complex epilepsies. With a strategy of collaborative working, sharing of expertise and access to advanced diagnostics EpiCARE anticipates an increased number of individuals with refractory epilepsy to have an underlying diagnosis as a cause for the epilepsy. By collecting information about where such patients exist, the ERN will be able to collate information on clinical presentation and evolution across the life span, constitute cohorts of these rare conditions and advance the development of clinical trials, utilising innovative trial design for small select numbers of patients.

The ESBACE project, which began in 2015 and for which EU funds were won following a successful submission, is looking at the cost and burden of epilepsy in a number of EU countries and is due to present its final report in 2018.

The EAE task force was also involved as one of the nine work packages in the Value of Treatment (VoT) project of the European Brain Council (EBC). This project looks at the value of treatment as opposed to the cost of non-treatment and focusses, in particular, on the patient pathway.

EAE organises events in the European Parliament each year at the time of International Epilepsy Day to highlight, to MEPs from the 28 European Member States, the need for increased funding for epilepsy research and for improved services and treatment for the 6 million people living with epilepsy in Europe.

One of the most valuable ways of interacting with MEPs is through private meetings with individual MEPs. In 2016, 36 such meetings took place. In addition, a poster exhibition in one of the most prominent areas of the parliament building, used posters to tell the individual stories of 12 people living with epilepsy in Europe.

The EAE task force is grateful to the European Advocates for Epilepsy group, led by Brian Hayes MEP, which has been extremely supportive to EAE in hosting epilepsy events in the parliament.

Throughout 2016, there was discussion on the need for increased research on epilepsy, not only in Europe, but, on a global scale. As the year came to a close, plans were being put in place for a major workshop on ‘A Global Alliance on Epilepsy Research’ to take place in Brussels at the time of International Epilepsy Day 2017 and involving participants from Europe, North America and, potentially, other regions of the world.

Information on all of the projects in which EAE is involved can be found on the website epilepsyallianceeurope.org.
Global Outreach Task Force

WHA Resolution on Epilepsy
Following the approval by the World Health Assembly of the Resolution on Epilepsy in 2015, there have been ongoing activities by the IBE/ILAE Global Outreach Task Force (GOTF) to encourage the adoption of its recommendations by national health authorities around the world. Meetings have taken place in Africa and Latin America and a Toolkit was produced by WHO.
IBE recognises the need to consider the varied requirements of its chapters, which will differ from region to region due to cultural and economic reasons, and is studying how best to address these divergent needs. The Resolution provides the golden opportunity for people with epilepsy.

The Epilepsy Resolution provides the IBE and its members with a powerful tool to engage governments into taking concrete action to improve epilepsy care, promote public awareness and allocate resources. The GOTF continues to work with the ILAE and the WHO to discuss opportunities to implement the key recommendations in the Epilepsy Resolution:
• A tool kit developed by WHO and situation analysis templates have been distributed to IBE chapters.
• WHO partnered with the GOTF to promote International Epilepsy Day. Photos and information about epilepsy were featured on the WHO website and materials were distributed through WHO health networks.
• GOTF contributed to the preparation of World Brain Day 2015 - the initiative of the World Federation of Neurology, to which WHO, ILAE and IBE were invited to participate and which was dedicated to ‘epilepsy’
• Meeting during the 12th ECE in Prague with WHO representative (Tarun DUA) and ILAE /IBE Presidents to discuss regions for demonstration projects and the components of the Global Epilepsy Report.
• A meeting with WHO Assistant Deputy General Dr Oleg Chestnov took place with a discussion on epilepsy as one of the key NCD comorbidities.
• Focus Group in Istanbul, during the 31st IEC; delegates from Latin America, Asia and Africa participated in a brainstorming session.
• The work on the Global Epilepsy Report is ongoing and planning discussions are taking place on a monthly basis.

Improving Access to AEDs
Given the importance of access to antiepileptic medicines, a workshop on this topic brought together key stakeholders from WHO, ILAE, IBE, Health Action International and representatives from Ministries of Health to discuss opportunities for achieving long-term affordable access to essential medicines for epilepsy.
It was stated that the treatment gap is a multifaceted domain, influenced by the diagnostic and therapeutic deficits, including lack of personnel (manpower gap), limited AEDs supply, poor adherence to medication, economic conditions, cultural beliefs and many other factors; the need to better define and investigate the treatment gap was appreciated.
A number of demands, especially important for the lower and middle income countries, were acknowledged, including the role of non-specialist health care providers and the impact of ignorance and stigma.

Young Adult Summit
A group of 20 young adults representing the United States, Canada, Puerto Rico and Jamaica gathered in Washington, DC, to participate in the ‘Young Adult Epilepsy Summit’ organized by the International Bureau for Epilepsy. The event comprised of a weekend filled with workshops and discussions to talk about the core issues of those affected by epilepsy. As a result of the summit, the Twenty-20s group was tasked with developing an initiative that would raise awareness about epilepsy through the sharing of their personal stories.
In October 2015, members of the group met in Toronto, Canada to film their personal videos. Using social media, the young adults have shared their stories worldwide. They have developed a governance structure and continue to meet monthly via teleconference. This group of epilepsy champions has established a Facebook site and continue to track the growth of their online audience. They are committed to working with young adults in all regions to reduce the burden of epilepsy on the individual, their family and their community.

Eastern European collaboration
Several other important activities targeted European countries of the Former Soviet Union – the area of huge unmet needs in the improvement of care for people with epilepsy and education in epilepsy. There are five countries in the region (Kazakhstan, Uzbekistan, Kyrgyzstan, Turkmenistan, Tajikistan), with 3 existing ILAE chapters (Kazakhstan, Uzbekistan, Kyrgyzstan). The collaboration with doctors from Turkmenistan and Tajikistan is ongoing with the potential formation of new chapters.
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