

Actions related to International Bureau for Epilepsy during my term as President 2013–2017

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Summary

The International Bureau for Epilepsy (IBE) Executive Committee for the term 2013–2017 began in June 2013 during the 30th International Epilepsy Congress in Montreal. From the beginning, our primary goals were to fulfil the mission of our organisation and address problems such as awareness, education, and social issues, while promoting and protecting the human rights of persons with epilepsy (PWE) and improving trans-regional equity in access to health care services, improved prevention, diagnosis and treatment and as a consequence, a reduction in the treatment gap and alleviation of stigma worldwide. By so doing, the quality of life of PWE and those who care of them will be significantly improved. In order to achieve these aims, the IBE joined forces with the International League Against Epilepsy (ILAE) and also the World Health Organisation (WHO), regional and national IBE organisations and other stakeholders.

In addition, the participation of the IBE President in many national epilepsy events worldwide has helped to promote care and human rights of PWE nationally. A major awareness event accomplished during our term in office was the launch of the International Epilepsy Day in 2015. An IBE-ILAE event celebrated the 2nd Monday in February each year at the European Parliament with the participation of many stakeholders, PWE and advocates for epilepsy MEPs.

In 2014 in order to improve access to care, treatment, appropriate treatment for PWE worldwide, particularly in developing countries, we developed our strategy plan becoming IBE's roadmap up to 2019 and with strategic priorities to establish epilepsy as a health priority worldwide. In June 2014, in Troina, Italy, WHO, ILAE, IBE and the Global Outreach Research Task Force organised a workshop to discuss how to improve access to anti-epileptic medicines in low- and middle-income countries and, as a consequence, to produce a white paper. A unique historical achievement during our term in office was the approval from WHO and subsequently from World Health Assembly (WHA) (May 26th, 2015) the Resolution on the Burden of epilepsy, and calls on United Nation Member States to implement the WHA68.20 actions and for WHO to report back in 2018. The creation by IBE/ILAE in 2016 the legal entity Epilepsy Alliance Europe has given the opportunity for both organizations to play a partnership role in many research projects aiming to reduce the epilepsy burden in Europe and worldwide.

Key words: International Bureau for Epilepsy · Cooperation with WHO, ILAE · National chapters

BACKGROUND

Epilepsy is a common, but treatable, chronic brain disease that affects all ages irrespective of ethnicity, gender, education, social and economic status. The incidence of epilepsy is twice as high in low- and middle-income

countries compared to high-income countries (Ngugi et al., 2011) mainly due to secondary causes (Katchanov and Birbeck, 2012; Newton and Garcia, 2012) that may vary according to the region and country, may cause

permanent brain damage and, in up to 30% of cases, are preventable. It is estimated that over 65 million people worldwide (Thurman et al., 2011) and 6 million people in Europe (Cross, 2011) are affected, making it an important public health problem with high levels of suffering. Today, despite the existing antiepileptic drugs, up to 30% of people with epilepsy continue to have seizures and those who have seizures, particularly severe, are often stigmatised, discriminated against and isolated from social activities in many parts of the world. These people are particularly prone to experience psychiatric problems, difficulties in cognition, sometimes maladaptive social function (Jacoby and Austin, 2007), and a higher risk of suicide (Christensen et al., 2007) and mortality rates (Cockerell et al., 1997). The psychological impact of epilepsy is relevant to quality of life, psychological state, educational achievement, employment and marital state. In a Global Burden Disease Study, the disability burden associated with severe epilepsy ranked fourth among 220 health states surveyed, irrespective of geographical boundaries (Salomon et al., 2012). If properly treated, up to 70% of people with this condition could live a normal and productive life; yet, two thirds of those newly diagnosed live in low- and middle-income countries, where the epilepsy treatment gap (ETG) is very high (80–90%). A more recent review that included 74 studies in English and other languages found the treatment gap in some lower-middle and low-income countries to be significantly higher as compared to high- and higher-middle income countries and that, in general, the ETG was higher in less affluent countries and in rural areas than in urban settings (Meyer et al., 2010). The global disparities in the ETG gap are mainly due to poor awareness, education, availability, accessibility and affordability. All these facts make epilepsy a significant health and socioeconomic burden (WHO, 1999) of low priority.

Major geographical differences, however, do exist in the magnitude of the treatment gap and it is well known that millions of people who live in developing countries could be effectively managed with inexpensive medical care (Perucca et al., 2014).

REPORT

International Bureau for Epilepsy

The primary mission of the International Bureau for Epilepsy (IBE), together with the International League Against Epilepsy (ILAE), is to increase awareness, un-

derstanding and education about the real facts of epilepsy, to improve health care and treatment options worldwide by supporting research, and protecting the human rights of people with epilepsy (PWE). By so doing, the quality of life of PWE with those who care of them will be significantly improved.

The IBE was founded in Rome in 1961, on the suggestion of leading members of the ILAE and had its first Constitution in place, as an independent organisation, in 1966. The IBE is an incorporated, not-for-profit international umbrella body representing PWE and their families and carers and professionals interested in the medical and non-medical aspects of epilepsy. The IBE works in partnership with various commercial, non-for-profit, governmental and non-governmental agencies around the world and addresses problems such as awareness, education, and social issues, while promoting and protecting the human rights of PWE and improving trans-regional equity in access to health care services, improved prevention, diagnosis and treatment and as a consequence, a reduction in the treatment gap and alleviation of stigma worldwide. By supporting research, new and more effective drugs and alternative treatments will be discovered to prevent seizures in drug resistant epilepsies and to improve autonomy, liberty and equal access to community integration in respect of civil, cultural, political and social rights. PWE, in any society, are the most powerful tool to influence policy makers and make epilepsy a worldwide top health priority. The IBE has a vision of the world where everywhere fear and ignorance about epilepsy are replaced by understanding and care and works to improve the social condition and quality of life of all people with epilepsy and those who care for them. Today the IBE represents 135 full and associate chapters in 100 countries covering almost 89% of the world's population.

IBE International Executive Committee 2013–2017: main activities

In June 2013, at the IBE General Assembly that took place during the 30th International Epilepsy Congress in Montreal, our term of office as the IBE Executive Committee for the term 2013–2017 began. From the beginning, our primary goals were to fulfil the aims of our organisation. In order to achieve those aims the IBE, in many activities, joined forces with the ILAE and also the WHO, regional and national IBE organisations and other stakeholders.

In September 2013, we celebrated the 13th European Conference on Epilepsy & Society in Ljubljana, Slovenia, in which the European Regional Committee played a major role. The conference program was excellent and much appreciated by those who were with us in the charming city of Ljubljana. The first meeting of the new IBE-ILAE Joint Task Force in Europe – Epilepsy Advocacy Europe – took place in Ljubljana and a Strategic Plan was agreed. As a next step, it was decided to create, under the auspices of ILAE/IBE, Epilepsy Alliance Europe and to register it as an entity in Europe, in order to be able to qualify to apply for funding under EU programs. This work was completed in 2016.

In October of the same year, on the invitation of our chapter in China, the IBE Management Committee attended an important national meeting in Chongqing and had the opportunity to meet many members of the China Association Against Epilepsy and other representatives of IBE chapters from the Western Pacific region.

The IBE was represented at the annual sessions of WHO Regional Committees in Europe, South East Asia and Western Pacific in September and October, strengthening our ties to WHO and making many important contacts.

In October 2013, we attended an important meeting at WHO headquarters in Geneva. This was the mhGAP Forum at which the WHO Director-General launched the Mental Health Action Plan 2013–2020. At the same time, we had the opportunity to meet with Tarun Dua at WHO offices in Geneva to discuss our future collaboration and to plan activities. Working in partnership with the WHO is ideal and leads to an effective global action plan against epilepsy, through coordinated efforts at the country level designed to (i) assess the size of the epilepsy burden and related specificities and needs; (ii) introduce and implement national epilepsy programs and services in accordance with international human rights norms and standards; (iii) minimise the gaps in diagnosis and treatment, by addressing inequalities in care and facilitating access to affordable medicines and other treatments; (iv) enact legislation to protect the rights of PWE; and (v) establish awareness initiatives to educate the public about the nature of the disease and remove stigmatisation.

Shortly after the 30th International Epilepsy Congress that took place in Montreal, ILAE President (Emilio Perucca) and I, in our roles as the new co-chairs of the Global Campaign Against Epilepsy, nominated the two co-chairs of the Global Outreach Task Force –

Alla Guekht (on behalf of ILAE) and Mary Secco (on behalf of IBE). Global Outreach acts as an umbrella under which sits some joint activities of IBE and ILAE – including Epilepsy Alliance Europe.

As 2013 came to close, we were planning for the IBE-ILAE regional congresses that would take place in 2014 and were beginning to draft an important survey of our members. This survey would play a pivotal role in the development of our Strategic Plan that would begin early in 2014. A new strategic plan was created and approved by the chapters, becoming IBE's roadmap up to 2019 and with strategic priorities to establish epilepsy is a health priority worldwide; to ensure that the human and civil rights of PWE are enhanced and protected worldwide; to see that PWE are empowered to maximise quality of life; to promote research into prevention, treatment, care and consequences of epilepsy; and to improve the unity, sustainability, and communication of the IBE.

In February 2014, we celebrated the last European Epilepsy Day as plans to supersede the European day for epilepsy with an international event were already underway. Similar to previous years, IBE associations across the regions organised a wide range of activities to create awareness about epilepsy and, at the same time, to raise funds for their work. At the European level, once again we were hosted in the European Parliament in Strasbourg, meeting with Members of the European Parliament and with a poster exhibition on the theme *Epilepsy is more than Seizures*.

During 2014, together with our partners, the ILAE, we organised three regional congresses; 2nd African Epilepsy Regional Congress, Cape Town in May; 10th Asian & Oceanian Epilepsy Congress, Singapore in August; and 8th Latin American Regional Congress, Buenos Aires in September. Each congress had a very successful 'Epilepsy & Society' program which had high attendance of delegates including people with epilepsy, their families and care-givers. In each region the 'Epilepsy & Society' program is included as part of the main Scientific Epilepsy program. Unfortunately, for some PWE, understanding English can be a problem and this can deter them from participating in congresses where there is no simultaneous translation to the local language. During the Asian & Oceanian congress, the Outstanding Persons with Epilepsy award was presented, as usual, to people with epilepsy who had achieved great things despite having epilepsy. It was suggested that the Outstanding Persons with Epilepsy awards

should be introduced also at other regional congresses. During the congress in Buenos Aires, a meeting took place to review progress on the PAHO Strategic Plan for the Americas since its launch in 2011 and to consider plans for its future.

In response to previous successful lobbying activities, ILAE and IBE created the Global Research Priorities Task Force to address regional and global research priorities working in close collaboration with other relevant organisations. The primary aim was to seek funding for ambitious research programs on an international scale, by providing a well delineated and consensual assessment of research priorities for improving health-care in epilepsy.

In addition, IBE created the Governance, Election and Legislation Task Forces (TF). The Governance TF had the task of revising the IBE Constitution and By-laws, the first since 2004. The revised documents were initially approved by the IBE International Executive Committee during its meeting in Athens, September 2014. Final approval, by a strong majority vote of chapters, took place at the IBE General Assembly in Istanbul, during the 31st International Epilepsy Congress, 2015. The Election TF also completed its task with the last elections in 2017.

In June 2014, in Troina, Italy, WHO, ILAE, IBE and the Global Outreach Research Task Force organised a workshop to discuss how to improve access to anti-epileptic medicines in low- and middle-income countries and, as a consequence, to produce a white paper. In Troina, we also discussed the possibility of bringing epilepsy to the attention of the WHO Assembly agenda. For this to take place a request must come from a member of the current WHO Executive Board and it was agreed that the People's Republic of China was the most influential member among them. Our very active Chinese contact, Dr Shichuo Li, took on the task to influence the Chinese government to put epilepsy on the WHO agenda and subsequently formulated a draft Resolution on Epilepsy to be presented for discussion at the following WHO Executive Board meeting, which took place between January 26th and February 3rd 2015, and for initial approval. Towards the end of the year, as our communication with Member States unfolded further, it became clear that the level of support was so strong that some governments were considering co-sponsoring the Resolution. The first country to be thus influenced and to become supportive by taking an active step was the Russian Federation, which liaised with

the Chinese delegation in advancing the draft of the Resolution. Another co-sponsor that came in at a later stage was the Maldives (Covanis et al., 2015). This was a mammoth task and required much hard work and dedication, not only by the IBE and ILAE boards, but by IBE and ILAE chapters and stakeholders around the world. This great effort of both organisations was nicely coordinated and made possible largely by the tireless work of Ann Little – IBE Executive Director.

Therefore, 2014 was a year of planning for the future. A lot of work took place in planning for the success of two very important events planned to take place in the first quarter of 2015, for which we are particularly proud: firstly, preparations to seek the support needed for the Resolution on Epilepsy to be put initially on the agenda for approval by the next WHO General Assembly January 26th – February 3rd 2015 in Geneva and subsequently to be referred to the World Health Assembly for final approval in May 2015; and secondly, preparations to launch and celebrate the 1st International Epilepsy Day on February 9th 2015 in Strasburg, a very important IBE/ILAE awareness and educational event to be celebrated worldwide. For this, we urged all IBE/ILAE chapters to coordinate their Epilepsy Day events around the second Monday in February and use any colour, or combination of colours, they wished.

Approval of Resolution on Epilepsy

The support of the People's Republic of China did not come about by chance but was positively influenced by a previous pioneering role it had played in addressing the ETG by conducting, in conjunction with WHO, ILAE, and IBE, one of the most successful demonstration projects in the history of the Global Campaign Against Epilepsy, which took place in six provinces in China between 2000 and 2004. These projects were not only very successful in reducing the treatment gap and increasing the proportion of seizure free individuals, but also in demonstrating that the care model was cost-effective (Covanis et al., 2015).

IBE and ILAE, the joint Global Outreach Task Force, the Global Research Task Force, Regional Commissions, national chapters and other stakeholders were urged to join forces and influence policy makers to become supportive during the discussion of the “Global burden of epilepsy and the need for coordinated action at country level to address its health, social and public knowledge implications” that took place during the 136th WHO Executive Meeting on February 2nd 2015, in Ge-

neva. A total of 28 countries also made statements supporting the Resolution, 20 of which were WHO Executive Board Members. The WHO Board 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 (WHA) May 26th, 2015, 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. During these meetings, both ILAE and IBE Presidents made statements. Further supportive statements were made by WHO itself and by civil organisations accredited to WHO, including the World Federation of Neurology and Health Action International.

The day on which the resolution was approved by the WHA 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. The WHA approval of the WHO Resolution on the Burden of epilepsy (WHO, 2015a) calls on UN Member States to implement the WHA68.20 actions 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 programs;
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, stigmatisation 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.

The Resolution sends a strong message to the international community and governments across the world on 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 chapters with a powerful tool to engage governments into taking concrete actions to improve and promote epilepsy care and public awareness and to allocate resources to epilepsy research.

An important component of the resolution relates to the role that the World Health Assembly assigned to WHO. This is the first time that WHO received a specific mandate from the Assembly to guide Member States in the design and implementation of action plans against epilepsy and to provide support for these actions, particularly in low- and middle-income countries (Covanis et al., 2015).

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 aim.

Post Resolution meetings and Action plans

In September 2015 in Accra, Ghana, WHO organised a workshop, attended by delegates from across Africa, to consider the implementation of the WHA Resolution on the global burden of epilepsy with the view to its implementation across the African continent. IBE was represented by the Vice Chair of the African Regional Executive Committee. Following this meeting a Global Information Kit on Epilepsy was produced by WHO. The objective of the kit is to provide easy-to-understand information about epilepsy to key stakeholder groups on what they can do to reduce the ETG. Such information was planned for policymakers, for specialist and non-specialist health-care providers, for people with epilepsy and their families, for NGOs and for the general public (WHO, 2015b). This was the first in a series of planned workshops in response to the resolution.

On November 4th 2015, in Santiago, Chile, during the World Congress of Neurology representatives from

ILAE, IBE, WHO and the Global Outreach Task Force held a meeting to discuss different strategies and priorities to implement the WHO resolution at regional and country levels. The perspective of developing the region-specific initiatives was presented and the importance of working with WHO collaborative centers was also stressed.

In September 2016, during the 12th European Congress on Epileptology and the 14th European Conference on Epilepsy and Society, in Prague, ILAE, IBE, WHO and the Global Outreach Task Force met to produce a strategy plan as to how to implement the Resolution at country level, improve health care and harmonise epilepsy care across Europe and the World. It was decided to develop an information and advocacy strategy, review the WHO information kit on epilepsy, and prepare a report on improving access to anti-epileptic medicines in Low-and Middle-income countries. During the meeting, the importance of writing a WHO/ILAE/IBE Global Epilepsy Report was stressed.

The Resolution WHA68.20, endorsed by all 194 Member States at the Health Assembly, calls on the WHO Secretariat to report back on progress during the 71st World Health Assembly in 2018 and we hope that we will see the introduction of many improvements in the interim.

The International Epilepsy Day

For many years the IBE had struggled to launch an international Epilepsy day, despite ongoing requests for this from members. Since the idea of an international day was first raised, as far back as the late 1990's, the biggest problem had been deciding on a date. However, since the beginning of our term in office we stress the fact that it would be impossible to find a date that would suit everyone, for a number of reasons. In addition, the delay in creating an International Epilepsy Day by the IBE and ILAE has allowed other activities to fill the gap challenging initiatives of our organisation. Within the first quarter of 2014 both Management Committees of the IBE and ILAE voted in favour of the proposal and during the meeting in Cape Town in May it was decided that the International Epilepsy Day should take place, every year on the second Monday of February, connected to Saint Valentine's Day February 14th, substituting European Epilepsy Day (EED). Up to 2014 five very successful EEDs had been celebrated in the European Parliament setting, involving patient and Members from the European Parliament, belonging to

the Epilepsy advocate group, organised by the Joint IBE/ILAE European Task Force and European Alliance Europe. Saint Valentine's Day was chosen because Valentinus was also considered the most effective patron saint for epilepsy and February 14th 270 AD was the date he was executed for refusing to deny Christ by the order of the Roman Emperor Claudius II. This day has been also connected with exchanging messages of affection, love, and devotion around the world.

It was agreed that International Epilepsy Day would serve a real purpose, similar to the already successful European Epilepsy Day, in raising awareness and education of the general public on the true facts about epilepsy and in providing a means to approach government and other national bodies with a serious message on the need for improved services, treatment and care, together with greater investment in epilepsy research, for quality successful treatments. The day would promote awareness on epilepsy around the world and would be a powerful opportunity to highlight the problems faced by PWE, their families and carers, in every region of the world. The launch of the first International Epilepsy Day occurred on February 9th, 2015 at the European Parliament in Strasbourg with the theme "Epilepsy is more than Seizures". A logo and a hashtag (#epilepsyday) were also produced for the day.

2016 began with the celebration of the 2nd International Epilepsy Day – with activities organised by IBE and ILAE chapters in all four corners of the world. The IBE, together with our colleagues in the ILAE, travelled to the European Parliament in Strasbourg, where we had organised a number of activities to highlight the day. As a result, we increased membership of the European Advocates for Epilepsy MEP group from 24 to 56.

We believed that with both the IBE and ILAE in official working relations with the WHO, and with IBE having Special Consultative Status on the Economic and Social Council of the United Nations (ECOSOC), our organisations can bring a high level of distinction and prestige to the celebration of an international day for epilepsy when we will highlight, at international, regional and national levels, the huge problems still faced by the estimated 65 million people living with epilepsy world-wide today.

At the official launch of International Epilepsy Day 2015 in the European Parliament, Carlos Moedas, EU Commissioner for Research, opened a week-long exhibition with posters telling the personal stories of people with epilepsy. In his speech, Commissioner Moe-

das stated *In the developed world our societies must be exemplary in removing obstacles rather than perpetuating them and in developing countries the fear, prejudice and suspicion surrounding conditions like epilepsy must be countered with education. Throughout the world, people have the right to discrete, effective and affordable treatment. Above all, it's important to demystify epilepsy.*

The launch of International Epilepsy Day was a great success and another step forward in promoting awareness and improving the lives of PWE, who are the most powerful advocates of our mission in all societies. Further successful International Epilepsy Days took place in 2016 and 2017 with a steady increase in the numbers of IBE and ILAE chapters, epilepsy centres and other supporters arranging events to celebrate the day in their respective countries.

During each International Epilepsy Day, our delegation had an excellent opportunity to hold private meetings with many MEPs, each of whom demonstrated their interest in, and dedication to, supporting PWE in Europe and in recognising also our objectives:

- To promote research into the epidemiology, causes, diagnosis, treatment and prevention of epilepsy and its comorbidities.
- To advance and disseminate awareness and knowledge concerning the epilepsies.
- To establish epilepsy as a healthcare priority in Europe.
- To protect the rights of PWE by fighting stigma, prejudice and unjustified life restrictions.
- To improve the quality of life of all PWE, their families, care-givers and healthcare providers through European Union policy.

Following each event in Strasburg, IBE sends a personal membership certificate to each member of the Advocate for Epilepsy MEP Group, with the hope that they will be able to use it to show to their constituents that they recognise the need for improved services and care, and greater research, to ensure that PWE have the best possible quality of life and treatment.

Following the approval of the WHA Resolution, the World Federation of Neurology (WFN) took the welcome decision to dedicate World Brain Day July 22nd, 2015 to epilepsy with the motto “Epilepsy is more than seizures” and to invite us to work together in the communication campaign for this event. We were privileged to join forces with the WFN in this effort. Brochures,

posters and press releases were prepared and joint communications were forwarded to all neurological and epilepsy societies worldwide to promote the epilepsy vision and to increase awareness. ILAE and IBE also agreed to participate in an Epilepsy Awareness Day in Disneyland in November 2015, with International Epilepsy Day as a main theme.

International Epilepsy Day has proved to be a very successful awareness and education event and the 2017 event was celebrated in 40 countries worldwide, recognised also by the WHO, with their website homepage dedicated to epilepsy for the day. We have learned that by joining forces we can make the vision and mission of the IBE a reality.

Epilepsy Alliance Europe

In late 2014, the European IBE/ILAE Joint Task Force drafted a Strategic Plan to develop a legal entity, registered in Europe, in order to be able to apply for funding from EU sources to further develop its activities. The new entity, Epilepsy Alliance Europe (co-chairs: Athanasios Covanis and Philippe Ryvlin) was successfully established and registered in 2016, strengthening our lobbying activities towards the European parliament and commission. This was necessary in order for the Joint IBE/ILAE Task Force to play a partnership role in applications for funding and also in promoting partnerships worldwide for research funds and collaboration.

The European Advocates for Epilepsy MEP group was reformed following the European elections in early 2014 and consists of cross-party, cross-national MEPs with particular interest in epilepsy. Since then we have been building up the membership list of MEP supporters and had two meetings of the group – in September 2014 and March 2015. Since 2014 the events in the European Parliament have been hosted by Brian Hayes MEP, the President of the European Advocates for Epilepsy Working Group. Our presence in Strasbourg, with a poster exhibition telling the personal stories of people living with epilepsy, has also encouraged more than 30 MEPs to join the Advocates group in 2016 and 2017.

The ILAE/IBE Joint Task Force-Epilepsy Alliance Europe is always present during the celebration of International Epilepsy Day. The Joint Task Force/Epilepsy Alliance Europe was invited to partner on a number of applications submitted for EU funding under Horizon 2020 in early 2015. As a consequence, IBE has been actively involved, through Epilepsy Alliance Europe – of which I was co-chair, in supporting various research

projects in Europe, including the European Brain Council ‘Value of Treatment’ project, European Reference Networks (ERN) – the pilot ERN E-PILEPSY and the applicant ERN EpiCARE, as well as the EU funded European Study on the Burden and Care of Epilepsy (ESBACE) program (www.esbace.eu).

In 2013 Epilepsy Alliance Europe held a workshop in the European Parliament to highlight the need for a European study on prevalence rate of epilepsy, using appropriate and standardised methodology. ESBACE is a project that ILAE and IBE had lobbied for and which was funded by DG Sanco. The objective of the project is to look prospectively into the prevalence of epilepsy and the cost burden in a number of different countries in Europe. This is important because, at present, there are conflicting data across the region and no clear picture of accurate prevalence (EUCARE, 2003; WHO, 2010; Forsgren et al., 2005; Epilepsy Alliance Europe). The ESBACE project was approved with the primary aim to facilitate the development of high quality epilepsy care, equitable across EU countries. Epilepsy Alliance Europe is key in the implementation and dissemination of the project to decision makers in the European member states (www.esbace.eu).

During the last decade very little progress has been made in improving medical outcomes of PWE, particularly priority issues acknowledged by the epilepsy community:

1. Prevention of epilepsy
2. Prevention of sudden unexpected death in epilepsy (SUDEP)
3. Optimisation of epilepsy surgery
4. Worldwide development of mobile health programs to disseminate essential knowledge about epilepsy
5. Assembling of a very large well characterised cohort of PWE that could participate in all the above projects and in the development of personalised therapies for seizures, syndromes and related comorbidities.

All of these objectives would require recruitment and financial capacities that could only be achieved at the global level, and justify the building of a global alliance program for epilepsy research.

Despite a number of major research calls funded by US National Institutes of Health (NIH) and by the EU during the last decade, financial support for epilepsy research lags behind most comparably prevalent or severe neurological and non-neurological disorders.

Accordingly, no significant progress has been made in reducing:

1. The incidence or prevalence of epilepsy,
2. The proportion of patients, whose seizures remain treatment-resistant,
3. The death toll resulting from the disease.

Currently, 65 million people suffer from epilepsy worldwide, one third being refractory to treatment and at an increased risk sudden death (SUDEP, about one every 10 minutes worldwide), suicide and seizure-related fatal accidents.

For all these, the celebration of International Epilepsy Day 2017 was combined with a unique workshop to facilitate research worldwide with researchers and policy makers. This Global Research Initiative was planned in Brussels to accomplish our plans and involved the MEP advocates Group, European Alliance Europe, Global Outreach Task Force and representatives from NIH in the US and from Canada.

The discussion concentrated on how resources in North America, Europe and, possibly, Asia might be pooled so that each region was not working independently but as a joint collaborative unit. The workshop was very successful with action plans to be accomplished in the future.

Other IBE Activities

For many years the IBE and ILAE have joined forces to address the Global Burden of Epilepsy and the need for coordinated actions at country level in order to improve awareness, education and health care provision and human rights for PWE. With WHO the partnership started in 1997 with the Global Campaign Against Epilepsy “Out of Shadows”, followed with various demonstration projects at country level, the WHO publication of Atlas on Epilepsy Care in the World and two special activities during our term in office – the workshop in Troina, Italy in 2014 on improving access to antiepileptic medication and the most important as yet achievement in May 2015 the World Health Assembly adopts the Resolution WHA68.20 on the Global Burden of Epilepsy.

We continued our partnership with the Economic and Social Council of the United Nations (ECOSOC) and the European Medicine Agency (EMA) that began in 2007 and 2012 respectively. In our Observer role at the Patients’ and Consumers’ Working Par-

ty (PCWP) at EMA, members of the IBE European Regional Committee have been invited to attend annual meetings whenever space is available, as well as invitations to training workshops and other meetings and various teleconferences. These activities specifically included advice in drug development, training sessions for patients, a special meeting on sodium valproate use in women and IBE's contribution to the vetting of various patient information leaflets related to anti-epileptic drugs.

In 2013, the IBE re-joined the European Federation of Neurological Associations (EFNA) and subsequently the Executive Director of IBE was elected President of EFNA, providing a unique opportunity in promoting IBE interests in the neurology community.

In December 2016, I was invited to participate, together with Shekhar Saxena (WHO) and Alla Guekht (ILAE), at the External Engagement Summit in Geneva organised by UCB to discuss how to implement the WHA Resolution Worldwide. At the same time, together with the IBE Secretary General and Executive Director, we were involved in producing the toolkit in the management of prolonged seizures at schools.

Despite economic restrictions we faced during our term in office, we continued activities such as a) providing support to chapters with very limited means through our Solidarity Fund b) providing funds on a competitive basis for sustainable projects aimed at improving the quality of life for PWE in developing countries through the Promising Strategies Program c) offered bursaries to a group of young adults to attend leadership courses aimed at creating future advocates for epilepsy d) in collaboration with ILAE, presented congress awards to special individuals to recognise their outstanding personal contributions to activities that have resulted in a significant advance in the social wellbeing and/or quality of life of PWE.

Congresses

Every year we were involved in organising a number of regional and national epilepsy congresses through our congress secretariat office. With a few exceptions, each IBE/ILAE regional congress included a special Epilepsy & Society program for PWE and their carers. In many other national epilepsy congresses the IBE was invited to participate. In all those meetings, it was a unique opportunity to stress the primary vision and mission of the IBE, facilitate and promote regional and national activities, advance, liaise and facilitate activ-

ities through website and create new chapters worldwide. Above all, in all those meetings, we had to join forces with regional, national organisations attempting to increase awareness and education on epilepsy, contributing to reducing the treatment gap and alleviating social stigma, promoting and protecting human rights of PWE, based on internationally accepted human rights standards.

During our term in office, two IBE/ILAE International Epilepsy Congresses took place – in 2015 full of activities and action plans and in 2017, full of emotional business meetings as they marked the end of 4-year term of the current IBE committees; a wonderful journey full of experience, very interesting and admirable achievements, particularly those as the result of ILAE/IBE collaboration. The International Epilepsy Congress in Barcelona September 2nd–6th, 2017 marked the end of my term so I have to thank my fellow committee members, both those who retired from the committee, as well as those who have been re-elected to serve for another four years. I also wish all the best to the incoming President and his committee, in which I will serve as Immediate Past President.

IN CONCLUSION

It has been an honour to serve the IBE during the past four years and a fulfilling experience. I am greatly impressed by the incredible work that IBE chapters have carried out to improve the quality of life and the social conditions of PWE throughout the regions, sometimes working under difficult conditions with efforts made to cope with stigma, which can have a negative effect on the quality of life of PWE. Being invited to many regional and national events as key speaker, we joined forces to pressurise policy makers to improve health-care for PWE and to apply or enforce human rights in social life, education and employment.

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

CONFLICT OF INTEREST

The authors declared no conflict of interest.

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