

INTERNATIONAL

Epilepsy News

Reporting epilepsy news for 52 years

1963-2015

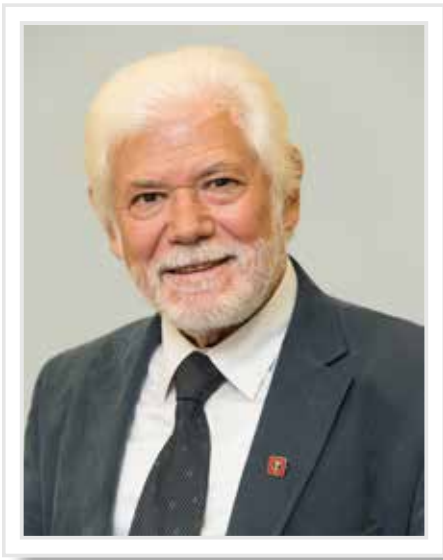


STRATEGIC PLAN 2015-2018

Constitutional Review

WHO Resolution Approved

PRESIDENT'S LETTER



Dear Friends

Following the approval of the WHO Resolution on the burden of epilepsy at the time of the WHO Executive Board Meeting in February, we had to renew our energy and join forces for the next step in the process - discussion of the resolution during the World Health Assembly, from May 18th to 26th.

Once again, we mobilised the WHO Member States and a delegation from IBE and ILAE (Mary Secco and Alla Guekht, co-chairs of the Global Campaign Against Epilepsy; Shichuo Li, member of the Global Outreach Task Force; Emilio Perucca and me as ILAE and IBE Presidents; and Ann Little, IBE Executive Director) travelled to Geneva for the event.

We also took the opportunity to meet with Shekhar Saxena and Tarun Dua from the WHO, to discuss plans beyond the endorsement of resolution. In brief we discussed how best to promote the resolution to all stakeholders through the creation of a library of documents such as information leaflets and reports. Also we discussed the follow-up on a collaborative activity, organised by WHO in Troina, Italy last year, on improving access to AEDs in low and middle-income countries.

As you should already know, the WHO Resolution was approved on the last day of the World Health Assembly, with the outstanding support from a huge number of countries. I would like to take this opportunity to thank all those Member associations and individuals who worked at national level to encourage national health departments to speak up for the Resolu-

WHO approves Resolution on Epilepsy

tion during the assembly. I realize that this was not always easy to achieve – so thank you for your persistence.

What happens now is that the documents discussed at the meeting with the WHO are now beginning to be formulated and I know that these will support all stakeholders in encouraging governments to address the issues highlighted in the resolution document which is, in essence, to address the need for coordinated action at country level to address health, social and public knowledge implications of epilepsy. The WHO is mandated to report back on progress during the World Health Assembly in 2018 and I hope that we will see the introduction of many improvements in the interim.

So, let's start moving to make progress. The 31st International Epilepsy Congress in Istanbul will give the first opportunity for further discussions.

In the meantime, I would also like to draw your attention to an event organized by the World Federation of Neurology (WFN). For World Brain Day, the WFN has this year chosen Epilepsy as its focus and events around the world will be organised on 22nd July to highlight the day. For this event ILAE and IBE have become partners and very soon all IBE and ILAE associations will receive material to celebrate the day together with the national neurology associations. If there is something happening in your locality, I hope that you will be able to participate.

With best wishes to all,

Athanasios Covanis
President



International Epilepsy News
Issue 2 - 2015

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INTERNATIONAL RELATIONS AND PARTNERSHIPS

WHO

IBE is in official relations with the World Health Organisation (WHO).

ECOSOC

IBE enjoys Special Consultative Status on the Economic and Social Council of the United Nations (ECOSOC).

CoNGO

IBE is a member of The Conference of NGOs in Consultative Relationship with the United Nations CoNGO.

EFNA

IBE is a member of the European Federation of Neurological Associations (EFNA).

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In this issue



Dear Readers



This issue of the magazine is a clear indication of how busy it has been in the last few months. More significantly, it also shows some very positive advances in the work of IBE to meet its goals.

In the last magazine, we reported on the approval of the WHO Resolution on the Global Burden of Epilepsy at the WHO Executive Board meeting in early February. Now, three months later, it is great to be able to report that the resolution had its final approval at the World Health Assembly at the end of May. When you read the report you will see the tremendous level of support that the document obtained from Member States.

For more than four years, the Governance Task Force has been reviewing the IBE Constitution and drafted changes are now ready for approval by the General Assembly. A draft, showing the proposed changes and explaining the reason why these are being proposed, has been circulated to members. The report on page 6 explains the process.

A small task force, mandated by the President, has been busy preparing a draft strategy document to be presented at the General Assembly for discussion and approval. You can see a sneak preview on page 12.

But, of course, there is much more to read in this issue. So, enjoy!

Until next time -

Ann Little
Editor



Coming in the next issue

ISTANBUL SPECIAL CONGRESS ISSUE





RESOLUTION on Global Burden of Epilepsy approved at World Health Assembly

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

1. strengthen effective leadership and governance to address the specific needs of people with epilepsy, and make resources available as necessary to implement evidence-based plans and actions;
2. introduce and implement national health care plans of action for epilepsy management, aiming to overcome inequalities and inequities in health, social and other related services;
3. integrate epilepsy management into primary health care where appropriate to reduce the treatment gap, by training non-specialist health care providers and by empowering people with epilepsy and their carers for greater use of specified self and home care programmes;
4. improve accessibility to and promote affordability of safe, effective and quality-assured antiepileptic medicines;

5. ensure public awareness of and education about epilepsy, in particular in primary and secondary schools, to help to reduce the misconceptions, stigmatization and discrimination regarding people with epilepsy and their families;
6. promote actions to prevent causes of epilepsy, using evidence-based interventions;
7. improve investment in epilepsy research and increase research capacity;
8. engage with civil society and other partners in these actions.

How the resolution developed

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

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

The draft received early co-sponsorship

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

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

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

Ensuring implementation of the Resolution?

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

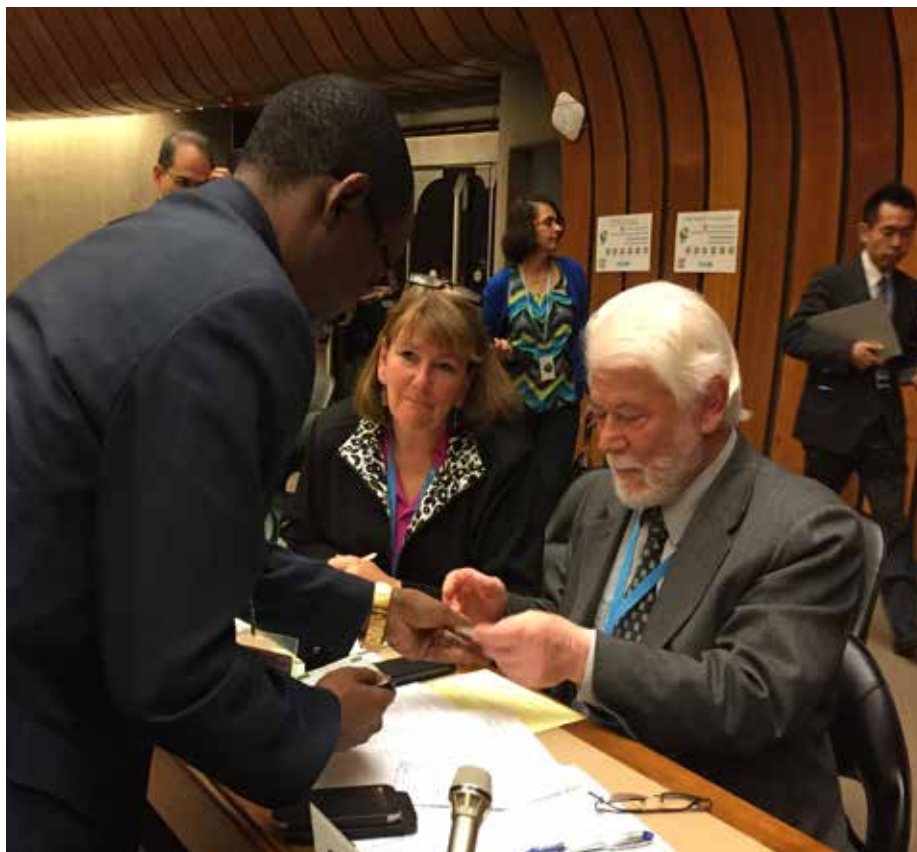
to epilepsy research. The Joint ILAE-IBE Global Outreach Task Force has already started drafting a set of recommendations to assist all stakeholders, including IBE Members and ILAE Chapters, in ensuring that the Resolution translates into effective actions. Other planned activities include the organisation of meetings and workshops to facilitate the involvement of stakeholders, including policy makers, and the engagement of national and international institutions in order to achieve the goals of the Resolution. All these activities will be conducted in close partnership with WHO.

Importantly, the Resolution calls for the WHO Director General to identify the relevant best practices to address the burden of epilepsy and to develop, in consultation with relevant stakeholders, a set of technical recommendations guiding Member States in the development and implementation of epilepsy programmes and services. The Resolution also requests WHO to provide technical support to Member States in actions for epilepsy management, especially in low- and middle-income countries.

These are great times for all those who work towards ensuring better lives for people with epilepsy. The Resolution is just the beginning – it now our duty to exploit this unprecedented opportunity to its utmost potential. By working together, there are no limits to what we can achieve!

Co-sponsoring countries

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



Main photo from left: Thanos Covanis, IBE President; Shekhar Saxena, WHO; Shichuo Li, IBE/ILAE Global Outreach Task Force; Tarun Dua, WHO; Emilio Perucca, ILAE President; Brooke Short, WHO; Ann Little, IBE; Alla Guekht and Mary Secco, Co-chairs ILAE/IBE/WHO Global Campaign Against Epilepsy, attending a preparation meeting at the WHO Building in Geneva.

Photo above: Mary Secco and Thanos Covanis meet with Prof Ayoub R Magimba, Tanzania, just after approval of the declaration at the UN Building in Geneva.

Countries statements in support of the Resolution

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



Constitutional Review

A major review of IBE's Constitution & Byelaws, the first since 2004, has just been completed.

Detailed information on all of the proposed changes will shortly be made available to the Full Members of the Bureau. The Full Members will be invited to vote on the changes presented by the Governance Task Force, at the time of the General Assembly in Istanbul in September.

In this article we present an overview of three of the main changes being proposed.

In 2011, former IBE President, Mike Glynn, created a Governance Task Force, which was asked to review IBE's Constitution and Byelaws, and to propose changes to address issues that had arisen in recent years.

While there had been one amendment, in 2009, to introduce a Regional Membership category, the Constitution in its present form had otherwise remained unchanged since its adoption at the end of December 2004.

What's in a name - Member or Chapter?

When the Constitution was adopted on 31 December 2004, one of the changes introduced was a change of title from Chapter and Friend to Full and Associate Member. Until then, both IBE and ILAE had used the term Chapter in referring to its voting membership. However, unlike ILAE, IBE had a second a third category of membership - Friend and Provisional Chapter.

At the time, it was considered that Friend did not adequately describe members who had all the rights and privileges of a Chapter, other than the right to vote. It was also debated that term 'Chapter' might not be readily understood globally.

The new terms have been successful only to a certain extent and there have some problems:

- Many of our longer established Members (and sometimes even new associations) still use the term 'chapter';
- It can be an issue in having to use both terms - Member and Chapter - in relation to joint initiatives undertaken with ILAE;
- There is the issue of confusing language - for example, a Member of a Member, or a Member of and Associate Member!

At the request of the IBE International Executive Committee, the Governance Task Force is now suggesting that the Constitution and Byelaws revert to the old term Chapter, in relation to voting members, and to introduce the title Associate Chapter for non-voting members. Applicant associations, whose membership has not yet been fully ratified, would be described as Provisional Chapters.

The members of the task force were Johan Falk-Pedersen (Chair), a lawyer based in Norway and a former Treasurer of IBE; were Sandy Finucane, a lawyer with Epilepsy Foundation of America; Christopher Morris-Coole, a barrister based in the UK; Grace Tan, former IBE Secretary General; and Susanne Lund, IBE Past President and CEO of the Swedish Epilepsy Association.

Much of the work of the group was carried out by email but the task force

Changes to Election Procedures

Elections can be a complicated business and the guidelines and rules drafted to adequately document how an election should be run, are also likely to be complicated. The IBE election procedures, as detailed in Byelaw III, were drafted in 2004 to cover the first elections in which all of the members of the International Executive Committee (other than the Past President) were nominated and balloted on my the Full Members.

In addition, the Byelaws needed to cover the election process for the seven Regional Committees, which up to then had been called Commissions, and with membership in the gift of the President. It's not surprising then, that some deficiencies, as well as some confusing and/or conflicting text has been identified.

In reviewing the Constitution & Byelaws, identified issues were made known to the Governance Task Force and the task force, in turn, also identified other text that required amendment.

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

Despite the fact that the Constitution states that Members should play an active role in all of the activities of IBE, the level of participation in the International and Regional elections has been very disappointing. If the new changes are ratified by the Full Members, the new procedures will be in place for the next elections, which will begin in late 2016, to elect the International Executive Committee and the Regional Executive Committees for the term 2017-2021.

also met on three occasions. At its last meeting, the final task of drafting new text began. The draft revised Constitution and Byelaws were then approved by the International Executive Committee, when it met in Dublin in March 2015, and will be presented to the General Assembly for ratification in September of this year.

IBE would like to take this opportunity to thank the members of the task force for its excellent work.

Staggering of Board Terms

Continuity of knowledge and expertise is very important for the smooth running of an organisation. Without staggering of terms of office, there is the possibility that the entire Executive Committee could change at the time of Board elections. In the case of IBE, the only Officer who is almost guaranteed to remain for the next term is the incoming Past President.

To address this situation, the Governance Task Force is recommending a staggering of the four-year term of office, beginning with the next term 2017-2021. If this change is ratified, in order to begin staggering of terms, the Regional Vice Presidents will serve for a two-year term, while the President, Secretary General, Treasurer and Immediate Past President will have a four-year term.

This means that there will be further elections in 2019 for the Vice President positions. Thereafter the terms of office will be four years for all members of the committee.

To compensate the Vice Presidents for the shortened term of office, this once-off two-year term will not count as part of the total term for which a Vice President is allowed to serve - subject, of course, to being successfully elected.

An additional proposed change is that the elected Regional Vice Presidents will be deemed to be the Chair of their Regional Executive Committee, serving both roles. The Regional elections will, therefore be limited to electing a Vice Chair and a Secretary (as well as two Members in the European region).

This latter proposed change will serve to smoothen communication between the International and Regional Committees and clarify reporting duties.



Future EU Agenda on Patient Safety and Quality of Care

Opinion adopted by Health Expert Panel

October 2014

In October 2014, the independent Expert Panel which advises the European Union (EU) Health Commission on matters related to “effective ways of investing in health” adopted its opinion on the Future EU Agenda on Quality of Health Care with a special emphasis on Patient Safety.

The Expert Panel identified a subset of commonly accepted dimensions of quality and safety applicable to all health services, indicating that these should be prioritised at EU level in order to improve the quality of health care. Regardless of the level of health care provided, all services have to be effective, safe, appropriate, patient-centred, efficient and equitable, according to the panel.

On the information needed to assess quality and safety of health care in the EU, the Expert Panel highlighted a subset

of indicators potentially suitable to quantify these quality and safety core dimensions.

In addition, the Expert Panel acknowledged that the European Commission could play a crucial role in boosting actions to be taken at EU level aimed at improving the quality of health care and the safety of patients. The actions proposed cover:

- the use of a comprehensive conceptual framework in relation to quality and safety;
- development of guidelines and the inter-professional sharing of good practices;
- funding research on quality and safety;
- economic issues related to the defined quality dimensions;
- education and training for the new

roles of both patients and health professionals;

- information technology and information systems significant for health quality and safety;
- quality and safety aspects of the burden of chronic diseases and inequalities in health;
- the HTA network, and increasing attention to Health System Impact Assessment.

This opinion was requested by the Commission's Health and Consumers Directorate General. It was subject to a public consultation that ran from 1 August to 21 September 2014.

Overall, the 174 contributions received agreed with the opinion and provided additional elements, where necessary. This opinion, as all advice given by the Expert Panel, is non-binding.

The Expert Panel on Effective ways of Investing in Health (EXPH) was asked to provide an opinion on a possible future EU agenda on quality of health care with a special emphasis on patient safety. Specifically, the EXPH was asked:

- to consider the core dimensions of quality of health care, including patient safety in the EU;
- to define the dimensions that should be given priority at EU level in order to improve quality of health care as well as the actions that could be taken at EU level to address the selected dimensions;
- to demonstrate what would be the added value of proposed EU actions;
- to specify what information is needed to assess quality and safety of health care in the EU.

These issues were considered in the context of the Directive on Cross Border Health Care (Directive 2011/24/EU). The EXPH opinion relies on the main findings from a literature review, jointly carried out with the European Commis-

sion, as well as from the evaluation of the former EU projects on quality/safety within the Framework Programs 5, 6, and 7.

The EXPH identified a subset of commonly accepted dimensions of quality/safety applicable to all health services, which should be prioritized at EU level. Indeed, regardless of the level of health care provided, all services have to be effective, safe, appropriate, patient-centred, efficient and equitable.

With regard to the information needed to assess quality and safety of health care in the EU, the EXPH highlighted a subset of indicators potentially suitable to quantify these quality/safety core dimensions. In addition, the EXPH acknowledged that the EU Commission could play a crucial role in boosting actions to be taken at EU level aimed at improving the quality of health care and the safety of patients.

The actions proposed cover:

- the utilisation of a comprehensive conceptual framework in relation to quality and safety;

- guideline development and the interprofessional sharing of good practices;
- funding research related to quality and safety;
- economic issues related to the defined quality dimensions;
- education and training in relation to the new roles of both patients and health professionals;
- information technology and information systems significant for health quality and safety;
- quality and safety aspects of the burden of chronic diseases and inequalities in health;
- the HTA network, and increasing attention to Health System Impact Assessment;
- miscellaneous recommendations.

The EXPH considered that undertaking such actions Europe-wide would yield financial and social benefits and would fit with the context of the recent EU actions against health inequalities, both between and within countries.



IBE Executive Director elected President of EFNA



Empowering Patient Neurology Groups

IBE is pleased to announce that Ann Little, IBE Executive Director, has been elected as President of the European Federation of Neurological Associations (EFNA) for the two-year term 2015-2017. The election took place at the General Assembly of EFNA, held during the 1st Congress of the European Academy of Neurology (EAN) in Berlin.

EFNA is a network of neurological patient advocacy groups, focused on the field of neurology whose mission is to influence policy makers and legislators, particularly in European Member countries but also across the continent of Europe.

Members of EFNA include:

- European Multiple Sclerosis Platform
- European Headache Alliance
- Motor Neurone Disease Association
- Stroke Alliance Europe

as well as associations representing rare neurological disorders such as:

- International Huntington Association
- Dystonia Europe
- euro-ATAXIA
- European Alliance for Restless Legs Syndrome.

In line with IBE's own mission, EFNA aims to encourage the implementation of the necessary resource priorities in order to reduce stigma and improve the quality of lives of people with a neurological disorder.

Whilst remaining independent, EFNA co-operates with the EAN and other agencies working in the field including:

- European Brain Council
- European Patients Forum
- European Alliance for Access to Safe Medicines
- European Medicines Agency
- European Platform for Patient Organisations, Science and Industry.

MOTION!



Promoting successful transition from school to the workplace and adult life for young people with a disability

MOTION was an EU Leonardo Da Vinci Partnership project funded under the LifeLong Learning Programme, in which the Caritas Malta Epilepsy Association participated between July 2012 to July 2014. The project also had partners from Turkey and Germany, specifically the Mamak Özkent Akbilek Special Education Vocational Training Center (School) Ankara, Turkey, Mamak Guidance and Research Center, Ankara, Turkey, Taşköprü Ticaret Odası, I Hamburg, Kasthamonu, Turkey, C Hamburg Consulting Gbr, GelsenKirchen, Germany.

The main aim of *MOTION* was to enhance the vocational skills and abilities of students with special needs to enter world of work; to improve the professional competencies for disabled via school activities; to create network for professionals working with the job insertion of persons with disabilities; to direct involvement of families in vocational education of disabled; to discuss with employers about creating/adapting jobs for disabled people; to consider not only medical disabilities but also social exclusion. This project included the staff and

trainees (teachers, special education teachers, guidance teachers, counsellors, administrators, academics and experts) of 5 participating institutions. Through this project, the participating institutions had a chance to transfer of knowledge and experiences related with individuals with special needs, including persons with epilepsy. The target groups were young persons with special needs, centres for vocational guidance and counselling, establishments for learners/pupils with special needs, prospective employers and NGOs working in the area, such as CMEA.

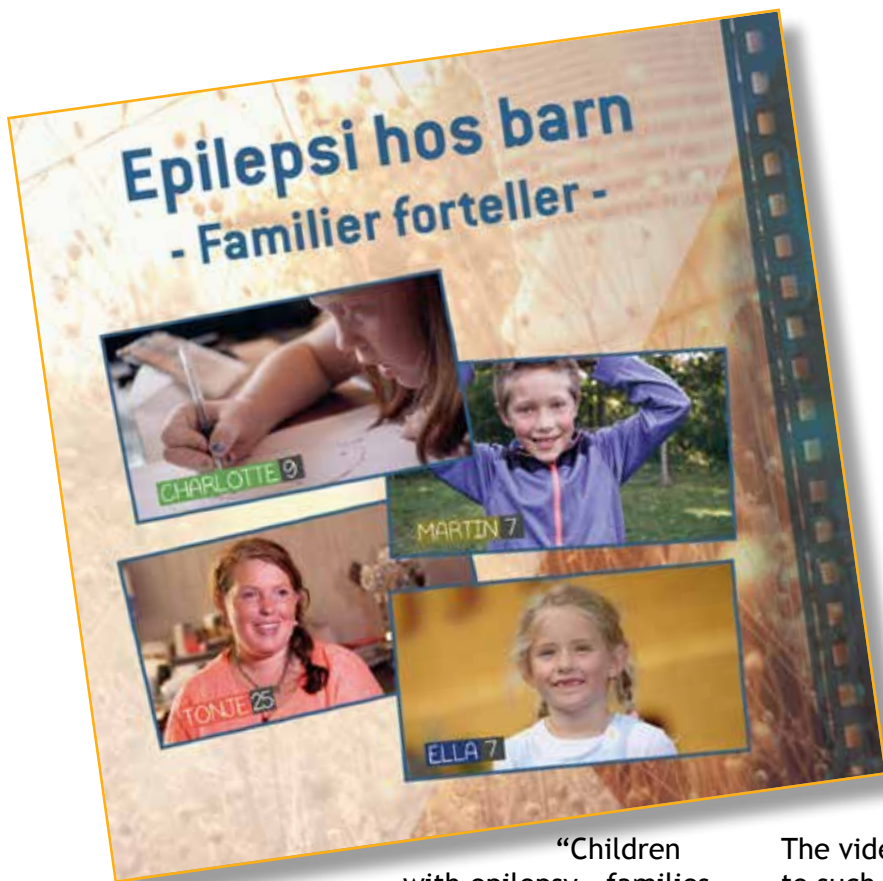
Each participating institution and its staff had a chance to familiarise themselves what has been done in other European Countries for the vocational guidance and placement of disabled individuals. They also exchanged experiences with respect to educating teachers and educators in main stream education about



various conditions such as epilepsy that could have an impact on the learning abilities of the student learn how the various stakeholders: academics, policy makers, teachers, schools, NGOs can work together to improve education for persons with special needs.

Main photo: CMEA members attending a workshop in Gelsenkirche in Germany, October 2013

Above: CMEA President, Mario Dimech and past secretary, Victoria Dimech, visiting Special School in Ankara Turkey, May 2014



Everyday stories of lives lived with epilepsy

“Children with epilepsy - families tell their stories” are four films recently published by The Norwegian Epilepsy Association. The films were created by Elisabeth Aspelin and Halvor Nittteberg, two film producers who are also parents to a young boy with epilepsy.

Elisabeth and Halvor have produced the type of films that they wished had existed when their own son was diagnosed with epilepsy almost two years ago.

YouTube Link:

<https://www.youtube.com/watch?v=x4U6ziKW8s4&list=PLxqbpeSnm04Xgde1bYK4Be8FkOarch8XS>

The videos have very positively received in Norway to such an extent that they now have English subtitles to satisfy an international audience. You can find them on YouTube using the link at the end of this article. The Norwegian association hopes that the films, which give insight into how families manage everyday life without being controlled by the fear of seizures, will be an inspiration to families living with epilepsy.

To find out more about the videos, contact Henrik Peersen at henrik@epilepsi.no.

Thank you to all those Members who have already settled their dues payments for 2015 and a special **THANKS** to those who donated to the Solidarity Fund.

If you haven't already paid, we would ask you to do so as soon as possible. IBE needs your financial support, not only to help us maintain our activities but, more importantly, to help us develop new programs. With member associations in 100 countries worldwide, IBE is a powerful network - don't let lack of resources hamper our work.

Full Members should also note that only those in good standing, with dues payments up to date, will be able to vote on the revision of the Constitution and Bye-laws and on other matters that will be presented during the General Assembly in Istanbul in September.

Failure to pay dues can also jeopardise membership.

If you need any help in making a payment, please contact Karen at ibeadmin@eircom.net. She will be happy to assist.

**ANNUAL
DUES
2015**

Strategic Plan 2015-2018

During the General Assembly in September, IBE Members will be invited to discuss the new Strategic Plan for IBE that has been prepared by a small Task Force comprising Philip Lee (UK), Phil Gattone (USA), Sari Tervonen (Finland) and Ann Little (Ireland).

In preparing the document, the group carefully considered the priorities that best reflected future direction for IBE and the goals that could be aimed for over the coming three years.

While the full document will be circulated in advance of the Assembly with agenda papers and reports, here is a shortened version of the draft document as it looks at present.

Full Members will be invited to approve the document during the meeting in Istanbul but comments are welcome at any time.

If you would like to send your comments or suggestions, please email ibeexecdir@eircom.net.

Strategic Priorities



Epilepsy is a health priority worldwide



Human and civil rights of people with epilepsy are enhanced and protected worldwide



People with epilepsy are empowered to maximise quality of life



Promotion of research into prevention, treatment, care and consequences of epilepsy

WHO WE ARE

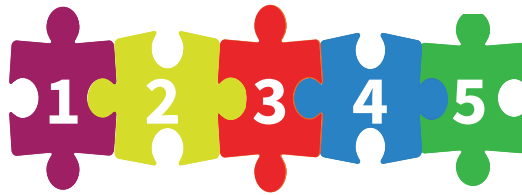
IBE is an international organisation for national epilepsy organisations (IBE members) that exists to provide support for a strong global network, encourage the development of new members in underserved areas of the world, and to encourage communication and collaboration among all members so as to meet our mission and vision.

OUR CORE VALUES

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

A roadmap for IBE for the next 3 years

OUR GOALS



Make epilepsy a worldwide health concern and priority

- a. Advocate with WHO, UN to recognize epilepsy as a worldwide need and to aggressively pursue strategic global outreach
- b. Encourage member organisations to support making epilepsy a health priority within their country
- c. Encourage and incentivize each IBE member country to report on progress on strategic global outreach targets
- d. Share and promote accurate, up to date information about the impact of epilepsy



Advocate for improved human and civil rights for people with epilepsy worldwide

- a. Create and share model legislation and guidelines with IBE members
- b. Encourage member countries to implement legislative and regulatory changes to promote human and civil rights for people living with epilepsy
- c. Encourage regions to identify human and civil rights goals for their member organisations
- d. Encourage all members to include people impacted by epilepsy on their boards and in their activities



Empower people with epilepsy and their families to maximize quality of life

- a. Provide accurate information exchange on evidenced based best practices in self-management of epilepsy, epilepsy in schools, youth and young adult programs
- b. Promote the use of electronic and social media to inform and exchange information
- c. Ensure that all international, regional and national meetings in which IBE is involved, include tracks for lay organisations, social services, and for people and families affected by epilepsy
- d. Seek support to allow lay organisations and people with epilepsy to attend IEC meetings or regional meetings
- e. Assist with the development of new member organisations in areas that are not currently served
- f. Ask member countries and community partners to link to IBE website and track growth in participation
- g. Encourage youth councils in member organisations



Promote prevention and research focused on care, and treatment of epilepsy and its consequences worldwide

- a. Encourage member organisations to pursue awareness and education campaigns
- b. Promote the prevention of epilepsy
- c. Promote access to currently available treatments



Improve the unity, sustainability, and communication of the IBE

- a. Evaluate dues and means of financial support for IBE and make recommendations for changes to improve IBE's financial status, sustainability and independence
- b. Create representative inter-regional and cross-regional task forces for each IBE goal to foster inter-organisational mentoring, and best practice exchange
- c. Utilize electronic platforms for meetings within regions and cross regionally to promote information exchange and to support the creation of collaborative learning groups
- e. Establish a mentoring program where member organisations offer to provide information exchange
- f. Utilize all communications vehicles (available as identified in opportunities document) to implement goals



Sheltered employment in Taiwan - a perfect recipe!

Shung-Lon Lai, MD PhD, former IBE Vice President for the Western Pacific region, brings us this report

When people gain income, they gain choice, and that is fundamental to dignity

In one respect, our main goal is to ensure that the rights of persons with epilepsy (PWE) are the same as those of everyone else. We need to realise that PWE can attain the same life achievement as people who do not have the disease. In this aspect, fighting stigma is the main target.

In another respect, it is evident that PWE are not always well treated. In reality, as well as in literature, we can see that only 50~60% of PWE will get a good result from their epilepsy treatment and nearly 30% of PWE will suffer from intractable seizures. For persons with intractable seizures, the difficulties they encounter are much more serious, be it in their social life, including going to school, making friends, getting married, and finding job. They face not only the

stigma issue but also the economical burden from the disease.

For stigma and life quality issues, we reviewed the survey of public awareness, understanding and attitudes toward epilepsy in Taiwan that was conducted in 1992. In a population sample of 2,610 adults:

- 87% had read or heard about epilepsy
- 70% knew someone who had epilepsy
- 56% had seen someone having a seizure
- 18% would object to having their children associated with persons with epilepsy
- 72% would object to having their children marry a person with epilepsy
- 31% believed that persons with

epilepsy should not be employed in jobs in the same way as those who did not have epilepsy.

In the intervening years efforts have been made to combat stigma through public education channels, including TV, printed media, internet, in schools and through the government system.

In 2012 we followed up with a further survey, through a population sample of 5,845 adults:

- 98.4% had read or heard about epilepsy
- 36% knew someone who had epilepsy
- 41% had seen someone having a seizure
- 25% would object to having their children associated with persons with epilepsy
- 49% would object to having their children marry a person with epilepsy
- 25% believed that epileptic persons should not be employed in jobs as people who did not have epilepsy.

We can see that the stigma toward PWE has reduced a little but stigma is still a huge issue. PWE, especially those with intractable seizures, face severe problems in applying for a job. Low employment rates for PWE is well documented.

We can't wait for public opinion to change, to allow PWE to find work but we need, so we needed to do something to help those with intractable seizures to have a safe place in which to work. The decision was taken to create sheltered employment for people with intractable seizures was the result.

In establishing the sheltered employment service in 2012, we read an encouraging book: *The Blue Sweater – Bridging the gap between rich and poor in an interconnected world*, written by Jacqueline Novogratz, (2012, Second Edition, HarperCollins).

In this book, the author provided many good examples of how to create sheltered service with advice on a range of issues on this topic. The following is one of her wise observations:

“When people gain income, they gain choice, and that is fundamental to dignity.”

This point is very true for PWE with intractable seizures who are unemployed. It's the fundamental basis for us to establish a shelter in these unfriendly

circumstances. Jacqueline Novogratz as made the following two statements:

“Traditional charity and aid are never going to solve the problems of poverty.”

“Traditional charity speaks of donors and grantees, but this passive language creates a power dynamic that might as well call the two groups the givers and the takers. I had seen so many dysfunctional conversations where a grantee would give a would-be or existing donor misleading and evasive answers because they feared losing funding if they told the truth about the difficulties of their work. And I'd seen those same grantees agree to do things the donors thought they should, even if it made no sense for the mission of the organization. It is hard to say no to someone who has the power to finance your dreams – or more to the point, your payroll.”

These two points reflect current patient groups, or charities', goal and might not be the goal of PWE with intractable seizure who cannot find work. We considered that we might need to set up a patient shelter and the important point is as follows:

“Our investment style was focused on what we termed patient capital – not traditional charity, not traditional business investment, but something in-between. Patient capital is money invested over a longer period of time with the acknowledgment that returns might be below market, but with a wide range of management support services to nurture the company to liftoff and beyond.”

The shelter's work from PWE with intractable seizure would be not so profitable. The goal should be adjusted accordingly.

“My dream is to find individuals who take financial resources and convert them into changing the world in the most positive ways.”

“I've learned that solutions to poverty must be driven by discipline, accountability, and market strength, not easy sentimentality. I've learned that many of the answers to poverty lie in the space between market and charity and that what is needed most of all is moral leadership willing to build solutions from the perspectives of poor people themselves rather than imposing grand theories and plans upon them.”

To develop a shelter financial resources

is the key, and how to do this work? The answer is that we need more resources.

In the mean time, we discussed our ideas with some companies. They provided us with the idea of a social enterprise. We began to look at this possibility and learned that social enterprises have different models, including community enterprises, credit unions, trading arms of charities, employee-owned businesses, co-operatives, development trusts, housing associations, social firms, and leisure trusts.

Whereas conventional businesses distribute their profit among shareholders, in social enterprises the surplus tends to go towards one or more social aims which the business has – for example education for the poor, vocational training for disabled people, environmental issues or for animal rights.

Social enterprises are distinct from charities (although charities are also increasingly looking at ways of maximising income from trading) and from private sector companies with policies on corporate social responsibility. An emerging view, however, is that social enterprise is a particular type of trading activity that sometimes gives rise to distinct organisation forms, reflecting a commitment to social cause working with stakeholders from more than one sector of the economy.

With the social enterprise model as our basis, we worked with companies to begin to set up the shelter. As the first step we already had a small bun shop that had been operating for some years and we looked to enlarge the business and to hire more persons with epilepsy who would run the business by themselves with guidance from the enterprises who had guided us along the way.

In 2013, we organised a large fund raising dinner with these enterprises. The surplus was used to set up a new work place with better equipment in order to upgrade the previous bun shop.

More people now work with us and, what is certain, there is no stigma here!



THE HISTORY OF THE INTERNATIONAL LEAGUE AGAINST EPILEPSY

Part 8: 1993-1997: Global and Regional Development

In part7 (Issue 1, 2015) Ted Reynolds described eight years of consolidation of ILAE following the end of Epilepsy International. Now the story continues....

Beginning at the IBE/ILAE International Epilepsy Congress in Oslo, 1993 I was privileged to serve as President of the 1993-1997 ILAE Executive, together with Peter Wolf (Germany) as Secretary General and Pete Engel (USA) as Treasurer.

An immediate objective was to improve the lines of communication within a fast growing ILAE. For the first time we had a staffed office for the Secretary General, who was supported by Mrs Irene Kujath. In 1994 we produced the first of our ILAE Annual Reports and in the same year initiated our twice-yearly newsletter, *Epigraph*, under the editorship of Simon Shorvon (UK).

In January 1996, *Epilepsia* expanded to a monthly journal under our new editor, Tim Pedley (USA). Subscription rates for the journal were reduced and at the same time a pilot trial of a low cost quarterly *Epilepsia Digest*, for developing countries, was started under the editorship of Rajendra Kale (India). Plans were developed for an ILAE website.

These necessary improvements in internal communication were associated with a remarkable increase in the number of Chapters of ILAE from 39 in 1993 to 62 by 1997, a growth rate of over 50% in 4 years. The 23 new Chapters were: Bulgaria, Burkina Faso, Croatia, Egypt, Georgia, Greece, India, Ireland, Jordan, Latvia, Lithuania, Macedonia, Moldova,

Romania, Russia, Saudi Arabia, Slovakia, Slovenia, Taiwan, Thailand, Tunisia, Turkey and Ukraine. Although one third of the 62 Chapters were in Europe, by now every continent was represented and the ILAE had become a truly global organisation on which, as had been said of the British Empire, the sun never set.

Likewise the number of delegates attending the International Congresses had grown from approximately 2,000 in Oslo (1993) and Sydney (1995) to nearly 5,000 in Dublin (1997).

The rapid growth of ILAE was also reflected in the activities of 15 Commissions and 2 Sub-Commissions, including new Commissions on developing countries, economics, neuroimaging and outcome measurement.

The rapid global growth of ILAE required the introduction of regional structures and activities. Having the largest number of chapters, the first Regional Commission was on European Affairs, chaired by Simon Shorvon (UK). The objective was to improve co-operation and communication in epilepsy services, teaching, research and regulatory affairs. Unusually this Commission reported both to the Executive and to a new European Advisory Council, consisting of one delegate from each European Chapter and chaired by Peter Wolf (Germany). This led to the first ILAE European Epilepsy



Simon Shorvon, ILAE Vice-President, first Editor of Epigraph and first Chairman of the Commission on European Affairs.

Congress in Oporto in 1994, followed by The Hague in 1996. A first Regional ILAE Asian and Oceanian Epilepsy Congress was held in Seoul in 1996, following which a new Commission on Asian and Oceanian Affairs was established, chaired by Masakazu Seino (Japan).

The objectives were the same those in Europe with the additional goal of promoting more Chapters in the Region.

These two Regional Commissions were the forerunners of later Regional Commissions in other parts of the world, including Latin America which already had a tradition of "Pan American" congresses.

ILAE/IBE/WHO Global Campaign against Epilepsy: "Out of the Shadows"

The ILAE and the IBE are Non-Governmental Organisations (NGO's) affiliated to the World Health Organization (WHO). Every December the WHO invites the Presidents of ILAE, IBE and all neurological and neuroscience-related NGO's to Geneva for an exchange of information. After two such meetings it occurred to me that a more productive partnership with the WHO might be possible. I therefore returned to Geneva on 15 January 1996 together with my ILAE colleague, Pierre Jallon (Switzerland), Chairman of the Commission on Developing Countries, to meet Professor J Costa e Silva, Director of the WHO Division of Mental Health, together with his colleague, Leonid Prilipko (Russia), Chief of the Unit on Neuroscience, and Professor Li Shichuo, the Chinese delegate on the WHO Executive Board who had a special interest in epilepsy. My proposal of a Global Campaign for the global problem of epilepsy, aimed especially at developing countries, where recent evidence suggested 60 to 98% of patients were not receiving any effective treatment, the so-called treatment gap, was encouragingly endorsed that day. Throughout the 1993-1997 Executive period relations between ILAE and IBE were excellent. After some initial financial concerns, IBE soon supported ILAE and the WHO in planning the Global Campaign. President Hanneke de Boer



Photo top right: Launch of the 2nd Phase of the Global Campaign, Geneva, February 2011, chaired by WHO Director General, Dr Gro Harlem Brundtland.

Above from left: Ted Reynolds, President ILAE; Shichuo Li, Chinese delegate on the WHO Board; Hanneke de Boer, President IBE; Leonid Prilipko, WHO Unit on Neuroscience. Global Campaign launch, Geneva, June 1997.



(The Netherlands) became a dedicated supporter of the Campaign.

The first step in the summer of 1996 was a conference on "Epilepsy in Developing Countries" held in Geneva on 6 and 7 June. This focused on the needs of people with epilepsy in developing countries with the help of colleagues from many such countries (Jallon 1997). The ILAE/IBE/WHO Global Campaign Against Epilepsy: "Out of the Shadows" was announced at the Hague and Seoul congresses in September 1996.

The campaign was formally launched in Geneva on 19 June 1997 in the presence of the ILAE, IBE and WHO leadership, together with leaders of related NGO's, and supported by John Bowis, former Minister of Health in the UK and now a member of the European Parliament.

Two weeks later, on 3 July, the campaign was again launched at the International Epilepsy Congress in Dublin with the support of Mary Robinson, the Irish

President. A highlight of that congress was a session on "The Politics of Epilepsy", with John Bowis (UK), Senator Tony Coelho (USA), Senator Joe Doyle (Ireland) and Mary Banotti, MEP (Ireland).

The Mission Statement for the campaign is "To improve the acceptability, treatment, services and prevention of epilepsy worldwide".

Objectives are:

1. to increase public and professional awareness of epilepsy as a universal, treatable brain disorder;
2. to raise epilepsy on to a new plane of acceptability in the public domain;
3. to promote public and professional education about epilepsy;

4. to identify the needs of people with epilepsy on a national and regional basis;
5. to encourage governments and departments of health to address the needs of people with epilepsy, including awareness, education, diagnosis, treatment, care, services and prevention.

A programme of global, regional and national activities were initiated which will be discussed in the next and subsequent instalments of this History.

The on-going Campaign has recently culminated in Resolution (EB136/SR/14) by the WHO Executive Board on February 2nd this year urging all member states to develop national healthcare plans for epilepsy management, particularly in low and middle-income countries (see EI News 2015, issue 1) and which has now received global national support and approval by the General Assembly of WHO (World Health Assembly) on May 26th this year (see the current issue of EI News).

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3. WHO Press Release. Bringing epilepsy out of the shadows. A Global Campaign is launched. WHO/48, June 19th 1997. http://www.who.int/entity/mental_health/neurology/epilepsy/Press_Release_WHO_48_1997_en.pdf?ua=1

IBE General Assembly 2015

Marmara Room - Istanbul Lutfi Kırdar

International Convention and Exhibition Centre (ICEC)

Istanbul - Turkey

Tuesday 8 September 2015

16:00 - 20:00

Followed by Cocktail Reception

All IBE Members are invited to attend the assembly.

Three interactive workshops will start things off, followed by the business element of the meeting.

The assembly will close with a Cocktail Reception.

WE HOPE TO YOU SEE THERE!

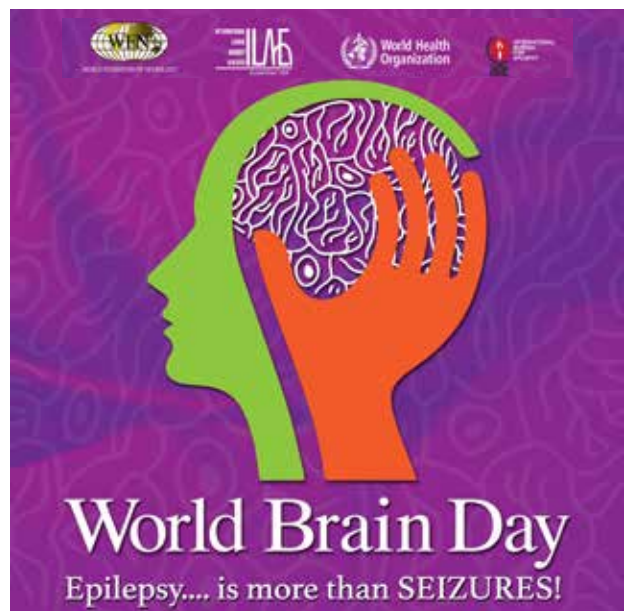


EPILEPSY **WORLD**
BRAIN
DAY

IBE and ILAE are pleased to announce that, in recognition of the recent approval of the WHO Resolution on the Burden of Epilepsy, the World Federation of Neurology WFN has selected epilepsy as the theme for World Brain Day 2015.

To celebrate the day, on 22nd July, events will take place around the world at national.

www.wfnepilepsy.org



Epilepsy Australia: a very successful website



Attending Epilepsy Australia annual meeting: Shireen Cook; Graeme Shears, CEO Epilepsy Foundation, Denise Chapman, Executive Officer, Epilepsy Australia and Robert Cole, President Epilepsy Australia.



Rod Martin, Epilepsy Australia Director, Professor Mark Cook, Chairman of the Epilepsy Foundation, Brian McNab, President of Epilepsy Tasmania and Phil Baker, CEO of Epilepsy Tasmania.

There have been changes afoot in Australia, with a change of name for IBE's Full Member. Formerly the Joint Epilepsy Council of Australia, JECA, the coalition of epilepsy associations that came together to form the Full Member, is now known as Epilepsy Australia Ltd.

Not standing on its laurels, Epilepsy Australia is making considerable impact in Australia with its website: www.epilepsyaustralia.net. In 2014 traffic to the website topped 5.7 million hits.

The most visited pages are those providing information on seizures, treatment, medications and lifestyle issues. For instance, more than 15,000 First Aid posters were downloaded in 2014. Com-

munity awareness activities are also well visited with Epilepsy Australia national awareness campaigns contributing to the large numbers of visitors.

Epilepsy Australia is working to reducing epilepsy stigma and the website provides the greatest opportunity to do this by promoting activities that help bring 'epilepsy out of the shadows'.

Ensuring that the website is responsive to community needs, Executive Officer Denise Chapman, also the site's webmaster, continues to ensure that the information is current and relevant. All activities of Epilepsy Australia are reviewed at the annual strategic planning meeting held in Melbourne each year.

MEMBERS

Epilepsy ACT

Epilepsy Association of Western Australia

Epilepsy Association of Tasmania

Epilepsy Association of South Australia & Northern Territory Inc.

Epilepsy Foundation

Epilepsy Queensland Inc.

Congratulations!

Prof Helen Cross, a member of the IBE International Executive Committee and Secretary General of the International League Against Epilepsy, has been awarded the Order of the British Empire (OBE) for her work with children with epilepsy.

Helen Cross, who is The Prince of Wales's Chair of Childhood Epilepsy and Honorary Consultant in Paediatric Neurology at UCL-Institute of Child Health, Great Ormond Street Hospital for Children NHS Trust, and Young Epilepsy, was one of those named in the Queen's Birthday Honours in the UK recently. The honours list recognises the achievements of people who have made significant differences across a wide range of issues.

Helen has published research papers on seizures and neuropsychological and behavioural outcomes in children who have undergone brain surgery for treatment of their epilepsy. Her research has also focused on improving outcomes for children with early onset epilepsy. She conducted the first randomised controlled trial of the ketogenic diet in the treatment of children with drug resistant focal epilepsy.



31st International
Epilepsy Congress
05 - 09 September 2015
Istanbul 2015

ILAE

