

INTERNATIONAL

Epilepsy News

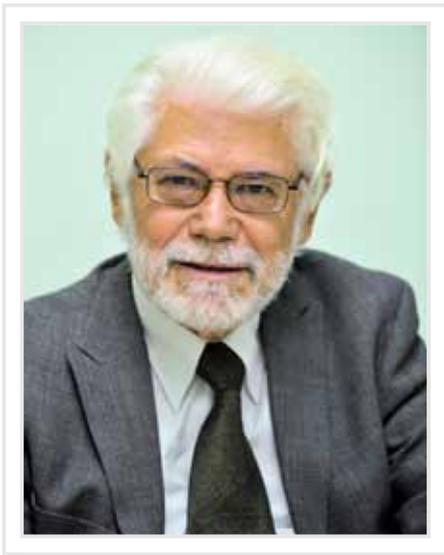
Reporting epilepsy news for 50 years

1963-2013



**EUROPEAN EPILEPSY
DAY 2014**

PRESIDENT'S LETTER



Dear Friends

Already we are almost one quarter way through the year and I am sure that, like me, you often wonder at the speed at which time is flying by. 2014 will be yet another very busy year for IBE, with many interesting activities already arranged, or being planned, despite the financial constraints under which we need to work.

In February we celebrated the 4th European Epilepsy Day (EED) with great success. As has become the custom, the Joint Task Force - Epilepsy Advocacy Europe - brought EED to the European Parliament in Strasbourg, hosted by Gay Mitchell MEP. With more than 30 private meetings with Members of the European Parliament (MEP) and a reception opened by the EU Commissioner for Health, Tonio Borg, there was little more we could have asked of the event. I would like to thank Kalle-Pekka Hietala, a young man from Finland, who spoke about his life with epilepsy at the reception. Throughout Europe, EED was celebrated during the week of 10th February and I am delighted to see that more members are becoming involved each year. In the magazine you will find information of some of the inventive activities that celebrated the event. You will find even more on the IBE website.

Our next major meeting will be in Cape Town at the end of May, when the 2nd African Epilepsy Congress takes place. New to the congress will be the Epilepsy & Society Programme that has already proven to be successful at other regional congresses. The Epilepsy & Society programme is especially developed to address the issues of most relevance to people

A busy start to the year

with epilepsy, their families and care-givers.

I look forward to the meeting in Cape Town and, in particular, to having the chance to talk with many IBE members (and potential members) from the African Region. A meeting of the African Regional Committee will afford the opportunity to share experiences and make new contacts.

Later in the year we have two further regional meetings - in Singapore in August and Buenos Aires in September. Both of these conferences will also have special programmes focussed, not just on the social problems of epilepsy, but, on how these issues have particular resonance in the region. In Singapore, the now well established Outstanding Persons with Epilepsy Awards will be presented. The recipients are being selected by IBE members across the region. The awards recognise brave people with epilepsy who have surmounted problems they have encountered in their lives because of their epilepsy; they act as an inspiration to us all. I look forward to being there in person to applaud them.

An initiative that will involve all IBE members is a survey that is about to get underway. Responses to the survey will influence the IBE strategic plan for the coming three years and provide us with the foundations of a road map for the future. Sari Tervonen, Secretary General, is compiling the survey document and you can expect to receive it in the next few weeks. The survey will be web-based, so you will be able to complete it online. I would ask all of the IBE members to do so. IBE is your organisation, and, your involvement in determining its future focus is of the utmost importance to us.

With best wishes to all,

Athanasios Covanis
President



International Epilepsy News
Issue 4 - 2013

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- Emilio Perucca
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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



The big event, so far this year, was European Epilepsy Day and we have an extended report on activities both in the European Parliament and in countries across the continent. There are some very inventive ideas that you might like to borrow from for your own association!

Life on the High Seas is adventure in itself, but, when you have epilepsy such a voyage can make a particular impact - as it did for some young Italian novice sailors last summer.

Paola Testori Coggi, Director General for Health and Consumers, European Commission tells us about a new EU Directive that will see EU citizens having the right, not just to decide where in Europe they would like to be treated, but, to be reimbursed for costs. While at WHO, Dr Margaret Chan launches the Mental Health Action Plan.

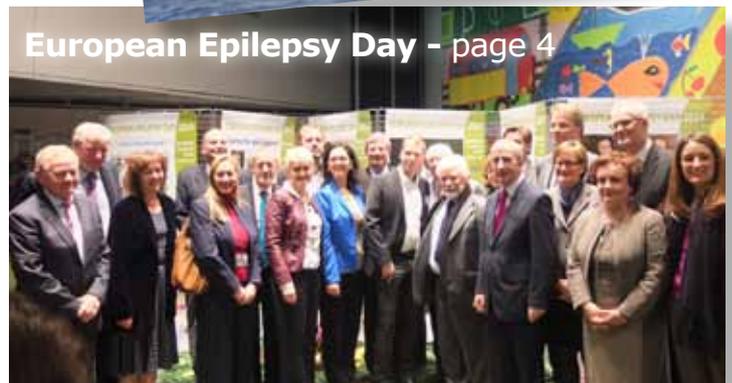
The 6th part of the series on ILAE's history is provided by Ted Reynolds, giving us another fascinating insight into the history of the League.

For this issue, I must leave you on a sad note, as we mark the passing of Harry Meinardi, a former IBE President and who also served as IE News editor. Harry may have left this world just before Christmas but his legacy will carry on.

I wish you happy reading.

Ann Little
Editor

Coming in the next issue





10 FEBRUARY 2014
eed
 EUROPEAN EPILEPSY DAY

Strasbourg - 4 February 2014

European Epilepsy Day (EED) began early for some, as a group of 11 people, from IBE's European Regional Executive Committee (EREC) and Epilepsy Advocacy Europe, joint task force of ILAE-IBE (JTF), travelled to Strasbourg to launch the event in the European Parliament, a week before the official EED, 10 February.

By the end of a very long day there had been 32 private meetings with MEPs; 38 MEPs had attended an Evening Reception, with guest speaker Commissioner for Health, Tonio Borg; and 11 MEPs had agreed to join the special interest group of MEPs in the Parliament - the European Advocates for Epilepsy

Group - bringing total membership to 46 MEPs from 18 EU member states.

The theme of EED 2014 was 'Epilepsy is more than seizures', recognising the social problems faced by people with epilepsy and those who care for them. This was highlighted by a Poster Exhibition featuring the stories of six people, both young and not so young, some who live fulfilling lives and others who face daily challenges.

The exhibition was launched by EU Commissioner for Health Tonio Borg, who has a particular interest in introducing measures to combat the stigma, discrimination and inequities faced by people with a disability and by minority groups.

Mr Borg stated: "I applaud the choice of theme for this year's event – *'Epilepsy is more than seizures'* – which draws attention to the wider

challenge that the millions of Europeans with epilepsy face beyond the disease itself. These challenges extend to social and labour implications, which need to be addressed."

Mr Borg also mentioned a conference he is convening in Brussels in March, entitled *'Health in Europe - making it fairer'* which will address the issue of discrimination and stigmatisation of people with diseases.

"The EU Charter of Fundamental Rights states that human dignity is inviolable, prohibiting any discrimination on the basis of disability. In addition, the Treaty on the Functioning of the EU requires the Union to combat discrimination based on disability when defining and implementing its policies", he said.

IBE would like to thank Gay Mitchell MEP for hosting the event and his staff for their



"I applaud the choice of theme for this year's event – *'Epilepsy is more than seizures'*"
 EU Commissioner for Health, Tonio Borg





Photo: Marcus Glynn

support and assistance with arrangements. On the following pages you can see how EED 2014 was celebrated across Europe. Further information on EED 2014, including the full text of Mr Borg's speech, can be found on www.ibe-epilepsy.org and on www.epilepsyadvocacyeurope.org.

Photos (clockwise from above):

- MEPs with EU Commissioner Tonio Borg and speakers at the reception.
- From Finland, Hannu Takkula MEP; Kalle-Pekka Hietala, a speaker at the reception; and Petri Sarvamaa MEP.
- Members of EREC and the JTF with Gay Mitchell MEP (wearing a pink tie)
- EU Commissioner for Health, Tonio Borg at the exhibition launch.
- Cover: Christian Elger, Meir Bialer, Gay Mitchell, Commissioner Borg, Philippe Ryvlin and Athanasios Covanis.



Photos: Ann Little

BRINGING EPILEPSY TO THE EUROPEAN PARLIAMENT

MEPs who met privately with IBE and ILAE representatives

- | | |
|--|------------------------------------|
| 1. Heinz Becker, Austria | 17. Roberta Metsola, Malta |
| 2. Angelika Werthmann, Austria | 18. Marlene Mizzi, Malta |
| 3. Miroslav Ouzky, Czech Republic | 19. Jan Mulder, Netherlands |
| 4. Pavel Poc, Czech Republic | 20. Marisa Matias, Portugal |
| 5. Theodoros Skylakakis, Greece | 21. Alda Sousa, Portugal |
| 6. Georgios Stavrakakis, Greece | 22. Zofija Mazej Kukovič, Slovenia |
| 7. Nikki Tzavela, Greece | 23. Alejo Vidal-Quadras, Spain |
| 8. László Surján, Hungary | 24. Carl Schlyter, Sweden |
| 9. Nessa Childers, Ireland | 25. James Elles, UK |
| 10. Emer Costello, Ireland | 26. Jill Evans, UK |
| 11. Marian Harkin, Ireland | 27. Fiona Hall, UK |
| 12. Gianni Pittella, Italy | 28. Roger Helmer, UK |
| 13. Vittorio Prodi, Italy | 29. Stephen Hughes, UK |
| 14. Claudette Abela Baldacchino, Malta | 30. Jean Lambert, UK |
| 15. David Casa, Malta | 31. Linda McAvan, UK |
| 16. Joseph Cuschieri, Malta | 32. Mariana Yannakoudakis, UK |

MEPs who attended the Evening Reception

- | | |
|-------------------------------------|-------------------------------------|
| 1. Karl-Heinz Florenz, Austria | 20. Giancarlo Scottà, Italy |
| 2. Angelika Werthmann, Austria | 21. Laima Andrikiienė, Lithuania |
| 3. Bart Staes, Belgium | 22. Vytautas Landsbergis, Lithuania |
| 4. Milan Cabrnoch, Czech Republic | 23. Joseph Cuschieri, Malta |
| 5. Miroslav Ouzky, Czech Republic | 24. Robert Metsola, Malta |
| 6. Eija-Riitta Korhola, Finland | 25. Marlene Mizzi, Malta |
| 7. Sirpa Pietikäinen, Finland | 26. Filip Kazmarek, Poland |
| 8. Petri Sarvamaa, Finland | 27. Edite Estrela, Portugal |
| 9. Hannu Takkula, Finland | 28. João Ferreira, Portugal |
| 10. Sampo Terho, Finland | 29. Nuno Melo, Portugal |
| 11. Liam Aylward, Ireland | 30. Zofija Mazej Kukovič, Slovenia |
| 12. Emer Costello, Ireland | 31. Alojz Peterle, Slovenia |
| 13. Brian Crowley, Ireland | 32. Alf Svensson, Sweden |
| 14. Pat the Cope Gallagher, Ireland | 33. Michael Cashman, UK |
| 15. Marian Harkin, Ireland | 34. Diane Dodds, UK |
| 16. Jim Higgins, Ireland | 35. Jill Evans, UK |
| 17. Sean Kelly, Ireland | 36. Nikki Sinclair, UK |
| 18. Mairead McGuinness, Ireland | 37. Struan Stevenson, UK |
| 19. Gay Mitchell, Ireland | 38. Derek Vaughan, UK |

European Epilepsy Day



Ireland Rugby head coach Joe Schmidt (originally from New Zealand) lined out for epilepsy with a new TEAM at Dublin's Aviva stadium and asked for people to 'Be Seizure Aware' in advance of European Epilepsy Day.

Joining Joe for the official launch were three young Irish rugby fans who have epilepsy - James Devine aged 10 years, Joar Ryan aged five years and Sean Delaney aged 10 years.

Joe has a particular interest in epilepsy: his 10 year old son, Luke, was diagnosed with epilepsy at the age of four, and has undergone numerous brain surgeries since then.

The Seizure Aware campaign was in full swing in time for European Epilepsy Day and aims to raise awareness of the 'do's and don'ts' when responding to a seizure.

A series of advertisements, voiced by Joe Schmidt, were broadcast on national and local radio focusing on the acronym TEAM:

T - Take care to protect the person

E - Ensure you stay with them

A - Allow the seizure run its course

M - Move the person on to their side when the seizure is over

First aid posters were distributed nationwide, a number of events were held around the country and the website of Epilepsy Ireland presented further resources on the correct ways to respond to a seizure.

GEORGIA



A Piece of Cake!

European Epilepsy Day has been celebrated in Georgia since its introduction in 2011.

This year was no exception with a special event held at the Institute of Neurology and Neuropsychology, in Tbilisi.

Nino Gzirishvili sent IE News some great photos of a very special EED cake. She told us that the Georgia association invited a pharmacology agency, which has supported the association every year with its EED celebrations, to the institute and had a special Thank You event that included a cake decorated with the image of the EED 2014 poster.

Members of the agency were presented with certificates to recognise their support and this also gave the association the opportunity to talk about epilepsy in Georgia and to discuss plans for next year's European Epilepsy Day.

across Europe

FINLAND



Nora Klemola, Assistant of the Supreme Court and Juha Karjula, kindergarten teacher speak openly about how their drug resistant epilepsies have affected their capacity to work in their professions. Klemola and Karjula were the faces of EED 2014 in Finland



In her early 50's, Marja Suonpää enjoys life. "I have been able to study and am successful in my work, despite my epilepsy". She is senior inspector in the Finnish Safety and Chemicals Agency

The Finnish Epilepsy Association (FEA) promotes the rights of people with epilepsy with the European Epilepsy Day (EED) theme 'Epilepsy is more than seizures'. The campaign takes place throughout year and nationwide.

EED was launched in Helsinki with an educational event for Human Resource Managers of large companies. FEA also launched a special EED 2014 website www.epilepsia.fi/kampanja_2014. There are personal stories and an electronic postcard on the website. The card can be sent to decision-makers with messages such as "Have the courage to make good decisions". The card can also be sent to a friend with a free message.

FEA sent almost 2,000 emails to Finnish decision-makers, including Members of

the European Parliament (MEP), members of the Finnish Parliament; and local city councils and communities.

Continuing from now, local chapters of FEA will have face-to-face events at markets and fairs, with volunteers talking about the effects of epilepsy in everyday life. Almost 30 events are planned for 2014. FEA has produced materials to support this drive, including flyers, magazines, match-boxes, balloons and posters. There are also tents with the association logo for use when they campaign in the street.

An EED press release was used widely in the media and there is still further publicity to come. In addition, FEA asked its volunteers to send electronic cards from the campaign website to their local poli-

ticians and government officials focussing, in particular, on Finnish candidates standing in the European Parliament elections. The message calls for more resources for epilepsy research, because this area is greatly underfunded. The messages will be delivered jointly with the Finnish chapter of the International League Against Epilepsy.

FEA has been active during every EED since the initiative was introduced in 2011. Little by little the association is learning how best to use the campaign in order to achieve the most publicity.

At the same time FEA communicates how epilepsy is a many-sided disease and hopes, thereby, slowly to make changes in the attitude and knowledge of Finnish decision-makers towards epilepsy.

Introduced by Dr Rocía Mateos Ruiz, President of Federación Española de Epilepsia, Dr Jaime Parra, a neurologist at the San Rafael Hospital in Madrid, presented a 15 minute video about epilepsy.

The video can be viewed on YouTube <http://www.youtube.com/watch?v=6qjQcByEs34>



SPAIN

European Epilepsy Day

HUNGARY

Thinking outside the box, the Hungarian Chapter of the ILAE came up with an interesting event, to raise awareness about epilepsy, to mark European Epilepsy Day.

On 15th February, epilepsy was in focus in the famous Budapest Zoo, with participation of representatives of the League, the lay organizations, the president of the International Children's Safety Service and children and adults living with epilepsy. When the official programme ended, special tours of the Zoo were available, in small groups with guides who talked about the animals and their habits.

The event was initiated by Dr Judit Saracz, a paediatric neurologist who, unfortunately, was not able to participate in the event on the day due to illness. However, despite her illness, she had gone to great lengths to make the event as joyful as possible for people living with epilepsy.

A second event, organized by the Hungarian League, was a meeting with representatives at the Ministry of Public Administration and Justice, the Ministry of Human Resources, the Presidents of the Hungarian lay organizations and the executive Board of the Hungarian Chapter of ILAE.



Photo: Ann Little

SEIN, Netherlands had a heart for epilepsy!



Wearing a heart for epilepsy

Stichting Epilepsie Instellingen Nederland (SEIN) created a special landing page for EED 2014 on its website and promoted it on Facebook and Twitter. There was a heart-shaped badge that could be stuck to your FB profile photograph to show that you had 'a heart for epilepsy.' There was also a give-away competition of 10 heart-shaped candles to promote EED 2014, to raise awareness for epilepsy and to raise awareness for SEIN.

Photo left: Caroline Morton with her Hart voor epilepsie badge on Facebook.

Balloons fly high

On the morning of European Epilepsy Day pupils at De Waterlelie school gathered excitedly in the schoolyard with 170 red balloons in the shape of a heart. After the opening speech by director Peter Klein and the anniversary song, the balloons were released. The event was twofold: to celebrate European Epilepsy Day as well as the 75th anniversary of the school.

The school, which is part of the De Waterlelie Foundation of SEIN in the Netherlands, is a center for special education and outpatients services for chronically ill children with epilepsy and other neurological and chronic diseases.



across Europe

European Epilepsy Day 2014 in Croatia was organized by the Croatian Association for Epilepsy. The main event was a public conference in Zagreb, which was promoted using electronic and social media (webpage and Facebook). Both public and professionals showed great interest in the event, so there was almost not enough space for all the participants! The conference was opened by a representative of the City Office for Health. This was followed by three short presentations by medical professionals on the topics of:

- ◆ An introduction to EED and its objective
- ◆ New possibilities for epilepsy treatment
- ◆ Family life when a child has epilepsy

These presentations were followed by open discussion and a small banquet, which provided the opportunity for the participants to share their personal experiences in a relaxed and enjoyable atmosphere. Those who attended expressed their satisfaction with the event and plans for further activities were initiated.

CROATIA



NETHERLANDS

Epilepsiefonds

Epilepsy research

Epilepsiefonds (the Dutch Epilepsy Foundation) sought extra attention for epilepsy and, specifically, for research of a severe form of epilepsy in children with radical consequences.

Some types of nocturnal epilepsy in children occur without visible seizures. Although this epileptic activity disappears at puberty, in the meantime some serious disturbances in the development and behaviour of the child occur.

Child neurologist Floor Jansen, from the UMC Utrecht Brain Center, conducts research into this form of epilepsy: epilepsy with ESES (Electrical Status Epilepticus in Sleep).

In February, under her leadership, a research study was launched in twenty European centres into the best treatment of this 'invisible' epilepsy, subsidized by the Dutch Epilepsy Foundation.

Media events

De Telegraaf, the most widely read Dutch newspaper, placed an article about this research and an article describing the experience of Melanie, a girl who suffers from epilepsy, on its website.

Hart van Nederland, a news/human interest program on Dutch TV, broadcast an item about epilepsy with ESES on European Epilepsy Day. In an interview, Melanie and her mother were asked about the period in which Melanie's development suddenly greatly declined. Invisible seizures during sleep proved to be the cause. Dr Floor Jansen was also interviewed and told more about the European research into epilepsy with ESES.

RTL Late Night, a popular TV talk show had Erwin Koeman, a well known soccer coach and ambassador of the Dutch Epilepsy Foundation, and his daughter Wendy, who has epilepsy, as guests. Erwin and Wendy talked openly about Wendy's epilepsy. After the broadcast, there were many positive responses on Twitter. It also resulted in an interview with Erwin in a well-read football magazine, which was published a week after the show.

*Top: Dr Floor Jansen
Bottom: Wendy and Erwin Koeman
Photos: Annet Delfgaauw*





THE HISTORY OF THE INTERNATIONAL LEAGUE AGAINST EPILEPSY



ESTABLISHED 1909

Part Six: 1973-1981: Marriage and Divorce

In part 4 (Issue 3, 2012) and part 5 (Issue 1, 2013) Ted Reynolds described how IBE evolved out of ILAE in the 1960's and how the two organisations established a practical working relationship.

At the quadrennial International ILAE/ IBE Congress in Barcelona in 1973 David Daly, the former ILAE Treasurer, was elected President, with fellow American J Kiffin Penry as Secretary General and Karl-Axel Melin (Sweden), former Vice-President, as the new Treasurer.

In the December 1974 issue of the IBE Newsletter, Daly and Penry, together with Ellen Grass (also from the USA) and George Burden (UK), who were continuing as President and Secretary General, respectively, of IBE, published a "Declaration of Intent" for a much closer working relationship between ILAE and IBE under the joint umbrella of "Epilepsy International".

Initially the League and the Bureau would retain their separate identities but

Epilepsy International would act as their agent, with a view to eventual merger. This objective would save duplication, resources and costs, and facilitate greater fundraising.

Negotiations towards these goals encountered difficult practical issues relating to constitutional details; chapter membership and dues; commissions; Epilepsia and much else. Unfortunately, unrelated tensions between the four Officers resulted in the resignation of both Ellen Grass and George Burden and, by 1977, little progress had been made.

The next ILAE Executive was elected in 1977 at the ILAE/IBE Congress in Amsterdam, in conjunction with the 11th World Congress of Neurology. Kiffin Penry was now President with Francisco

Rubio Donnadiu from Mexico was Secretary General. At the same time Mexico, Canada and the Dominican Republic were admitted as League Chapters.

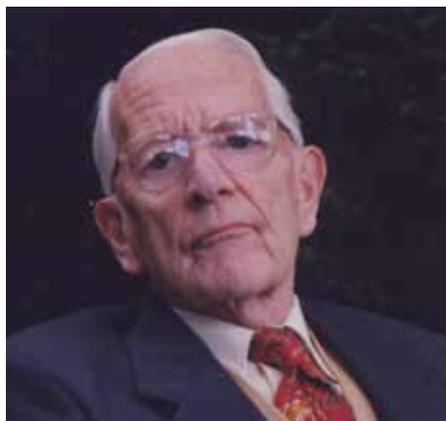
IBE now also had a new Executive with Harry Meinardi (Netherlands) as President and Richard Grant (UK) as Secretary General.

Both Executives gave renewed impetus to the Epilepsy International project and a new target date for merger, subject to Chapter approval, was set for 1981 at Kyoto. The League and Bureau Executives constituted the Board of Directors of Epilepsy International with the two Presidents, Secretaries General and Treasurers as the Executive Committee of the new organisation.

The plan for a single office was imple-



Ellen Grass, Founding President of IBE.



George Burden, Founding Secretary General of IBE.



J Kiffin Penry, ILAE Treasurer 1973 -1977 and President 1977-1981

mented in 1978 at a neutral, but expensive, site in Geneva, Switzerland, where Richard Gibbs, another American, took up his new role as "Executive Director". The London office of IBE closed. The League had no fixed office and relied on the, largely voluntary, efforts of its Secretary General.

The Geneva Office soon fell apart for lack of funding and communication difficulties. Richard Gibbs returned to the USA in 1979 and was released from his contract in 1980. The Epilepsy International office was moved to Milan, where Patsy McCall-Castellano (USA) and her husband, Francesco Castellano (Italy), both Officers of IBE, were based and where Patsy acted as temporary voluntary Executive Director for Epilepsy International.

At the Epilepsy International Symposium in Kyoto in 1981, the IBE voted in favour of a merged Epilepsy International but the ILAE General Assembly voted against in a ratio of 2 to 1.

It was clear that many in the League were unimpressed with the proposed merger. They felt that the Board of Directors of Epilepsy International had not been acting as an agent for ILAE but had been running and controlling the League, largely under the influence of the Bureau. Duplication had not reduced but had, in

fact, increased; money had been wasted on an expensive office and staff in Geneva; and fundraising had not increased. The League's Treasurer, Karl-Axel Melin, was concerned about ILAE's dwindling finances.

After the negative 1981 vote, some in the Bureau and a few in the League, including the new 1981-1985 President, Mogens Dam (Denmark) still hoped that Epilepsy International might be salvaged with better communication with the Chapters, which had certainly been poor.

The wounded, and not yet legitimised, Epilepsy International limped on for four more years, until it was finally disbanded at the next quadrennial Epilepsy International Symposium in Hamburg in 1985.

In retrospect, it is very surprising that so soon after the emergence of IBE from ILAE in the second half of the 1960's a new, largely Anglo-American, proposal to integrate them should evolve in the mid-1970's, partly driven by the same IBE Officers who had successfully campaigned for, and established, an independent IBE.

Although no doubt well intentioned, it was undermined from the start by serious practical challenges; poor planning and communication; personality clashes and financial disputes. It was a marriage that was never consummated and ended in divorce.

Many lessons can be, and were, learned by both ILAE and IBE, who have continued to work successfully together since then as independent but interlocking organisations. This unhappy story diverted much of the attention, and energy, of ILAE between 1973 and 1981. The annual European Conferences, which had been initiated by IBE in 1967, now continued at Brussels in 1974; Berlin in 1975; and Dublin in 1976.

After 1977, international conferences continued annually under the label of "Epilepsy International Symposia" and were held at Vancouver in 1978; Florence in 1979; and Copenhagen in 1980. Only two new Chapters - Colombia and Finland - joined ILAE at Kyoto in 1981, bringing the total number of Chapters to twenty-nine.

One new initiative by the ILAE Executive was a Commission on Antiepileptic Drugs, in addition to the Commission on Classification and Terminology, discussed in part 5.

Preceded by a Pharmacological Advisory Committee led by Treasurer Daly in 1970, the first Commission, from 1973-1977, was chaired by Maurice Parsonage (UK), with whom I served as secretary.

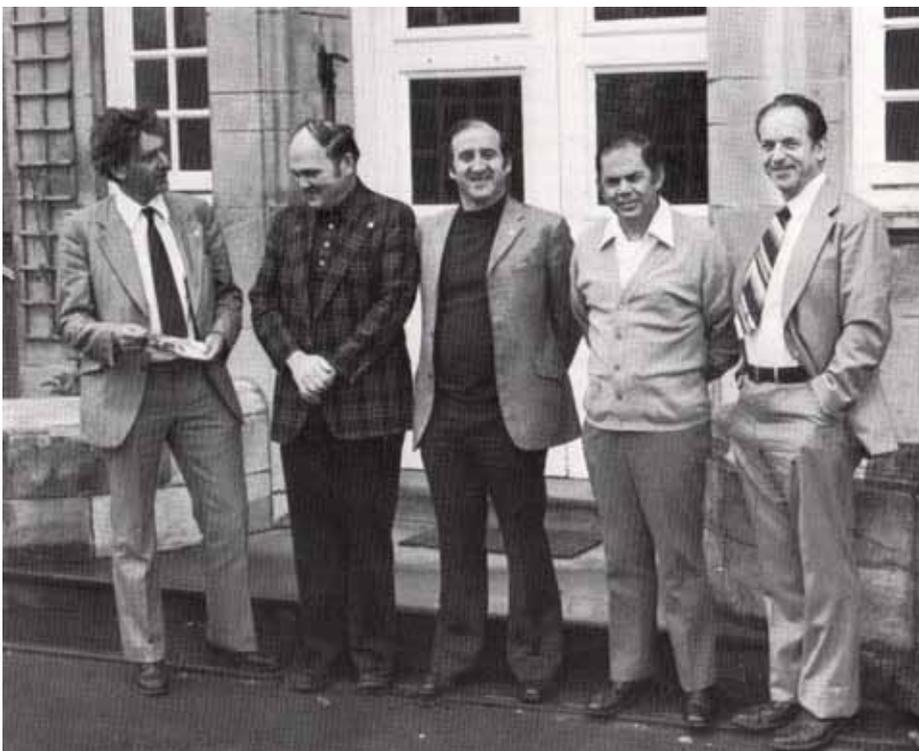
The driving force, however, was Kiffin Penry, who, as Head of the Epilepsy Branch at the National Institutes of Health in Washington, spearheaded the scientific and political campaign to improve the availability, evidence and better use of currently available antiepileptic drugs, and to develop new antiepileptic drugs.

He stimulated many symposia and publications on the subject, including the authoritative multi-author "Antiepileptic Drugs", which ran to five updated editions by 2002.

The ILAE Commission on Antiepileptic Drugs has continued to the present time, more recently under the broader title of "Therapeutic Strategies", and has remained one of the most influential ILAE initiatives.

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2. Parsonage M. Guest Editorial. *Epilepsia* 1984; 25: 405-407.



Members of the Executive Committee of Epilepsy International in 1978. From left to right Harry Meinardi, IBE President; J. Kiffin Penry, ILAE President; Richard Grant, IBE Secretary General; Francisco Rubio Donnadieu, ILAE Secretary General; and Richard Gibbs, Epilepsy International Executive Director.

It was with great sadness that IBE learned of the recent death of Harry Meinardi, who passed away on 20 December 2013, aged 81 years. During his long career, and well into his retirement, his input into the field of epilepsy was significant. Harry also played an important role in IBE, as Honorary Editor of IE News (1973-1977), President (1977-1981) and Past President (1981-1985).

More recently, he has entertained us with his great series of articles in IE News on the history of IBE as detailed in the newsletter. His final article was printed in Issue 2-2013.

To honour his contribution to IBE over a period of 40 years, in addition to an obituary provided by Hanneke de Boer, we are also including some words from Ted Reynolds, whose history of ILAE, as reported in the newsletter of the League, alternated with Harry's reports. There are also messages from IBE members and colleagues who worked with Harry during his long career.

At this sad time, IBE would also like to extend its sympathy to his son Floris, his daughter Hermelyn, his grandchildren and to his partner Annemarie Harting. Harry will be greatly missed.



Obituary

Harry Meinardi

1932 - 2013

family. Through his friend he got in touch with "Meer en Bosch", the former name for SEIN, and, as he himself said: 'I became fascinated by the possibility of being engrossed in the research and holistic treatment of a disease that was, rightly so, called the neurologists' "great teacher", by Wilder Penfield (a famous neurosurgeon from Canada).

Prof Meinardi obtained his PhD in neuro-psychiatry in 1960. In 1962 he moved to the Rockefeller Institute in the US to participate in

a number of research projects. In 1966 he returned to the Netherlands at the request of Prof Lorentz de Haas to work at SEIN. Half of his time was occupied with patient care and the other half was spent on research. In 1985 he became the first Professor of Epileptology in the Netherlands.

He became Director of the Epilepsy Institute (SEIN) in Heemstede and was to remain there until his official retirement in 1992, after which he slowly diminished his epilepsy activities and, according to his plans, stopped his formal duties on 20-02-2002, the date of his 70th birthday. However, even then, he continued to help out whenever he was called upon.

Harry's interest in all aspects of epilepsy led to a variety of managerial and administrative positions, both nationally and internationally. For twelve years he was a

member of the Executive Committee of IBE and, following that, of the Executive Committee of ILAE. In both organisations he also served as President.

He was one of those unique individuals who moved easily between the many psychosocial and medical issues of epilepsy and the study of the basic mechanisms of epilepsy in the laboratory. He was also the only person to have served as both President of IBE (1977-1981) and President of ILAE (1989-1993).

Over the last three years, Harry provided a fascinating series of articles for IE News – *Look Back with Pride* – the last instalment of which was published as recently as Issue 2 – 2013. His articles, which were extremely popular with readers, catalogued IBE's history as detailed through the newsletter.

In recognition of his years of service in the field of epilepsy, Prof. Meinardi was awarded the IBE/ILAE Ambassador for Epilepsy Award and the ultimate award presented by IBE and ILAE – Lifetime Achievement Award in 2001.

Down through the years, both ILAE and IBE benefitted from Harry's wit and wisdom as well as the many junior colleagues whom he mentored (including myself, although I was not his student). Harry himself, was a "great teacher" of neurologists and of others in the field of epilepsy. *HMdB*

Harry Meinardi was born in Nice, France and spent much of his childhood in the Dutch East Indies (Indonesia) where his father worked in the sugar industry and his mother was a doctor. During the war, together with his mother and his brother, Harry was taken captive and was held in a Japanese prisoner camp.

After his return to the Netherlands, Harry studied medicine in Leiden. During his study period he worked together with two other students in the laboratory, one of whom was a young woman who had a sister with epilepsy. The sister was a very bright child but, since she had developed epilepsy, it seemed as if her intellectual abilities had come to a halt.

When contacts with the family grew stronger, Harry began to realise that the consequences of the young girl's epilepsy was putting a heavy burden on the entire

Harry Meinardi: A Tribute

I first met Harry, in June 1968, at the European Epilepsy Conference ("European Institute") organised by IBE in Dunblane, Scotland. As Director of Research at a major Dutch Epilepsy Institution Harry's friendly interest in my first research efforts were much appreciated by me at the time. From slightly different backgrounds, we had since then been in regular contact as colleagues, collaborators and friends.

Throughout the 1970's, we both participated in the biennial "Workshops on the Determination of Antiepileptic Drugs in Body Fluids", the so-called WODADIBOF Meetings. During the 1980's we met at a series of British/Danish/Dutch ILAE Chapter meetings, culminating in the Northern European Symposium, i.e. including other Scandinavian countries, in 1989.

From 1989 to 1993 Harry was President of ILAE and I had the pleasure of supporting him on the Executive as a Vice President. When I succeeded him as President (1993-1997) Harry was, likewise, a very supportive Past President.

I also recall the occasional pleasant visit to Heemstede and to Harry's home in The Hague. I last met Harry, appropriately enough, at the Centenary Congress of ILAE in Budapest in 2009, but since then

we have continued to keep in touch and collaborate on a series of articles on the history of IBE and ILAE in IE News.

The Netherlands has been at the forefront of the Epilepsy Movement. As Director of one of the most famous Epilepsy Centres in the world Harry was the epitome of that Dutch tradition. Harry, however, was unique in serving as President of both the Bureau (1977-1981) and the League (1989-1993).

This of course reflected his commitment to every aspect of patient care and academic epileptology, from the neurochemical and neuropharmacological, to the medical, social and political. This also culminated in his appointment as probably the first Professor of Epileptology in the world.

Harry's whole career was committed to people with epilepsy locally, nationally and internationally. This he carried

out with great dedication, skill and diplomacy. He had a friendly and engaging style, facilitated by an almost British sense of humour, which endeared him to his professional colleagues. He was not driven by any philosophical or religious inclinations, but by practical, humanitarian and diplomatic considerations, with enormous attention to detail. The Epilepsy Movement has lost a great champion, reflected in his many achievements. I will personally miss our regular, friendly, humorous but ultimately serious and constructive interactions over nearly five decades.

Ted Reynolds



From left: Harry Meinardi, Annemarie Harting, Ted Reynolds and Angela Reynolds at ILAE Centenary celebrations, Budapest 2009.

Messages of Condolence

Thank you for letting us know about this great loss. It is with sorrow that we add our voice to yours to pay condolences to Harry's family. May his soul rest in peace.

Nahida El Assi, Lebanon

Toutes nos condoléances les plus attristées pour cette douloureuse disparition qui a frappé notre association. Que Dieu soutienne sa famille et lui permette de traverser les instants de cette dure séparation.

Dr Elong Ngono, Neurologist, Cameroon

On behalf of Indian Epilepsy Society (IES), it is very sad news to learn the demise of Professor Harry Meinardi.

Dr Man Mohan Mehndiratta

GADEP adds its sorrow to that of Harry Meinardi's family at this time. He was one of the most important persons devoted to the attention of people with epilepsy and we all recognize his valuable work.

Dr Lilia Núñez Orozco, President, GADEP, Mexico

I send Annemarie and Harry's children my deepest sympathy. I considered him a

special friend. He lives in you, and in me, and in all his friends, colleagues, patients, and probably millions of people whose lives he touched.

Pete Engel, USA

We deeply regret the death of Harry Meinardi who was a great man, kind, full of virtues and who contributed significantly to a better understanding of epilepsy.

He received numerous academic awards and achieved the highest academic positions and respect of the entire international community linked to epilepsy. No doubt that everyone linked to epilepsy is grieving and missing him, especially those who knew him closer as friends.

Carlos Acevedo, former IE News Editor

The news of Harry Meinardi's passing away was nothing short of a bolt from the blue. Harry was a personal friend, even more importantly he was valued as a great well wisher for the sufferers with epilepsy in the developing world.

My first acquaintance of this great figure came about in 1978 by my short stint at

his epilepsy institute at Meer en Bosch, Heemstede.

We persuaded him to come to India in 1986 to address a symposium on psycho-social aspects where his participation brought out one unintended consequence. Indian law on divorce had been changed to the detriment of epilepsy sufferers without even the realization of our medical care-givers and Harry helped by getting us to collect useful information from 55 countries. The law could be amended only after much struggle spread over 13 years. We in IEA owe a personal gratitude to him.

Vinod Saxena, India

We are sorry to hear the news about Prof Harry Meinardi's death. He made a great contribution, not only to IBE and ILAE as President, but also to Epilepsy. We would like to extend our deepest sympathy to his partner Annemarie and to his children and grandchildren.

Dr Tomás Mesa, President, Liga Chilena contra la Epilepsia

A rather special maritime adventure!



Jaw-dropping beautiful, the Nave Italia is a sailing vessel with two square-rigged masts, known in nautical terms as a brig, which is run by the Fondazione Tender To. The foundation was set up in 2007 by the Marina Militare (Italian Navy) and the Italian Yacht Club. With a base in Genoa, the brig is intended mostly for social cruises, with a crew of 15 Italian Navy officers.

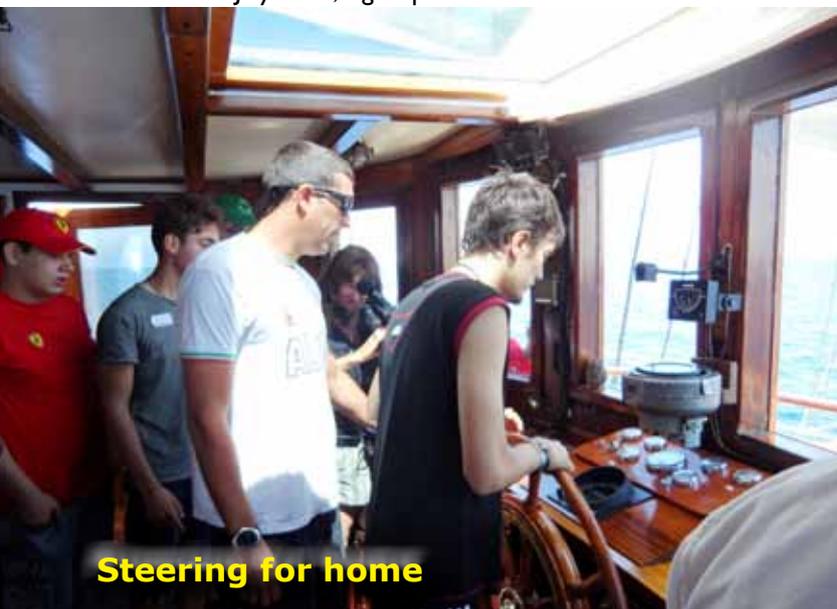
However every summer, from June to September, the brig provides a unique opportunity for young persons with varying medical conditions such as diabetes, Down's syndrome, metabolic disorders, or behavioral problems to go on a six-day cruise, sailing around the coast of Italy and the Mediterranean. From 2 to 7 July 2013, a group of 14

young people with epilepsy - eight boys and six girls - assisted by fundraising by Bambino Gesù Hospital in Rome - were invited to join a cruise. Six of these young people had focal epilepsy, seven had been diagnosed with generalized epilepsy, and one girl had Dravet syndrome. Only six boys were seizure-free, four also had motor disabilities and one had vision problems. Joining the group were a neurologist, an anesthesiologist, a pediatrician, a psychologist and two nurses, who were at hand for any medical emergency that have might have arisen during the voyage.

Throughout the cruise, there were activities designed to promote educational psychology and to increase group self-

esteem. Everyone was delegated chores and was expected to pull his or her weight on board. The young people were taught the principles of sailing, helped to haul sails, steer the craft and learned to make nautical knots. With the help of safety ropes they were even able to climb the mast (including those with mobility problems and visual impairment!). During the cruise, contact with parents and carers with their mobile phones was limited to a few minutes each evening.

Feedback from the young people and their families clearly indicated that it was an incredible opportunity and perhaps for the first time the "disease was turned into a privilege". It is planned to repeat the experience in summer 2014.



Steering for home



**Heave away, haul away!
Learning to haul sail**

ON THE MOVE!

RAISING AWARENESS ON NAMIBIA

Project funded by the Promising Strategies Program of IBE

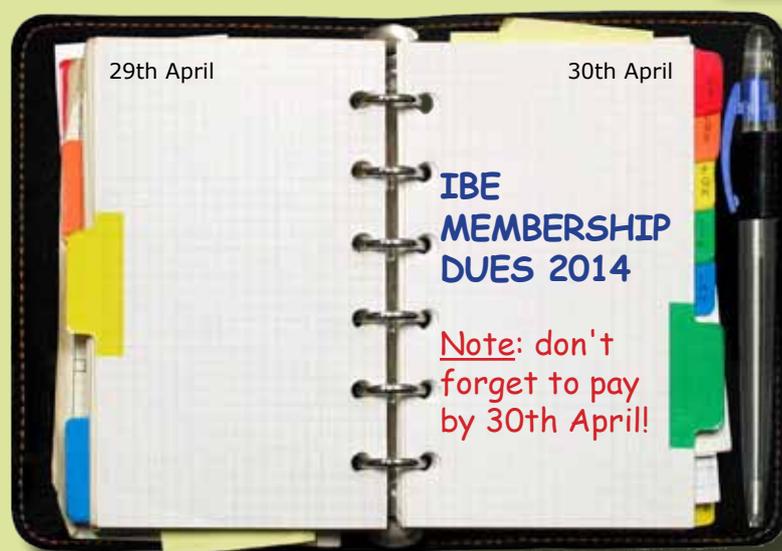
Epilepsy Namibia is taking an awareness program on the road. Through past contacts, and from figures from the latest census results, the association has identified four areas where it could reach the highest number of people. By the time the program is completed more than 4,000 km will have been covered.

At each point, contacts will be established with the clinic which forms the backbone of care for patients in the region. Public awareness is planned in town centers with information distribution, as well as a DVD presentation. Special invitations will be sent to people with epilepsy in the area, for a come-together to boost support groups. Translators to local languages are obtained from the local community.

In February, Epilepsy Namibia packed its bags and started its mammoth journey to the four corners of Namibia. First stop was Gobabis where information and awareness about living with epilepsy were provided. The association visited hospitals, clinics and doctors with information about the organization and delivered training manuals and information DVDs.

On a Saturday morning in mid-February an information stand was set up close to shops in the centre of Gobabis, providing the general public the opportunity to learn more about epilepsy. People with epilepsy, who had questions about their condition, or who needed support, were also invited to visit the stand.

As people with epilepsy are stigmatized and discriminated against, Epilepsy Namibia especially wished to encourage those who are coping with living with epilepsy to join as advocates, to prove that people with epilepsy can take their place in their communities. IBE wishes Epilepsy Namibia every success with this great initiative.



Promising Strategy Projects, such as the project of Epilepsy Namibia, need your support in order to help us continue with this program, which has already provided more than \$300,000 in support funding to projects around the world.

All donations, no matter how small, can help to make a difference. So, once again, we are asking you to consider making an extra payment when settling your dues payments for 2014.

Members will already have received dues notices and it is now easier than ever to make a payment. You can now pay securely online via the IBE website using Paypal or a Credit Card.

WHO Director-General launches the Mental Health Action Plan

"...and many of the actions are also relevant to conditions such as epilepsy."



WHO Director-General, Dr Margaret Chan, launched the Mental Health Action Plan 2013-2020 during the mhGAP Forum in October 2013. She described the Mental Health Action Plan as a landmark achievement: it focuses international attention on a long-neglected problem and is firmly rooted in the principles of human rights. The action plan calls for changes in the attitudes that perpetuate stigma and discrimination that have isolated people since ancient times, and it calls for an expansion of services in order to promote greater efficiency in the use of resources.

"Mental well-being is a fundamental component of WHO's definition of health. Good mental health enables people to realize their potential, cope with the normal stresses of life, work productively, and contribute to their communities," Dr Chan said.

"This comprehensive action plan recognizes the essential role of mental health in achieving health for all people. It is based on a life-course approach, aims to achieve equity through universal health coverage and stresses the importance of prevention," she added. "Although the targets of this action plan are ambitious, WHO and its Member States are committed to fulfilling them," Dr Chan said.

About the Mental Health Action Plan

In 2012, the World Health Assembly adopted a resolution on the global burden

of mental disorders and the need for a comprehensive, coordinated response from health and social sectors at the country level. It requested the Director-General to develop a mental health action plan, in consultation with Member States, covering services, policies, legislation, plans, strategies and programmes.

No health without mental health

The plan has been developed through consultations with Member States, civil society and international partners with an emphasis on promotion, prevention, treatment, rehabilitation, care and recovery. It also sets out clear actions for Member States, the Secretariat and international, regional and national level partners, and proposes key indicators and targets that can be used to evaluate levels of implementation, progress and impact. It has, at its core, the globally accepted principle that there is "no health without mental health".

The plan has been designed to create synergy with other relevant programmes of organizations in the United Nations system, United Nations interagency groups and intergovernmental organizations. It builds upon the work of WHO's mental health gap action programme (mhGAP). The focus of the latter was to expand services for mental health in low resource settings. The action plan is global in its scope and is designed to provide guidance for national action

plans. It addresses, for all resource settings, the response of social and other relevant sectors, as well as promotion and prevention strategies.

In the action plan, the term "mental disorders" is used to denote a range of mental and behavioural disorders that fall within the International Statistical Classification of Diseases and Related Health Problems, Tenth revision (ICD-10).

These include disorders that cause a high burden of disease such as depression, bipolar affective disorder, schizophrenia, anxiety disorders, dementia, substance use disorders, intellectual disabilities, and developmental and behavioural disorders with onset usually occurring in childhood and adolescence, including autism.

Furthermore, the plan covers suicide prevention and many of the actions are also relevant to conditions such as epilepsy. The term "vulnerable groups" is used in the action plan to refer to individuals or groups of individuals who are made vulnerable by the situations and environments that they are exposed to (as opposed to any inherent weakness or lack of capacity). The term "vulnerable groups" should be applied within countries as appropriate to the national situation.

Mental Health Action Plan 2013-2020

http://www.who.int/mental_health/publications/action_plan/en/index.html



The clock ticking away in the countdown to the 2nd African Regional Epilepsy Congress - as I write this article the countdown marker on the website shows just 72 more days to go before the congress starts. The final pieces are being put in place and an excellent informative and interactive programme is guaranteed under the congress theme: 'Epilepsy in Africa: Bridging the Gap'.

EPILEPSY & SOCIETY

After a very successful inaugural congress in Nairobi two years ago, the programme and structure of the African congress has been further developed for Cape Town. A new addition to the programme is the day-long Epilepsy & Society Seminar, which will take place on Saturday 24th May.

The Epilepsy & Society programme has already proven to be very successful at the Asia Oceania and Latin American regional congresses, with the target audience of people with epilepsy, their families and caregivers, and focuses in large on social topics related to epilepsy. It is hoped that the programme will be equally popular in Cape Town.

While the seminar is part of the main congress programme and is free of charge for those registered for the congress, to facilitate those who wish to attend the seminar only, there is a special registration fee of \$35 available.

Among the interesting topics included in the seminar programme are:

- Targeting improved care for people with epilepsy
- Epilepsy and the family and personal experiences
- Women's issues, including contraception, pregnancy and motherhood
- Men's issues
- Epilepsy and schooling and epilepsy in old age
- Traditional healers
- Anti-epileptic drugs in Africa.

BURSARIES

Thanks to funding provided by the IBE African Regional Committee and matched by IBE General Funds, nine bursaries have been awarded to applicants from Cameroon, Kenya, Lesotho, Malawi, Niger, Nigeria, Swaziland, Uganda and Zimbabwe.

MEETING OF THE AFRICAN REGIONAL COMMITTEE

Chaired by Youssouf Noormamode, the IBE African Regional Committee will meet during the congress. Arrangements for the meeting are currently being finalised and details will be circulated to all IBE members in the region as soon as possible. This is a great opportunity to hear about activities being carried out by lay associations across Africa and to exchange experiences with others.

The meeting will be open to representatives of member associations and will also welcome anyone interested in learning more about IBE and its membership.

EARLY REGISTRATION

With the closing date for early registration now only days away, take advantage of the reduced rate and register before the deadline on 21st March.

www.epilepsycapetown2014.org



French Collaboration in Mauritius



Above from left: Dr Hon Vasant Kumar Bunwaree, Minister of Education and Human Resource, Mrs Valerie Rawat, CEO Apollo Hospital BRAMWELL and Dr Arnaud Biraben, President of the French League Against Epilepsy.

Below: Edycs Epilepsy Group Team at Bagatelle, Mauritius.



Mr Youssef Noormamode, President of the Edycs Epilepsy Group Ile Maurice, Mauritius, and Chair of the IBE African Regional Committee, had a busy month in October.

In early October, the association welcomed Dr Arnaud Biraben to Mauritius. Dr Biraben, a French neurosurgeon, is President of the French League Against Epilepsy - the ILAE chapter in France. The visit celebrated collaboration between the French League and Edycs Epilepsy Group with a series of activities over seven days.

To mark World Mental Health Day on 10 October, Edycs Epilepsy Group organised a medical seminar for carers and professionals at the Apollo Bramwell hospital with the theme 'Epilepsy in the Elderly'. One hundred and twenty (120) carers from both public and private health care institutions, including NGOs in the health sector, were invited to attend.

Dr Arnaud Biraben was chief guest and resource person for the seminar. The Minister for Education and Resources, Dr Vasant Bunwaree, was also invited to host the opening ceremony.

Other events during the week included a meeting with the Lord Mayor of Port Louis, Mr Aslam Adam Hossenally; a courtesy meeting with the Minister of Social Security, Honourable Sheilabai Bappoo, GOSK; a visit to Brown Sequad Hospital; radio interviews and an award ceremony to recognise volunteers who help Edycs Epilepsy Group with its fundraising activities.

VISIT TO EPILEPSY IRELAND

While in Dublin at the end of February, for the meeting of the Organising Committee for the 31st International Epilepsy Congress, Istanbul 2015, Robert Cole, IBE Treasurer (pictured left) and Thanos Covanis, IBE President, paid a visit to Mike Glynn, IBE Past President and CEO of Epilepsy Ireland.





European Cross-border Healthcare Directive enters into force

Paola Testori Coggi, Director General for Health and Consumers, European Commission explains

European citizens, no matter where they live, now have the right to choose where to receive medical treatment across the EU, and to be reimbursed for it. This right is now spelled out in the Directive on Cross-Border Healthcare which entered into force throughout the European Union in October 2013.

Under previous EU laws, European citizens benefitted from their own countries national social security scheme if they became ill while travelling in another Member State. However, for planned cross-border care, a Member State could require that patients first applied for prior authorisation and the Member State was only compelled to grant the authorisation, if patients could be treated at home within a time limit considered medically justified.

The new Directive introduces three major changes focusing on patients' rights:

- Firstly, citizens have the right to

choose and be reimbursed for treatment, either public health care or private health care, anywhere within the EU.

- Secondly, prior authorisations for cross-border healthcare will become the exception rather than the rule.
- Finally, citizens will now have the right to make informed decisions about treatment options. They are, therefore, entitled to receive any relevant information from EU National Contact Points, established under the new Directive, and information from health care and treatment providers directly.

In order to increase transparency on quality and safety standards across the EU, the Directive advocates mutual assistance and cooperation between Member States, in particular on inter-operability of eHealth tools and the use of health

technology assessment. It also facilitates recognition of prescriptions for medical products in every Member State.

Eventually, the Directive will provide for the development of European reference networks, to encourage the pooling of knowledge and thereby maximise the cost effective use of resources in highly specialized healthcare, such as diagnosis and treatment of rare diseases.

This new law marks a real breakthrough for European citizens: not only will European citizens be able to take more control over their own health care, this will in turn help patients associations promote higher quality and safety of care. This can only have a beneficial effect on our healthcare systems.

Link to the full text of the Directive:
<http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:088:0045:0065:EN:PDF>

FUTURE CONGRESSES



2nd AFRICAN EPILEPSY CONGRESS
CAPE TOWN, SOUTH AFRICA
22nd – 24th May 2014



11th European Congress on Epileptology
STOCKHOLM
29th June - 3rd July 2014



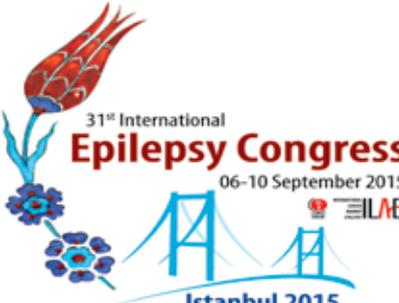
10TH ASIAN & OCEANIAN
Epilepsy
CONGRESS



SINGAPORE 2014
7 - 10 AUGUST



17-20 Setiembre 2014
BUENOS-AIRES
VIII CONGRESO LATINOAMERICANO DE EPILEPSIA



31st International
Epilepsy Congress
06-10 September 2015
Istanbul 2015

